Maggi A. Budd · Sigmund Hough
Stephen T. Wegener · William Stiers *Editors*

Practical Psychology in Medical Rehabilitation

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ISBN 978-3-319-34032-6 ISBN 978-3-319-34034-0 (eBook)
DOI 10.1007/978-3-319-34034-0

Library of Congress Control Number: 2016949405

Printed on acid-free paper

This Springer imprint is published by Springer Nature
The registered company is Springer International Publishing AG Switzerland

Foreword

The ambitious editors of *Practical Psychology in Medical Rehabilitation* took on a Herculean task, one that must at times have felt Sisyphean, given the scope of the project. It's easy for the author of a Foreword to say: "It was well worth the effort," but I hope the editors share my view; I know readers will.

To call this volume wide-ranging is a vast understatement. The editors solved what might be called the "handbook quandary" of how to organize a text (By diagnosis? By setting? By problem area? By technique?) by covering all the bases. Chapters are notable for both their conciseness (with effective use of telegraphic language) and their comprehensiveness, and when, because of the former feature, readers don't immediately locate the material they are seeking, the references will likely point them to what they need. The emphasis on "practical" is apparent throughout.

Practical Psychology in Medical Rehabilitation was designed to be accessible, to summarize what is essential about the topic at hand, and to offer guidance to the psychologist in problem-solving about how best to proceed. In meeting that goal, *the volume is* an estimable success.

As rehabilitation psychology has blossomed in the last 25–30 years, the availability of specific training in the specialty has lagged behind, meaning that some new entrants to the field come from related specialties such as neuropsychology, health psychology, or school psychology, whose graduate programs tend to offer little education about disabling conditions and their consequences. *Practical Psychology in Medical Rehabilitation* can be recommended (no, mandated!) as an effective tutorial for fledgling rehabilitation psychologists about conditions and problems they may be encountering for the first time, how to manage common clinical conundrums, work with and support other members of the treating team, and promote post-discharge success, and a host of other skills and strategies that are the unique province of rehabilitation psychologists. More seasoned rehabilitation psychologists—who may have extensive experience working with patients with traditional rehabilitation diagnoses such as spinal cord injury, brain injury, stroke, and amputation—will also benefit from portions of the volume that deal with newer target populations such as those in intensive care units and transplant recipients (who may need evaluation of rehabilitation potential) or previously foreign professional roles such as administration and billing.

Rehabilitation psychologists of all vintages should find room in their budget for *Practical Psychology in Medical Rehabilitation*. It is a laudable achievement rich in clinical wisdom and practical (there's that word again) advice.

Bruce Caplan, Ph.D.

Preface

Specialty psychology practice requires specialized knowledge, skills/abilities, and attitudes/values. The specialty of rehabilitation psychology has developed over the past 70 years, beginning during the 1940s, as health professionals worked to understand and treat complex injuries and disabilities arising from World War II (Scherer et al. 2010). Psychology theorists and practitioners worked to assist persons with physical and cognitive impairments, conducted research on individual and interpersonal reactions to persons experiencing disability, and studied the social psychology of disability-related stereotyping and prejudice (e.g., Barker et al. 1946; Barker and Wright 1952; Dembo et al. 1956).

Based on this early work, the field of rehabilitation psychology developed a disability-specific body of theory and research regarding issues of individual and social adjustment (Shontz and Wright 1980; Gold et al. 1982; Dunn and Elliott 2005; Cox et al. 2013). As specialized assessment and intervention techniques and increasingly sophisticated interdisciplinary consultation models were developed, psychologists working in these settings have had to master increasingly complex rehabilitation-specific knowledge, skills/abilities, and attitudes/values.

Practical Psychology in Medical Rehabilitation is in response to the need for comprehensive practical information that is useful to psychologists working in medical rehabilitation settings. Because psychological principles affect all rehabilitation providers and their practice, this book can be a valuable and easily accessible resource for all disciplines in the field as well. The authors in *Practical Psychology in Medical Rehabilitation* are experts in each content area and provide trustworthy and high-quality information to guide patient care and practice management.

This book brings together contributions in over 60 topics from over 90 experts to provide a concise, accessible, and comprehensive summary of the current state of the art in rehabilitation psychology. Information on specialized populations, problems, and procedures, as well as information about team collaboration, practice management, research, and other topics important to the specialty, is easily accessible. This book is meant to be the primary "go to" information source for all providers working in medical rehabilitation. The information can be especially valuable to specialties in psychology such as behavioral medicine, health psychology, and clinical psychology, as well as to non-psychologists.

In order to make the information rapidly accessible to busy practitioners, the chapters all follow a common outline format of five sections:

I	Topic	–	*What is this?*
II	Importance	–	*Why is this included?*
III	Practical Applications	–	*How to?*
IV	Tips	–	*If I were you, I would…*
V	References	–	Where to go for *additional resources*

Within each chapter section, the information is provided in an outline and bullet format to allow rapid retrieval.

We hope that this book supports psychologists in providing services that help to maximize the psychological welfare, independence and choice, functional abilities, and social participation of persons with disability and chronic health conditions.

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Part I

Basics and Biopsychosocial Practicalities

Information Gathering and Documentation

1

Nathan M. Parmer

Topic

The medical record is the central source for information in the inpatient and acute medical setting. While the organization of the medical record may differ slightly depending on setting, medical documentation is universal in medical care and provides the essential vehicle for communicating and documenting information across multiple disciplines. In the acute and subacute medical setting, the medical record is a dynamic and "living" document with contributions from those providing direct clinical care and treatment, documentation of results, as well as information to determine future intervention and discharge. The following chapter provides basic information on record organization, data-gathering strategies, and typical types of clinical documentation used in medical rehabilitation.

Importance

It is important for psychologists to be familiar with the medical record and interview components as well as effective documentation to ensure efficient data gathering and to provide salient information to aid in patient care.

Practical Applications

A. ***Medical record organization***

Reviewing all sections of the record is seldom necessary; however, being familiar with the contents of each section is helpful. Different settings will use different formats; however, the list below provides a basic framework of typical sections with descriptions of the information each includes.

Sections

Admission

Contains general demographic and family contact information, general consent forms, insurance data, social work, and psychosocial intake assessments.

History and physical (H&P)/referral

Contains reason for admission, injury history, pertinent medical history, results of the physical examination and the original problem list. In the rehabilitation setting, H&P will typically include the timeline and course of treatment prior to admission to

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_1

the rehabilitation setting. This section often serves as the most complete narrative of the patient's condition.

Test results/diagnostic/imaging studies

Contains results from diagnostic studies. The organization can be variable but typically includes cardiac rhythm testing, echocardiogram, electrocardiogram (EKG), electromyography (EMG), swallow studies, sleep studies, X-ray, electroencephalogram (EEG), and imaging such as computed tomography (CT) and magnetic resonance imaging (MRI).

Orders/treatment/Tx

Treatment orders and physician order sets

Pharmacy

Contains pharmacy orders and medication history

Laboratory/labs

Results of chemistry, microbiology, hematology, urinalysis/stool testing, and blood alcohol (ETOH) and illicit drug testing

Consultation/consults

Contains consultation notes from specialties outside of the primary medical service line. Psychology and psychiatry consultation reports are often found in this section.

Assessment/evaluation

Contains evaluations from audiology, physical therapy (PT), occupational therapy (OT), speech and language pathology (SLP), social work, and pressure sore flow sheets. OT/PT/SLP may have independent sections in the rehabilitation setting.

Progress/progress notes/H&P progress

Daily documentation of patient progress with multiple providers documenting their encounter with the patient

Discharge/plan/care plan/treatment plan

Contains individual treatment plans, critical care plans, and/or behavioral management plans

Legal

Contains powers of attorney, advance directives, and legal guardianship

B. ***Clinical interview***

After review of the medical record, interviewing the patient and available family is typically the next step in information gathering. Primary team members can also serve as key informants about patient progress (e.g., primary nurse, OT/PT, treating therapist). The interview is a key portion of psychological assessment in the acute medical and rehabilitation setting. An interview is a component of several types of procedures including the *Psychiatric Diagnostic Interview* (Current Procedural Terminology (CPT 90791)) [1], the *Health and Behavior Initial Assessment* (CPT 96150) [1], and the *Neurobehavioral Status Examination* (CPT 96119) [1]. The type of assessment procedure used is dependent on the goals of assessment and the nature of the diagnosis being treated (i.e., medical vs. mental health) (see Chap. 54, CPT and Billing Codes in this book). Irrespective of the procedure used, there is considerable overlap of information gathered.

The Health Insurance Portability and Accountability Act (HIPAA) seeks to protect patient information and provide standards for the transmission and storage of medical information [2]. Clinicians should be aware that HIPAA provides patients greater access to their health records, but some records still demand a greater level of protection (e.g., psychotherapy notes). This can create a challenge for providers with ensuring privacy and confidentiality while at the same time allowing for greater access to patient information. Be aware of privacy laws in your state that might require an even greater degree of protection than HIPAA. Clinicians should be mindful of what information they include in the medical record given the accessibility of the data.

C. ***Documentation***

General guidelines

Accurate and timely documentation are critical to safe and effective patient care. The clinician must be aware of hospital or facility policies on documentation requirements and timelines. Although there is institutional and practice variation, inpatient encounters are typically documented in the medical record on the day the encounter takes place. If a delay in providing a complete report is necessary, interim documentation needs to be done to communicate contact with the patient and any urgent information (i.e., "hold" note). Outpatient encounters are generally required to be completed within one week, although as EMR become more commonplace, quicker turnaround is becoming the new standard.

Interview reports

The interview report is used to provide a clear and concise initial impression and framework for developing an actionable treatment plan. The documentation should focus on pertinent information that guides patient care. Clinicians should work to avoid redundancy with other easily accessible parts of the medical record (e.g., medical history). Emphasis should focus on the factors assessed by psychology such as cognition, mood, behavior, social/environmental variables, impairments, and retained abilities or the patient's assets. Recommendations should make up the most significant portion of the interview report and should provide guidance to the team, patient, and family.

Progress notes

Progress notes provide encounter-specific information and documentation of treatment and intervention progress. The purpose is to document the clinician's intervention and that you are following acceptable standards of care and clear rationale and results of interventions. In multidisciplinary settings, progress notes allow the team to stay abreast of each provider's observations and interventions. Progress notes are significantly different than psychotherapy process notes, which might include hypotheses, treatment, or diagnostic considerations that are later discarded. Thus, information provided in the progress note should be brief and provide salient information to document and communicate important information to other clinicians for the explicit purpose of improving recovery. They are not intended to provide a detailed narrative. If the progress note is serving as the supporting documentation for billing purposes, which is often the case, the note must include required elements (e.g., date/time of encounter, procedure used, time devoted (if a time-based CPT), and diagnosis).

Tips

A. ***Steps for efficient record review***

1. **Determine the referral question**
    - May not be explicit.
    - Review physician requests in the "Orders" section or H&P.
2. **Review admission and H&P**
    - Review for emergency contact information of family members who can provide collateral information.
    - EMS data sheets that can provide information regarding injury specifics/dates of onset of illness and behavioral observations. For example, this can be particularly helpful when trying to determine head injury characteristics such as the length of loss of consciousness (LOC) and posttraumatic amnesia (PTA).
    - Review H&P for timeline of admission, results of the physical examination, pertinent medical history, family medical history, and results of initial diagnostic testing.
    - Look for evidence of psychiatric history—note mention of terms such as "depression" and "anxiety."
3. **Review consultation reports/ evaluations/progress notes**
    - Typically presented in reverse chronological order with the most recent information on "top."
    - May be helpful to compare original evaluations/notes with the most recent documentation to determine progress and trajectory.
    - Look for mention of the patient's emotional and psychological status, pain ratings, and behavioral observations.

  - SLP evaluations can provide information about cognitive status prior to formal neuropsychological testing.
4. **<u>Review pertinent imaging study reports</u>**
   - Neuroimaging studies provide information about the nature of central nervous system (CNS) damage (acute vs. remote) (e.g., hemorrhagic vs. ischemic stroke, diffuse cerebral axonal injury, focal contusion, traumatic hemorrhage, complete vs. incomplete spinal cord injury or impingement).
5. **<u>Review medication list(s)/pharmacy orders</u>**
   - Note common agents used for pain (e.g., opioids) and psychiatric management (e.g., SSRI, SNRI, benzodiazepine, antipsychotics, and MAOI).
6. **<u>Note important laboratory findings</u>**
   - Not typically in the purview of all clinicians.
   - Be aware of elevations and/or deficiencies that might contribute to cognitive or psychological symptoms.
   - Note evidence of substance use or intoxication.
   - Sections usually provide the acceptable/optimal value ranges for each test. Abnormal findings may be "flagged" as to bring to the attention of the reader. Electronic records often highlight abnormal findings in colored font.
7. **<u>Keep abreast of discharge planning</u>**
   - Review for any changes to length of stay or discharge disposition.
   - Note contact information for social work or case management professionals.

B. ***<u>Key components of a diagnostic interview, questions to address, and domains to be documented</u>***

This list is not exhaustive and should be tailored based on the referral question and the patient's capacities.

Identification—Basic demographic information such as age, date of birth, date of assessment, gender, and referral source

Reason for referral—A brief statement about *why* such an evaluation is being conducted

Informed consent—Document that the patient was made aware of the nature and reason for such an evaluation and the limits of confidentiality and that they agreed to the evaluation. Example: *Potential risks and benefits, limits of confidentiality, and test procedures were discussed. Following this discussion, the patient agreed to complete the evaluation.*

Chief complaint—What is the main reason for this evaluation? What symptoms initiated concern? Does the patient have a history of mental illness or treatment? Are there specific psychological or behavioral symptoms impeding rehabilitation progress?

History of present illness**—**Include a description of the onset of the patient's symptoms including level of severity and/or episodes. One goal here is to establish a timeline of the patient's symptoms, evolution of such symptoms, and any responses to intervention. It is useful to directly quote the patient's own words to describe symptoms.

Past medical history—Note any significant medical history including surgeries and hospitalizations.

Medications—List the patient's current medications. Be sure to note any discrepancies between medical records and the patient's report.

Psychiatric history—Include previous psychiatric diagnoses and any history of treatment (e.g., psychotropic medication management, individual/group psychotherapy, psychiatric hospitalizations). What was the response to treatment? Adherence to treatment? Is the patient currently in treatment?

Substance use—Ask about current and past substance use, both legal (e.g., ETOH, tobacco, prescriptions, marijuana in some states) and illicit. When did use begin? At what age? When asking about alcohol use, it helps to *assume* drinking by asking *How much alcohol do you drink?* This eliminates a simple yes/no answer while still allowing the patient to deny. Ask about frequency and nature of substance use (e.g., *how many* *drinks do you have in a typical day—typical week? how many days a week do you drink? what types of alcohol do you prefer?*). Inquire about past difficulties arising from substance use: family/marital discord, employment problems, and financial/legal problems (*have you ever been or has anyone else ever been concerned about your substance use*?). Does the patient have any history of formal treatment (i.e., detoxification, inpatient rehabilitation, response to these)? Results of formal substance abuse screening tools can be included here.

Family medical/psychiatric history—Document family members with history of chronic illness or treated or untreated mental disorders and/or substance abuse.

Social history—Report evidence of developmental delays (*Do you know of any problems with your mom's pregnancy with you? Did she ever say that there were complications? Did you walk and talk on time?* Is there history of abuse (e.g., emotional, physical, or sexual)? Document educational achievement, history of grade retention, or academic remediation (i.e., *special classes*). What is the patient's work history? Is the patient married/divorced/widowed/in a committed relationship? Number of children?

Current status:

Living environment—Type of dwelling (single-family house/mobile home/apartment), how many other residents?

Activities of daily living—Can the patient attend to basic tasks (e.g., feeding, bathing, dressing) independently? Instrumental tasks (e.g., cooking, cleaning, basic financial transactions)? In the acute medical setting, assistance is likely. Note the functional needs indicated by PT/OT documentation (i.e., contact guard, level of supervision, modified independence).

Mood status:

What is the patient's described mood? *Over the past couple of weeks including today, in a word or a phrase, how would you describe your mood? How have you been feeling?*

Sadness/anxiety: *Have you been feeling sad lately….anxious, tense, or nervous? How would you describe it (mild/moderate/severe)?*

Suicidal ideation: *Are you having any thoughts of hurting yourself? Do you want to hurt yourself? Do you have a plan?* Be sure to distinguish between passive thoughts of death (i.e., "I just want this pain to end") and active suicidal thoughts. *In the past, have you had thoughts of hurting yourself? When, what, why? Any attempts? What kept you from doing it?* If suicide is a concern, formal screening tools are available. It is imperative to document evidence of suicidality, assess intent, and take appropriate steps to ensure safety.

Energy, Interest, and Participation—What do you enjoy doing? (Assessing for loss of interest and/or anhedonia) *Are you doing more or less than you did before? What's keeping you from doing things?* Are limitations due to physical/environmental barriers or emotional factors?

Sleep quality—Are there changes in sleep quality such as insomnia, hypersomnia, or fragmented sleep? Does the patient have difficulty going to sleep, staying asleep, or both? Is the patient having nightmares? Is there evidence of a REM behavior disorder such as acting out dreams or waking in a different place than where they went to sleep? Does the patient use medication sleep aids? Does the patient use a breathing device (e.g., C-PAP)?

Appetite—Are there any changes in the patient's hunger? (Increased appetite, cravings, decreased appetite, or binge eating) Has there been unusual weight gain or weight loss? (How much and over what period of time?)

Strengths/assets—*What keeps you going? What things are important to you?* Inform providers about the person's values facilitating resilience as well as indications of patient's goals of care.

Behavioral observations and mental status:

This section provides the reader with the *context* in which clinical information was gathered and includes information about the patient's general presentation and emotional and cognitive status. This section should include only findings present and observable at the time of the interview. Behavioral observations and the mental status examination, in combination with historical data, form the basis for formulating a diagnosis and treatment plan. The format matters less than completeness and organization.

Who?—Note who was present during the evaluation. Include family members and staff. Include a statement about whether or not collateral information was provided by others (i.e., participation).

Appearance—Gender, race, does the patient look their stated age? Grooming and personal hygiene (e.g., disheveled, unkempt, adequate, well groomed), dress (e.g., casual vs. hospital attire), any distinguishing features of note (e.g., tattoos, piercings, wounds/scars, bandages, etc.), and build and stature (e.g., average, tall, short, large, thin).

***Motor*—**Evidence of gross or fine motor impairment? Is there evidence of lateralized deficit (e.g., unilateral/bilateral, worse on one side)? Does the patient utilize any assistive devices (e.g., cane, wheelchair, walker, hands-free device)? Note the patient's gait (unsteady, normal, shuffled, altered, short, long). If gait is not observed, state this.

***Sensorium*—**Describe the patient's basic vision and hearing. Is there evidence that these are decreased or altered? Does the patient report problems? Do they squint or frequently ask for information to be repeated or for the speaker to increase volume? Does the patient wear eyeglasses (if so, always, only for reading)? Does the patient have hearing aids (do they wear them)?

***Speech*—**Describe speech rate, volume, and prosody. Is there evidence of slowness? Is articulation intact or poor (i.e., do you have difficulty understanding them)? Slurring? Does the patient speak with an accent? Is volume normal, loud, or soft? Prosody—does the speech follow a normal cadence (e.g., rhythm, tone, pitch, stress, intonation)?

Thinking and perception:

***Orientation*—**Is the patient aware of person, time, and place? Often this is noted as "Ox3" which stands for "oriented in three spheres." You can also include whether or not the patient is aware of the situation (e.g., treatment, injury, timeline of events) or "oriented in four spheres (Ox4)."

***Thought process*—**Are the patient's thoughts linear, logical, and goal directed? Is there evidence of tangential thought, circumstantial speech, or circumlocution? If impaired, can you redirect the patient to the task at hand?

Thought content and language—Expressive—Is the patient's speech fluent? Is there evidence of word-finding difficulty, halting, or hesitations? Does the patient exhibit paraphasia (i.e., *phonemic*, "shammer" vs. "hammer"; *semantic*, "hammer" vs. "wrench")? Receptive—Is the patient's basic comprehension intact? Is there evidence of incoherence, neologisms, automatisms, "word salad"? Positive psychiatric symptoms (e.g., paranoia, hallucinations, delusions)?

Judgment and insight—Does the patient demonstrate understanding and appreciation of his or her condition/situation? Can they express a logical/appropriate course of action if given a scenario with attention to important details: (i.e., *what would you do if you saw smoke coming from the window of your neighbor's house*)?

Memory—Basic recall of recent and remote events. Is there evidence of rapid forgetting within the interview? Is the patient a reliable historian? Does patient report match medical records?

Formal cognitive screening tools are helpful in assessing key cognitive domains.

***Affect*—**Include a statement about the observed affect, notably whether or not behavior is congruent with the described mood. Common descriptors include *blunted, flat, indifferent, normal, expansive, agitated, reserved, pleasant, nervous, anxious, exasperated, happy, and tearful*.

Pain behaviors—Note any observation of pain behavior such as wincing, shifting, or vocalizations. If pain appears to be a significant contributing factor, consider utilizing pain-reporting scales.

Summary and impressions

This section provides the rationale for diagnosis and treatment by combining information from the patient's history as well as observations of behavior and mental status. The goal is not to reiterate the information already provided but instead to highlight the salient points that lead the clinician to arrive at a diagnostic conceptualization and strategies to address symptoms. This section can be brief but should include a clear rationale for diagnosis and future intervention.

Diagnosis

Documentation should include a clear diagnosis. Depending on the institution, this may be done using the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) [3], *International Classification of Diseases, Tenth Revision* (ICD-10) [4], or the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5) [5]. The multiaxial system used in *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR) [6] has been replaced with a non-axial system in the DSM-5. The former Axis I, II, and III diagnoses have been combined with separate notations for "important psychosocial and contextual factors" (formerly Axis IV) and qualifiers for severity, duration, and type to clearly identify the most appropriate diagnosis. DSM-5 also dropped the Global Assessment of Functioning (GAF) scale; however, the World Health Organization Disability Assessment Schedule (WHODAS) is referenced as a measure to help note level of disability important to treatment. The WHODAS is based on the International Classification of Functioning, Disability and Health for use across health-care domains. While the psychiatric diagnostic interview is used to identify mental health disorders, formal notation of disability status is a key area of focus in rehabilitation populations. Note—the diagnosis in an H&B assessment would be the primary medical diagnosis.

Treatment plan/recommendations

This portion of the interview note is of greatest interest to the team and potentially has the greatest impact on patient care. It is not an afterthought, rather the treatment plan/recommendations section is the culmination of the information-gathering process. An effective section provides detailed recommendations in response to the referral question, guidance to treatment team members in their care of the patient, and a description of actions the psychologist is going to take following the report.

C. ***Components of a progress note***

Documentation can take many formats (e.g., S.O.A.P, D.A.P). Irrespective of the format, documentation should include these key elements:

Date and time of documentation: When the patient encounter occurred.

Data: Subjective—How does the patient describe their problem or progress? Quote the patient directly and use their own words. Quotes should accurately capture the essence or theme of the session. Example: *I think I'm struggling…not sure what to do*. Objective: What are *your* observations of the patient's behavior/mood/status? Document what services were provided to the patient, and provide time documentation for billing. These are written as statements of fact. Example: *Provided 60 min of H&B intervention. Patient appeared initially indifferent but was later tearful and more engaged. Discussed alternative coping strategies and practiced relaxation techniques.*

Assessment: What is your impression of the patient's status? What progress has been made toward treatment goals? This section should include any serial objective assessment results (e.g., pain scales, mood screeners). Example: *Patient's subjective pain appraisal is increased as measured by objective screener. It will require continued monitoring and reinforcement of alternative strategies to opioid use.*

Plan: How will you support the patient in pursuing their established goals? Do goals need to be changed/altered? What recommendations do you have for other clinicians? Include any intent to contact or communicate with family or staff. Provide any updated information regarding timeline of treatment. Example: *(1) Continued work toward treatment plan goal of decrease in subjective pain levels by two points. (2) Patient will attempt to use thought stopping when negative thinking takes hold. (3) Patients will contact PT regarding potential co-treatment. (4) Next session scheduled for tomorrow.*

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Language of Rehabilitation

2

Kristina A. Agbayani

Topic

This chapter summarizes important terms commonly used in rehabilitation settings.

A. ***Common Language***

The World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) provides a common, standard language for classifying and describing health and health-related states in health and health-related sectors. The ICF is the WHO's framework for defining, measuring, and formulating policy in the realm of health and disability. The ICF describes a biopsychosocial model of disability that is illustrated in the figure below. This model incorporates the medical, physical, personal, social, and environmental aspects of disability. In this model, human functioning is defined by the physical, task, and societal levels, while disability involves a breakdown at one or more of these levels. Thus, "disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders, and injuries) and contextual factors. Among contextual factors are external environmental factors and internal personal factors that influence how disability is experienced by the individual" [1].

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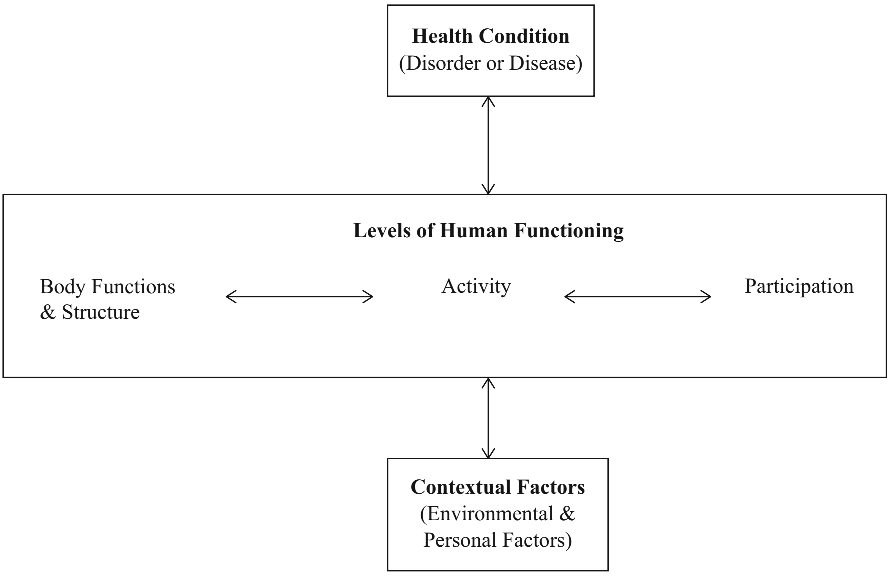
M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_2



1. **Functioning and Disability**

   Functioning refers to all *body functions and structures, activities, and participation.* Disability refers to a breakdown in each level of functioning, respectively, including *impairments, activity limitations, and participation restrictions.*
   - *Body functions and structures* refer to the physical level of body structures and their associated functions. *Impairments* are problems in body functions or anatomical structures, such as diabetes, amputation, or paralysis.
   - *Activity* occurs at the task level and refers to the performance of a task or action by an individual. *Activity limitations* involve disturbed abilities in the performance of usual age-appropriate activities, such as feeding, dressing, shopping, and operating a motor vehicle.
   - *Participation* occurs at the societal level and refers to involvement in a life situation. *Participation restrictions* involve disturbance in social role performance, such as vocational or recreational participation.
2. **Person- and Identity-First Language**

   The American Psychological Association (APA) has advocated using person-first language when referring to people with disabilities (e.g., "person with an amputation" rather than "amputee") to help reduce negative attitudes and stigma surrounding disabilities. However, disability culture advocates suggest the use of not only person-first, but also identity-first language (e.g., "amputee"). They assert that not all individuals with disabilities use person-first language, and that its exclusive use may unintentionally communicate that disabilities are undesirable and negative, as it separates the person from the disability. Alternatively, disability culture advocates suggest using both disability- and person-first language interchangeably, while taking into account individuals' and groups' preferences, which "ensures inclusion, addresses issues raised by disability studies and disability culture, respectively, and allows APA-style writing to evolve along with contemporary trends" [2].
3. **Medical Abbreviations**

   Significant system-wide efforts by the Joint Commission on Accreditation of Healthcare Organizations and Institute for Safe Medication Practices have been made to improve language precision in order to reduce errors and patient morbidity and mortality through the identification of error-prone and problematic abbreviations, symbols, and medication dose designations. For example, the abbreviation “tiw” may be misinterpreted as “3 times a day” or “3 times in a week.” Instead, it is advisable to write out “3 times weekly” to reduce misinterpretations and errors [3, 4]. The following are commonly used and permissible abbreviations in medical and rehabilitation settings [5]:

- ADL = activities of daily living
- AMA = against medical advice
- BKA = below knee amputation
- bx = biopsy
- cath = catheter
- CVA = cerebrovascular accident
- L.E. = lower extremities
- LOC = loss of consciousness
- L(R)UE = left(right) upper extremity
- L(R)LE = left(right) lower extremity
- MVC = motor vehicle crash
- NKA = no known allergies
- NPO = nothing by mouth
- OOB = out of bed
- prn = as needed
- PMH = past medical history
- ROS = review of symptoms
- SCI = spinal cord injury
- W/C = wheelchair
- WNL = within normal limits

B. ***Rehabilitation Programs***

The Commission on Accreditation of Rehabilitation Facilities (CARF International), founded in 1966, is an independent, nonprofit accreditor of health and human services in the field of medical rehabilitation, among others (e.g., aging, behavioral health). CARF International’s mission is to “promote the quality, value, and optimal outcomes of services through a consultative accreditation process and continuous improvement services that center on enhancing the lives of persons served” [6]. CARF accreditation is an ongoing process that applies set international organizational and program standards to service areas and business practices which highlights providers’ commitment to improving services, encouraging and utilizing feedback, and serving the community.

CARF-defined types of medical rehabilitation programs [7]

Program	Focus	Setting
Comprehensive Integrated Inpatient Rehabilitation	24-hour comprehensive rehabilitation driven by the individual’s needs and predicted outcomes	Hospitals, skilled nursing facilities, long-term care hospitals, acute hospitals, hospitals with transitional rehabilitation beds
Outpatient Medical Rehabilitation	Individualized, coordinated, outcomes-driven program geared toward early intervention that optimizes an individual’s activities and participation	Hospitals, freestanding outpatient rehabilitation centers, day hospitals, private practices
Home and Community Services	Promote and optimize the individual’s activities, function, performance, productivity, participation, and quality of life	Private homes, residential and community settings, schools, and workplaces
Residential Rehabilitation	Outcomes-driven services primarily focused on home and community integration and engagement in productive activities	Transitional or long-term settings
Vocational Services	Individualized services to help people meet their identified vocational outcomes	Hospitals, freestanding outpatient rehabilitation centers, residential and community settings, schools
Pediatric Specialty	Family-centered care primarily serving children/adolescents who have substantial functional limitations secondary to acquired or congenital conditions	Hospitals, freestanding outpatient rehabilitation centers, residential and community settings, schools
Amputation Specialty	Focuses on collaboration to inform perioperative care, prevention, minimizing impairment, maximizing independence, and maximizing quality of life	Hospitals, healthcare systems, outpatient clinics, community-based programs, transitional or long-term residential settings

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Program	Focus	Setting
Brain Injury Specialty	Focuses on the unique medical, physical, cognitive, psychosocial, behavioral, vocational, educational, and recreational needs of individuals with acquired brain injury	Hospitals, healthcare systems, outpatient clinics, community-based programs, transitional or long-term residential settings
Cancer Rehabilitation Specialty	Addresses preventative, restorative, supportive, and palliative needs unique to individuals diagnosed with cancer	Hospitals, healthcare systems, outpatient clinics, community-based programs
Spinal Cord System of Care	Focuses on identifying care options and facilitating utilization of such options, achieving predicted outcomes, providing and facilitating medical interventions, lifelong follow-up, providing education and training	Hospitals, healthcare systems, outpatient clinics, community-based programs, transitional or long-term residential settings
Stroke Specialty	Focuses on minimizing impairments and secondary complications, reducing activity limitations, maximizing participation and quality of life, and decreasing environmental barriers, and preventing the recurrence of strokes	Hospitals, healthcare systems, outpatient clinics, community-based programs, transitional or long-term residential settings
Interdisciplinary Pain Rehabilitation	Focuses on minimizing impairments and secondary complications, reducing activity limitations, maximizing participation and quality of life, and decreasing environmental barriers	Hospitals, healthcare systems, outpatient clinics, community-based programs
Occupational Rehabilitation	Focuses on return to work while minimizing risk and optimizing work capability	Hospital-based, outpatient programs, private or group practice, at the job site

C. ***Basic and Instrumental Activities of Daily Living***

1. **Basic ADLs or ADLs**: these include routine tasks of everyday life, including eating, toileting, bathing, dressing, and transferring.
2. **Instrumental ADLs (IADLs):** complex everyday tasks, including driving/independent transportation, managing the household finances, managing medications, phone use, shopping, cooking, and managing the home.
3. **Measuring independence with activities of daily living:**
    - Assessment of an individual's functional status is essential in determining his or her ability to perform tasks necessary for independent and safe living within the community. Additionally, independence with such tasks affects individuals' feelings of self-efficacy and perceived quality of life.
    - Can be used in combination with or are included in outcome measures (discussed below).
    - Can be assessed via interview with the patient and/or family/caregivers or through formal measures.
        a. The most commonly used measure of basic ADLs is the *Katz Index of Independence in Activities of Daily Living* [8].
        b. The most commonly used measure of IADLs is The *Lawton Instrumental Activities of Daily Living Scale* [9].

Importance

Given the multidisciplinary nature of rehabilitation settings, it is vital that a common language is utilized among providers across the various disciplines (e.g., medicine, nursing, physical therapy, occupational therapy, psychology) and with the patients and caregivers to optimize and ensure effective communication and treatment planning/goals.

Practical Applications

A. ***Outcomes Measurement***

1. **Purpose**
    - Outcomes are the desired benefits of rehabilitation program efforts, and reflect the quality of care and effectiveness of a particular program.
    - Results from outcomes measurement can be utilized to direct quality improvement within programs and organizations.
    - Of particular interest are measures that focus on an individual's level of participation, or involvement in and fulfillment of activities and roles within society (e.g., as an employee).
2. **Commonly Used Measures of Rehabilitation Outcomes**
    - *FIM™:* previously an acronym for Functional Independence Measure, is the most widely used measure of outcome. It is an 18-item ordinal rating scale of disability across seven areas (self-care, sphincter control, mobility, locomotion, communication, psychosocial adjustment, and cognitive function). It allows for tracking changes/progress in an individual's functional status in these areas over time [10].
    - *Disability Rating Scale (DRS):* a short, 8-item scale used frequently in traumatic brain injury (TBI) research to measure changes in adult TBI recovery. Total scores reflect level of disability, with the 8 items measuring eye opening, communication ability, motor response, cognitive ability to feed, cognitive ability to toilet, cognitive ability to groom, overall level of functioning, and employability [11].
    - *Craig Handicap Assessment and Reporting Technique (CHART):* consists of 38 items that measure the level of social integration of individuals with disabilities across six scales (physical independence, mobility, occupation, social integration, economic independence, and orientation). Also available in a 19-item short form (CHART-SF) [12].
    - *Extended Glasgow Outcome Scale (GOS-E):* The GOS-E extends from the original five categories to eight categories (Dead, Vegetative State, Lower Severe Disability, Upper Moderate Disability, Lower Good Recovery, and Upper Good Recovery) in a structured interview format [13].
    - *Satisfaction with Life Scale (SWLS):* a 5-item measure of life satisfaction and subjective well-being [14].

Tips

A. ***Language matters***

When possible, avoid the use of medical jargon and unfamiliar acronyms when providing information to the patient and family/caregivers, which can be confusing and overwhelming.

B. ***Be consistent***

Providers from various disciplines should use the same language/terminology among each other and with patients/family for consistency and to minimize confusion and misunderstanding.

C. ***Simplify***

Explain and simplify the terminology used, and provide information in both verbal and written format to improve communication and ensure understanding.

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Practical Ethics

3

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Topic

This chapter presents a proactive perspective of bioethics in clinical practice. The ethical foundations for this chapter can be found in Beauchamp and Childress's *Principles of Bioethics* [1] and in Jonsen, Siegler and Winslade's *Clinical Ethics* [2]. The ethics codes of every health care discipline comprising the rehabilitation treatment team provide the practitioner with a set of foundational principles and practice standards that act as field-tested guidelines for effective, efficient, and quality patient-centered care. The challenge for every practitioner is to translate the philosophically based tenets of bioethical principles into readily applicable referents that guide clinical practice. The practice standards embodied in ethics codes attempt to provide that translation from principle to application. However, becoming facile in the process of applying ethics standards requires both understanding and regular practice. To that end, we will endeavor to assist in skill building.

First, we provide the reader with an applied ethical decision-making tool with which to approach analysis of ethical conflicts. This clinical tool has been successfully implemented by individual practitioners and ethics committee consultation teams across several decades (see Kerkhoff and Hanson [3] for the latest iteration). Then we discuss various concepts that illustrate optimizing ethical practice in clinical settings. We then distill the content of the chapter into several practical tips gleaned from years of professional experience that emphasize the critical contribution of ethical thinking to provision of quality health care. Finally, a set of brief case scenarios will allow the reader to put into practice the ethics decision-making process. Accompanying commentary will clarify ethical issues embedded in the scenarios.

Importance

Each health care discipline in the United States has established and published discipline-specific ethics codes. These ethics codes, with which their members must comply to remain in good standing, and to attain and retain their licenses, have resulted in applied bioethics becoming almost indistinguishable from adherence to nationally accepted standards of care.

Contextual factors must be considered when ethics conflicts develop—supporting the ethical

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_3

principle of ***Justice***. Ethical conflicts do not arise in a social vacuum. However, it is easy to lose sight of contextual influences when the conflict to be resolved rises to the level of being noticed, often in dramatic fashion. A multiplicity of factors beyond the behavior of specific individuals contributes to situations in which ethical principles and/or standards are contravened. Consider broad-ranging issues like: business conflicts of interest, limits of confidentiality, financial constraints or incentives, allocation of scarce resources, issues of religious beliefs and values, clinical research and educational agendas, and public health and safety. Any or all of these seemingly peripheral factors may play roles of significance in the occurrence of ethical conflicts, and serve to increase the circle of key figures with personal or organizational interests in the conflictual situation. Thus, we urge the health care provider to be inclusive when initially evaluating the requirements of pursuing potential ethical conflicts to resolution.

Practical Applications

The first application of ethics concepts to everyday practice involves a useful tool for case analysis and decision-making, first published in Hanson, Kerkhoff, and Bush [4]. This tool remains a viable method for considering ethical implications of varied alternative solutions to ethical conflicts arising in the course of clinical service provision. The steps in this decision-making model are described in summary form below.

A. ***Ethical Decision-making Model***

Operationally defined, ethical conflicts involve a minimum of two ethical principles (e.g., autonomy, beneficence, nonmaleficence, justice) being in opposition.

Step 1. Critical Incident—An event involving a potential ethical conflict. Evaluate a critical incident in light of two initial responses: a) the incident involves an ethics conflict; b) the incident involves a difficult clinical decision. In the former instance, ethical analysis is warranted, whereas in the second situation the decision is referred back to the treatment team, often with supportive strategies appended.

Step 2. Ethics Principles or Concepts—Assistance with focusing investigative efforts is achieved when relevant factors in the critical incident are linked to ethical principles, concepts, or discipline-specific standards.

Step 3. Historical Context and Key Figures—Identifying biological, psychosocial, and physical environmental factors that may have influenced the situation under consideration provides a developmental and contextual view of the ethical conflict. Additionally, strategic inclusion of relevant figures or players helps to define and distribute decision-making roles and responsibilities.

Step 4. Organizational and Legal Issues—Identify organizational policy and procedure challenges [5], along with legal/statutory issues [6] that apply to the situation. Standards of care are pertinent in this analytical step, in order to address potential risk of negligent behavior. Involving organizational Risk Management or Legal Departments as consultants to the decision-making process may be appropriate in some instances.

Step 5. Resolution—After sufficient information regarding the facts of the situation has been amassed and shared for decision-making, the key figures are asked to propose potential strategic solutions to resolve the ethical conflict, along with pro and con arguments for each alternative resolution proposed. The goal is to reach consensus among the discussion participants regarding a desired outcome, keeping the welfare of the patient as the central focus of the process.

Step 6. Disposition—Implementation of the consensus resolution and tracking the actual outcome is the goal. If problems arise during implementation or the actual outcome differs significantly from the desired outcome, modifications of the resolution strategy can be proposed and attempts to resolve the conflict resume anew until an outcome satisfactory to the key figures is achieved.

While this ethical decision-making tool is described as a formal process potentially involving multiple individuals, a sole clinician can utilize this decisional rubric with ease, considering the relevant investigative steps, and then posing alternative resolutions with pro/con arguments for each. This single practitioner approach is most appropriate for use with narrow scope conflicts (e.g., a witnessed inadvertent breach of confidentiality to a single recipient; most ethics codes advocate a direct attempt by the clinician to rectify the situation). Nonetheless, the balanced decision-making process is preserved, simply reduced in scale. Finally, documentation of the pertinent details of the ethics decision-making process, outcome and recommendations to the treatment team should be entered into the patient's medical record.

B. *Ethical Issues in Clinical Practice*

1. Informed Consent

Autonomy is the ethical principle underlying consent. The elements of informed consent include: **a. Freedom from coercion** and**; b. Agency**—the ability to act upon an unhindered decision. Given the highly technical and complex nature of many health-related decisions, being "fully informed" can be an unnecessary burden upon the patient. Rather, being "adequately informed" is the norm. In this latter instance, the patient's ability to repeat the essential factors pertinent to the decision in his/her own words is sufficient. Emphasis upon understanding the factors inherent to any decision is the goal of health care provider communication. Only with adequately informed consent can the patient validly authorize evaluation and/or treatment. In the case of minors, the legal guardian has the sole authority to consent. However, assuming that the minor is capable of understanding the decision under consideration, seeking ***assent*** from the minor is strongly recommended. Assent simply increases the likelihood of compliance with and adherence to the requirements of a health-related intervention, while respecting the minor's personhood.

2. Treatment Refusal

This is a legal right supported in both federal and state statute, but it is also ethically supported in ***autonomous choice***. Any reasonably prudent person has the right to refuse recommended treatment, even if the treatment is justified by standards of care. An important factor for the mindful health care professional is that the patient's refusal should be knowing the benefits and risks attendant to the decision are clearly understood. An ethical caveat arises when there is a high likelihood of irreversible harm to the patient or others in the refusal (e.g., refusal to inform sexual partners in light of positive HIV test results). Only in such an extreme circumstance is the health care professional able to ethically exercise justified paternalism and intervene. Even then, the least autonomy-restrictive alternative action that will increase benefits and decrease risks is required. Finally, treatment refusal is most commonly observed when there is a lack of trust and understanding between the patient and health care professional—essentially framed as a self-protective response by the patient to perceived threat. Taking the time necessary to develop a truthful, honest, and open working relationship (rapport) is important to avoid such "reflexive" treatment refusals.

3. Disclosure

The moral rule of *veracity* underpins disclosure. The paternalistic view that disclosure of bad news or use of deceptive disclosure when the information is negative is harmful to patients has been proven blatantly false. Communicating truthfully and effectively regarding the probabilistic nature of anticipated benefits and risks related to evaluation findings, diagnosis, treatment, and prognosis is expected by both patients/families and peers. However, consideration of nurturing hope may require staged or incremental disclosure of negative information across time. Additionally, cultural and spiritual values and beliefs vary among individuals, and among practitioners alike. These contextual factors need to be accounted for in the sensitive and respectful manner in which disclosure is accomplished. Assuming the patient is cognitively capacitated, never disclose to family members before communicating with the patient, before securing the patient's release to talk with family.

4. **<u>Capacity or Competence</u>**

   Autonomous choice regarding self-determination supports decisional capacity. While capacity has traditionally been associated with cognitive function, with competence falling into the legal realm, the legal and cognitive applications of these two terms have converged in recent literature, rendering them effectively synonymous. Capacity, in fundamental terms, is the ability to perform a task. In the case of ethics, this cognitive task is decision-making. In order to make knowing decisions, the individual must be able to *both* comprehend and communicate the elements of the decision accurately. The complex networked cognitive processes necessary to accomplish this task are subject to significant variability when an individual's neurological status has been compromised in illness or injury. Indeed, serial assessment of cognitive capacity may be necessary when delirium, psychosis, or other severe affective state (anxiety or depression) are present. In the latter instances, the clinician is cautioned that the mere presence of severe anxiety or depression, or in some cases dementia, does not constitute sufficient grounds for automatically concluding decisional incapacity. Cognitive reasoning processes must be severely disrupted (and supported by evaluative evidence) to warrant a declaration of incapacity. In clinical settings, the dynamic and variable process of emergence from a confused mental state requires the clinician to amass as much observational data from health care staff attending the patient as practical, in order to determine a trend toward resolution of the confused state. Importantly, assessing varied cognitive domains, including attention and concentration, sensation/perception, learning/memory, executive and language functions, in the context of health history information is necessary when determining decisional capacity. The clinician can be confident about a patient's decisional capacity only when consistently accurate responses to cognitive processing tasks are secured across time. Failing to gain decisional capacity requires involvement of a **surrogate decision-maker**. The gold-standard in instances of surrogate decision-making is application of ***substituted judgment***. The surrogate's decision reflects the values, beliefs, and preferences of the patient when he/she was capacitated.

5. **<u>Standard of Care</u>**

   From the ethical perspective this concept is defined as what a patient is due and is based in the principle of ***Beneficence*** (doing good). The responsibility of a health care professional to keep abreast of his/her literature regarding best practices and incorporate relevant evaluative/interventive methodologies into practice, also involving adherence to community practice standards, serve to assure quality care. In a related issue, limits of confidentiality must be clearly communicated to each patient prior to initiating services. This informative communication clarifies protective boundary that governs the psychologist's professional responsibilities to both patient and the community. Continuing professional development in the form of periodic formal demonstration of competencies for peer review throughout one's career is becoming the norm and a requirement for specialty board certification in an increasing number of health disciplines. It must be noted that health care specialists are held to more stringent competency requirements than generalists. Finally, legal protections against malpractice are afforded health care professionals who demonstrate consistent adherence to currently established standards of care, assuming this adherence is clearly and frequently reflected in the patient's health record.

6. **Prevention of Errors**

   Practice errors inevitably occur in health care practice. The problem of medical errors speaks to the ethics principle of ***Non-maleficence*** (do no harm). If the Centers for Disease Control (CDC) kept data related to errors resulting in patient deaths, errors would be the 6th most frequent cause of death in the US health care system [7]; for background, see the original medical errors report from the Institute of Medicine [8]). Types of errors include: Technical, Judgmental, and Normative. ***Technical*** errors occur when training or information falls short of what the task requires (e.g., a trainee is asked to perform a procedure for which he/she has not been adequately trained). ***Judgmental*** errors involve a conscientious professional developing and following an incorrect "good faith" strategy (e.g., developing an exercise routine that results in a pattern of ligamentous joint injuries). ***Normative*** errors represent a failure to discharge a moral obligation conscientiously (e.g., failure to respect universal precautions with an immune-compromised patient, resulting in an acquired infection, despite regular service provider training in infection control procedures). It is important to note that any error on the part of a health care professional results in culpability. It is the responsibility of both health care providers and health care organizations to routinely incorporate error reduction strategies in everyday practice, to avoid a culture of blame, and to have available corrective mechanisms (e.g., root cause analysis) to investigate errors when they occur. While a charge of negligence can only be adjudicated when an error has caused harm to a patient, errors that result in no harm ("near miss") are invaluable data for review of error reduction policies and procedures.

7. **Supervision**

   Provision of expert supervision to professional trainees and treatment extenders (regardless of experience) addresses health care educational responsibilities, as well as state and federal statute and regulations, and supports the ethical principles of ***Beneficence and Non-maleficience***. Additionally, supervision provides a level of protection in service of patient safety. One of the responsibilities of health care supervisors is to ensure that the individuals under their responsibility are aware of rules and regulations that govern their job performance roles and boundaries of competence. Additionally, the working relationship between trainees/assistants/extenders and the supervisors should be based upon reciprocity. This concept assumes that both the supervisor and supervisee support honest and open bidirectional channels of communication, knowing that there will be supportive back-up when situations become challenging, and the creation of adaptive corrective action plans when necessary. Orienting new supervisees to the supervisory process and performance expectations is an important first step in ensuring that adequate knowledge of roles and responsibilities is communicated. The intensity and frequency of supervisory sessions are then determined by the performance of supervisees, directly related to the supervisor's knowledge of the supervisees' training experience and ongoing performance evaluation. Finally, mentors and supervisors fulfill different roles in the professional educational process. Mentors are typically characterized as aspirational guides or advisors for the budding health care professional, without a formal set of legal responsibilities regarding the trainee's work performance. Supervisors, on the other hand, are directly responsible for the work performed by their supervisees, and must maintain a level of vigilance over those working under their guidance.

C. ***Case Scenarios***

Instructions: In this practical exercise, the reader is encouraged to carefully review each scenario and attempt to identify relevant ethics concepts. Additionally, the authors suggest that the reader take on the role of a key figure or figures (to appreciate differing perspectives) in the scenarios and rise to the challenge of reaching a practical solution to the ethical conflict presented. Finally, read the Commentary and compare your ideas with those of the authors.

The following case scenarios are largely fictitious for educational purposes. However, selected elements of the scenarios are loosely based upon actual cases. In all instances, patients were adequately informed and consented to allow de-identified aspects of their personal health information to be used for educational purposes.

1. **Cedric Finthingmold**

A retired senior citizen who prided himself in being "old school." He proffered blind trust upon any health care professional providing him services. "After all, he'd say, those people went to school longer than it took me to grow up. They oughta know what they're about." When Cedric heard from a specialist, to whom he'd been referred by his PCP, that he had been diagnosed with a serious illness, he readily agreed to invasive and aggressive treatment. He barely understood the technical words used to explain the procedure and couldn't recall any mention of possible complications. However, once OP treatment had begun, Cedric complained bitterly to the tech administering the IV agent about the pain and cramping of the procedure, stating that he couldn't go about his everyday life. He asked if there was anything else that could be done, and threatened to go to management if nothing was done to relieve his suffering. What are the ethical concepts involved and what should the tech do?

COMMENTARY

This scenario addresses several ethics concepts. The first is *informed consent*. While Cedric didn't have any mistrust issues impeding his comprehension of the treatment explanation provided by the specialist, he likely erred on the opposite side of the issue. His blind trust in any acknowledged expert may have clouded his ability to weigh alternative treatment options, assuming that they were indeed offered by the specialist during disclosure. *Adequate disclosure* of relevant health information, beyond the diagnosis, was apparently ineffectively accomplished in this case. The patient certainly has the *right to refuse treatment*, but he apparently desired an alternative treatment that did not negatively affect his quality of life. Providing this information is a next important step in the ongoing provision of data that would allow adequate informed consent—in this case, a process that likely has to occur incrementally to allow Cedric time to both comprehend and consider his choices. It is easy to appreciate the intertwined relationship between disclosure and informed consent. The ethical challenge for the specialist is the fact that treatment was begun without sufficient evidence that the patient understood the implications of his consent. Adjusting the style of disclosing pertinent information to allow Cedric to make a balanced treatment decision is critical. Finally, the tech—staying within *boundaries of competence* and job description—is required to alert the specialist of the patient's concerns.

2. **Garnette Portchleight**

   A recent graduate Physical Therapy Assistant, was asked by her supervising therapist to provide a specific exercise to a patient. Unfortunately, Garnette was unfamiliar with that treatment procedure, but felt embarrassed to admit this. Her supervising PT was very busy, as was the whole clinic. Garnette wanted desperately to impress her supervisor with her initiative and energy. So, she made her way to the clinic treatment resource files and located a rather general exercise protocol that resembled the specific treatment mentioned by the PT. Garnette then explained and administered the treatment to the patient, who readily agreed. Unfortunately, the patient experienced a severe muscle rupture during the treatment. What are the ethical issues involved, and what should both Garnette and her supervisor do?

   COMMENTARY

   Several ethical and organizational/legal issues arise in this case scenario. ***Boundaries of competence*** applies to the PTA's lack of sufficient expertise and experience to administer the specific exercise regimen described by her supervisor. Failing to question the busy supervisor regarding the regimen and mention of the fact that she was unfamiliar with that treatment may have altered the PT's actions, resulting in re-prioritizing treatment activities, closer supervision, and offering instruction. The supervising PT is ultimately accountable for the actions of trainees assigned to him. Providing necessary and sufficient *supervision* in a manner that meets the varied needs of trainees, treatment extenders, and protects patients is required for ethical practice, as well as being specified in health care organization policy and procedure.

   A ***technical error*** was committed in this case by the inadequately experienced PTA. This error resulted in harm to a patient, meeting the definition of ***inadvertent negligence***. Responsibility for this error lies with the PTA, with her supervisor, and with the health care organization—since the injury occurred on the clinic premises. Failure to follow ***standard of care*** (PT and PTA) and organizational ***policy and procedure*** regarding supervision are notable. The supervising PT and the PTA need to provide needed treatment for the patient's muscle rupture, support the patient—offering an explanation of what occurred, and ensure follow-on care. Next, they need to alert management and carefully fill out an incident report detailing all relevant facts. From an organizational perspective, risk management involvement to address liability and a continuing quality review of the incident should be undertaken, with appropriate revisions to policy and procedure in order to reduce the likelihood of such incidents occurring in the future.

3. **Dr. Melchiore Mitchell**

   A Rehabilitation Psychologist, was asked to immediately respond to a nurse calling for assistance with a patient newly admitted to the rehabilitation facility. As he walked down the long hall toward the patient's room, Dr. Mitchell became aware that there was loud yelling issuing from the room that was his destination. Upon entering the room, it was immediately obvious that the patient was assailing CRRN Bobbie Plaincoat with repeated demands to leave the facility. After introducing himself, and excusing the relieved nurse, Dr. Mitchell asked the patient to help him understand the situation. Afton Smedley, a 49-year-old unemployed baker, launched into a vitriolic explanation of how he had been "railroaded" into coming to the rehabilitation facility by his doctor, who didn't tell him that he was not permitted to "smoke cigarettes OR weed," and was then expected to do regular painful exercises with a broken hip! He went on angrily to explain that he was entitled to smoke "medical marijuana" for his chronic pain condition and planned to take his sweet time getting better from his broken hip (fall from a bar stool, with an ED blood alcohol level of 1.8). Mr. Smedley then stated that the consent form to treat and bill for physician services was "shoved in my face, with print smaller'n a flea"; he concluded with a refusal to sign what he considered "that torture agreement," and demanded immediate release. What are the ethical issues involved, and what should Dr. Mitchell do?

COMMENTARY

The first issue to be addressed relates to current trends in tertiary program admissions from acute care hospitals; that being management of the DRG (diagnostic-related group) system to optimize reimbursement and open beds for anticipated admissions. Facilitating rehabilitation facility admissions is an intensely complex process involving monitoring patient health status regarding admission criteria, addressing the attending physicians' follow-up plans to provide proper follow-on care and treatment, exploring patient and family preferences, awaiting health insurance authorization, not to mention competing with other rehabilitation programs for the same patients. In the midst of this complex "dance," patient awareness of transitional care and treatment plans is often limited, partially by health conditions and treatments that often impede complex cognition required for decision-making, and failure to adequately explain the workings of the health care system before decisions need to be made.

In this case, the patient reported not being aware of the behavioral restrictions and performance expectations attendant to rehabilitation facility admission; implying that had he known, he would have elected to return directly home. Congregate living in a rehabilitation facility milieu is part and parcel of the therapeutic process, requiring accommodating all manner of personal preferences, and at the same time creating social boundaries necessary to maintain orderly operation, promote program participation, and ensure patient safety. Note that Mr. Smedley's perspective does not appear to be one of minimizing his health needs, but seems to be based upon external constraints upon his lifestyle choices. Questions remain regarding him being *adequately informed during disclosure* of his health status in the acute hospital. His *right to refuse treatment* (including rehabilitation admission) remains valid regardless of his level of understanding of his health care and treatment needs. From the ethics perspective, the patient's awareness of his health status and possible risk exposure linked to pushing for rehabilitation discharge should be carefully explored, in order to provide him with information necessary to make a *knowing and balanced decision*. However, Mr. Smedley's willingness to open himself to that information or encouragement to remain in the program from Dr. Mitchell remains suspect.

Further, we must attempt to determine if this patient is actually pushing for immediate discharge, or is instead asking for a relaxation of organizational rules and regulations to accommodate his personal preferences. In health care organization ethics (see Weber [5]), the rehabilitation facility's goals (providing for patient safety and quality health services) trump *patient preferences* (smoking and inconsistent treatment participation), but not *patient rights* (treatment refusal, including immediate discharge). Again, the patient's willingness to negotiate in good faith remains open to challenge. If discharge is elected by the patient, the program is ethically obliged to arrange proper community-based follow-on care *(standard of care)* in light of his health needs. Failure to provide this necessary linkage to the health care system could be interpreted as abandonment. In cases where patient safety is considered at risk with an abrupt discharge prior to rehabilitation program completion, adding Social Services to the Home Health Care team is urged. In extreme cases of probable health and safety compromise, referral to the local Health Department, division of Adult Protective Services is recommended. Finally, any decision to discharge must be authorized by the admitting physician, who may choose to discharge against medical advice—a possibility with negative consequences that must be explained to the patient prior to effecting discharge.

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Tips

- A fundamental approach to **all** clinical service delivery turns on the ethics concept of the patient *authorizing* your evaluation and/or treatment. This concept is based in ***Respect for Autonomy*** and presumes several important ethical considerations: adequately informed consent, disclosure of benefits and risks, communication regarding limits of confidentiality and demonstration of focal virtues to engender trust in the patient. This epitomizes patient-centered care.
- Trust-building necessarily takes time, repeated contacts, and reinforcement in order for the health care provider and patient to establish a reciprocal professional relationship. Gathering personal information that provides a context within which to evaluate and treat the patient increases the likelihood that evaluation and treatment services rendered will be relevant to and accepted by the patient and family.
- Thorough knowledge of the current interpretation of ethics code principles and standards is given for all ethical health care practice. The clear benefit stemming from this knowledge base is the awareness that ethics codes are iterative, with episodic updates reflecting the evolution of specific discipline-based values and practices, along with addressing ethical responses to broader societal mores and values. Applied ethics is a proactive and positive process.
- Continuing professional development of the focal virtue of *discernment* throughout one's career imbues the health care provider with skills to focus upon relevant issues embedded in clinically challenging situations, resistance to distraction (especially emotionally laden factors peripheral to the problem), and practical decision-making. Discernment combines critical personal attributes required for effective leadership in a team treatment environment.
- Consider any potential ethical conflict as involving more parties and influencing factors than just those present in and relevant to the immediate situation under consideration. Exhaust all possible opportunities for inclusion

in the ethics problem-solving process, even if such participation by individuals and/or organizational representatives is peripheral or consultative to the active discussion surrounding generation of alternative resolutions among key figures.

- Consider a successful ethics conflict resolution (desired and actual outcomes realized) as an opportunity to advise management regarding modification of organizational Policy and Procedure and initiating treatment team education in order to reduce the likelihood of such an incident occurring in the future.
- Finally, mindful and intentional incorporation of ethical principles espoused in the APA Ethics Code (2010) [9] into daily professional activities can serve as a preventative strategy to reduce ethical and legal risk.

The societal emphasis upon applied clinical ethics in recent decades has added an encouraging positive dimension to training health care professionals working in the field of medical rehabilitation, by providing discipline-specific guidelines for effective professional practice. What was earlier often a specialized topic in philosophy courses, focused upon development of formal arguments for debate, has now become an applied decision-making skill set with expected mastery by members of the varied health care disciplines comprising the interprofessional treatment team. It is this hands-on, user-friendly approach to applied clinical ethics that forms the foundation of quality patient-centered care.

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Assessing Acute Mental Status: Basic Laboratory Findings

4

Rebecca Baczuk and Marlís González-Fernández

Topic

The onset of encephalopathy may be difficult to detect on the rehabilitation floor for a variety of reasons. The rehabilitation patient's premorbid cognition may be unknown making it difficult to detect decline or subtle changes in a patient's mental status may be masked by their acute illness (e.g., cognitive slowing after stroke may mask a metabolic deficiency). However, there are several causes of encephalopathy which may be elucidated through laboratory analysis. This chapter is intended to assist clinicians in the diagnosis of reversible causes of encephalopathy using basic laboratory findings.

Importance

Use this guide to help identify laboratory abnormalities which may point to exacerbating factors or potentially reversible causes of encephalopathy.

Practical Applications

This chapter is intended to assist clinicians in the diagnosis of acute or chronic encephalopathy using basic laboratory findings.

A. ***Basic Labs*** [1]: reasonable to order when an etiology is not apparent.
  1. **Complete Blood Count (CBC)**: blood, with or without differential
    a. **White Blood Cell (WBC) Count**: adding a differential count should be considered to provide more detailed information if infection or inflammation is suspected.
      i. **Increased Neutrophils**: infection (usually bacterial, also viral, fungal); inflammation (acute rheumatoid arthritis, myositis, vasculitis, hypersensitivity reaction); metabolic (uremia, diabetic acidosis); drugs (heparin, lithium, histamines, steroids). Symptoms: none, particularly in the early stages of infection and may precede fever, fatigue, cough, and other signs and symptoms of infection.
      ii. **Increased Lymphocytes**: infection (usually viral, some bacterial), protozoan (toxoplasmosis), inflammation (ulcerative colitis), metabolic (hypoadrenalism), hematologic

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_4

disorders (multiple myeloma, aplastic anemia, leukemia). Symptoms: see (i) above.

b. **Hemoglobin (Hgb)/Hematocrit (HCT)**: Hgb level reflects the oxygen carrying capacity of blood. The HCT can be calculated or measured directly (by blood centrifugation) to determine the volume of red blood cells present.

i. **Increased** (polycythemia) in dehydration, high altitude, chronic tobacco use, shock/surgery/trauma/burns. May also be due to a genetic mutation (polycythemia vera) with an associated increase in WBCs, platelets, splenomegaly, and risk of stroke. Symptoms: none; in rare, severe cases headache, dizziness, fatigue, pruritus, night sweats, bone pain.

ii. **Decreased** (i.e., anemic) in nutritional or genetic deficiencies (vitamin B12, folate, iron, G6PD enzyme), blood loss, dilutional (pregnancy, edematous state), renal failure, chronic disease, congenital disorders (thalassemias, sickle cell). Symptoms: (from hypoxemia): pallor, dizziness, fatigue, malaise, dyspnea, tachycardia, confusion.

c. **Platelet Count**:

i. **Decreased (i.e., thrombocytopenia)** due to increased destruction (e.g., autoimmune diseases, infection, disseminated intravascular coagulation—DIC, heparin-induced), decreased production (e.g., leukemia, aplastic anemia, radiation, chemotherapy, genetic), drugs (e.g., valproate, Plavix), pooling (splenomegaly), liver disease, toxins (e.g., snake bite). Symptoms: none; in severe cases (critically low-level platelet count<$10 \times 10^3/\mu L$) bleeding (e.g., gingival bleeding, petechiae, epistaxis). Intracranial bleeding may result in symptoms of stroke.

2. **Basic Metabolic Panel (BMP): Blood**

a. **Sodium**

i. **Increased** in Cushing's syndrome, Diabetes Insipidus, diabetes, dehydration (especially from gastrointestinal loss). Symptoms: fatigue, confusion.

ii. **Decreased** in Syndrome of Inappropriate Diuretic Hormone (SIADH), Cerebral Salt Wasting associated with brain tumors, drugs (e.g., diuretics), dilution (IVFs, water intoxication), hypothyroidism, steroid/adrenal deficiency, CHF, nephrotic syndrome, GI loss (diarrhea and vomiting). Symptoms: agitation, delirium, muscle cramps, confusion.

b. **Potassium**

i. **Increased** in renal failure, drugs (potassium supplements, insulin, beta blockers, digitalis), muscle damage (e.g., drugs, alcohol abuse, injury), discontinuation of steroids (e.g., adrenal insufficiency), acidosis (on arterial blood gases). Symptoms: Can cause arrhythmia (ECG: peaked T waves); usually no other symptoms. If muscle damage is suspected, a CK level would also be increased.

ii. **Decreased** in GI loss (vomiting/bulimia, low magnesium, nasogastric tube, diarrhea, laxative abuse), urine loss to diuretics (e.g., lasix, hydrochlorothiazide) or excess steroids (e.g., Florinef or Cushing's syndrome), and alkalosis (on arterial blood gas). Symptoms: Can cause arrhythmia (ECG: flattened T waves), fatigue, muscle weakness, muscle spasm, paresthesias.

c. **Blood Urea Nitrogen (BUN)**

i. **Increased** in dehydration, GI hemorrhage, renal disease, steroid therapy, high protein diet, burns, congestive heart failure. BUN/Creatinine ratio is usually 10:1; 15–20:1 indicates prerenal etiology

        (usually dehydration). Symptoms: no direct symptoms.
    ii. **Decreased** in liver disease, malnourishment, SIADH, pregnancy. Symptoms: no direct symptoms.
  d. **Creatinine**: creatinine clearance is calculated to gauge kidney function
    i. **Increased** in acute or chronic renal injury, muscle injury, and dehydration. Symptoms: dizziness, lightheadedness, fatigue.
    ii. **Decreased** in patients who are cachectic (due to low muscle mass), muscle disease, and amputees. Symptoms: None.
  e. **Glucose (fasting)**
    i. **Increased** in diabetes, Cushing's syndrome, carcinoid, drugs (phenytoin, steroids, diuretics), infection, stress. HgbA1c (ideally <6.0) should be obtained to differentiate a chronic versus acute process.
    ii. **Decreased** in malnutrition, infection (malaria), malignancy, liver disease, adrenal insufficiency, overtreatment (usually in diabetics) may also occur as a result of increased exercise. Symptoms: anxiety, nervousness, sweating, hunger, palpitations, flushing, nausea, confusion, fatigue, dizziness.

3. **Urinalysis (UA):** If there is suspicion of urinary tract infection (UTI), e.g., dysuria, frequency, or urgency, with a normal UA, a urine culture should be ordered. UTIs are a common cause of mental status change in the elderly (see TIPS below).

Some common lab values [2]

Test	Specimen	Normal range
WBC count	Blood	3.9–10.7 × 10^3 cells/μL
Hemoglobin	Blood	12–17 g/dL
Hematocrit	Blood	36–51 %
Platelet count	Blood	150–350 × 10^3/μL
Sodium	Blood/serum	136–145 mEq/L
Potassium	Blood/serum	3.5–5 mEq/L
Chloride	Blood/serum	98–106 mEq/L
Bicarbonate (CO$_2$)	Blood/serum	23–28 mEq/L
BUN	Blood/serum	8–20 mg/dL
Creatinine	Blood/serum	0.7–1.3 mg/dL
Glucose (fasting)	Blood/serum	70–105 mg/dL

   The below values are usually absent or negative with a **normal UA**:

   a. Protein: usually absent; present in renal disease
   b. Leukocyte esterase (released from leukocytes): present in UTI and/or inflammation of the urinary tract
   c. Glucose: present in diabetes mellitus (DM), pancreatic disorders, liver disease, drugs (steroids, diuretics).
   d. Nitrite (produced by certain bacteria): present in UTI
   e. Bilirubin: present in liver and biliary tract disease
   f. RBCs: present in renal disease, UTI, urinary tumor, urolithiasis
   g. Ketones: present in uncontrolled DM, starvation, vomiting/diarrhea, alcoholics
   h. Specific Gravity (SG): nml range 1.00–1.03; elevated SG may indicate dehydration, SIADH

B. ***Secondary Blood Tests***

Should be considered if the history (e.g., alcohol abuse), signs/symptoms (e.g., jaundice, hallucinations), or basic labs (e.g., elevated transaminases) warrant further investigation into the cause of acute or chronic mental status change.

1. **Cerebral Spinal Fluid (CSF)**

   Obtained through lumbar puncture; contraindicated if coagulopathy is present (e.g., on Coumadin, presence of liver disease) or in the presence of papilledema.

   a. Opening pressures: increased in meningitis, tumors; normal in multiple sclerosis (MS).
   b. Protein (IgG antibodies): increased in encephalitis, meningitis, MS, cerebral abscess/tumor, post-infectious polyneuropathy (e.g., AIDP/CIDP), Intracranial Hemorrhage (ICH) and stroke due to increased permeability at the blood–brain barrier.

    c. WBC count: increased in bacterial and viral meningitis, MS.
    d. RBC count: increased in ICH.
    e. Glucose: decreased in bacterial, fungal, or TB meningitis.

2. **Toxicology Panel**: Blood and Urine Drug Screen (UDS) [3]

   Most toxicology panels are fairly extensive, and include dozens of analytes such as salicylates, alcohol, amphetamines, barbiturate, acetaminophen, iron, lead, THC, carbon monoxide, ethylene glycol, benzodiazepines, morphine or other opioids, PCP, tricyclic antidepressants. Adding prescription medications may be indicated.
3. **Liver function tests (LFTs)**: Serum ALT and AST are elevated in liver disease, exercise, myopathy, medication (e.g., acetaminophen, antibiotics, several diabetic and cardiovascular meds, valproate, tizanidine); 10× normal indicates severe hepatic disease. Gamma glutamyl transpeptidase (GGT) is often added to rule out bone pathology and to help confirm liver disease.
4. **Ammonia (NH3)**: Increased in liver disease, sepsis, GI bleed, medication (valproate), genetic metabolic disease.

C. ***Differential Diagnosis of Encephalopathy*** [4]

1. **Metabolic**
    a. Electrolyte abnormalities
        1. Calcium
            a. Increased: associated with renal disease; fatigue that can progress to coma.
            b. Decreased: associated with hypomagnesia; weakness, hallucinations, behavioral changes.
        2. Phosphate (decreased levels): associated with renal disease; symptoms include weakness (esp. diaphragm), confusion, ataxia.
        3. Sodium: see BMP (above).
    b. Liver disease: check for trigger (exacerbation of liver disease, cerebral edema, infection, alcohol, high protein intake, drugs such as diuretics, GI bleed); check LFTs, NH_3.
    c. Renal failure: seen in acute and chronic disease; symptoms may include behavioral change (psychosis), memory deficit, disordered sleep. Symptoms improve with hemodialysis.
2. **Nutritional/Dehydration**
    a. Vitamin abnormalities
        i. B1 (thiamine) deficiency: Wernicke's encephalopathy (triad of ataxia, ophthalmoplegia, and confusion), Korsakoff psychosis; associated with alcohol use, malnutrition, chemotherapy. Should be supplemented with other B vitamins.
        ii. B3 (niacin) deficiency ("pellagra"): Symptoms are three Ds: diarrhea, dermatitis, dementia.
        iii. B6 (pyridoxine) deficiency: may occur when taking isoniazid (INH-tuberculostatic) without B6 supplementation; irritability and confusion.
        iv. B9 (folate) deficiency: associated with B12 deficiency (megaloblastic anemia), tobacco and alcohol use, malabsorption, hepatorenal disease; several drugs interfere with absorption (valproate, salicylate, metformin, methotrexate). May cause irritability and depression.
        v. B12 (cobalamin) deficiency: may be due to decreased absorption in gut (pernicious anemia); if severe may cause confusion, dementia.
        vi. D deficiency: may cause weakness, fatigue, depression.
    b. Malnourishment: due to anorexia/bulimia, also medication side effect, chronic illness (renal disease, cancer); associated with anemia, low WBCs, electrolyte imbalance (low sodium, potassium), urine ketones. Testing prealbumin, albumin, and cholesterol should be considered.
3. **Toxins: toxicology panel (blood) and screen (urine)**
    a. Illicit drugs: Urine and blood toxin screens (new admission, visitors providing illicit prescriptions).

b. Supratherapeutic levels/overdose of prescribed medications (phenytoin, quinidine, isoniazid, tricyclic antidepressants (TCAs)); check specific drug levels, performing ECG should be considered (e.g., TCA may show increased QRS duration).
    i. CNS depression: narcotics, barbiturates, benzodiazepines, hypoglycemic, beta blockers, lithium.
    ii. CNS stimulation: anticholinergics, stimulants (e.g., methylphenidate), phenothiazines (e.g., promethazine), theophylline, digoxin, phenytoin.

c. Medication side effects: Anticholinergics (esp. TCAs, diphenhydramine), opioids, digoxin, sedatives, immunosuppressants after transplant (e.g., FK 506 tacrolimus, steroids, cyclosporine).

d. Withdrawal syndromes:
    i. Alcohol: (see B1 deficiency above). Reversed with IV thiamine (IV "banana bag" containing vitamins and minerals esp. thiamine, magnesium, and folate).
    ii. Narcotics: nausea, vomiting, irritability.
    iii. Benzodiazepines: nausea, vomiting, irritability, insomnia, anxiety, panic attacks.
    iv. Barbituates: irritability, tremors, insomnia, psychosis, and seizures.

e. Environmental Toxins: if indicated by history
    i. Carbon monoxide: via ABG, may be elevated in smokers; due to hypoxia, may cause delayed encephalopathy. [5]
    ii. Cyanide: inhaled in fire (especially burning furniture); note oxygen supply is adequate but extraction of oxygen to cells is impaired causing confusion, tachypnea, tachycardia, and coma.
    iii. Heavy metals:
        1. Lead: ingestion, respiratory, skin; headache, anemia, anorexia, nephritis.
        2. Mercury: consumption of fish, occupational, e.g., "Mad Hatter" disease, urine mercury more accurate than serum.
        3. Copper (Wilson's disease): disorder of copper metabolism causing liver disease, neurological symptoms, and Kayser–Fleischer corneal rings.

4. **Infection and Inflammation**: Look for signs/symptoms (e.g., elevated WBC count, fever). If infection or inflammation is suspected in the context of mental status change, imaging (CT or MRI brain) should also be considered.
    i. Encephalitis, Meningitis (e.g., HIV, HSV, toxoplasmosis); obtain CSF, blood cultures.
    ii. Sepsis: often from UTI in the elderly, pneumonia, infected wound, or other site; obtain UA and cultures of blood, urine, wound (if indicated), sputum (if productive cough); consider imaging.

5. **Endocrine**
    a. Diabetes Mellitus: Diabetic Ketoacidosis, ketosis, lactic acidosis.
    b. Adrenal Insufficiency (AI): most often from autoimmune disease (Addison's), more acutely from sudden withdrawal of long-term corticosteroid administration, or infection Waterhouse–Friderichsen syndrome. Usually, 21-hydroxylase autoantibodies (autoimmune); BMP, cortisol, ACTH test utilized to confirm diagnosis. Symptoms: dehydration, weight loss, fatigue, anorexia, dizziness, disorientation.
    c. Thyroid: hyper- and hypothyroidism are most often due to an autoimmune process. If a thyroid-stimulating hormone (TSH) level is abnormal, a full thyroid testing panel should follow. Symptoms:
        i. Hyperthyroidism (usually Graves' disease) causes positive symptoms (agitation, weight loss, diarrhea, GI upset, tachycardia).

    ii. Hypothyroidism causes negative symptoms (weight gain, fatigue, decreased cognition).

d. Pituitary Insufficiency: most often due to pituitary tumor, less often radiation, infection; is associated with traumatic brain injury. The pituitary directly affects hypothalamus, thyroid, and adrenal function through hormonal feedback loops thus hormones levels are used to help confirm diagnosis (cortisol, ACTH, LH, FSH, prolactin, TSH, GH). Symptoms: see AI and hypothyroidism (above), also polydipsia, polyruria in Antidiuretic Hormone (ADH) deficiency.

e. **Delirium**: Secondary to prolonged hospital stay. Disturbance in attention and cognition which develops over a short period of and tends to fluctuate during the course of the day. May be seen at all ages, but most common in the elderly.

Tips

- An infectious etiology is usually more acute in onset while a metabolic one is usually more insidious.
- Have a low threshold for including UTI in the differential diagnosis in the elderly as it may be elusive due to comorbidities (e.g., baseline urinary retention may mask new onset urinary frequency, diabetic neuropathy may mask dysuria) and the elderly have a decreased immune response such that an elderly patient with a UTI may have a normal WBC count and be afebrile. Patients may present only with vague symptoms of fatigue, dizziness, agitation, or confusion in the absence of other signs or symptoms of UTI which may otherwise be attributed to aging.
- Check the medication profile, both home and inpatient, to look for common side effects of new medications, drug-to-drug interactions between prescribed and over the counter medications, noncompliance (under- or overdose), and withdrawal in the event certain home medications were omitted from the inpatient medication profile.

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5

Neurological Examination and Classification in Spinal Cord Injury

Steven Kirshblum and Monifa Brooks

Topic

Accurate communication between clinicians and researchers working with persons with spinal cord injury (SCI) requires that consistency be used in the classification of neurological impairment. The most recognized and standardized method for performing the neurological examination and classifying the injury is based upon the International Standards for Neurological Classification of SCI (ISNSCI). This was first developed by the American Spinal Injury Association (ASIA) in 1982 and has since been revised a number of times; most recently in 2011 with an update in 2015 with a new worksheet [1–3]. The ISNSCI describes the components of the examination used to help classify the injury utilizing the American Spinal Injury Association (ASIA) Impairment Scale (AIS).

A. ***Definitions used in SCI***

1. **Tetraplegia**

   The impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within spinal canal.

   - Impairment of function in arms, trunk, legs, and pelvic organs.
   - Replaced the term "quadriplegia" in 1992
   - Does not refer to brachial plexus lesions or injury to peripheral nerves (those located outside the neural canal).

2. **Paraplegia**

   Impairment or loss of motor and/or sensory function in thoracic, lumbar, or sacral (but not cervical) segments of the spinal cord.

   - Trunk, legs, and pelvic organs may be involved, but arm function is spared.
   - Also refers to cauda equina and conus medullaris injuries but not to lower motor neuron lesions, such as lumbosacral plexus lesions, or injury to peripheral nerves outside the neural canal.

3. **Dermatome**

   Area of skin innervated by the sensory axons within each segmental nerve (root).

4. **Myotome**

   Collection of muscle fibers innervated by the motor axons within each segmental nerve (root).

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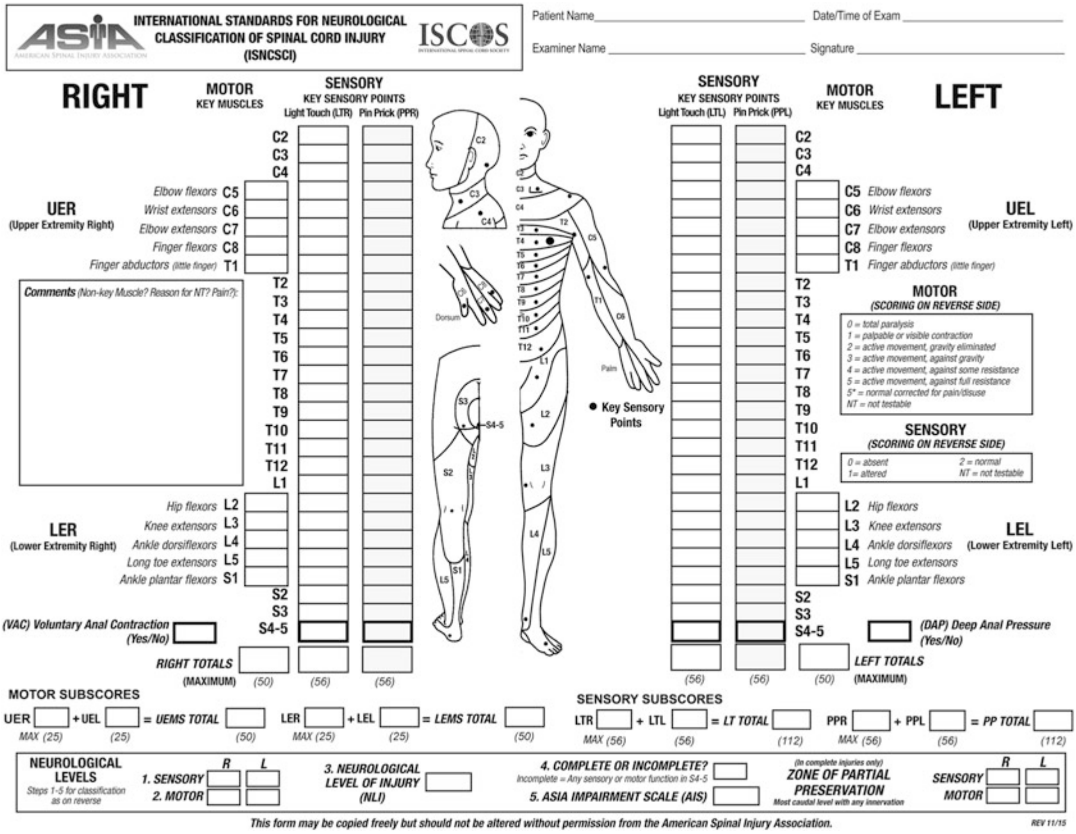
M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_5

Importance

- Understanding the extent of natural recovery after spinal cord injury (SCI) is extremely important to clinicians in prognosticating outcomes. Identification of a patient’s neurological impairment and potential prognosis allows for the development of a goal-oriented rehabilitation program, more focused discussion with the patient and family, as well as a baseline and outcome measure for research when studying new treatments to measure surgical, pharmacologic, or rehabilitation interventions.
- The performance of a comprehensive examination according to the guidelines of the ISNCSCI is paramount to determining the accurate classification according to the American Spinal Injury Association (ASIA) Impairment Scale (AIS). The AIS is the most widely used classification scheme for determining the severity of injury in SCI and for predicting the probability of subsequent spontaneous recovery.
- In addition to being used as a predictor of outcomes, the AIS has been used as a relevant clinical endpoint in research studies. Therefore, the ability of the ISNCSCI to appropriately classify patients is critical.

Practical Applications

A. ***ISNCSCI*** ***Neurological Examination***
   - The examination is composed of **sensory and motor components** and is performed with the patient in the **supine position (lying on their back)** to be able to compare initial and follow-up exams.
   - The information from this examination is recorded on a **standardized flow sheet** (Fig. 5.1) and helps determine the sensory, motor, and neurological level of injury


INTERNATIONAL STANDARDS FOR NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY (ISNCSCI)

Patient Name ______ Date/Time of Exam ______

Examiner Name ______ Signature ______

RIGHT — UER (Upper Extremity Right); LER (Lower Extremity Right)

LEFT — UEL (Upper Extremity Left); LEL (Lower Extremity Left)

Right motor key muscles	Level	Right motor	Right sensory Light Touch (LTR)	Right sensory Pin Prick (PPR)	Left sensory Light Touch (LTL)	Left sensory Pin Prick (PPL)	Left motor	Level	Left motor key muscles
	C2							C2	
	C3							C3	
	C4							C4	
Elbow flexors	C5							C5	*Elbow flexors*
Wrist extensors	C6							C6	*Wrist extensors*
Elbow extensors	C7							C7	*Elbow extensors*
Finger flexors	C8							C8	*Finger flexors*
Finger abductors (little finger)	T1							T1	*Finger abductors (little finger)*
	T2							T2	
	T3							T3	
	T4							T4	
	T5							T5	
	T6							T6	
	T7							T7	
	T8							T8	
	T9							T9	
	T10							T10	
	T11							T11	
	T12							T12	
	L1							L1	
Hip flexors	L2							L2	*Hip flexors*
Knee extensors	L3							L3	*Knee extensors*
Ankle dorsiflexors	L4							L4	*Ankle dorsiflexors*
Long toe extensors	L5							L5	*Long toe extensors*
Ankle plantar flexors	S1							S1	*Ankle plantar flexors*
	S2							S2	
	S3							S3	
	S4-5							S4-5	
RIGHT TOTALS / LEFT TOTALS									
(MAXIMUM)		(50)	(56)	(56)	(56)	(56)	(50)		

Comments (Non-key Muscle? Reason for NT? Pain?):

(VAC) Voluntary Anal Contraction (Yes/No) ☐

(DAP) Deep Anal Pressure (Yes/No) ☐

MOTOR (SCORING ON REVERSE SIDE)
0 = total paralysis
1 = palpable or visible contraction
2 = active movement, gravity eliminated
3 = active movement, against gravity
4 = active movement, against some resistance
5 = active movement, against full resistance
5* = normal corrected for pain/disuse
NT = not testable

SENSORY (SCORING ON REVERSE SIDE)
0 = absent
1= altered
2 = normal
NT = not testable

● Key Sensory Points

MOTOR SUBSCORES
UER ☐ MAX (25) + UEL ☐ (25) = UEMS TOTAL ☐ (50)
LER ☐ MAX (25) + LEL ☐ (25) = LEMS TOTAL ☐ (50)

SENSORY SUBSCORES
LTR ☐ MAX (56) + LTL ☐ (56) = LT TOTAL ☐ (112)
PPR ☐ MAX (56) + PPL ☐ (56) = PP TOTAL ☐ (112)

NEUROLOGICAL LEVELS
Steps 1-5 for classification as on reverse

	R	L
1. SENSORY	☐	☐
2. MOTOR	☐	☐

3. NEUROLOGICAL LEVEL OF INJURY (NLI) ☐

4. COMPLETE OR INCOMPLETE? ☐
Incomplete = Any sensory or motor function in S4-5

5. ASIA IMPAIRMENT SCALE (AIS) ☐

(In complete injuries only)
ZONE OF PARTIAL PRESERVATION
Most caudal level with any innervation

	R	L
SENSORY	☐	☐
MOTOR	☐	☐

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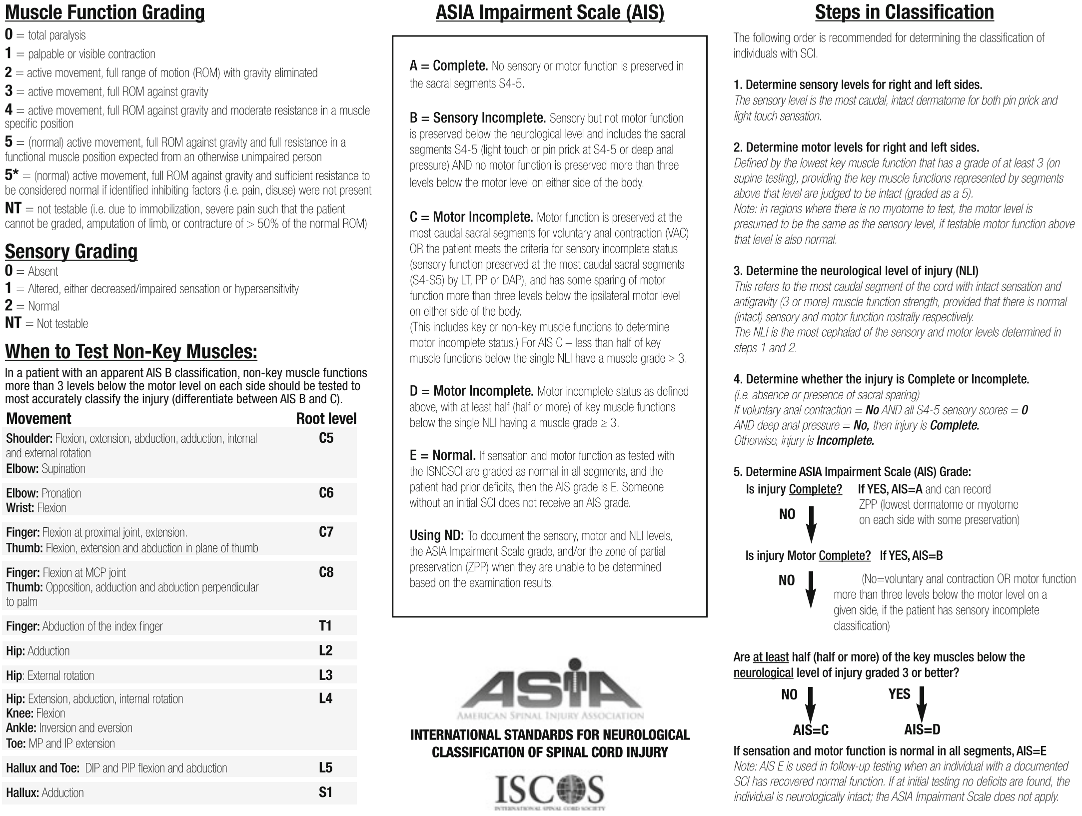
REV 11/15

Fig. 5.1 2015 Worksheet



Muscle Function Grading

0 = total paralysis
1 = palpable or visible contraction
2 = active movement, full range of motion (ROM) with gravity eliminated
3 = active movement, full ROM against gravity
4 = active movement, full ROM against gravity and moderate resistance in a muscle specific position
5 = (normal) active movement, full ROM against gravity and full resistance in a functional muscle position expected from an otherwise unimpaired person
5* = (normal) active movement, full ROM against gravity and sufficient resistance to be considered normal if identified inhibiting factors (i.e. pain, disuse) were not present
NT = not testable (i.e. due to immobilization, severe pain such that the patient cannot be graded, amputation of limb, or contracture of > 50% of the normal ROM)

Sensory Grading

0 = Absent
1 = Altered, either decreased/impaired sensation or hypersensitivity
2 = Normal
NT = Not testable

When to Test Non-Key Muscles:

In a patient with an apparent AIS B classification, non-key muscle functions more than 3 levels below the motor level on each side should be tested to most accurately classify the injury (differentiate between AIS B and C).

Movement	Root level
Shoulder: Flexion, extension, abduction, adduction, internal and external rotation **Elbow:** Supination	**C5**
Elbow: Pronation **Wrist:** Flexion	**C6**
Finger: Flexion at proximal joint, extension. **Thumb:** Flexion, extension and abduction in plane of thumb	**C7**
Finger: Flexion at MCP joint **Thumb:** Opposition, adduction and abduction perpendicular to palm	**C8**
Finger: Abduction of the index finger	**T1**
Hip: Adduction	**L2**
Hip: External rotation	**L3**
Hip: Extension, abduction, internal rotation **Knee:** Flexion **Ankle:** Inversion and eversion **Toe:** MP and IP extension	**L4**
Hallux and Toe: DIP and PIP flexion and abduction	**L5**
Hallux: Adduction	**S1**

ASIA Impairment Scale (AIS)

A = Complete. No sensory or motor function is preserved in the sacral segments S4-5.

B = Sensory Incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5 (light touch or pin prick at S4-5 or deep anal pressure) AND no motor function is preserved more than three levels below the motor level on either side of the body.

C = Motor Incomplete. Motor function is preserved at the most caudal sacral segments for voluntary anal contraction (VAC) OR the patient meets the criteria for sensory incomplete status (sensory function preserved at the most caudal sacral segments (S4-S5) by LT, PP or DAP), and has some sparing of motor function more than three levels below the ipsilateral motor level on either side of the body.
(This includes key or non-key muscle functions to determine motor incomplete status.) For AIS C – less than half of key muscle functions below the single NLI have a muscle grade ≥ 3.

D = Motor Incomplete. Motor incomplete status as defined above, with at least half (half or more) of key muscle functions below the single NLI having a muscle grade ≥ 3.

E = Normal. If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an initial SCI does not receive an AIS grade.

Using ND: To document the sensory, motor and NLI levels, the ASIA Impairment Scale grade, and/or the zone of partial preservation (ZPP) when they are unable to be determined based on the examination results.

AMERICAN SPINAL INJURY ASSOCIATION

INTERNATIONAL STANDARDS FOR NEUROLOGICAL
CLASSIFICATION OF SPINAL CORD INJURY

INTERNATIONAL SPINAL CORD SOCIETY

Steps in Classification

The following order is recommended for determining the classification of individuals with SCI.

1. Determine sensory levels for right and left sides.
The sensory level is the most caudal, intact dermatome for both pin prick and light touch sensation.

2. Determine motor levels for right and left sides.
Defined by the lowest key muscle function that has a grade of at least 3 (on supine testing), providing the key muscle functions represented by segments above that level are judged to be intact (graded as a 5).
Note: in regions where there is no myotome to test, the motor level is presumed to be the same as the sensory level, if testable motor function above that level is also normal.

3. Determine the neurological level of injury (NLI)
This refers to the most caudal segment of the cord with intact sensation and antigravity (3 or more) muscle function strength, provided that there is normal (intact) sensory and motor function rostrally respectively.
The NLI is the most cephalad of the sensory and motor levels determined in steps 1 and 2.

4. Determine whether the injury is Complete or Incomplete.
(i.e. absence or presence of sacral sparing)
If voluntary anal contraction = ***No*** *AND all S4-5 sensory scores =* ***0***
AND deep anal pressure = ***No,*** *then injury is* ***Complete.***
Otherwise, injury is ***Incomplete.***

5. Determine ASIA Impairment Scale (AIS) Grade:

Is injury Complete? **If YES, AIS=A** and can record ZPP (lowest dermatome or myotome on each side with some preservation)

NO ↓

Is injury Motor Complete? **If YES, AIS=B**

NO ↓ (No=voluntary anal contraction OR motor function more than three levels below the motor level on a given side, if the patient has sensory incomplete classification)

Are at least half (half or more) of the key muscles below the neurological level of injury graded 3 or better?

NO ↓ **AIS=C**

YES ↓ **AIS=D**

If sensation and motor function is normal in all segments, AIS=E
Note: AIS E is used in follow-up testing when an individual with a documented SCI has recovered normal function. If at initial testing no deficits are found, the individual is neurologically intact; the ASIA Impairment Scale does not apply.

Fig. 5.1 (continued)

(NLI); sensory and motor index scores; and to classify the impairment.

1. **Sensory Testing**
   - There are **28 key sensory *dermatomes from each side*** *of the body* that are individually tested for *light touch* and *pinprick* modalities. The face is used as the normal control point.
   - A three-point scale is used to score light touch and pinprick sensation separately (see below).
   - **Not testable (NT)** is used when the key sensory point cannot be accurately scored because of a cast, burn, amputation, or if the patient is unable to appreciate sensation on the face.
2. **Pinprick (PP) testing**

   Using the sharp edge of a safety pin, sensation is compared to that of the face. The patient must be able to differentiate the sharp and dull edge of a safety pin.

Score	Definition
0	No sensation felt by the patient or unable to differentiate between the sharp and dull edge
1	The sharpness of the pin is not felt to the same degree as on the face, but able to differentiate sharp from dull
2	Pin is felt as sharp as on the face
NT	Not testable

3. **Light touch (LT) testing**

   A cotton tip applicator is used and sensation is compared to the face.

Score	Definition
0	Absent sensation
1	Altered (impaired or partial appreciation, including hyperaesthesia)
2	Light touch is felt and is the same as on the face
NT	Not testable

NOTE: It is very important to test the S4–S5 dermatome (ano-mucocutaneous junction) for light touch and pinprick sensation, as this is used to determine if the patient has a neurologically complete or incomplete injury.

4. **Deep Anal Pressure (DAP)**

   This is performed by applying gentle pressure to the anorectal wall with the examiners distal thumb and index finger while asking the patient if they perceive pressure in that area. Consistently perceived pressure should be graded as present or absent.

5. **ASIA Key Sensory Levels** (See Fig. 5.1)

C2	At least 1 cm lateral to the occipital protuberance (alternatively 3 cm behind the ear)
C3	Supraclavicular fossa (posterior to the clavicle) and at the midclavicular line
C4	Over the acromioclavicular joint
C5	Lateral (radial) side of the antecubital fossa (just proximal to elbow crease)
C6	Thumb, dorsal surface, proximal phalanx
C7	Middle finger, dorsal surface, proximal phalanx
C8	Little finger, dorsal surface, proximal phalanx
T1	Medial (ulnar) side of antecubital fossa, just proximal to the medical epicondyle of the humerus
T2	Apex of axilla
T3	Third intercostal space (IS) (at midclavicular line)
T4	Fourth IS (nipple line) (at midclavicular line)
T5	Fifth IS, midway between T4 and T6 (at midclavicular line)
T6	Xiphoid, sixth IS (at midclavicular line)
T7	Seventh IS, at midclavicular line (midway between T6 and T8)
T8	Eighth IS, midway between T6 and T10 (at midclavicular line)
T9	Ninth IS, midway between T8 and T10 (at midclavicular line)
T10	Tenth IS at umbilicus (at midclavicular line)
T11	Eleventh IS, at midclavicular line
T12	Inguinal ligament at midpoint at midclavicular line
L1	Half the distance between T12 and L2
L2	Mid-anterior thigh at midpoint connecting T12 and medial femoral condyle
L3	Medial femoral condyle above the knee
L4	Medial malleolus
L5	Dorsum of foot at third metatarsal phalangeal joint
S1	Lateral heel (calcaneous)
S2	Popliteal fossa in the midline
S3	Ischial tuberosity or infragluteal fold
S4–S5	Perianal area <1 cm lateral to the mucocutaneous junction (taken as one level)

6. **Motor Strength Testing**

   There are **ten key myotomes** on the left and right sides of the body that are tested in the supine position:

Myotome	Muscle Action
C5	Elbow flexors (biceps, brachialis)
C6	Wrist extensors (extensor carpi radialis longus and brevis)
C7	Elbow extensors (triceps)
C8	Finger flexors (flexor digitorum profundus of middle finger)
T1	Small finger abductor (abductor digiti minimi)
L2	Hip flexors (iliopsoas)
L3	Knee extensors (quadriceps)
L4	Ankle dorsiflexors (tibialis anterior)
L5	Long toe extensors (extensor hallucis longus)
S1	Ankle plantarflexors (gastrocnemius, soleus)

   a. ***Manual Muscle Testing Grading System***

0	No movement (total paralysis)
1	Palpable or visible contraction but no movement
2	Active movement through full range of motion (ROM) with gravity eliminated
3	Active movement through full ROM, against gravity
4	Active movement, full ROM, against moderate resistance in a specific muscle position
5	Normal strength with full ROM
5*	(Normal) active movement, full ROM against gravity and sufficient resistance to be considered normal if identified inhibiting factors (i.e., pain, disuse) were not present
NT	Not testable (i.e., due to immobilization, severe pain such that the patient cannot be graded, amputation of limb, or contracture of >50 % of the ROM)

7. **Voluntary Anal Contraction (VAC)**

   The index finger is inserted into the rectal vault, and the patient is instructed to squeeze the examiners finger as if to prevent a bowel movement. Reproducible voluntary contractions around the examiner's finger are graded as present or absent.

B. ***Determining Levels of Injury***

1. **Sensory level of injury**: most caudal segment of the spinal cord with normal sensory function on both sides of the body for both pinprick and light touch sensation.
2. **Motor Level of Injury:** most caudal key muscle group that is graded ≥3/5 with the segments above graded 5/5 in strength. Motor level can be determined for each side of the body.
   - When defining the motor level in a patient with no correlating key motor function to test (i.e., above C5, between T2–L1, and S2–5), the motor level is presumed to be the same as the sensory level, if testable motor function above (rostral) that level is intact (normal) as well**.**
     - **Motor Index Scoring**: a **maximum total score of 100** can be obtained when adding the muscle scores of the key muscle groups (25 points per extremity). It is recommended that the **motor score should be separated into two scores**, one composed of the **ten upper limb muscle functions**, and another of the **ten lower limb muscle functions**, with a **maximum score of 50 each**.
3. **Neurological Level of Injury (NLI)**

   Most caudal segment of the spinal cord with both normal sensory and motor function (≥3/5 with rostral segments 5/5) on both sides of the body
4. **Complete vs. Incomplete SCI**

   Differentiating between a neurologically complete vs. incomplete injury is by determining if there is ***sacral sparing*** present in the most caudal aspect of the spinal cord. This is represented by the sparing of sensory function (LT or PP) at the S4–S5 dermatome, voluntary anal sphincter contraction (VAC), or deep anal pressure (DAP) on rectal examination. Sacral sparing is present if any of the above are present to any degree, i.e., intact or impaired on either side of the body.

a. ***Complete Spinal Cord Injury***
   - No sacral sparing is present: absence of sensory and motor function in the lowest sacral segment (S4–S5 dermatome for LT or PP sensation), DAP and VAC.
   - The term **zone of partial preservation** (ZPP) is only used with neurologically complete lesions and refers to the dermatomes and myotomes caudal to the NLI that remain partially innervated. While the motor level defers to the sensory level in the regions where there is no key motor function to test (C1–C4, T2–L1, etc.), motor ZPP is based only on the presence of voluntary muscle function below the motor level and does not defer to the sensory ZPP. Specifically, if the NLI is T6 in a case with a neurologically complete injury, with impaired sparing of light touch sensation through T8 bilaterally and all other sensations absent, T8 should be documented on the worksheet for the sensory ZPP but the motor level of T6 should be placed in the ZPP box bilaterally [3].

b. ***Incomplete Spinal Cord Injury***
   - Presence of sacral sparing—indicates at least partial preservation of sensory and/or motor function below the NLI that includes the lowest sacral segments.
   - In cases of an incomplete injury early after SCI, there is improved prognosis for motor and sensory return below the level of injury as well as the possibility of return of bowel and bladder function relative to persons with a neurologically complete injury.

C. ***The ASIA IMPAIRMENT*** ***SCALE***

1. **Classification**

A Complete	No motor or sensory function is preserved in the sacral segments S4–S5
B Sensory Incomplete	Sensory but not motor function is preserved at the most caudal sacral segments S4–S5, AND no motor function is preserved more than three levels below the motor level on either side of the body
C Motor Incomplete	Motor function is preserved at the most caudal sacral segments (S4–S5) on voluntary anal contraction (VAC) **OR** the patient meets the criteria for sensory incomplete status (sensory function preserved at the most caudal sacral segments (S4–S5) by LT, PP, or DAP), with sparing of motor function more than three levels below the motor level on either side of the body. This includes key or non-key muscle functions more than three levels below the motor level to determine motor incomplete status. For AIS C—less than half of key muscle functions below the single NLI have a muscle grade ≥3
D Motor Incomplete	Motor incomplete status as defined above, with at least half (half or more) of key muscle functions below the single NLI having a muscle grade ≥3
E = Normal	If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an SCI does not receive an AIS grade

Note: When assessing the extent of motor sparing below the level for distinguishing between AIS B and C, the ***motor level*** on each side is used; whereas to differentiate between AIS C and D (based on proportion of key muscle functions with strength grade 3 or greater) ***the single neurological level*** is used

2. **Steps in classifying the injury according to the ASIA Impairment Scale (AIS)**
   a. **Determine sensory levels for right and left sides.**
      - Starting from the top of the flow sheet for sensory function, go down the worksheet until you see a "1" or "0."
      - Going up 1 level gives you the sensory level.

   b. **Determine motor levels for right and left sides.**
      - The motor level is the most caudal key muscle group that is graded ≥3/5 with all segments above graded 5/5 strength.
      - In regions where there is **no myotome** to test, the motor level is presumed to be the same as the sensory level, if testable motor function above that level is also normal.

   c. **Determine the neurological level of injury.**

      The most rostral of the sensory and motor levels determined in steps 1 and 2.

   d. Determine whether the injury is **complete or incomplete (sacral sparing).**

      Sacral sparing = sensory or motor function in the lowest sacral segments, that includes PP or LT at S4–S5, VAC, or DAP.

   e. **Determine AIS grade:**
      1. Is injury **complete (i.e., no sacral sparing)?**

         If yes, AIS = A; and record ZPP if present.
      2. If **incomplete**, is injury motor incomplete?
         - **No:** AIS = B. (AIS B refers to a case where there is no voluntary anal contraction OR motor function more than three levels below the motor level on a given side, if the patient has sensory incomplete classification).
         - **Yes:** presence of voluntary anal contraction OR motor function >3 levels below the motor level on a given side if the patient has sensory incomplete classification.
      3. **If motor incomplete**, are ≥50 % the key muscles below the neurological level graded 3 or better? **If no**—AIS = C. **If yes—**AIS = D.
      4. If **sensation and motor function is normal in all segments, AIS = E.**
         - Note: AIS E is used in follow-up testing when an individual with a

documented SCI has **recovered normal function**. If **no deficits are found at initial testing**, the individual is considered to be neurologically intact, and the ASIA Impairment Scale **does not apply**.

3. **Non-Key Muscle Functions**

   Non-key muscle functions should be tested more than three levels below the motor level on each side of the body in cases that a patient is classified as sensory incomplete (AIS B) to rule in (or out) a motor incomplete status (AIS B vs. C). The results should be placed in the comment box. The levels of non-key muscle functions are listed below:

Non-key muscle movements	Root level
Shoulder: Flexion, extension, abduction, adduction, internal and external rotation	**C5**
Elbow: Supination	
Elbow: Pronation	**C6**
Wrist: Flexion	
Finger: Flexion at proximal joint, extension	**C7**
Thumb: Flexion, extension, and abduction in plane of thumb	
Finger: Flexion at MCP joint	**C8**
Thumb: Opposition, adduction, and abduction perpendicular to palm	
Finger: Abduction of little finger	**T1**
Hip: Adduction	**L2**
Hip: Ext rotation	**L3**
Hip: Extension, abduction, and rotation	**L4**
Knee: Flexion	
Hip: Inversion and eversion	
Toe: MP and IP extension	
Hallux and toe: DIP and PIP flexion and abduction	**L5**
Hallux: Adduction	**S1**

MCP metacarpophalyngeal joint, ***DIP*** distal interphalangeal joint, *PIP* proximal interphalangeal joint, ***MTP*** metatarsal phalangeal joint, ***IP*** interphalangeal joint

D. ***Incomplete Spinal Cord Injury Syndromes***

1. **Central Cord Syndrome (CCS)**
   - Most **common of the incomplete SCI syndromes** (~9 % of total SCI).
   - Clinically, there is **sacral sensory sparing, greater motor weakness in the upper limbs than the lower limbs**, with variable loss of sensation, bowel, and bladder function.
   - Possibly due to the **neuroanatomy of the corticospinal tracts** having cervical distribution being more medial and sacral distribution more lateral. Earlier suggestion was that CCS affected the central aspects of the spinal cord, thereby affecting the upper extremities more than lower extremities. However, the proposed lamination as such in humans has not been proven and is now felt to be a predominantly white matter injury.
   - May occur at any age, but **more common in older patients** with cervical spondylosis who sustain a hyperextension injury usually from a fall.
   - **Recovery:** Muscle strength recovery of the lower extremities is usually seen first and to a greater extent than the upper extremities. This is followed by improvement in bladder function, and then proximal upper extremity and finally intrinsic hand function. Age below 50 is a key positive prognostic indicator of functional recovery.

1. **Brown-Sequard Syndrome**
   - Constitutes **2–4 % of all traumatic SCI**.
   - Results from a lesion that causes a relative hemisection of the spinal cord.
   - Associated classically with stabbing but can occur from other causes (e.g., motor vehicle crashes).
   - Neurological deficits distal to the level of the l**esion vary** from the different nerve tracts crossing at different locations:
     - **Ipsilateral loss of all sensory modalities** at the level of the lesion
     - **Ipsilateral flaccid paralysis (motor loss)** at the level of the lesion
     - **Ipsilateral loss of position sense and vibration** below the lesion
     - **Contralateral loss of pain and temperature** below the lesion
   - Overall, patients clinically present most often with a relative ipsilateral

motor and proprioceptive loss, and contralateral loss of pain and temperature (**Brown-Sequard Plus Syndrome**).
  - **Recovery:** Patients with this syndrome most commonly have the greatest prognosis for recovery of ambulation.
2. **Anterior Cord Syndrome**
  - A lesion affecting the **anterior 2/3 of the spinal cord** while preserving the posterior columns.
  - This can occur from flexion injuries, retropulsed disc or bone fragments, direct injury to the anterior spinal cord, or anterior spinal artery lesions.
  - Results in variable loss of motor function (corticospinal tract) and sensitivity to pain and temperature (spinothalamic tract), pinprick sensation, with preservation of proprioception and light touch and deep pressure sensation.
  - Spinocerebellar tract involved.
  - **Recovery**: Patients with this injury have a poor prognosis for ambulation (only ~10 to 20 %).
3. **Posterior Cord Syndrome**
  - This type of clinical picture is rarely seen from trauma and therefore has been omitted from recent versions of the International Standards.
  - Injury to the posterior columns results in proprioceptive loss (dorsal columns) with muscle strength, pain, and temperature modalities spared.
  - **Prognosis** for ambulation is poor, secondary to the proprioceptive deficits.
4. **Conus Medullaris and Cauda Equina Syndromes**
  - The conus medullaris, which is the terminal segment of the adult spinal cord, lies at the inferior aspect of the L1–L2 vertebrae. Injuries at this level will usually result in a reflexic bladder and bowel and may affect the lower limbs as well.
  - Injuries below the L1–L2 vertebral levels usually affect the cauda equina (nerve rootlets), which innervate the lumbar and sacral segment and results in lower motor neuron injury.
  - Produces motor weakness and lower motor neuron lesion of the lower extremity muscles with bowel and bladder involvement, impotence, sexual dysfunction, and areflexia of the ankle and plantar reflexes. There will also be an absent bulbocavernous reflex.
  - **Prognosis**: True conus lesions are not common from trauma and the clinical picture depends upon the exact site of the lesion. Cauda equina lesions may offer a **better prognosis for motor recovery since** the nerve roots affected are more resilient to injury relative to upper motor neuron lesions that occur from an SCI above L1, as they are histologically peripheral nerves and regeneration can occur.

Tips

Knowledge of the ISNCSCI is important in understanding how to perform the neurological examination in persons with spinal cord injury and be able to appropriately classify the injury utilizing the ASIA Impairment Scale. An online educational program called the **International Standards Training eLearning Program (InSTeP)** is available and includes modules on anatomy as well as how to perform the examination and classify the injury based upon the AIS [4].

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6 Everyday Psychopharmacology

Randall D. Buzan and James Schraa

Topic

Medications can help a broad range of behavioral problems, mood, anxiety disorders, and cognitive impairments during rehabilitation. We describe basic assessment and prescribing guidelines.

Importance

A. ***Psychiatric Disorders in the General Population***

Psychiatric disorders are common in the general population (Table 6.1, ranges vary by study) [1, 2]:

B. ***Psychiatric Disorders in Rehabilitation Populations***

Psychiatric disorders are also common in a number of rehabilitation populations, including traumatic brain injury, spinal cord injury, stroke, and chronic pain. These populations have not been studied as rigorously as in the large multisite surveys noted above, but findings include:

1. **Traumatic Brain Injury (TBI)** [3]:
   - ***Depression***—there is often a delay in depression onset by weeks or months following injury, but 22–77 % of TBI patients develop depression within 1 year of injury. Depression worsens functional outcomes.
   - **Occupational impairment or cannot work** occurs in 50 %
   - ***Mania***—Up to 9 % of patients develop a manic episode following TBI
   - ***Pain***—30 % of patients have pain at 1-year following TBI, and depression was eightfold more common in those with persisting pain [4]—this emphasizes the need for a holistic approach, i.e., treating pain and psychiatric issues together
   - ***Suicide***—risk of suicide is increased fourfold in TBI patients
2. **Spinal Cord Injury (SCI)** [5–7]:
   - ***Depression***—12 % of SCI patients have major depression at 1-year post-injury, and 10 % at 5 years
   - ***Suicide***—suicide is at least three times more common after SCI and in one large study of over 9000 patients [7] was the leading cause of death for SCI patients with complete paraplegia

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_6

Table 6.1 Lifetime prevalence of psychiatric disorders

Condition	Lifetime prevalence (%)
Major depression	13–20
Bipolar disorder	2–4
Panic disorder	3–7
Social phobia	12–25
Obsessive-compulsive disorder	2–7
Generalized anxiety disorder	5–14
Post-traumatic stress disorder	7
Alcohol abuse/dependency	10–26
Cannabis dependency	4–18
Schizophrenia	1–2
Attention deficit/hyperactivity disorder	7–10
Intermittent explosive disorder	5
Non-EtOH drug abuse	10

anx anxiety, *ETOH* alcohol

Practical Applications

A. ***Assessment***

1. **First, evaluate psychiatric diagnostic criteria**

   Criteria for 6 of the most common disorders seen in rehabilitation patients requiring assessment and treatments are highlighted below:

   a. ***Major Depressive Disorder (MDD)***

   - Symptoms lasting 2 or more weeks and a change from previous functioning. At least one symptom is: (1) feeling depressed most of the day more days than not, or (2) markedly decreased interest. May also include increased or decreased sleep, appetite and motor activity, guilt, decreased energy and concentration, thoughts of death or suicide
   - Are the symptoms **recurrent**? That is, are there 2 separate episodes with at least 2 months of no depression between them?
   - Does the patient have **psychotic features**? These increase risk of suicide and usually require addition of an antipsychotic medication to antidepressant medication for adequate response (response rates drop to <30 % with just an antidepressant medication in psychotic depression)
     - ○ **Psychosis** = impaired reality testing with either:
       - a) abnormal content of thought (hallucinations, delusions, paranoia) and/or
       - b) abnormal process of thought with slowed thinking, paucity of thought (or as in mania, with rapid or disorganized thought)
   - **NOTE:** DSM-V observes the following: “Responses to a significant loss [such as] serious medical illness or disability may include the feelings of intense sadness, rumination about the loss, insomnia, poor appetite, and weight loss that may resemble a depressive episode. Although such symptoms may be understandable or considered appropriate to the loss, the presence of a major depressive episode in addition to the normal response to a significant loss should also be carefully considered” [8, p. 125–126]. Studies show significant improvement in mood, even with prolonged bereavement with antidepressants; therefore, caution against under-treating patients who might benefit.
   - **Evaluation** for **bipolar illness** in every patient meeting criteria for a depression is important. The presence or history of a hypomanic or manic episode overrides diagnosis for MDD and instead warrants diagnosis of a bipolar disorder rather than MDD.

   b. ***Bipolar Disorders***

   First, assess for hypomania (which requires less severity than full mania) to see if **bipolar II** might be present. Hypomania is “a distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased activity and energy, lasting at least 4 consecutive days and present most of the day, nearly every day" [8, p. 132]. If three of the following symptoms are present during the mood disturbance and represent a noticeable change from usual behavior, then bipolar II might apply: Distractibility, Racing thoughts, Speech rapid, Grandiosity, Agitation-goal directed activity, Sleep need decreased (e.g., rested with 3 h), excessive involvement in Pleasurable activities with painful consequences ("DRS GASP"). Bipolar II patients also must have experienced a current or past major depression to meet diagnostic criteria. If patient has **full mania**, i.e., the symptoms last a week and cause marked impairment in social or occupational functioning, or necessitate hospitalization, or are associated with psychotic features, then the patient has a **bipolar I disorder**.

c. ***Panic Disorder (PD)***

Recurrent unexpected panic attacks, involving "an abrupt surge of intense fear or intense discomfort that reaches a peak within minutes, and during which four or more of the following are present": palpitations, sweating, trembling, shortness of breath, choking, chest pain or discomfort, nausea/gastrointestinal distress, dizzy/lightheaded, chills/hot sensations, paresthesias, derealization, fear of losing control/going crazy, fear of dying [8, p. 208]. *At least one attack has been followed by either 1 or more months of persistent worry about additional attacks, or a significant maladaptive change in behavior related to the attacks*, such as avoiding exercise or unfamiliar situations.

NOTE: Unlike DSM-IV, DSM-V PD stands as separate diagnosis from agoraphobia, which is now listed (if present) as a separate diagnosis.

d. ***Acute Stress Disorder (ASD) and Post Traumatic Stress Disorders (PTSD)***

(Summarized here—for full criteria see DSM-V): Exposure as a victim or witness to actual or threatened death, serious injury, or sexual violation:

ASD—presence of *9 or more* of the following 14 symptoms from any of five categories of intrusion, negative mood, dissociation, avoidance, and arousal: recurrent intrusive memories, dreams, flashbacks/dissociative reactions, intense psychological distress, inability to feel positive emotions, altered sense of reality, inability to remember important aspects of the event, efforts to avoid distressing memories or thoughts about it, efforts to avoid external reminders like people or places associated with the event, sleep disturbance, irritable behavior, hypervigilance, problems with concentration, exaggerated startle response. Duration for **Acute ASD** is *3 days to 1 month*.

PTSD—the patient must have symptoms from each of the four categories of intrusion, negative mood, avoidance, arousal (dissociation is coded separately as a modifier) *lasting at least 1 month* causing clinically significant distress or impairment in relationships.

e. ***Intermittent Explosive Disorder***

Recurrent behavioral outbursts representing a failure to control aggressive impulses manifested by EITHER: (1) Verbal aggression—temper tantrums, tirades, arguments, or fights—or physical aggression toward property, animals or other individuals, occurring *twice weekly, on average, for a period of 3 months*. The physical aggression does not result in damage or destruction of property or physical injury to animals or others; OR (2) Three behavioral outbursts involving damage or destruction of property and/or physical assault involving injury against animals or people *within a 12-month period*. The magnitude of aggression is grossly out of proportion to any provoking stimulus, is not premeditated, causes marked distress or psychosocial impairment or financial-legal consequences, and is by someone *at least 6 years old*.

NOTE: The above diagnoses are not given but are modified if the disorder is thought to be due to the use of a substance or directly related to the physiological effects of a medical condition, e.g., "substance/medication induced 'x' disorder" or "'x' disorder due to another medical condition."

f. ***Neurocognitive disorders***
   - **Major Neurocognitive Disorder**—evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on: (1) concern of the individual or a knowledgeable informant or the clinician that there has been a significant decline in cognitive function, and (2) a substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing, or, in its absence, another quantified clinical assessment. Cognitive deficits interfere with independence in everyday activities (at a minimum requiring assistance with complex activities of daily living (ADL) such as paying bills or managing medications), and is not due to delirium or better explained by another mental disorder such as major depression or schizophrenia. Specify cause: Alzheimer's disease, TBI, Parkinson's disease, human immunodeficiency virus, vascular disease, multiple etiologies, or another medical condition.
   - **Mild Neurocognitive Disorder**—the cognitive decline is "modest" and does ***not*** interfere with capacity for independence

2. **<u>Second, consider medical causes or contributors</u>**
   a. **Medications** can cause depression, mania, anxiety/panic, and cognitive impairment. For instance, beta-blockers often make patients tired or feel "flat"; muscle relaxants and neuropathic pain medications like gabapentin or pregabalin often cause cognitive impairment or fatigue; antibiotics (rarely) cause depression; steroids frequently cause hypomania or even manic psychoses; opiates impair alertness and can cause not only euphoria, but also memory impairment, dysphoria, irritability, and depression. Effects of anticholinergic medications are additive and can impair not only bowel motility and saliva formation but also make patients feel tired and "hazy or spacey" cognitively. Thus, sometimes "less is more" and the first step can be to simplify the patient's medical medications before adding psychotopics.
   b. **Sleep deprivation** can drive depression, worsen pain, and impair cognition and participation in daytime rehabilitation tasks (e.g., due to frequent bed checks, breakthrough pain, nocturnal procedures, hospital noise, or restless roommates)
   c. **Other medical causes of mood problems:**
      - TSH and free t-3 and free t-4 (central hypothyroidism is not uncommon so a lone TSH to assess thyroid status is inadequate as the TSH might be low or normal due to pituitary hypofunction even in the presence of a hypothyroid state)
      - B12 and folate and magnesium abnormalities in patients with alcoholism or dubious nutritional status

- HIV or other studies for patients at risk for sexually transmitted infections
- Pain may drive depression as does sleep deprivation. Adequate treatment of both sometimes resolves psychiatric symptoms

3. **Third, obtain the patient's psychiatric history**

   Information from previous providers/family members can help to better understand the patient's diagnosis and history of treatment response. Many rehabilitation patients have communication or cognitive/memory problems and obtaining collateral data from family or care providers can be extremely helpful.

4. **Fourth, obtain the family psychiatric history**

   Most psychiatric conditions have a familial/genetic contribution, and diagnoses and medication responses tend to run in families. Suicide also runs in families and this history should lower the clinician's threshold for careful and repeated assessment of the patient's suicide potential.

5. **Fifth, consider the psychosocial context**

   Family dynamics are powerful and may drive depression, hopelessness, and suicidality. Conversely, and more commonly, families represent a bastion of support that can be used to help patient get past the acute distress caused by their illness or injury and proceed toward recovery. Thus, providing support to and problem-solving with families as they cope with the ramifications of the illness or injury can augment and strengthen the rehabilitation process.

6. **Sixth, assess suicidality**

   Don't be afraid to ask about this; you won't "give the patient ideas." Suicidal thinking is on a continuum: determine if the patient is thinking about being dead or wishing they had died (ideation). Has the patient considered ways to do this (any plan) and if so, what are those? Does the patient have the means available in the hospital or at home to execute the plan? (If so, try to eliminate means—have family remove guns from the home if possible). Does the patient really want to die/making plans to do so (intent)? In general, it is best for patients with active and unremitted mood, anxiety, impulse control, or psychotic disorders not to have access to guns (suicide by shooting kills the victim in 80 % of attempts vs. a 1–2 % fatality rate with overdose). Two-thirds of gun fatalities in the USA are suicides, not homicides [9].

B. ***Treatment***

Consider non-pharmacological treatment alternatives first. Psychotherapy, exercise, meditation, family meetings/work, and use of sitters (with agitated patients) can often obviate the need for or at the very least complement pharmacological approaches. Electroconvulsive therapy and rapid transcranial magnetic stimulation are effective options for very severely depressed patients who cannot tolerate medications.

1. **Antidepressant Medications**

   "Antidepressants" is a shorthand term for a group of drugs that are not only first-line agents for depression, but also first-line agents for anxiety disorders such as panic, PTSD, and generalized anxiety disorder. All antidepressants are roughly equally efficacious, with the exception of Wellbutrin (bupropion), which does not generally help anxiety or panic and can make those worse, but has special efficacy for smoking cessation and may help ADHD symptoms in some patients. However, some patients respond to one antidepressant medication but not another, others may respond to both of those antidepressants, so one can conceptualize drug response as overlapping (Venn diagrams) groups of patients. Positive response rates for depression are 70–80 %, but complete resolution of symptoms with a given drug occurs 20–30 % of the time; therefore, sequential trials and augmentation strategies are often necessary. Panic disorder response is in the 60–80 % range, but OCD only responds positively about one-third of the time with partial improvement in another one-third. Cognitive behavior therapy (CBT) augments the response to antidepressants in MDD, panic, and OCD, and meditation augments response in MDD. Selective Serotonin Reuptake Inhibitors (SSRI) enhance neuroplasticity and improve recovery after stroke even in the absence of depression. All antidepressants confer a small but real risk of pushing a patient into hypomania or mania (rate is about 1/100 patients overall; but up to 10 % of patients with very severe depression). Antidepressants also all carry a risk of seizures in approximately 1/200 patients. Some antidepressants and their properties are listed in Table 6.2.

a. ***Selective Serotonin Reuptake Inhibitors (SSRIs)***

SSRIs are first-line antidepressants due to their lower risk of overdose and having less anticholinergic side effects, less weight gain, and less orthostatic hypotension than tricyclic antidepres-

Table 6.2 Properties of antidepressant medications

Generic name	Trade name	Half-life (h)	Dose range (mg)	Comments
SSRI medications				
Citalopram	Celexa	35	10–40	Use ≤40 mg/day due to QTc prolongation found in OD; approved for MDD
Escitalopram	Lexapro	27–32	5–30	Approved for MDD and GAD
Fluoxetine	Prozac, Sarafem, (part of Symbyax)	90–250	5–60	FDA approved for MDD, panic, bulimia, OCD, PDD, bipolar I depression; Use up to 80 mg/day for OCD
Fluvoxamine	Luvox	16	50–300	FDA approved only for OCD but also used in MDD
Paroxetine	Paxil	21	10–60	Approved for MDD, PDD, panic, OCD, GAD, social anxiety, PTSD; some anticholinergic properties
Sertraline	Zoloft	26	25–200	FDA approved for MDD, PTSD, PDD, OCD, panic, social anxiety
Vilazodone	Viibrid	25	10–40	Approved for MDD; Some 5HT1a agonism making it like a combination of SSRI and buspirone
Vortioxetine	Brintellix	66	5–20	Approved for MDD; 5HT3 antagonism and 5HT1a agonism
SNRI medications				
Duloxetine	Cymbalta	12	30–120	FDA approved for MDD, diabetic neuropathic pain, GAD, fibromyalgia, chronic musculoskeletal pain (in Europe also used for stress urinary incontinence)
Milnacipran	Savella	6–8	12.5/day to 100 mg BID	FDA approved for fibromyalgia, not major depression
Venlafaxine	Effexor	5–11	25–375	FDA approved for MDD, panic, social anxiety, GAD
TCA medications				
Amitriptyline	Elavil	10–46	10–300	Approved for MDD, diabetic neuropathic pain; also used for post-herpetic neuralgia and migraine; is the parent tertiary amine of nortriptyline (with more anticholinergic SEs)
Clomipramine	Anafranil		25–250	The only TCA effective in OCD

(continued)

Table 6.2 (continued)

Generic name	Trade name	Half-life (h)	Dose range (mg)	Comments
Desipramine	Norpramine	12–27	10–300	MDD; secondary amine of imipramine; mainly norepinephrine uptake blockade so very activating
Doxepin	Sinequan Silenor	15.3–31	25–300	MDD and anxiety; potent antihistamine so an excellent sleep agent
Imipramine	Tofranil	11–25	10–300	Approved for MDD
Nortriptyline	Pamelor	18–44	10–200	Approved for MDD
Other medications				
Bupropion	Wellbutrin Zyban	21	75–300	Approved for MDD; IR form approved up to 450 mg in divided doses; no sexual dysfunction or weight gain; no help with anxiety disorders
Mirtazapine	Remeron	20–40	15–45	Approved for MDD; good sleep agent, no sexual dysfunction, but often weight gain and therefore good for cachectic elderly
Trazodone	Desyrel	3–6	25–300	Approved for MDD but mainly used as adjunctively as a sleeping agent; no more than 200 mg at HS; rare cases of ventricular arrhythmia

MDD major depressive disorder, *OCD* obsessive compulsive disorder, *GAD* generalized anxiety disorder, *PDD* premenstrual dysphoric disorder, *FDA* Food & Drug Administration, *SE* side effect, *HS* bedtime, *IR* immediate release

sants (TCA). SSRIs are effective for OCD whereas TCAs are not; they have differing FDA approvals, but clinically all can be effective for depression and anxiety. Sexual dysfunction, sweating, and GI upset are quite common, and while some patients lose weight acutely, many gain weight long term. SSRIs are typically taken in the morning with food as they can disrupt sleep, but some prefer to take these at bedtime. Watch for akathisia (intense physical restlessness making it hard to sit still and creating anxiety). Start the dose at one-half the smallest starting dose, especially in patients with panic disorder who require 1–2 weeks at low doses to accommodate; then titrate up slowly as tolerated every 3–7 days to maximum dose until dose-limiting side effects occur or until response is robust.

- **Serotonin Syndrome.** SSRIs, when used by themselves, rarely can cause a potentially life-threatening serotonin syndrome, but this more often occurs when combined with other serotonergic drugs (e.g., SSRIs and SNRIs, TCA, lithium, fentanyl, tramadol, buspirone, tryptophan, monoamine oxidase inhibitors, intravenous methylene blue, linezolid). Symptoms may include mental status changes (agitation, hallucinations, delirium, coma), autonomic instability (tachycardia, labile BP, dizziness, diaphoresis, flushing, hyperthermia), neuromuscular symptoms (rigidity, myoclonus, hyper-reflexia, incoordination), seizures, and/or GI symptoms (nausea, vomiting, diarrhea).

b. ***Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)***

SNRIs are often more activating than SSRIs; some data suggest faster and more robust response than SSRIs though this is not consistently observed. Effexor is currently a much less expensive alternative to Cymbalta, but there are patients who do better on Cymbalta than Effexor and vice versa.

c. ***Tricyclic antidepressants (TCAs)***

TCAs are among the first antidepressants discovered in the 1950s. Named for the structure that includes 3-rings, TCAs block both norepinephrine and serotonin reuptake, and have more anticholinergic blockade (causing dry mouth, constipation, and hazy cognition) than SSRIs or SNRIs. They also have more alpha-adrenergic blockade, resulting in orthostatic hypotension, and more antihistamine effects, causing in sedation and weight gain. They tend to increase stage III and IV sleep (restorative sleep) so tend to be good sleeping meds and should be taken at bedtime (with the exception of desipramine which is activating).

- **Cardiac effects of TCAs**—may cause orthostatic hypotension and modest tachycardia. TCAs (and some SSRIs like citalopram) also can increase QTc (creating risk for lethal ventricular arrhythmias/torsades), slow AV conduction (lengthening PR interval), and widen QRS (making bundle branch blocks worse and again predisposing to dangerous ventricular arrhythmias). TCAs should not be used in patients with bifascicular blocks; check an EKG in any patient 50 years old or greater before starting. Do not use in the first 6 months after myocardial infarction (heart attack). Discuss with cardiology before using in patient with any bundle branch block.

d. ***Side effects of antidepressants***

*S*exual dysfunction is common for those taking ADs with the exception of bupropion, trazodone, and mirtazapine. Weight gain is another risk with the exception of bupropion and trazodone.

e. ***Tapers***

MDD usually is treated for 9–12 months after a first episode, panic and OCD for 1 year or more after remission, before a taper is instituted. Then, decrease the dose gradually and taper over 4–8 weeks. The shorter the half-life, the more likely the potential for SSRI-withdrawal (nausea, vomiting, dizziness, gooseflesh, electrical shock sensations, anxiety, and dysphoria) and occasionally cross tapering by adding 2–3 weeks of 10–20 mg of fluoxetine can assist with this due to its having a long half-life. Anticholinergic withdrawal of nausea, vomiting, flu-like myalgias, and diarrhea also can occur with rapid tapers of TCAs or anticholinergic antipsychotics (see below).

2. **Anxiolytic Medications**

"Anxiolytic" means to "lyse" or "cut" anxiety. Barbiturates, once used to treat anxiety, had high lethality in overdose due to respiratory depression, and have been supplanted by newer medications.

a. ***Benzodiazepines***

Benzodiazepines bind to one type of gamma amino butyric acid receptor ($GABA_A$) where they move the receptor into a conformation in which it has a greater affinity for GABA. This increases the frequency of the opening of the associated chloride ion channel in the $GABA_A$ receptor, hyperpolarizing the membrane of the associated neuron and thereby decreasing the neuron's excitability. The inhibitory effect of the available GABA is thus potentiated, leading to sedative and anxiolytic effects. This slowing of neuronal firing in different brain regions accounts for the muscle relaxant, anticonvulsant, and anxiolytic effects, but also can cause slurred speech, slowed mentation, and sedation.

b. ***Buspirone***

An A 5HT1a agonist and modest $dopamine_2$ receptor blocker approved for GAD but clinically is best used to augment ADs in incompletely responsive depression.

c. ***Non-benzodiazepine hypnotics***

Non-benzodiazepine hypnotics such as zolpidem have short half-lives (which promotes amnesia), sometimes contributing to amnesia for middle-of-the-night behaviors. Warn patients not to make phone calls (due to risk of disinhibition and lack of recall) or to drive after taking these medications, and to consider placing car keys in unusual places in the very rare event that they wake up at night and decide to go for a drive.

d. ***Cautions with Anxiolytics***

- **Addiction risk** is 1/100 to 1/300 patients. Risk of physical dependence with daily use is much higher. Ideally patients should be treated for less than 1 month, if possible. However, anxiolytics are effective for long-term treatment for patients with panic disorder or severe generalized anxiety disorder who do not respond to or tolerate psychotherapy or SSRIs.
- **Anxiolytics work synergistically** and therefore should NOT be combined with alcohol. Patients should be cautioned to be extra careful when using these medications and driving. Explicit warning to NOT drive particularly if feeling at all sedated or with impaired coordination.
- **Alcohol** works synergistically and therefore should not be combined. Patients should be cautioned to be extra careful when using these medications and driving. Explicit warning should be given not to drive particularly if feeling at all sedated or uncoordinated.

e. ***Specific Treatment Application***

- **Treatment of Insomnia** for the long term is controversial; however, many sleep experts are in favor. Behavioral strategies should be utilized first, along with limiting nightly use for 1 or 2 weeks followed by further reduction to two or three times per week, or less, to limit physical dependence (Table 6.3).
- **Epileptics** using anxiolytics as anticonvulsants can be treated for decades without problems, as can patients

Table 6.3 Properties of anxiolytics and sedative-hypnotics (pts = patients; QHS = every bedtime)

Generic name	Trade name	Half-life (h)	Dose range (mg)	Comments
Benzodiazepines				
Alprazolam	Xanax	12	0.25–10	Approved for anxiety and panic disorder
Chlordiazepoxide	Librium	18	5–60	Approved for anxiety, preoperative anxiety, and alcohol withdrawal for which max is 300 mg/day
Clonazepam	Klonopin	34	0.5–10	Approved for seizure disorders and panic but also can be used for periodic leg movements, GAD, and neuralgia
Clorazepate	Tranxene	100	3.75–90	Approved for anxiety, alcohol withdrawal, and partial seizures
Diazepam	Valium	60–90	2–60	Approved for anxiety, muscle spasm, preop and procedural anesthesia, alcohol withdrawal, seizure disorder adjunctive treatment, status epilepticus
Estazolam	Prosom	10–24	1–3	Approved for insomnia
Flurazepam	Dalmane	15–30	72	Approved for insomnia
Lorazepam	Ativan	15	0.5–10	Approved for anxiety insomnia, status epilepticus, chemo-vomiting, preop sedation. No active metabolites. The only benzo well absorbed with IM injection

(continued)

Table 6.3 (continued)

Generic name	Trade name	Half-life (h)	Dose range (mg)	Comments
Oxazepam	Serax	8	10–120	Short half-life and lack of active metabolites make it safer for pts with liver disease
Temezepam	Restoril	8–11	15–30	Approved for insomnia
Triazolam	Halcion	2	0.125–0.5	Approved for insomnia but its short half-life makes amnesia episodes more likely
Non-benzodiazepines				
Eszopiclone	Lunesta	6	1–3	Approved for insomnia; avoid administering with high fat meals
Zaleplon	Sonata	1	5–20	Approved for insomnia; avoid with high fat meals
Zolpidem	Ambien	2.5–3	5–20	Use lower doses in women; approved to 10 mg but studied up to 20 mg QHS and some men need 20 mg for benefit
Ramelteon	Rozerem	1–3	8	Nonaddictive; binds to melatonin MT1 and MT2 receptors to induce sleep. Do not take with fatty meal. DO NOT combine with fluvoxamine (increases fluvoxamine levels 190-fold)
Buspirone	Buspar	2–3	5–60	Approved for GAD; better as AD augmenting agent; anecdotal evidence of help with agitated brain-injured patients

with anxiety disorders. Gradual tapers over 1–2 months are necessary to discontinue in order to avoid a severe (and potentially life-threatening) withdrawal syndrome that can progress from tremors, tachycardia, clammy skin, rebound anxiety, and insomnia to withdrawal seizures, severe hypertension, and delirium.

- **Severe COPD or pulmonary compromise** are conditions that warrant caution and close monitoring due to the risk of suppression of respiratory drive.
- **Panic** (50–80 %), **GAD, insomnia**, and **acute agitation/aggression** (often in combination with an antipsychotic) respond well to anxiolytics. However, anxiolytics are not as effective to relieve symptoms of PTSD.

3. **Antipsychotic medications**

Antipsychotic medications can be divided into conventional and “atypical” groups. Conventional antipsychotic medications were invented in the 1950s, and work by blocking D_2 receptors (dopamine). Because D_2 receptors are dense in the basal ganglia, Parkinsonism, and other movement problems like acute dystonic reactions (muscle spasms of the tongue, eyes, neck, arms, jaw) frequently occur with conventional antipsychotic medications, but can be managed with dosage adjustment or the addition of anticholinergic medicines like benztropine, trihexyphenidyl, diphenhydramine, or amantadine. Conventional antipsychotics also have a 3–4 % risk/year of tardive dyskinesia (TD; tardive meaning “delayed” and dyskinesia meaning “abnormal movement”), which can be irreversible if not noticed and addressed in the first few months of its manifesting. The TD risk is cumulative, such that at 10 years between 30 and 40 % of patients treated chronically with conventional antipsychotics may have evidence of abnormal movements of the tongue, facial, or trunk musculature. Atypical antipsychotics have a much lower risk of TD, between 1/100 and 1/500 patients per year. All antipsychotic medications can cause weight gain, sedation, dizziness, and cognitive slowing, and may slow recovery from brain injury, so should be used judiciously in TBI/stroke/dementia patients. Table 6.4 summarizes these agents.

a. ***Atypical antipsychotic medications***

Atypical antipsychotic medications have been available since the early

Table 6.4 Properties of antipsychotic and other medications for aggression

Generic name	Trade name	Half-life (h)	Dose range (mg)	Dose equivalent to 100 mg thorazine	Comments
Conventional antipsychotic medications					
Chlorpromazine	Thorazine	5–16	25–2000	100	Approved for schizophrenia, preoperative sedation, intractable hiccups, tetanus, acute intermittent porphyria
Droperidol	Inapsine	2	0.625–1.25 mg IV	1–2	Approved for nausea/vomiting
Fluphenazine	Prolixin	15	1–40	2	
Haloperidol	Haldol	13–36	2–40	2–3	Some use up to 100 mg for emergency treatment of agitation
Perphenazine	Trilafon	8–21	4–64	10	
Pimozide	Orap	55	0.5–20	1–2	
Thioridazine	Mellaril	7–42	50–800	90–100	Second line due to risk of torsades with increased QTc. Do not use more than 800 mg/day given possible risk of retinopathy/blindness
Thiothixene	Navane	34	1–60	3–5	Approved for psychosis
Trifluoperazine	Stelazine	18	2–40	5	Approved for psychosis and anxiety
Atypical antipsychotic medications					
Aripiprazole	Abilify	75–146	1–30		Approved for schizophrenia, bipolar I manic/mixed as single treatment or adjunctive to lithium or valproic acid, agitation with schizophrenia or bipolar I, MDD adjunctive to antidepressant medication; a D_2 partial agonist
Asenapine	Saphris	24	5–20 (SL tab)		Approved for schizophrenia acute and maintenance, bipolar I manic/mixed as single or adjunctive treatment
Clozapine	Clozaril Fazaclo	4–66	12.5–900		Approved for resistant schizophrenia and suicide prevention in schizophrenia; no tardive dyskinesia
Iloperidone	Fanapt	18–33	1–24		Approved for schizophrenia
Lurasidone	Latuda	18	20–160		Approved for schizophrenia, bipolar I depression; take with food to enhance absorption
Olanzapine	Zyprexa (part of Symbyax)	33	2.5–20 (some use up to 40 mg/day)		Approved for schizophrenia, bipolar I manic/mixed as single treatment or adjunctive treatment, agitation with schizophrenia or bipolar I, bipolar I depressed, treatment-resistant MDD
Paliperidone	Invega				A metabolite of risperidone
Quetiapine	Seroquel	6–7	12.5–800		Approved for schizophrenia, bipolar I manic/mixed, bipolar I depressed; can significantly raise triglycerides
Risperidone	Risperdal	20	0.25–6		Approved for schizophrenia, bipolar I manic/mixed, and irritability associated with autism. Studied up to 16 mg and just not found better than 6 mg/day but some patients need more

(continued)

Table 6.4 (continued)

Generic name	Trade name	Half-life (h)	Dose range (mg)	Dose equivalent to 100 mg thorazine	Comments
Ziprasidone	Geodon	7	20–80		Approved for schizophrenia, bipolar I manic/mixed as single or adjunctive agent, agitation associated with schizophrenia; tends to cause less weight gain; can see unusual dyskinesia
Other medications for agitation					
Amantadine	Symmetrel	17–29	50–200		Approved for influenza, extrapyramidal symptoms, Parkinsonism, 2013 large DBPC trial showed improved agitation and cognition in TBI. A dopamine agonist and NMDA blocker
Carbamazepine	Tegretol Carbatrol Equatro	25–65	100–1200		Approved for seizures, trigeminal neuralgia, and bipolar I manic/mixed; screen patients of Asian descent for HLA-B*1502; consider screening for HLA-A*3101 (see package insert)
Lamotrigine	Lamictal	25 (59 with VPA)	12.5–600		Approved for bipolar I maintenance, partial or GTC seizures, Lennox-Gastaut; risk of severe skin reactions—dose slowly—see package insert
Lithium	Eskalith Lithobid	24	15–1800		Approved for bipolar maintenance and acute treatment, schizoaffective disorder. Renally excreted. Kidney impairment in 1 % so monitor BUN/creatinine every 1–6 months; 10 % get hypothyroid—monitor TSH
Propranolol	Inderal	3–5	10–480		Approved for HTN, angina, SVT, migraine prophylaxis, essential tremor, IHSS, pheochromocytoma, portal HTN, atrial fibrillation/atrial flutter; can help with intermittent explosive behavior; avoid in asthma or heart block
Valproic acid	Depakote Depakene	16	125–2000		Approved for partial and absence seizures, bipolar mania, migraine prophylaxis

Tx treatment, *anx* anxiety, *SZ* schizophrenia, *maint* maintenance, *wt* weight, *SE* side effects, *GTC* general tonic clonic, *HTN* hypertension, *SVT* supraventricular tachycardia, *IHSS* idiopathic hypertrophic subaortic stenosis, *pheo* pheochromocytoma, *a fib* atrial fibrillation

1990s. Initially, clozapine, the prototype, was taken off the market due to deaths from agranulocytosis; however, in 1989 clozapine was reauthorized with a white blood count (WBC) monitoring protocol. Atypical antipsychotic medications bind to serotonin receptors and other subtypes of dopamine receptors conferring a lower risk of movement disorders than conventional antipsychotic medications, and provide treatment response in some patients who do not benefit from conventional antipsychotic medications. Atypical antipsychotic medications may have a higher rate of metabolic syndrome than conventional antipsychotic medications. While they all received an FDA warning for an elevated risk of diabetes, that risk is most evident with clozapine and olanzapine.

b. ***Conventional antipsychotic medications***

Conventional antipsychotic medications impose a 3–4 %/year risk of tardive dyskinesia (TD) (delayed abnormal movements) that presents as choreoathetotic movement ("dance-like" writhing) usually of axial/facial musculature after 6 or more months of treatment. TD can be irreversible when dose is reduced or stopped if caught early though usually remits. The risk of TD with atypical antipsychotics are much less, perhaps 1/300 to 1/500 patients; and, clozapine is actually a treatment for TD.

c. ***FDA warnings***

Issued in 2005 and in 2008 for all antipsychotics due to the relative rate of death is 1.6–1.7 times higher (death of 4.5 % vs. 2.6 % on placebo in 10-week trial period). Recent studies suggest this increase in death rate is due to psychotic and agitated dementia patients having worse brain disease than non-agitated dementia patients, therefore confounding the effects of the medication with the effects of the underlying brain disease. Lopez et al. [9] studied 957 patients with mild-to-moderate Alzheimer's disease and time to death from 1983 to 2005: "The use of antipsychotic medications, both conventional and atypical, was not associated with either time to nursing home admission or time to death after adjustment for relevant covariates. Rather, it was the presence of psychiatric symptoms, including psychosis and agitation, that was linked to increased risk of institutionalization and death after adjustment for exposure to antipsychotics" (p. 1051).

d. ***Acute agitation***

Most often treated with antipsychotic medications, frequently in combination with benzodiazepines. All antipsychotics have roughly the same efficacy for psychosis or agitation, but, as with antidepressant medications, some patients respond to one drug and not another. Clozapine stands alone as the most efficacious antipsychotic in meta-analyses, and is also the only FDA-approved drug for reducing suicide risk in schizophrenia. Clozapine is available as a generic. Clozapine should only be prescribed after two or more agents have failed due to required WBC monitoring and potential side effects. Consultation with a psychiatrist with experience with this clozapine is recommended.

Cardiac concerns. Antipsychotics can prolong the QTc interval (a cardiac conduction measure on EKG) and if this lengthens beyond 500 ms there is a risk of rare but lethal ventricular arrhythmias (torsades de points). This is less common with olanzapine than ziprasidone, but most antipsychotics can increase QTc interval, so have a low threshold for checking an EKG before and/or after starting these drugs.

e. ***The Omnibus Reconciliation Act of 1987***

Mandate for periodic attempts to taper antipsychotic medications in nursing homes and other assisted care settings, until a "minimum effective dose" for the patient is identified. Overall the Act resulted in a 28–36 % reduction in antipsychotic use in nursing homes, and tapering studies suggest that up to 40–50 % of patients with dementia/brain-injury may eventually successfully taper off of their antipsychotics. Periodic taper attempts are prudent when using antipsychotics for agitation/aggression, since agitation/aggression in these patients may only be transient. In patients with chronic pathologies such as schizophrenia (and some with chronic psychotic bipolar illness) lifetime treatment is usually necessary. Nonetheless, dosage requirements can vary over time and should be kept at the minimum effective dose.

4. **Other drugs for acute and chronic agitation**

   In addition to antipsychotic and anxiolytic medications for acute agitation, some other agents can be very helpful for persisting brain injury-associated aggression and agitation, such as amantadine, beta-blockers, SSRIs, and mood stabilizing anticonvulsants such as carbamazepine and valproic acid and lamotrigine. None are FDA-approved for agitation, but there is substantial literature and clinical experience to endorse their use in this setting. Carbamazepine is particularly useful but use caution and test patients of Asian/Indian (India) descent for HLA-B*1502 allele. 10–15 % of individuals in Thailand, Hong Kong, Malaysia, Philippines, India have this allele which confers a tenfold increases in risk of toxic epidermal necrolysis (see package insert before prescribing). HLA-A*3101 is present in up to 15 % of individuals of Japanese, Native American, Latin American descent, and 10 % of European descent and also increases risk of hypersensitivity reactions. In addition to severe dermatological reactions, anticonvulsants can adversely affect bone marrow and liver function so these should be monitored periodically (every 1–8 months).

5. **Cognitive enhancing agents**

   There are approved drugs approved to improve cognition for patients with TBI. However, clinicians have exported drugs from other settings for this purpose. In our experience, these can be helpful, but rates of response are less than 50 % overall.

   a. ***Cholinergic medications***

      Cholinergic medications approved for treatment of Alzheimer's disease (donepezil, rivastigmine, glantamine) also have some research support for use to improve cognition in neuropsychiatric patients, and to reverse the anticholinergic cognitive-impairing effects of some antipsychotic medications (although this is a more speculative use). However, since acetylcholine is an excitatory neurotransmitter, these cholinergic agents can increase agitation in some patients with TBI.

   b. ***Memantine***

      Memantine is another medication for Alzheimer's disease that works by blocking NMDA receptors. Migraines may be improved in some patients, and it may have positive effects on depression in some patients. Some patients have been observed to become hypomanic on memantine.

   c. ***Psychostimulants***

      Psychostimulant medications have been approved for ADHD, and these dopamine reuptake inhibitors (methyphenidate, dextroamphetamine, mixed amphetamine salts [Adderall]) can improve focus and motivation in some patients with TBI but with potential for abuse/dependence, anxiety, agitation, irritability, sleep disturbance, and bruxism (teeth grinding). Some patients have improvement of the anhedonic component of depression with psychostimulants when used to augment antidepressants.

   d. ***Atomoxetine (Strattera)***

      Atomoxetine is a norepinephrine reuptake inhibitor approved for ADHD. Although trials for cognitive enhancement in TBI have been disappointing, nonetheless some clinicians find this drug helpful for select patients.

Tips

- Use the DSM-V—take it to the bedside—do not label a patient with a diagnosis for which they do not meet full formal criteria.
- Sometimes less is more. Consider tapering other medications if side effects could be the cause of your patient's symptoms before adding another drug.

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Psychological Resilience in Medical Rehabilitation

7

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Topic

Psychological resilience is the process of adapting well to adverse situations, including medical illness, disability, traumatic events, or extreme stressors. Research and theory in this area has been explicit that resilience is not simply the absence of psychopathology, but instead maintaining one's ability to return to stable psychological and physical function and even have the capacity for positive emotions in the wake of a difficult life event [1]. While past conceptualizations of resilience assumed that it was an inherent and stable construct, more recent theories and research suggest that psychological resilience is malleable and thus can be bolstered to help an individual recovery following an adverse event.

A. ***Factors of Psychological Resilience***

   Resilience is a multidimensional construct that is based on intra- and interpersonal resources. For example, many people who demonstrate high levels of psychological resilience display a sense of self-mastery, adequate self-esteem, and an effective social support network. Resilient people also encompass certain behaviors, thoughts, and actions that help them to maintain a particular equilibrium, even when presented with stressful situations. Below are a list of factors that have been shown in the research literature to be protective against psychopathology after an adverse event and foster positive outcomes.

1. **Social Support**

   One of the strongest attributes of resilient individuals is their available social support. The impact of social support can vary wildly by size (i.e., quantity), density, and perceived quality, which can all provide separate advantages based on individual need. However, people demonstrating high levels of resilience tend to either report a large social support network or report a high quality of social support network(s) regardless of size, or both. Social support in the wake of illness has long been considered a crucial component of adequate recovery, as it prevents feelings of isolation and helplessness. In addition, social support is associated with less disability and poorer health-related outcomes.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_7

2. **Ways of Coping**

   The way a person copes after an injury can affect a person's resilience and adaptation to the injury. People with higher levels of resilience tend to use more problem-focused coping and task-oriented coping to manage stress (e.g., focus on improving functioning after an amputation by working hard in rehabilitation). People with lower resilience are more emotion-focused with their coping (e.g., focus on how sad they are that they lost a limb). Though everyone uses emotion-focused coping at some point of their illness, highly resilient people tend to protected more against negative emotions and rebound quicker to problem-focused coping strategies [2]. In addition, resilient individuals also tended to find benefits in spiritual coping, which may provide a sense of purpose to the illness and provide another source for support and strength.

3. **Optimism**

   Defined as a trait disposition to expect or anticipate good outcomes, is protective against distress from a variety of illnesses and medical conditions. Not surprisingly, people with high levels of resilience also tend to be optimistic, which some genetic research has argued is a heritable trait. As such, it is a characteristic of resilience believed to facilitate development of other resilient traits later in life [3].

4. **Hardiness**

   A personality trait, hardiness may help to buffer against extreme stress. People who display high levels of hardiness tend to: be committed to finding meaningful purpose in life; feel as though they have control over their environment and outcomes; and believe that they can learn and grow from both positive and negative experiences in life. People with high levels of hardiness tend to have higher levels of confidence, making them better able to solicit social support and active coping and making stressors more manageable [4].

5. **Positive Emotions**

   Positive emotions during or after adverse situations tend to reduce negative emotions and helps people maintain connection with social supports. This is not to say that a resilient person does not display or experience any negative emotions, but they are able to balance negative and positive emotions in a productive fashion.

B. ***Trajectories of Psychological Functioning during Medical Rehabilitation***

   An important distinction regarding differences in how people function across time while recovering from medical illness has emerged in the empirical literature. Resilience, as described above, is about the ability of an individual to maintain a relatively stable path of functioning over time [1]. These are important when assessing the psychological health of an individual during medical rehabilitation. For example, if an individual displays moderate levels of symptoms, but reported even higher symptoms 2 months previously, it might be that the individual is not in need of intervention, as they are moving toward their baseline functioning using his/her own innate abilities. Intervention resources can be targeted toward those individuals who are displaying high levels of distress across time.

   1. **Recovered Trajectory**

      Some people display psychological distress soon after an aversive event, but gradually over time, possibly even over the course of months or years, they return to baseline functioning. This is estimated in approximately 15–25 % of individuals [5].

   2. **Delayed Trajectory**

      A small number of people (0–15 %) display minimal symptoms initially, but then over time symptoms increase [5]. Most research on resilience has been focused on delayed trajectories due to the consistent occurrence of symptom patterns across disease and health-related injury. People in delayed trajectories tend to show greater initial symptoms of depression and anxiety (compared to other trajectories) that then continue to increase over time.

3. **Chronic Trajectory**

   Some people tend to have a high level of distress initially that remains high across time. Around 5–30 % experience a chronic trajectory [5].

4. **Resilient Trajectory**

   The majority of people (35–65 %) display minimal symptoms of stress and disruption initially, but very quickly after the event symptoms decrease and stable function returns [5]. Resilience has consistently shown to be the most common trajectory across numerous traumatic events, including injury, bereavement, and natural or current events disasters.

Importance

A. ***Incidence and Prevalence of Resilience***

   While the majority of people will be exposed to a stressful medical event for themselves or a loved one in their lifetime, most people respond to those events in an adaptive and resilient way. In a review of PTSD literature, they noted that "roughly 50–60 % of the population is exposed to traumatic stress but only 5–10 % develop PTSD" [6]. In studies of resilience, results have mirrored this statistic showing that up to 65 % of people show a resilient trajectory after suffering a traumatic event, with the remaining experiencing a delayed or consistent trajectory characterized by persistent psychological distress.

   It is important to remember that resilience is not just the absence of any major distress; just because there is an absence (or a significantly reduced) reaction to a traumatic event does not necessarily mean someone is resilient. Paying particular attention to how one copes with their distress, the prevalence of positive vs. negative affect and cognitions during the recovery process, and the persistence (or lack thereof) of negative psychological and health-related dysfunction over a period of time are the best identifiers of highly resilient people.

B. ***Strength-Based Approach to Bolstering Resilience***

   Although the field is divided on whether resilience is a personality trait or modifiable, there have been several programs in recent years aimed at increasing or "bolstering" resilience to better handle stressful situations. These programs mainly target the five factors of resilience mentioned above. Similar to self-control or exercise, people with low resilience can build on their stress management and coping skills that are associated with people with high resilience. Many of these programs can be as short as a one-day workshop to several intensive sessions, but all focus primarily on enhancing the use of self-regulatory and coping skills under stressful conditions, promoting more positive affect in the wake of stress, and increasing general self-esteem and self-enhancement.

1. **Here are a few of the most recently tested resilience interventions**

   Penn Resilience Program (PRP): Based on training from Seligman and colleagues, this training program focuses specifically on the improvement of cognitive behavioral skills, in order to address anxiety and depression and improve well-being and performance [7]. PRP has also been used in samples of high-risk populations, medical students, and young adults [8].

   Stress Management and Resilience Training (SMART): The SMART training program, adapted from Attention and Interpretation Therapy, consists of focus on basic foundations of perceiving and interpreting experiences, and then transitions to skill-building to strengthen positive engagement and emotional intelligence [9]. This program has been developed and tested extensively with medical professionals, staff, and patients with chronic illness within the Mayo Clinic. Collectively, the SMART program has shown to increase resilience, mindfulness, and overall quality of life, while decreasing anxiety and perceived stress weeks later [9]. A computerized, self-managed version of the program has also been tested and available.

   Families Overcoming Under Stress (FOCUS): Designed as a trauma-informed, skill based resilience enhancing program for military families with children ages 3–18, the program uses multiple components including computerized psychological health check-ins; training in emotional regulation, problem-solving, stress-management, and goal setting; and specific psychoeducation on the impact of stress on children as well as traumatic brain injury and PTSD. Initial studies have suggested that both parents and children who have participated in this program showed significant improvements in anxiety, depression, and general decrease in emotional symptoms as well as improvements in children's use of positive coping skills [10].

Resilience Interventions in the Military: The Department of Defense (DOD) has been actively involved in identifying strategies and programs to enhance resilience. The military clearly recognizes that for both the individuals serving and their families, the psychological toll of frequent deployments and continued conflict in Afghanistan and Iraq is significant. This is evident in not only the rates of PTSD in these conflicts but also the rates of suicide, which appear to be at a record high. Thus the DOD has taken a lead role in not only better understanding and identifying what factors contribute to resilience but also how to build and foster resilience. In a recent review by the RAND Center for Military Health Policy Research [11], current military relevant resilience building programs were assessed on a number of factors including strategies for promoting resilience, any barriers, and the effectiveness of the programs. The study defined a resilience program as "one that targets any of the factors that research has shown to improve resilience and healthy responses to stress, and provides a means for helping individuals to incorporate resilience into their daily lives." The recommendations from this extensive review of current military intervention programs suggest that resilience should be integrated as a policy, standardized resilience measures across programs should be adopted, and more intense program evaluations should be conducted to garner support for their implementation.

C. ***Impact of Psychological Resilience on Health Outcomes***

Resilience is a complex and dynamic system of positive characteristics, which together contribute to significant reductions in physical and mental distress during recovery. Research has shown that resilient characteristics are associated with better physical health outcomes that include (but are not limited to) cardiovascular, immune, chronic pain, and cancer, along with significant decreased risk for mortality. The key factor between the resilience and good health outcomes seems to be how positive and engaged people are when facing and managing their illness. Highly resilient people tend to engage in more self-care, adhere more to treatment, manage their perception of illness and pain, foster their own self-efficacy during recovery, and look for the potential for growth and benefits after illness [12]. For example, in multiple studies of cardiovascular patients, better health outcomes by the end of the studies were associated more with psychological factors like higher sense of control over their health, high self-efficacy, and finding positive meaning in their illness.

Simultaneously, endorsing these skills also significantly reduce the occurrence of depression and anxiety symptoms that impede recovery. Most research examining the effect of resilience have studied the impact on lower depressive and anxiety symptoms over time. Across disease, highly resilient individuals tend to have better outcomes.

Resilience, whether already present or bolstered through intervention, increases the likelihood of better health outcomes through its protective influence against illness and injury. Bolstering empowerment for patients in their own care following discharge is the best method to boost resilience, and in turn reduce rates of utilization and illness in the long term.

Practical Applications

A. ***Measuring Resilience***

Measuring resilience has been conceptually challenging. However, standardized measures of resilience do exist. Below is a list of common measures of resilience used in research and clinical practice. For each scale, resilience is first operationally defined and the scale described. Following these descriptions are qualitative strengths and weaknesses based on validations and reviews made by several researchers [13, 14]. Samples in which each measure is utilized are also mentioned.

1. **Connor–Davidson Resilience Scale**

The CD RISC was developed as a measure of five factors (personal competence, strengthening effect of stress, acceptance of change and secure relationships, control, and influence of spiritual) involved with stress and coping ability [15]. The measure is available in 25, 10, or 2 items with a 5-point scale ranging from 0 (not true at all) to 4 (true nearly all of the time). Several strengths of this measure include its strength under psychometric evaluation relative to other measures, along with its ability to detect levels of resilience in several populations. A weakness would be a lack of theoretical clarification, specifically to how resilience is defined (i.e., "a personal quality that reflects the ability to cope with stress"). The scale has been used to measure resilience linearly (i.e., total score) or nonlinearly in groups (i.e., low, intermediate, and high resilience using ±1SD over the mean). To date, the CD RISC has been used to measure resilience in patients in a variety of samples, including with TBI, SCI, with exposure to trauma, and more.

2. **The Brief Resilience Scale (BRS)**

This BRS was developed as a means to briefly measure resilience, defined as "one's ability to bounce back or recover from stress" [16]. The measure consists of six items targeting abilities associated with faster recovery (i.e., "I tend to bounce back quickly after hard times," and "I usually come through difficult times with little trouble"). The measure uses a 5-point rating scale ranging from 1 (strongly agree) to 5 (strongly agree). Strengths of this measure include its brevity, its emphasis on stress perception and its relatedness to other measures of resilience, coping styles, health-related outcomes, and other personal characteristics. A weakness of the measure is its lack of insight into mechanisms that help faster recovery. In addition, scale development was based on sample feedback and initial piloting of the scale rather than empirical validation. However, the scale does fare well under qualitative assessment relative to other resilience measures. The scale was validated with four samples of young adult students and older adults in a behavioral medicine setting, with differentiations tested in patients with cardiac issues and fibromyalgia. To date, this scale shows limited application in a clinical setting, though the authors make clear the implication for use in projecting health outcomes. In a study of residents from a rehabilitation unit of a nursing home in the Netherlands, the BRS performed well in recognizing persons with high resilience conceptualized as the absence of depression and anxiety [17].

3. **The Resilience Scale for Adults (RSA)**

This RSA was developed as a means of identifying protective factors that facilitate adaptation in the wake of psychosocial adversity [18]. The measure consists of 45 items grouped into five psychosocial factors believed to protect against adversity which include personal competence, social competence, structured style, family cohesion, and social resources. A strength of the RSA is that it measures resilience on a multiple levels of social support and dispositional beliefs, such as optimism, coping style, and satisfaction with life over time. In addition, the RSA ranks high on measures of qualitative assessment, including internal consistency and construct validity, with ability to differentiate resilience between normal and clinical settings. A weakness is a lack of theoretical support in its creation and validation. The scale was developed and validated cross-culturally with adults aged 30 years for use in clinical health settings. However, in later exploration of the scale, the construct validity of the RSA was strongly supported across three dimensions (examining subscales, differentiation between patients and randomly chosen sample of the "normal population," and comparison of results from previous, longitudinal findings).

4. **Brief Resilient Coping Scale (BRCS)**

   This BRCS is a 4-item measure to means of identify protective, dispositional factors that facilitate an adaptive coping process [19]. The purpose of the scale is to measure attributes related to effective, active problem-solving coping that led to resilience as defined by Polk [20]. The measure consists of nine items grouped into five believed attributes of resilience—perseverance, self-reliance, meaningfulness, existential aloneness, and equanimity. Participants are asked to rate how well items describe themselves based on a 5-point rating scale from 1 (the statement does not describe you at all) to 5 (the statement describes you very well). A strength of the BRCS is the scale's attention to attributes that can be affected by therapeutic intervention. Additionally, the scale is assessed by authors as qualitatively comparable to associated coping and well-being scales. Weaknesses of the scale are its lack of comparison with other resilience-related constructs, including only reaching acceptable standards against qualitative assessment like validity testing. The scale was validated based upon women with rheumatoid arthritis. To date, other samples that have used the BRCS include surgeons and cross-cultural youth.

5. **Rosenberg self-esteem scale (RSES)**

   The RSES was designed to evaluate global self-esteem as well as feelings of self-worth, and known to relate strongly to resilience [21]. The measure consists of ten items, with a 4-point Likert scale ranging from 0 (strongly disagree) to 3 (strongly agree). The unidimensional scale was initially validated using a large sample of students and has since become a widely used to assess self-esteem in nonclinical and clinical populations, including patients managing chronic disease, mental health, and for intervention for mental and physical disorders. RSES is a popularly, and widely used scale, due in part to the uncomplicated language and brevity. The RSES has been translated and used worldwide, and appears to be culturally universal. However, despite being one of the most widely used instruments, there is still disagreement regarding the scale's structure. There is uncertainty whether the scale assesses global self-esteem as one factor, or as two separate constructs that represent the positive and negative aspects of self-esteem.

6. **Ego-Resiliency Scale 89 (ER-89)**

   The ER-89 was designed to assess components of ego-resiliency, a construct defined as one's adaptability, or ability to "change and return" to normal levels of ego-control after a stressful experience [22]. The measures contains 14 items related to components of ego-resiliency such as confidence, interpersonal warmth and insight, skilled expressiveness, etc. and is scored on a 4-point scale ranging from 1 (does not apply at all) to 4 (applies very strongly). A strength of this measure is its theoretical underpinnings, of which have been tested and studied in personality research. A weakness is the lack of systematic development to changes in the scale over time. The scale has been used primarily to measure resiliency as a stable personality trait and more focused on everyday change rather than adversity.

Qualitative Considerations: Several researchers have attempted to judge the comparative merit of these scales with thorough reviews [13, 14]. However, a clear, distinct "gold standard" for conceptualizing and measuring resilience is still under debate. Use of these scales will vary based on the aspects of resilience that relate to the sample and research question (i.e., observing resilience as a dispositional trait vs. identifying protective factors or active coping styles).

B. ***Populations and Resilience***

Multiple medical conditions have been included now in studies of resilience. These include individuals hospitalized after a traumatic injury, diabetes, stroke, cancer, and arthritis. Some differences between chronic illnesses do exist, depending on the severity of the illness and the ability to control or maintain symptoms or aspects of treatment. Overall, resilience tends to moderate the maintenance of illness, with positive associations with life satisfaction, self-esteem, stress management, and social support and negatively associated with psychological distress. Below are examples of medical rehabilitation populations in which resilience has been studied.

1. **Spinal Cord Injury (SCI)**

Research examined if resilience might have a predictive role in later outcome after SCI, and how resilience is correlated with other factors such as depression, self-efficacy, and quality of life [23]. For example, a recent study observing symptom trajectories after spinal cord injury, 50.8 % of the patients ($n = 208$) showed stable low depression whereas 12.5 % showed chronic high depression and 12.8 % delayed depression symptoms over a period of 2 years [24]. Resilience may be viewed as a more inherent trait rather than a modifiable factor, thus allowing clinicians to identify those that may be a risk for the development of emotional distress postinjury. By better understanding an individual's resilience, clinicians can direct more time intensive interventions to those with lower resilience. For those with higher resilience, interventions could be tailored to enhance already existing positive coping factor. Most recently, work has been done to develop and validate a patient-reported, spinal cord specific measure of resilience (SCI-QOL Resilience) using itemized response theory which should improve our understanding of resilience in this population [25].

2. **Traumatic Brain Injury (TBI)**

Similar to findings of resilience in other populations, initial longitudinal work has shown that most individuals tend to follow a pathway of resilience after injury [26] and that fewer individuals seem to experience chronic distress. However, using resilience as a predictive factor may be more difficult in those individuals with more moderate-to-severe TBI given cognitive deficits. So far, resilience has been shown to help protect against common symptoms like depression, stress, sleep disorders, and fatigue [27]. Interventions to enhance resilience have so far only speculated that managing stressors and adaptive coping styles are key mechanisms behind resilience and mild TBI. This remains an area for which more research is needed.

3. **Stroke**

Trajectories of emotional recovery after stroke are beginning to be explored. In a study of 23 poststroke participants, five exhibited a resilient trajectory, with the remaining experiencing either chronic, emergent, or recovery trajectories [28]. In a comprehensive review of studies of adjustment after stroke, Sarre and colleagues (2013) suggest that personal characteristics, strategies for adjustment, social support, and structural factors such as the health care system were all either contributory or negative in regards to outcome [29]. Further, they suggest that when studying resilience specifically in the stroke population, the concepts of the acute event of the stroke as well as the long-term impact of living with stroke should direct a more temporal approach to understanding resilience after stroke.

4. **Solid Organ Transplant**

   Organ transplant can be a profound psychological experience for both the donor and the recipient. As such, psychological evaluation pretransplant is often required to assist in the decision-making process and reduce the risk of posttransplant complications such as poor medical adherence or substance abuse relapse. Resilience is now being explored in the transplant population as a protective factor that may indirectly promote health [30]. In a study of 53 individuals with heart transplant, resilience was significantly related to psychological adaptation posttransplant [31]. A study of 161 living kidney donors showed that resilience was a significant predictor for quality of life prior to the donation and there was a significant correlation in predonation resilience scores with quality of life after donation [32]. Continued research is needed in the transplant population to better identify how the resilience construct can be used to improve outcome.
5. **Resilience and Caregivers**

   Assessing resilience is not only critical in persons with an injury or illness but also for family members and loved ones who may be providing care. Caregiving has been associated with both medical and psychological consequences for the patient, and a more comprehensive understanding of resilient caregivers may help develop interventions to reduce negative consequences on those caregivers who appear to have inherently less resilience. Studies have looked at the impact of resilience on caregivers from a variety of populations including those with SCI, TBI, stroke, and dementia. For example, a model using resilience trajectories was used to examine the experience of family members providing care for someone with a SCI, finding that most individuals are initially resilient in the first year of caregiving. However, in family members who showed poor long-term adaptation, significant degree of distress was observed acutely [33]. Resilient caregivers of those with either SCI or TBI were shown in another study to have higher positive affect and less negative affect and lower caregiving burden as compared to those who viewed themselves as less resilient [34]. These and other studies suggest that assessing resilience in caregivers early after a caregiving role is assumed, and providing support for those who are less resilient, may have an impact on the quality of caregiving for the injured or ill individual.

Tips

- ***Include resilience assessment in clinical evaluation***
- Completing a standardized resilience measure allows patients to discuss areas of strength, especially when many assessment measures typically given after injury or illness are focused on negative experiences (i.e., depression and anxiety).
- ***Provide education about resilience and use these concepts in intervention***
- After an injury or illness, individuals often feel vulnerable, and tend to forget about their preinjury inherent coping skills and strengths; therefore, communication about what resilience is can be used as an intervention strategy.
- ***Identify those with low resilience***
- Individuals who are inherently low in resilience may benefit from additional intervention, including monitor for the development of negative psychological consequences as well as additional time spent bolstering other coping skills.
- ***Understanding resilience is not only useful for patients but also for colleagues***
- There appears to be a relationship between low resilience and negative psychological consequence in clinicians taking care of patients as well [35], thus helping clinicians examine their own resilience and seek additional support if needed can reduce the impact of providing care.

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Behavioral Medicine: Nutrition, Medication Management, and Exercise

8

Laura E. Dreer and Alexandra Linley

Topic

Behavioral medicine is the interdisciplinary approach dedicated to the (1) study of the biopsychosocial interactions between behavior, psychosocial, and biomedical science knowledge, (2) development of techniques relevant to the understanding of health and illness, and (3) application of this knowledge and techniques to the prevention, diagnosis, treatment, and rehabilitation [1]. These evidence-based practice methods are focused on improving the well-being of individuals, families, communities, and populations. Topics and health issues relevant to behavioral medicine may include health maintenance behaviors (e.g., exercise/physical activity and nutrition) and adherence to medical regimens (e.g., medication management) for conditions/disabilities such as traumatic brain injury (TBI), spinal cord injury (SCI), pain, diabetes, obesity, cancer, HIV/AIDS, cardiovascular disease, diabetes, multiple sclerosis (MS), and respiratory disease. For the purpose of this brief chapter, we focus on the importance of nutrition, medication management, and physical activity (PA) as they all are behaviors that play a key role in the treatment and prevention of a range of adverse health outcomes relevant to overall health, rehabilitation, and recovery.

A. ***Key Concepts***

1. **Nutrition/Dietary Intake**
   - Dietary guidelines for Americans recommend a balanced diet containing nutrient dense foods such as vegetables, fruits, whole grains, low-fat dairy products, and lean protein foods containing dietary nutrients without too many calories. Nutrient dense foods and beverages should not be diluted by the addition of calories from added solid fats, sugars, or refined starches, or by the solid fats naturally present in food. Evidence has shown that people who are successful in managing their weight have found ways to monitor how much they eat in a day.
   - Caloric intake needs may vary slightly depending on individual circumstances, and it is important to keep in mind that recommendations for foods, nutrients, and supplements may be restricted or adjusted for certain groups depending on an individual's stage in life, their gender, and activity level (e.g., hospitalized patients, pregnant women, and older adults).

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_8

- Over the course of rehabilitation and into recovery, the key to achieving and sustaining appropriate body weight is by caloric balance. In other words, weight maintenance depends on the relationship between calories consumed from foods and beverages and calories expended in normal body functions (i.e., metabolic processes and physical activity). Calories consumed must essentially equal calories expended for a person to maintain body weight. Consuming more calories than expended will result in weight gain. Conversely, consuming fewer calories will result in weight loss.
- ***Nutrition and Rehabilitation*** Achieving and maintaining adequate nutrition following a traumatic injury requiring rehabilitation (e.g., SCI, stroke, heart attack, and TBI) is a critical goal for recovery [2]. Depending on the type of injury, dietary intake may require complete assistance (e.g., feeding tube) with daily monitoring by hospital staff, and then a gradual adjustment as functioning is regained. Immediately postinjury, appetite and weight are influenced by complex anatomical, biochemical, and endocrine pathways in the central nervous system that may be disrupted by the trauma [3]. During the acute phase of recovery, individuals tend to lose weight because of hypermetabolism, hypercatabolism, reduced caloric intake, and altered gastrointestinal function. Nutritional supplementation through a gastric feeding tube may be provided within the first 24-h of a major trauma.
- Over the course of the following days/weeks postinjury other issues, such as dysphagia (problems with swallowing) or soreness of throat muscles, may result. Thus, the need for assisted nutrition may continue across recovery with most patients regaining their nutritional independence within the first 6-month postinjury.
- In the later phases of recovery, the situation is often reversed. Feeding is well established, there is a reduced energy expenditure relative to an increased caloric intake, along with a relatively sedentary lifestyle after injury, all of which can result in weight gain. A hypothalamic disorder that impacts endocrine control (i.e., growth hormone or thyroid deficiency) can also influence weight gain [4], as can medications. Without an appropriate adjustment for the dietary caloric intake, energy intake can easily exceed daily energy requirements, which predisposes affected individuals to weight gain during the later phases of recovery.

2. **Medication Management**
    - Medication adherence refers to the extent to which patients take medication as prescribed by their doctors. This involves factors such as filling prescriptions, remembering to take medications on time, taking the correct amount, and understanding the directions (e.g., taking medications with meals, checking insulin levels).
    - Poor adherence can interfere with the ability to manage many diseases or injuries, leading to greater unnecessary secondary health problems/complications (e.g., infections, progression of a disease or health condition, and relapse), additional health care costs, and thereby lower quality of life.
    - ***Medication Management and Rehabilitation*** Taking medications as prescribed is critical for a variety of reasons post injury (e.g., preventing infections as well as secondary health conditions and controlling symptoms). Health care providers monitor medications closely during hospitalization and rehabilitation. However, upon discharge, patients and/or their caregivers must immediately take over medication management. Depending on the medication regimen and number of health conditions, this can be quite a complex undertaking.

3. **Physical Activity (PA)**
   - Recommended guidelines based on current evidence indicate that getting at least 150 min per week (e.g., 2 h and 30 min) of *moderate* PA (e.g., brisk walking) or 2 or more days a week or 1 h and 15 min (75 min) of *vigorous-intensity* aerobic activity (i.e., jogging or running) every week and muscle-strengthening activities that work all major muscle groups (e.g., legs, hips, back, abdomen, chest, and shoulders/arms) helps to promote health and prevent secondary health problems.
   - Similar to healthy dietary intake, engaging in regular PA and exercise is important for overall health, independence, prevention of chronic diseases, and engaging in activities of everyday living (e.g., climbing stairs, walking around to shop, employment). Inactivity associated with sedentary lifestyles can result in changes in body composition as evidenced by an increase in body fat and a concomitant reduction in lean body mass, particularly over extended periods of inactivity. It has been shown that persons with disabilities are at an even greater risk for obesity than non-disabled persons.
   - ***Physical Activity and Rehabilitation*** Physical activity is often compromised immediately following a traumatic injury due to factors such as orthopedic injuries, pain, hemiparesis, loss of muscle strength and tone, poor balance, cervical injury, medications, and/or mood. Limitations for PA depend on the nature of the trauma, severity, type, and location, and the reason for hospitalization. At the onset of acute inpatient hospitalization, patients are often restricted to bed rest. However, gradual resumption of PA intensity and frequency occurs as participation in physical therapy begins to take place. Encouraging gradual PA can help to minimize risk for secondary health conditions (e.g., obesity) [5].
   - Determining the type, quantity, and frequency of PA to prescribe following an injury or disability should rely on strict guidance from allied health professionals including physicians as well as physical therapists, occupational therapists, and dietitians. This is important for safety considerations. Other factors for consideration should include medical limitations, medications, and weighing of risks/benefits postinjury is particularly important when making PA recommendations.
4. **Other Determinants Influencing Health Behaviors**

   Neurocognitive, psychological (e.g., stress, depression, and personality) and environmental factors (e.g., lack of access to healthy foods, transportation, uneven paths to walk in neighborhoods, safety concerns/high crime rates, and affordability) can also influence healthy lifestyle behaviors and choices postinjury. For example, everyday tasks necessary for achieving and maintaining a balanced and healthy diet high in nutrition often include daily meal planning, grocery store shopping, food selection, meal preparation, and cooking, which can be difficult for a person with a traumatic injury. For example, performing these tasks requires a person to understand nutritional information, attend to information, plan and organize, read ingredients on labels, select among different types of foods that vary in nutritional value, chop/cut/process and prepare foods correctly and safely, understand and follow the sequence of recipes, divide attention when cooking, and operate appliances (oven, microwave, blender, and food processor). These tasks are often challenging for persons with normal cognitive/motor functioning due to busy schedules and daily demands. Persons with a disability are more likely to struggle with this important activity in daily living due to problems with motivation/drive, planning/organization, initiation, attention, memory/forgetfulness, sequencing, speed of processing, vision, visual scanning, self-regulation, fine/gross motor functioning, fatigue, depression and/or stress.

Importance

A. ***Epidemiology***

Nearly half of the United States (U.S.) adults have at least 1 of 10 chronic health conditions and approximately 25 % have at least 2 that account for most of health care expenditures [6]. Ten of the 15 leading causes of death in the U.S. were chronic health conditions. Estimates also indicate that at least 13 % of the U.S. population has a disability; or 56 million people according to the Centers for Disease Control and Prevention (CDC). By 2020, 48 % of the population is estimated to be living with a chronic disease.

- According to the CDC, a major cause for this state of affairs is problems with self-managing lifestyle behaviors (i.e., PA, poor nutrition/eating habits, and medication management) *all of which are modifiable, thus can be treated or possibly prevented with behavioral medicine approaches*.
- Unfortunately, adults with both disabilities and chronic conditions receive fewer preventative services and are in poorer health than individuals without disabilities who have similar health conditions.
- Additionally, it has been estimated that among patients with chronic illness, approximately 50 % do not take medications as prescribed. Poor medication adherence has been linked to increased morbidity and death, as well as unnecessary complications, progression of disease, and/or hospitalizations.
- Chronic health conditions contribute to substantial financial expenditures and societal burdens on global health care systems (e.g., lost productivity and medical expenses) [7]. Recent estimates indicate that the provision of care for people with disabilities and health conditions is very costly; in 2010, total spending for the Medicare population was more than $300 billion. However, primary and secondary chronic health conditions that impact life expectancy and health can often be prevented and/or managed by engaging patients in modifiable lifestyle behaviors.
- Given the projected increase in the epidemiology of chronic health conditions, life expectancy, and risk for comorbid health conditions over the next decade [8, 9], the application of evidence-based behavioral medicine techniques is critical, particularly for individuals with a disability.
- Immediately following a diagnosis of a chronic health condition or traumatic injury is an opportune time for rehabilitation providers to challenge patients' attitudes and changing unhealthy behaviors early on in recovery or in the disease management process (i.e., PA, dietary intake, and medication management). Changing health behaviors involves learning new adaptive behaviors and attitudinal changes that providers with a behavioral medicine approach can help address across the recovery continuum.

B. ***Challenges to Changing Health Behaviors Among Persons with a Disability*** People with disabilities can often experience unique challenges related to changing in such behaviors compared to nondisabled populations. Challenges related to establishing healthy nutrition and dietary intake may include lack of healthy food choices or resources (e.g., money, transportation, social support, and options for fresh food) as well as difficulty preparing meals (due to cognitive or motor deficits), chewing or swallowing food, sensitivity to taste, substance abuse (e.g., smoking and alcohol), manual dexterity or motor functioning and ability to feed self, poor or excessive appetite (e.g., due to depression, stress, and medications), or cultural factors. Challenges with physical activity may include lack of accessible environments (e.g., adaptive exercise equipment, parks, and sidewalks), energy, pain, depression, fatigue, medications that cause weight gain or loss, and physical limitations, as well as limited resources (e.g., money, transportation, and support). Lastly, problems related to medication adherence may include health literacy, poor cognitive functioning (e.g., comprehension, memory, and planning), poor doctor–patient communication, prescription of complex medication regimes and dosing schedules, adverse side effects, heath beliefs, length of treatment, and/or cost.

Practical Applications

A biopsychosocial conceptual approach should be taken in terms of screening and delivering behavioral medicine efforts by a multidisciplinary team of health care providers (physiatrists, registered dietitians, physical therapists, rehabilitation psychologists, occupational therapists, recreational therapists, and personal trainers). Health care providers should work to develop an individualized rehabilitation plan involving the patient and family in the context of biological, psychological, social, cognitive, and social aspects of the person's disability. Examining the influence of complex lifestyle behaviors is a critical first step in an effort to designing and implementing personalized, effective treatments.

- In addition to level of injury or severity of a chronic health condition, other important variables that impact health behavior changes and rehabilitation outcomes such as problem-solving abilities, cognitive appraisals, health beliefs and behaviors, personality, and social support should be assessed [10–14].

A. ***<u>Behavioral Medicine Evidence-Based Interventions</u>***

- The mainstay of contemporary approaches for lifestyle behavior changes (i.e., reducing caloric intake or improving dietary quality; increasing the frequency of PA; and enhancing medication adherence) is a treatment emphasis of behavioral medicine applications. In general, the efficacy of such approaches requires mindfulness of biopsychosocial issues using a combination of education, training in self-management strategies (e.g., self-monitoring), stress management and behavioral strategies, and relapse prevention [15, 16].
- Common theoretical frameworks include the ***health beliefs model*** [17], the ***theory of planned behavior*** [18], or those with more of a cognitive-behavioral therapy (CBT) emphasis and based on ***social cognitive theory*** [14, 19]. These theoretical approaches stress the role of the broader environment in hindering or enabling patients in their efforts to make healthy lifestyle choices.
- ***Evaluating*** the benefits of behavioral medicine interventions may include health outcomes such as reduced body weight and fat, fatigue, pain, depressive symptoms, substance consumption, lowered risk for complications and comorbid health problems, number of rehospitalizations and improved health behaviors (e.g., frequency of PA and quality of sleep), blood lipid profiles, and influence on brain plasticity (e.g., neurogenerative and neuroprotective processes).

1. **<u>BIOPSYCHOSOCIAL Aspects</u>**

- ***Early Intervention*** to foster healthy habits is critical for immediate and long-term recovery. Thus, an initial step is to conduct a comprehensive physical examination and blood work up in order to understand patients' overall health, identify other possible health conditions in need of management (e.g., high blood pressure, elevated heart rate, and blood sugar levels or cholesterol) and/or to detect health problems (e.g., impact of medications on organ functioning and presence of illegal or elevated substances). Regular check-ups and monitoring health indicators is also important for individuals with a disability.
- ***Evaluation of Global and Specific Health Behaviors*** Providers should take into account patient premorbid health behavior and lifestyle patterns. Information obtained

from both the patient and his/her caregiver will help shed light onto the patient's lifestyle choices, habits, and potential barriers in need of intervention.

- ***Physical Activity***
  - **Assessment** Determine premorbid level of physical activity and exercise habits. Health care providers should assess the type(s) of PA, intensity (e.g., light, moderate, and vigorous), frequency (e.g., how many times per day, week, month, and year), and duration (e.g., how long per event). PA assessment often involves a complex set of behaviors and can be difficult to measure. However, there are a variety of physiological or objective indicators of PA (e.g., pedometers, accelerometers, mobile apps; exercise treadmill testing; total distance walked on the 6-min walk test; heart rate monitoring; the step test cardiorespiratory endurance, muscular strength, body composition, and flexibility).

    While objective measures of PA are informative, there are also a number of subjective PA measures available (e.g., questionnaires and rating scales regarding energy expenditure during leisure and physical activities, PA recall, self-monitoring forms/mobile apps, PA self-efficacy, and barriers to PA). These can also be used to track the types of activities associated with objective measures or times during the day (e.g., diary of activity during peaks on accelerometers).
  - **Intervention** Studies have shown both mental and physical benefits of PA post-injury. A variety of adaptive PA and exercise programs or activities are available (e.g., walking, yoga, biking, aquatics, PA classes, flexibility, and strengthening workouts; see www.nchpad.org) and should be monitored by a physician in terms of prescription of intensity postdischarge and across recovery.
- ***Dietary Intake Assessment*** Assessment of premorbid nutrition, dietary intake, and eating habits is important during rehabilitation (e.g., overall dietary intake of essential nutrients and consumption of specific foods). Similar to assessing PA, the type, amount, and frequency of dietary intake should be evaluated. There are a variety of available methods such as food diaries, recall intake of 24-h food recalls, food frequency self-report questionnaires, software programs, and mobile apps.
- ***Medication Adherence*** Objective medication use can be monitored in a number of ways such as dosing aids (measuring proporation of days adherent), pill counts, blood serum levels, pharmacy claims data, refill history, and mobile apps. While objective measures have been found to be more accurate, self-report measures are also available and may help inform patient health beliefs about medications.
- ***Screening for Obesity*** Obesity is associated with problems with dietary intake, lack of PA, and poor health habits. Thus, assessment of body composition, body mass index (BMI), body caliper/skinfold method, and/or bone density, body fat mass, lean muscle mass, percentage of fat, bone, and water and muscle (e.g., dexa scan) should be evaluated.
- ***Sleep and Fatigue*** Because poor sleep and fatigue can lead to problems with sedentary lifestyles and unhealthy behaviors, physiological methods related to sleep quality should be considered during an overnight sleep study (e.g., polysomnography core assessing brain activity or electroencephalogram or EEG; eye movements or electro-oculography/EOG; and muscle activity or EMG). Other important aspects that should be monitored by a sleep technician in a sleep evaluation might include heart rate, patterns, blood oxygen levels, limb movements, and snoring.
- ***Substance Use*** Substance abuse can be evaluated in a number of ways (e.g., toxicology screens and physiological indicators related to withdrawal/dependence).

- ***Evaluate Readiness for Change*** Preparing and motivating patients to change unhealthy lifestyle habits or health behaviors is critical to the likelihood of successfully influencing health outcomes. Classifying a patient at a given stage of change to identify his/her level of problem awareness or reason for altering unhealthy behaviors, willingness to change, and actions for change is critical.
  - **Assessment** There are a variety of readiness for change measures available (e.g., University of Rhode Island Change Assessment Scale: URICA) [20] that have been adapted for various behaviors and based on the stages of change model (e.g., precontemplation, contemplation, preparation, action, and maintenance) developed by Prochaska and Di Clemente, and the Transtheoretical Model (TTM).
  - **Intervention** Brief interventions focused on a combination of education, motivational interviewing, and reducing barriers to treatment are effective [14].
- ***Screen for Depression and Quality of Life*** There tends to be great variability in adjustment to a disability. While the majority of patients learn to adapt over time following a traumatic injury, a subset are at risk for clinical depression and problems with quality of life.
  - **Assessment** There are a number of evidence-based self-report measures to evaluate depression (e.g., Patient Health Qustionnaire-9: PHQ-9) [21]. For example, the PHQ-9 is widely used and quick to administer, score, and quantify core symptoms related to clinical depression. There are also a number of population-specific quality of life measures available. Selection of a quality of life measures depends largely on the injury or health condition as well as psychometric properties.
  - **Intervention** There are a plethora of effective treatment interventions for depression related to adjustment to a disability. Many are based within a CBT framework and/or a combination with pharmacological treatment in more severe cases. These treatments have been found to improve mood and quality of life.
- ***Screening for Substance Use*** Studies suggest high rates of premorbid substance use (e.g., nicotine and alcohol) associated with traumatic injuries (e.g., TBI and SCI) and conditions (e.g., chronic pain).
  - **Assessment** Routine substance use screening is essential for patients in rehabilitation. Instruments such as the Alcohol Use Disorders Identification Test-Condensed (AUDIT-C) or CAGE Questionnaire offer a systematic means for identifying people at risk.
  - **Intervention** Many people experience readiness to change when faced with a radically altered situation that health care providers can capitalize on in terms of building motivation for change. Patients with substance dependence may have gone through withdrawal in the intensive care unit prior to rehabilitation, with remission in a structured setting. Major treatment efforts for substance use disorders typically cannot occur during acute rehabilitation because of time constraints. However, brief interventions focused on motivational interviewing, education, and reducing barriers to treatment can be effective [17].
- ***Evaluate Fatigue and Sleep*** Problems with sleep (e.g., insomnia) and fatigue can have a significant impact on health behaviors, quality life, and recovery.
  - **Assessment** In addition to a polysomnography, a medication revaluation along with medical history should also be considered when sleep problems are of concern given the potential impact of certain medications on sleep/fatigue. Self-report measures can also aid in the understanding of problems related to sleep/fatigue (e.g., Fatigue Severity Scale: FSS) [22].

  - **Intervention** A range of treatments may be applied to address problems with sleep (e.g., CBT; continuous positive airway pressure therapies; eliminating poor sleep habits, behaviors, and environmental disruptions that interfere with quality rest; and self-monitoring sleep schedules and changes in the contingencies and reinforcers that promote sleep)
- ***Pain Assessment*** Pain often accompanies an injury requiring hospitalization and rehabilitation. Chronic pain persists over a longer period of time than acute pain and can be resistant to medical treatments. Chronic pain has a physiological and psychology basis. Untreated pain can interfere with the healing process by affecting the immune system and leading to other undesirable outcomes, such as sedentary lifestyles, and poor quality of life.
  - **Assessment** Pain is subjective and defined by the person who experiences it. A variety of empirically validated scales are available to assess pain location, severity, intensity, and tolerance relevant to specific injuries or health conditions (e.g., Brief Pain Inventory) [23].
  - **Intervention** An interdisciplinary approach to managing pain typically used. Pharmacological treatments (e.g., nonsteroidal anti-inflammatory drugs; muscle relaxants; opioids; steroid injections; and nerve blocks) and physiological approaches [e.g., biofeedback and transcutaneous electronerve stimulator units (TENS)] can be effective in management pain. In addition to pharmacological treatments, behavioral medicine approaches such as relaxation training, visual imagery, and other CBT methods to cope with pain can also be effective.
- ***Understanding Social Support*** Given the influence of family and friends on behaviors, it is imperative to assess perception of support for health behavior changes. Several scales are available depending on the behavior or health habit of interest (e.g., social support for diet and exercise) [24]. Family counseling and caregiver training programs are important considerations in rehabilitation.
- ***Environment, Neighborhood, and Socioeconomic Factors*** Environment and social barriers/facilitators related to PA, nutrition, and medication management (e.g., lack of access to gyms, bike paths, stores with healthy or fresh foods; transportation; neighborhood safety; affordability/cost; and household consumption of food or engagement in PA) and other health behaviors should be evaluated. General and/or habit specific questionnaires and checklists are available to determine barriers to healthy habits [25, 26].

Tips

- **Emphasize Lifestyle Focus and Factors Within Patient Control** Often after a life altering injury or diagnosis of a chronic health condition, patients feel their lives are out of their control. It is important to focus on aspects of their lives and health they do control. Start with small obtainable goals to build self-efficacy and confidence. Keep in mind that information should be communicated in an easy-to-understand format and to check for understanding, particularly when a patient has neurocognitive deficits or lacks social support. For example, information on healthy eating and strategies to prepare appropriate intake can be challenging (e.g., how to read nutrient labels, tracking caloric intake, understanding how much and what types of exercises to do per week, and managing multiple medications with different doses or schedules). Writing clear instructions and simplifying prescriptions for nutrition, physical activity, and/or medication management is key.
- **Nonjudgmental Approach** Patients may have been recommended to change unhealthy habits previously. Taking a nonjudgmental approach with a motivational interviewing

emphasis will help to gain trust and plant the seed for change. It is important for health care providers to actively listen and validate patient struggles.

- **Go Beyond Education and Advice Giving** Other health care providers may have prescribed advice or education versus implementation of strategies with a behavioral medicine emphasis that are designed to initiate systematic training in specific, individualized strategies to cope with how to change and monitor unhealthy behaviors.
- **Make Rehabilitation Therapies Interactive and Fun** Many therapies (e.g., physical therapy techniques, occupational therapy) are focused on improving a certain function (e.g., fine motor functioning; meal preparation). Try to make therapies fun and social so that the patient is engaged and supportive of a biopsychosocial approach. Participation in sports, exercise, and recreation activities also helps with physical functioning, emotional well-being, and social functioning postinjury. Some of the numerous activities that people with disabilities can engage in postinjury or after being diagnosed with a chronic health condition include: ice hockey, tandem biking, wheelchair basketball and rugby, goal ball for people with vision impairments, water skiing, and Paralympic sports. Also consider gaming and alternative PA strategies (e.g., Wii fit).
- **Family concerns** may need to be addressed about safety. Educate about risks related to sedentary lifestyles and implications of poor behavioral choices (e.g., greater risk for obesity among people with disabilities and risk of daily alcohol consumption) as well as benefits to a healthy lifestyle.
- **Normalize the Process of Changing Health Behaviors** Patients often want immediate changes. However, any long-term change in behavior takes time and effort. Normalizing this process, whether it is changing an attitude or behavior (e.g., losing weight, building muscle, and healing), takes time and persistence. Some people respond better to a team approach or the health care provider as a "coach" helping them through rehabilitation and into recovery, particularly for mental health providers where there is often a stigma. Behavioral medicine techniques are effective and it may be beneficial to introduce or refer psychologists as health behavior coaches.
- **Focus on Patient Strengths** Many times, particularly for mental health providers, there is an emphasis on evidence-based treatments that change "maladaptive thinking" (e.g., thinking errors and mind tricks). While this approach is effective, growing support focuses on building upon strengths and fostering resilience and posttraumatic growth.
- **Communication** It is important to make sure to check for understanding on both the patient and his/her support system, particularly for medication management. Miscommunication between patients–doctors or nurses as well as the rehabilitation team can happen. Putting instructions in writing can help minimize misunderstandings. As health care providers, it is easy to forget how complex medication and rehabilitation regimens are in addition to trying to remember information from provider to provider, particularly when overwhelmed, stressed, or worried about the future.
- **Self-Monitoring** Self-monitoring is important for any meaningful change in behavior (e.g., proper nutrition and healthy eating habits; PA; and medication adherence). Thus, make sure to encourage tracking of health behaviors (e.g., writing medications down with time/date; tracking foods, quantities, and calories or weight; and type and amount of physical activity per day). Encourage traditional and nontraditional methods (e.g., notebook, journal, mobile apps, accelerometers, pedometers, health promotion platforms, and voice recorders). Remember the value of getting support (family/friends) involved to assist with strategies and interventions (e.g., importance of cooking healthy meals; using pill boxes; keeping routines; and encouraging physical activity).
- **Be Mindful of Cultural and Diversity Issues** Cultural differences in food preferences, health beliefs, and/or benefits of medications

(e.g., medications are poisonous or addictive) is important when working with different cultures. Be open to learning cultural values toward health. Recognize health disparities in care and outcomes and address.

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Disability Models

9

Erin E. Andrews

Topic

A. ***Five prominent disability models***

There are several different models of disability that are important for rehabilitation professionals working in medical rehabilitation to understand in order to work with persons with disabilities. Various ideas and theories exist regarding the nature and definition of disability. In this section, five of the most prominent and influential disability models are discussed: the moral model, the medical model, the rehabilitation model, the social model, and the diversity model. Terminology stemming from these models has personal, social, medical, and political implications for disability. Words such as impairment, handicap, and disability have specific meanings, and it is imperative that those in the field of rehabilitation medicine grasp the models that are the origins of, and understand the significance of, each of these terms.

1. **Moral Model**

One of the oldest models of disability is the moral model [1]. This model postulates that disability is a result of a moral failing or sin on the part of the individual or his/her family members (e.g., parents [1]). Disability is frequently associated with sin and viewed as a source of shame; it may be seen as a burden, particularly to families [2]. For example, individuals who perceive that an acquired disability is punishment for past deeds or families who view a disability as their "cross to bear" conceptualize disability using the moral model, which is heavily influenced by religious doctrine. Historically, under the moral model, those with disabilities were referred to in terms that would clearly be viewed as derogatory today. Such language reflected an inferior or pity-based attitude toward disability and a world where people with disabilities were believed to be the result of sin, or in need of charity. Terms such as "cripple," "[g]imp," (both gimp and imp were used as slang) or "imbecile" were used to describe people with disabilities. A juxtaposing slant on the moral model is viewing the disabled person as particularly virtuous, chosen to bear the burden of a disability. This is sometimes associated with religious doctrine. Moral model conceptualizations preclude a meaningful role in society for those with disabilities; instead, this framework promotes social ostracism and may even result in

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_9

self-hatred. Today, the moral model is less prevalent, but still present. For example, some disability charity organizations attempt to elicit pity in order to generate donations or obtain financial sponsors.

2. **Medical Model**

   In the early part of the twentieth century, the medical model, in which disability is viewed not as a moral matter, but as a medical problem, came to prominence. Following the world wars, the medical model was developed largely in response to injuries among military veterans. The medical model stipulates that the impairment is a problem in need of a remedy or cure [3]. In the words of Paul Longmore: "the medical model defines disability as the inability to perform expected social roles because of chronic medical pathology… It presents disability as a social problem, but it makes deviant individual bodies the site and source of that problem (p. 355)" [4].

   Medical model language often defines groups and individuals solely based on impairment [4]. In other words, the impairment, and therein the problem, lies within the individual. For example, terms such as the R-word, "deaf-mutes," "spastic," or "feeble-minded" were used. Under this model, which remains influential today, people are referred to by their impairments. A modern example might be a physician asking a nurse in a hospital, "*Have you seen the spinal cord injury in room 330*?" Medical model based programs focus primarily on curing impairment, with little to no attention to other causes of limitations, such as environmental or attitudinal barriers. Cultural and political factors are ignored under the medical model.

   The medical model placed people with disabilities in the sick role, excused from the normal obligations of society. Or, as critics suggest, people with disabilities under this model are excluded from full participation in society. In turn, disabled people are expected to submit to the authority of medical professionals. The medical modal has heavily influenced modern public policy. For example, the U.S. Social Security system defines disability as the inability to work, and there remain some financial disincentives to return to work; some with disabilities are faced with the choice between a fixed, steady income or less predictable, often low-wage jobs, with variable access to health care. Charities are often great proponents of the medical model, raising money to cure or eradicate disability. Today, much of this focus is on genetic identification of impairment, emphasizing detection, and elimination [5]. The medical model ideology views disability as a personal tragedy. The greatest criticism of the medical model is the assertion that those with disabilities are quite capable of participating in society, and the practices of confinement and institutionalization that accompany the sick role are simply not acceptable [1]. Activists argue that while an individual may require medical intervention, it is naive and simplistic to regard the medical system as the appropriate locus for disability related policy matters. Furthermore, many disabilities will never be cured.

3. **Rehabilitation Model**

   An offshoot of the medical model is the rehabilitation model, which is well known in medical rehabilitation settings. In this model, people with disabilities are regarded as being in need of services from rehabilitation professionals who can provide therapies to help them compensate for disabilities. The rehabilitation model gained acceptance after World War II to address needs of wounded veterans. It was also a result of advocacy efforts by consumers with disabilities; "We Don't Want Tin Cups. We Want Jobs" was an early slogan of the League of the Physically Handicapped [4]. State vocational rehabilitation programs are a current example of systems based on the rehabilitation model. As a derivative of the medical model, under the rehabilitation model it is assumed that physical impairment is a difficulty that requires rehabilitative efforts to compensate for or to ameliorate limitations; disabled people can become employed, with proper compensatory strategies or accommodations in place [4]. Consumers have offered criticism of the rehabilitation model as well, because sociopolitical and cultural issues often go unaddressed, and individuals still submit control to medically trained authorities, reducing personal autonomy. Evans [6] emphasized that a primary drawback to medical and rehabilitation models is the power differential between providers and consumers.

4. **Social Model**

   A newer model of disability, often called the social model, presents disability as a neutral characteristic or attribute, not a medical problem requiring a cure, and not a representation of moral failing. This model shifts the problem away from the individual and the impairments and focuses on the attitudinal, structural, and general environmental barriers, which inhibit those with disabilities from full participation in society. Disability is viewed as a social construction. The emphasis in the social model is on external barriers, such as physical obstacles to access, and attitudinal issues, such as prejudice and discrimination. One early advocate of the social model was social psychologist Beatrice Wright, who objected to language that dehumanized people with disabilities and ignored their other characteristics. Her work led to a shift in the field, away from equating people with impairment. Wright argued that the emphasis should be placed on the person, who comes before his/her disability. This concept, known as person first language, literally emphasizes the person rather than impairment. In practice, this would mean that "person with a disability" should be used rather than "disabled person." Wright argued that this approach preserved humanity while promoting individuality [7].

   Proponents of the social model, which stems from the disability rights and independent living movements, regard disability as a normal aspect of life, not as a deviance, and reject the notion that disabled people are inherently defective [8]. Social discrimination is hypothesized to be the most significant difficulty and the cause of many problems viewed as intrinsic to disability under other models. Critics emphasize that the social model does not clearly distinguish who qualifies as a person with a disability or how disability is measured or determined [9].

5. **Diversity Model**

   An extension of the social model, largely driven by the academic field of disability studies, is that disability is a distinct diverse cultural and sociopolitical experience and identity [8]. This diversity model postulates that like other demographic characteristics such as race and sexual orientation, disability may even be a valued or celebrated part of one's identity [10]. Advocates of the diversity model argue that disability is an often-overlooked individual difference within the spectrum of diversity, and that the major impediment in the lives of disabled people is "ableism," or discrimination against and prejudice toward disabled people. Instead of using person-first language as encouraged under the social model, subscribers to the diversity model proudly identify as disabled, recognizing a distinct and emerging disability culture [10]. Emulating the approach taken by Deaf culture, some scholars have adopted the use of the term Disabled with a capital D to signify an allegiance to disability culture rather than to describe impairment [11].

Importance

The differing philosophies of these models have led to significant splintering in the field of disability, with medical model proponents on one end of a spectrum, and social and diversity model proponents on the other, as the influence of the moral model lessened [6]. A comprehensive biopsychosocial model integrating the strengths of many of these models of disability is that of the World Health Organization (the International Classification of Functioning, Disability, and Health (ICF)) [12], developed to address the limitations of the medical model and incorporate elements of the social model of disability [12]. In this model, there is differentiation among disability, health, and functional impairment, instead of equating impairment and disability with poor health and functioning.

Practical Applications

A. ***Disability Model and Conceptualizations***

In the WHO International Classification of Impairments, Disabilities, and Handicaps (ICIDH), published in 1980 [13], "impairment" was defined as a difference in bodily function or structure, "disability" as a limitation in activity or a restriction in participation, and "handicap" as the interaction between a person with a disability and the environment that diminished role fulfillment, incorporating the concept of disability as a social construct. As depicted in Fig. 9.1, the most recent iteration, the ICF, retains "impairment" as an alteration in bodily function or structure; importantly though, impairments are no longer defined as problems [12]. Impairments can result from conditions such as spinal cord or brain injury, amputation, stroke, burn injuries, depression, anxiety, and a range of other acquired and congenital physical, cognitive, and emotional conditions.

"Activity limitations" is defined in WHO ICF as limitations in mobility or self-care. Examples of activity limitations are inability to walk, problems learning, difficulty toileting, restricted social abilities, or trouble communicating [13]. These may or may not be able to be ameliorated through the use of assistive device or environmental modifications.

The term "participation restriction" has replaced "handicap" in terms of life activities and roles such as attending school, maintaining gainful employment, or pursuing relationships. The previous concept was that the handicap resided in the person ("the person is

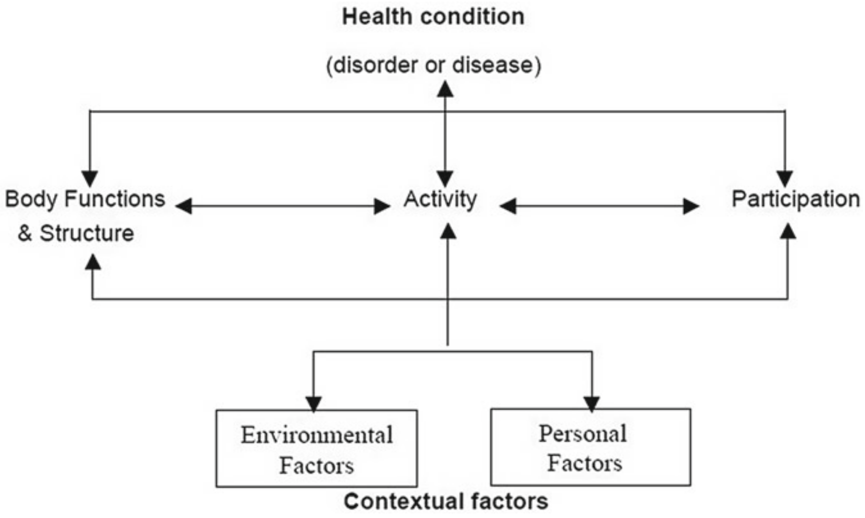

Fig. 9.1 The WHO ICF model of functioning, disability and health

handicapped"), but the new model emphasizes the role of the social and physical environments in either restricting or enabling participation ("the person needs accommodations to get to work"). Thus, participation restrictions can include problems in school or work or difficulty with mobility.

The term "disability" refers to both activity limitations and participation restrictions. For example, an individual with a missing digit may have impairment, but no disability. Individuals with amputation may have equal impairment and disability. Individuals with craniofacial abnormalities may have little impairment but great disability due to others' reactions.

The WHO ICF also includes additional "contextual factors" that influence functioning of the individual. "Environmental factors" are the external elements which affect the experience of the individual, including technology, attitudes, and services. Environmental factors that could enable activity and participation are assistive devices and technology, personal care attendants, physical modifications to the environment, policy or legal protections, or inclusive social atmospheres. In contrast, certain environmental factors could impede the individual, including the presence of abuse, inaccessible architectural structures, cold weather and rough terrain, and inflexible work environments. "Personal factors" can include intersecting elements such as gender identity, age, sexual orientation, socioeconomic status, education level, personality characteristics, and other identities that influence the experience of disability, such as important life events and developmental stages.

The WHO ICF model can be applied to a wide range of health conditions and disabilities. Sometimes impairment does not result in any functional limitations. An injury may not necessarily lead to impairment. Environmental factors can affect activity limitations. The dynamic nature of impairments and activity limitations are better reflected in this model than in more simplistic conceptualizations. Table 9.1 includes WHO ICF examples of the interface among health conditions, impairments, activity limitations, and participation restrictions, highlighting how environmental factors mediate functioning.

B. ***Disability Model and Interventions***

The ways in which disability is discussed and understood have direct influence on the behaviors of health care providers, family members, and patients. For example, if providers conceptualize disability following the medical model, the disability is viewed as the problem, and the focus is on curing the underlying impairment or medical condition.

Table 9.1 WHO ICF example chart

Health condition	Impairment	Activity limitation	Participation restriction
Leprosy	Loss of sensation of extremities	Difficulties in grasping objects	Stigma of leprosy leads to unemployment
Panic disorder	Anxiety	Not capable of going out alone	People's reactions leads to no social relationships
Spinal injury	Paralysis	Incapable of using public transportation	Lack of accommodations in public transportation leads to no participation in religious activities
Juvenile diabetes	Pancreatic dysfunction	None (impairment controlled by medication)	Does not go to school because of stereotypes about disease
Vitiligo	Facial disfigurement	None	No participation in social relations owing to fears of contagion
Person who formally had a mental health problem and was treated for a psychotic disorder	None	None	Denied employment because of employer's prejudice

Alternatively, providers operating from a diversity model standpoint may be more focused on addressing discrimination and attitudinal barriers adversely impacting their clients. Rehabilitation professionals must be able to recognize the models that have defined disability over time and be able to identify how these models influence people with disabilities, families, and providers.

Understanding the different models of disability is useful in the field of rehabilitation medicine. Patients and their families may operate from a moral or medical model of disability, both of which are perpetuated in stereotypic media portrayals of disability and may be likely to influence those with little exposure to disability, such as in the case of acquired disabilities. Language stemming from the moral model may include themes of "affliction," or the concept that disability is somehow related to sin, or to an important life lesson from a spiritual perspective. Most medical and rehabilitation professionals have been primarily trained in the tradition of the medical and rehabilitation models. Terminology linked to the medical model includes referring to "patients," and even describing and individual by his/her disability (e.g., "the new TBI"). Rehabilitation model vocabulary is likely to related to compensatory and adaptive techniques to ameliorate the effects of the disability; it is not uncommon to hear "coping" language under this model.

The concepts of disability culture and sociopolitical justice may be less familiar to people with disabilities, their families, and rehabilitation professionals. Proponents of the social and diversity models may use identity-first language (e.g., disabled people), rather than the widely popular people first language ("people with disabilities") [14]. Disability culture insiders may use disability slang (e.g., "crip," "[g]imp") to refer to themselves and to promote a sense of community or to challenge the dominant (nondisabled) culture [15, 16].

The ability of rehabilitation professionals, informed by the history and detail of each of these models, to educate others and offer a broader, biopsychosocial perspective, as outlined in the WHO ICF model, is invaluable when working on interdisciplinary teams or in interprofessional settings. This information enables rehabilitation professionals to advocate for and with patients, offering a full understanding of the complex medical, social, and environmental realities that comprise disability. In a team setting, for example, it could be important to bring up social or environmental barriers when they appear relevant, and the individual or the disability is being "blamed" for a difficulty when contextual factors are in fact responsible. Similarly, personal factors such as personality styles or other diversity factors such as age or sexual orientation may be overlooked when the focus is on rehabilitation and disability.

Informed professionals first identify the models at play, and then provide information about the model, whether to other professionals or to disabled consumers and their families. It is important to understand that each of the models has pros and cons. For example, although the moral model can be construed in destructive ways toward people with disabilities, the moral model also gives individuals ways to make meaning out of a challenging experience, such as acquiring a disability (e.g., "God will only give me what I can handle; there is a reason this happened to me"). However, when a model is used in damaging ways or contributing to psychological distress (e.g., "I am being punished"), it can be helpful to gently introduce alternative models of conceptualizing disability. Timing and a careful consideration of where the individual is in his/her adjustment process are paramount. For example, someone in the early stages of adjustment following an acquired disability may be highly unreceptive to the social model of disability, which postulates that the problem resides in the environment and the attitudes of others, rather than in the body of the disabled person. In contrast, someone who has lived with a disability for a long time or has begun to explore alternative ways of making sense of his/her experience may be very interested in hearing more about social justice movements and language trends from disabled peers as part of the social and diversity models. Even just a simple question can elicit dialogue with consumers (e.g., "I know there is disagreement within the disability community about whether to use terms like 'person with a disability;' what are your thoughts on language?"). It can be very helpful to link consumers with organizations such as a local Center for Independent Living, or disability rights coalitions such as ADAPT.

In rehabilitation medical settings, it is easy for the medical and rehabilitation models to reign, as the tasks of medical rehabilitation are a central part of the process. However, rehabilitation professionals have potential to offer a more rich experience.

Tips

- Incorporate other models of disability. For example, integrating explorations of spirituality, personal values, and other holistic conceptualizations may enhance the rehabilitation experience.
- Staff may benefit from training in disability culture or engaged in diversity awareness experiences not only exclusive to disability, but also including intersecting identities of race, ethnicity, sexual orientation, gender, gender identity, age, and other factors.
- Engage in self-reflection about one's own biases around disability. Think about the disability model(s) that may have influenced these ideas. None of us are immune to stereotypes and prejudices, even professionals and clinicians.
- Watch a movie or documentary about disability and critique the portrayal of disability; from which disability model(s) is the film influenced most?
- Choose to read works by disabled authors about the lived experience of disability. Have some of these readings available for consumers to borrow and read.
- Find out more about aspects of the disability rights movement pertinent to the population you work with or the location in which you practice. Be aware of activism happening in your community and know how to connect consumers.

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Social Participation and Ability/Disability

10

Angela Kuemmel and Katie Powell

Topic

Social participation following acquired disability is an important focus of rehabilitation for all members of the interdisciplinary rehabilitation team. Evidence demonstrates that social participation leads to increased life satisfaction and quality of life [1, 2]. However, "the presence of disability has been found to lead to participation that is less diverse, is located more in the home, involves fewer social relationships, and includes less active recreation" [3]. When individuals with disabilities return to their homes and communities, they often encounter psychological and physical barriers that limit their social participation. Historically the problems of people with disabilities were perceived to be more social and psychological rather than physical; however, later research examining all potential barriers found physical, medical, and political barriers to be more difficult [4]. This chapter outlines these barriers, highlights assessments to help identify or measure the barriers, provides interventions to overcome them, and expected outcomes of these interventions.

A. ***Key concepts***

1. **Social Participation**

   "Organized patterns of behavior that are characteristic and expected of an individual or a given position within a social system" [5]. In its simplest terms, social participation is the fulfillment of social roles in home, work, school, leisure, and community activities.

2. **Interaction Between Person and Environment**

   Social participation occurs as a result of a complex relationship between the person and his/her environment. Behavior is a function of the person and the person's environment [6]; thus, behavior and social participation of persons with disabilities are dependent on their ability to access the environment and interact with it via social roles. This theory later fueled the **Social Disability Model**, as well as many occupational science theories and frameworks [7].

3. **Social Disability Model**

   Fueled by the theory regarding the interaction of person and environment, it conceptualizes disability as a problem resulting from an unaccommodating and

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_10

inaccessible environment rather than the actual impairment. It stems from the disability rights movement.

Importance

Successful rehabilitation is not completed when a client leaves a hospital or rehabilitation center. Rehabilitation success is often measured by acceptance at work, inclusion into educational systems, and ability to resume one's right as a citizen in the built and social environment; rehabilitation takes place through reintegration into the community [8] and social participation is essential to this process.

A. ***Models and Evidence Supporting Social Participation's Impact on Quality of Life***
   1. **International Classification of Functioning (ICF)**
      The ICF outlines that "functioning and disability are results of the interaction between the health conditions of the person and their environment" [9]. Functioning is defined as "an umbrella term for body functions, body structures, activities and participation" [9]. This view of disability emphasizes that participation is essential to health and well-being. For rehabilitation professionals, this means that focusing on improving a patient's bodily functions and structures is no longer enough; attention to a person's meaningful activities, participation, and environments are essential to achieve the highest level of health and well-being.
   2. **Importance of Participation with Specific Subgroups**
      a. **Spinal Cord Injury** (**SCI**). Researchers [2] found in a longitudinal study of individuals with traumatic spinal cord injuries that participation (which included mobility and social integration) impacted life satisfaction and self-rated health 1 year after discharge. Other research also found life satisfaction is greater for those with SCI who are involved in productive activities such as work, education, and recreation [10, 11].
      b. **Traumatic Brain Injury** (**TBI**). Social participation, including occupational activity and mobility, mediates the prospective relationship of functional impairment and severity to elements of quality of life. Researchers hypothesized that participation "increases the probability for rewarding interactions with others and for experiencing positive emotions in these interactions" [1], which thus improves quality of life.

Practical Applications

A. ***Physical Barriers to Participation***
   These are architectural components of the physical environment, also referred to as the "built environment" [3, 8] that limit social participation. Physical barriers frequently exist, because "constructing the built environment to suit the needs of the average person restricts accessibility" for people with limited mobility [3]. **Architectural barriers** (**i.e.,** inaccessible design features) include but are not limited to steps and stairs; pathways and doors that are too narrow to accommodate a wheelchair; lack of wheelchair accessible parking and public transportation; counters, signs, dispensers, and drinking fountains that are too high or too low for a wheelchair user to utilize; and controls that cannot be manipulated by someone with decreased fine motor function.
   1. **Home and Community Barriers and How to Help**
      Research on populations with physical disability, like SCI and multiple sclerosis, identified multiple environmental barriers to productive community integration, including barriers in the natural environment, transportation, help at home, health care, government policy [4], affordable mobility aids, and inaccessible public transportation [12].
      a. **Psychologists**. Physical barriers in the home and community must be considered

by psychologists to increase social participation, as “interests often precede participation, but interests may not lead to participation because of environmental barriers” [3]. Psychologists play an important role to help patients foster problem-solving strategies needed to increase self-efficacy and independence upon return to home

b. **Occupational and physical therapists** can recommend home modifications and adaptive equipment to increase participation and independence in the home environment. Common recommendations include, but are not limited to purchasing or renting medical equipment such as hospital beds, commodes, handheld showerheads, and shower chairs; adding an exterior ramp or railing; and removing clutter and/or rugs to improve safe mobility [13].

B. ***Resources for identifying and managing architectural barriers within the community***

1. **The Americans with Disabilities Act (ADA)**

   Enacted July 26, 1990, the ADA is a comprehensive civil rights law that covers employment, public entities and public transportation, accessibility of public accommodations, and telecommunications, for individuals with disabilities. Title III concerns public accommodations, prohibits discrimination in the delivery of goods and services, and provides minimum guidelines for wheelchair accessibility in all public and private facilities. In 2010, the regulations in titles II and III were revised and published as the 2010 ADA Standards for Accessible Design, which are the most up-to-date accessibility guidelines [14]. Many physical barriers encountered by individuals with disabilities in the community are violations of the ADA; however, the ADA provides minimum guidelines, thus even community sites that comply with ADA may not be functionally accessible for someone with a disability.

2. **The Community Health Environment Checklist (CHEC)**

   The CHEC is an objective assessment based on the performance needs of individuals with mobility impairments within the community [15]. It asks the question, “Can a person with a disability get in, do what they need to do, and get out without much difficulty?” [16]. The CHEC-Mobility version examines the functional accessibility of community sites and was designed for use by healthcare practitioners, patients, and their families and to help identify objective barriers that limit participation.

3. **The Craig Hospital Inventory of Environmental Factors** (**CHIEF**)

   The CHIEF is an instrument that measures the “frequency and magnitude of physical, attitudinal, service, productivity, and policy barriers that keep people from doing what they need to do and want to do” [17].

4. **The Measure of the Quality of the Environment** (**MQE**)

   The MQE assesses “the perceived influence of specific environmental factors on social participation of people in relation to their abilities and limitations” [7].

C. ***Psychological Barriers to Participation***

1. **Attitudes**

   Negative attitudes regarding people with disabilities held by those without disabilities are prevalently documented in the literature and can serve as a barrier to social participation [18]. Social and cultural beliefs as well as anxiety stemming from ignorance of disability etiquette contribute to negative attitudes toward people with disabilities. Positive attitudes, in which people with disabilities are viewed as inspirational simply for living with their limitations, can also be problematic, as they focus more on the disability rather than the person.

2. **The Spread Phenomenon**

   Occurs when an individual assumes that another person's disability spreads to other parts of his/her body [19] For example, if one assumed that someone who uses a wheelchair also has a speech impairment. Individuals with disabilities assert that their disability is not the most important thing in their lives; however, others often perceive their disability to be a defining aspect of their personality [20].

3. **Social Stigma**

   Stigma is defined as an attribute that is deeply discrediting, reducing the person from whole and usual to tainted and discounted [21]. Stigma is associated with devaluation and inferiority. People with disabilities may feel that they needed to go above and beyond what able bodied individuals are able to do to be recognized as competent individuals [22].

4. **"Visible" vs. "Invisible" Disabilities**

   People with "visible" disabilities (e.g., those in a wheelchair) are likely to be ignored or experience patronization, pity, and stares. Society may not expect as much from people with "visible" disabilities; however, the opposite may be assumed of people with "invisible" disabilities, such as TBI. Although people with invisible disabilities may experience less stigma, at least initially, they are often judged according to standards for those without disability and may have difficulty meeting those expectations. As a result, people with "invisible" disabilities may try to hide their disabilities and avoid social situations in which they believe their limitations will be exposed or cause them to have problems [23].

5. **Adaptation (adjustment) to Disability**

   An individual's adaptation, as well as their family's adaptation, impact how comfortable and confident they are in their ability to navigate social barriers. This is especially relevant to individuals with visible disabilities who may feel self-conscious of their deficits or mobility devices.

D. ***Interventions to overcome physical and psychological barriers in the home and community***

   1. **Attitude Change Strategies**

      Overcoming psychological barriers in the community may involve changing negative attitudes of people in society. It is generally agreed that the most effective strategy for reducing negative attitudes toward people with disabilities is to combine contact (face to face) with information provision [24, 25]. Disability simulations, in which someone might spend a day in a wheelchair with the goal of gaining insight about living with disability, have not been found to be effective in modifying negative attitudes [25, 26].

   2. **Education for Patients**

      Education on physical and psychological barriers should be provided to patients and their loved ones by various members of an interdisciplinary team, given in both formal settings, like a patient education class, or informal, during an individual or group therapy session. Education should support the patient in advocating for themselves and educating their loved ones as well as others in the community about social disability issues. Education is also an important part of reshaping misperceptions in the short term; however, information alone is not sufficient to ensure lasting attitude change [24].

   3. **Education for Professionals**

      To improve the physical and psychological functioning of people with disabilities, rehabilitation professionals must not only be advocates of disability legislation, but also educators on the role of environmental factors in determining a person's status of ability.

   4. **Advocacy Skills for Patients**

      Includes pursuing their own interests, being aware of their rights, taking responsibility for tackling infringements of those rights, and joining with others to pursue the interests of the group of people with disabilities [27]. There is scant literature in the field of rehabilitation psychology regarding teaching patients with newly acquired disabilities self-advocacy skills. However, the special education field has considerable literature on teaching students with disabilities to be self-advocates, much of which is also applicable to patients with acquired disabilities.

a. **Self-Advocacy Framework**. Based on a review of education and psychology literature, consisting of four components: knowledge of self, knowledge of rights, communication, and leadership [28]. These components are very applicable to patients with acquired disability.
    i. **Knowledge of self:** includes understanding the long-term implications of disability, how it impacts their abilities, goals and needs, as well as possible accommodations they may benefit from.
    ii. **Knowledge of rights:** includes understanding their rights as a person with a disability as well as systems knowledge about other people or resources that may be helpful. An important part of this component is also knowing how to proceed when one's rights are denied or violated.
    iii. **Communication:** includes skills such as assertiveness, negotiation, persuasion, and listening.
    iv. **Leadership:** involves advocating for a group of people and may involve organizations or political action.
b. **Self-Advocacy and Rehab:** Patients in an acute rehab setting should have ample opportunities to practice their self-advocacy skills with the interdisciplinary team, especially as they are navigating the chaotic environment of a hospital unit and getting their care needs met. Internet websites such as YouTube and social networking sites can serve as great advocacy venues for people with disabilities [29]. Development of strong advocacy skills can lead to empowerment of people with disabilities. Patients with disabilities should be strongly encouraged to advocate for social change in the community not only for themselves but also to make the world better for others with disabilities.

5. **<u>Advocacy Skills for Professionals</u>**

Rehabilitation professionals should be active in the community to advocate for people with disabilities, provide education on social disability issues, and positively influence the attitudes of other individuals in society. They should be well versed in the Americans with Disabilities Act (see "Americans with Disability Act" above) as well as state statutes.

a. Advocacy opportunities are available in many shapes and sizes and are both formal and informal. Rehabilitation professionals can find these opportunities through active participation in:
    i. **Consumer groups** (e.g., Paralyzed Veterans of America and the National SCI Association).
    ii. **Local**, **state**, **and national professional organizations** (Division 22 of the American Psychological Association—Rehabilitation Psychology, and Academy of Spinal Cord Injury Professionals).
    iii. **Providing public and community education**.
    iv. Being involved in **political activity**, whether through a national professional organization or individually [30, 31].

6. **<u>Impression Management</u>**

A goal directed attempt to influence the perceptions of other people about a person, object, or event by regulating and controlling information in social interactions [25]. Impression management techniques include praise and humor and involve multiple aspects of self-presentation including appearance, behavior, and dress code. Impression management is an empirically validated approach to reduce stigma of people with disabilities in everyday interactions [32].

7. **Social Engineering**

   A concept related to impression management in which people with disabilities change their behavior to act in ways in which others feel comfortable around them. Strategies people with disabilities use to put others at ease include feeling comfortable in one's own skin and demonstrating it, conveying that one is not different, and reciprocating in relationships [22]. People with disabilities may also find humor, providing explanation, focusing on things in common rather than differences, or ensuring social activities are wheelchair accessible will make others feel more comfortable around them.

8. **Group therapy**

   Using themed "physical barriers" and "psychological barriers" group sessions for outpatients, inpatients, or a mixed group (families can also be included) can provide a forum for sharing problems encountered in the home or community environment and successful strategies and adaptations. Other members of the rehabilitation team can also be invited to attend to serve as resources: occupational and physical therapists for modification recommendations and social workers for recommendations for community and funding resources.

9. **Adaptation (adjustment) to Disability**

   Adjustment to disability should include issues related to social participation. An important aspect of adjusting to permanent disabilities is learning how to present oneself in a comfortable manner to those in the community [23]. This may include disclosure of one's disability and providing education. While this can certainly be an engaging group therapy topic, patients may appreciate the opportunity to discuss this in an individual session.

10. **Outcomes/Expectations of Interventions**

    In order to maximize success in the postrehabilitation world, it is essential to instill in patients the reality that even with education on potential barriers, self-advocacy skills, and adequate adjustment to disability, a person may still encounter physical and social barriers that limit participation. However, helping patients identify and learn to utilize facilitators to social participation, such as an individual's social support system, can serve as a last defense to overcoming barriers.

    a. **Example:** Individuals with disabilities will still encounter inaccessible community sites that are unwilling to become accessible, but choosing to patronize accessible community sites with family and friends still promotes social participation.

Tips

- **Be creative and have fun with your interventions:** Education does not have to be limited to the classroom or informal environment. The authors have utilized an "Americans with Disabilities Act Birthday Party" to educate patients on the ADA. The event included ADA trivia, an educational lecture, a booth with educational materials staffed by patients and team members, a panel of patients who acquired their disabilities before the ADA—and of course, birthday cake!
- **Preparation:** Planning ahead for community outings to new locations and traveling is essential to successful participation and must become part of a regular routine. This includes, but is not limited to calling ahead to ask a location about accessible features or potential barriers, utilizing the internet to research transportation options, and creating a checklist of medical supplies needed. Even individuals who have adjusted to their disability and embody social participation to the fullest can have their participation limited by a lack of planning ahead.
- **Work as an interdisciplinary team:** As this chapter outlines, social participation involves many physical, social, and psychological barriers; thus, utilizing cotreatment sessions with interdisciplinary team members can be a great intervention option.

Example: If a patient has a history of anxiety in new social situations or difficulty with behavioral management, the psychologist, recreational therapist, physical therapist, and/or occupational therapist could plan and attend a community outing with the patient.

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11 Forensic Issues: Health Care Proxy, Advance Directives, and Guardianship

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Topic

A. ***<u>Overview</u>***

Forensic issues are common in medical rehabilitation settings. A "forensic issue" is one that intersects with the legal system. The issues that might arise at the intersection of medical rehabilitation and law include *health care proxies*, *advance directives*, and *guardianship*. Clinicians in rehabilitation settings often need to determine *<u>what</u>* are the patient's preferences for care and *<u>with whom</u>* they can legally discuss health care decisions when a patient is unable to make decisions for him/herself. There are certain legally defined roles and documents that can assist a health care provider under such circumstances. The following is intended to provide guidance for professionals in medical rehabilitation settings. However, legal requirements may differ depending on the state in which one resides; therefore, it is recommended that treatment teams consult state and local guidelines. A list of state and local bar associations is provided by the American Bar Association [1].

B. ***<u>Terminology</u>***

1. **<u>Advance Directives</u>**

Instructions that indicate an individual's preferences for health care if the individual loses the ability to make or communicate decisions for him/herself. The types of decisions typically specified in an advance directive include health care proxy (HCP), a living will, organ and tissue donation, or power of attorney (POA).

a. ***Health Care Proxy*** (***HCP***), or health care power of attorney, is a legal document whereby the *Principal* (an individual) appoints an *Agent* (usually a family member or close friend) to make health care decisions if the individual loses the ability to make or communicate decisions for him/herself. The role of an Agent is variable, depending on whether the Principal has given the Agent the authority to make all health care decisions, or whether certain limitations have been placed on the Agent's authority.

b. ***Living Will*** documents preferences about life-prolonging measures, organ and tissue donation, and psychiatric advance directives. Preference for

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_11

organ and tissue donation may be listed on an individual's driver's license if it is not listed in a living will.

c. ***Power of Attorney (POA)*** is a written authorization to act/make decisions on someone else's behalf. There are many different types of POAs (i.e., durable POA, general vs. limited POA, financial POA, and medical POA), though the most relevant in medical rehabilitation settings is the Medical or Health Care POA, which is also known as Health Care Proxy (HCP), Health Care Surrogate, or Health Care Representative.

2. ***Guardianship***

The legal process whereby the Court appoints a guardian for a mentally or physically incapacitated person who is unable to make or communicate safe or sound decisions for him/herself. The incapacitated person is an individual who is unable to care for his/her basic needs, to the extent that his/her health or safety is in jeopardy. Guardianship may be appointed on an emergency (temporary) or permanent basis. Guardianship can be limited to specific areas of need, or unlimited. The decision-making powers of a guardian may not only include health care decisions, but also other aspects of personal well-being (i.e., housing and placement decisions and arranging caregivers), and financial decisions (i.e., designation as Social Security Representative Payee). There may be one guardian, or there may be more than one person, working together as coguardians.

Importance

A. ***Ethical responsibility to the patient***

The physical and cognitive impairments and disabilities that are experienced by patients in rehabilitation settings can render a patient unable to make or communicate his/her preferences for health care, and in some conditions, unable to make decisions about finances or basic well-being, such that health and safety may be in jeopardy. Unfortunately, many individuals may not have an HCP or Advance Directives to make their preferences known. The need for an HCP or Advance Directives may first come to the attention of the family when faced with a debilitating condition of a family member. The professionals who are part of treatment teams have legal and ethical standards that require them to look out for the best interests of their patients [2–4]. The ethical responsibility to an incapacitated patient is enhanced by clinicians' awareness of forensic issues that are most relevant to their clinical setting. Furthermore, the clinician's attentiveness to forensic issues can facilitate the process and ensure that the patient's desires for health care are met.

B. ***An informed treatment team***

Treatment teams play an important role by (1) facilitating a discussion about benefits of Health Care Proxy, Advanced Directives, or Guardianship, or (2) in providing documentation or information to guide decisions that will need to be made by an Agent or the court.

1. **Facilitate discussion**

Certain medical conditions allow for the opportunity to consider forensic issues before the patient becomes incapacitated. For example, in neurodegenerative disorders, prior to significant cognitive decline, the patient has time to set up Advance Directives and to have discussions with the individuals who he/she will entrust with making decisions when he/she is no longer able. Other medical conditions do not allow for the opportunity to discuss forensic issues beforehand, yet the treatment team can highlight key issues for individuals who are tasked with managing the affairs of such individuals. For example, a patient with a traumatic brain injury (TBI) may need assistance with certain activities of daily living (e.g., medication management, driving, financial management, and cooking) but not with other activities, depending on the location and severity of injury. Certain overlearned sequences are retained even with memory impairment from a neurological insult. Therefore, the individual with TBI may still maintain some independence for tasks that they have done for years or decades (e.g., familiar routines or hobbies). In most cases, the least restrictive environment is preferred to allow the patient to maintain independence as long as possible.

2. **Guide decisions**

   What decisions will the POA or guardian need to make? The team has a unique understanding of the medical treatment plan including areas of deficit and areas of preserved cognition and physical function. Based on this understanding of the patient, the treatment team can help the POA or guardian make informed decisions about the level of care needed for the incapacitated person's mental and physical health. Discussion of the patient's known values (what the patient values if he/she could speak for themselves) can help Agents make informed decisions on the patient's behalf. For this reason, documentation about both strengths and weaknesses are important (see documentation section below). Using residential placement as an example, the treatment team can guide decisions based on the medical, cognitive, and mental characteristics of the incapacitated person's condition to help the Agent determine the most suitable discharge disposition for the patient, such as discharge to home with support from family caregivers or home health care, or to a more structured long-term care setting if appropriate.

Practical Applications

A. ***Advance Directives***

An advance directive typically includes Power of Attorney, Health Care Proxy, Living will, Organ and tissue donation, and Psychiatric advance directives. Although an advance directive may include all elements defined below, each element may be specified in separate legal documents. For example, someone may have organ and tissue donation noted on his/her driver's license, and a separate document for HCP, whereas another person many have all elements specified in the Advance Directive (i.e., HCP, Living Will, and POA). The "Five Wishes" publication contains the legal documents for HCP and a living will, in addition to other questions that allow an individual to state their personal, spiritual, or emotional wishes [5]. An individual can *make and change* decisions in an Advance directive as long as he/she is still able/competent to do so.

1. **Power of attorney *(POA)***
   a. ***General* vs. *limited POA***
      1. A **general POA** allows an Agent to manage all of the Principal's affairs.
      2. A **limited POA** is restricted to specific types of transactions or decisions. The different types of limited POA commonly include financial POA, and medical POA, or more specific situations, such as management of a specific estate, trust, or investment portfolio, or to sign a contract. Most relevant to medical rehabilitation settings is a Health care POA, also known as Health Care Proxy (HCP). Although HCP is an especially important issue for rehabilitation providers, other types of POA may also be a discussion point for patients and their families, depending how an injury or illness affects their ability to make specific types of decisions.
   b. ***Durable* vs. *Springing POA***
      1. **Durable POA** is effective immediately as soon as the Principal (the individual who appoints an agent) signs the document and can take effect whether or not an individual has been determined to be incapacitated. If the treatment team is aware that a durable POA is in effect, once documentation is received by the Agent, the treatment team can consult

    with the Agent to assist in making decisions, according to the provisions of the POA.
    2. **Springing POA** is effective should the Principal become incapacitated. The criteria for determining whether or not an individual is incapacitated may be stated in the POA. The criteria often require a clinician's certification that the individual is incapacitated. If a clinician is called upon for a competency evaluation in the context of springing POA, it may carry a sense of urgency in order for the Agent to be able to make decisions in a crisis or an emergency.
  - c. ***Appoint/Revoke***. An individual can *appoint* a POA and he/she can also *revoke* a POA at any time, as long as he/she remains mentally competent to do so, with a written document that is signed by the Principal and witnessed (generally by a notary).
  - d. ***Oversight***. Unlike guardianship, there is no oversight of the POA by a court or other authority. If there is abuse of power, it is usually only dealt with in a court of law after suspicious activity has been identified.
  - e. ***If no financial POA*** is in place, family members, close friends, or other community agencies can apply to be the representative payee for an incapacitated person who receives Social Security Income.

2. <u>**Health Care Proxy (HCP)**</u>
    - a. An HCP has the ***authority to make any health care decision***, including access to medical records, the ability to admit the incapacitated person to health care facilities, the power to withhold or withdraw life-sustaining treatment or artificial nutrition and hydration, and organ donation. The HCP can access medical records to assist him/her in making informed decisions and to provide documentation for admission to health care facilities or to apply for medical benefits.
    - b. ***Advance Directive supercedes*** if HCP in Advance Directive is different from another HCP document.
    - c. Advance directive can indicate who an individual does NOT want as HCP.
    - d. ***No HCP***. If there is no designated HCP, medical personnel must identify a health care surrogate. State laws provide guidance for whom to select as a health care surrogate in the absence of an HCP. In order of priority, the health care surrogate should be the incapacitated person's: (1) guardian, (2) spouse, (3) adult child, (4) parent, (5) sibling, and (6) other relative or friend who is in regular contact and familiar with the incapacitated person's religious or moral beliefs. Without a clear guide for an individual's health care preferences, there may be a higher chance of misunderstandings or disagreement among family members during a medical crisis.
    - e. Check local laws as HCPs may or may not be mandatory in your jurisdiction.

3. <u>**Living Will**</u>

    Declares an individual's preferences for life-prolonging measures. The requirements vary somewhat by state, but in general a living will goes into effect if an attending physician certifies that an individual (1) has an incurable injury, disease, or illness with no reasonable expectation of recovery, and (2) the use of life-prolonging procedures will not prevent the dying process and serves only to prolong the dying process. A living will typically includes preferences for:

    - a. ***Artificial nutrition and hydration.*** many living wills only indicate preference for or against artificial nutrition and hydration.
    - b. ***Cardiopulmonary resuscitation*** **(*CPR*)**. If the preference is for no CPR, many states require an additional Do Not Resuscitate (DNR) form.
    - c. ***Mechanical respiration***
    - d. ***Pain relief***
    - e. ***Other*** procedures, such as major surgery, blood transfusion, dialysis, or antibiotics

4. **Organ and tissue donation**

   Whether or not an individual wishes to participate in organ and tissue donation upon his/her death.

5. **Psychiatric Advance Directives (PAD)**

   Psychiatric Advanced Directives (PAD) are similar to general Advanced Directives discussed elsewhere in this chapter. However, Psychiatric Advanced Directives specify instructions and preferences of an individual, if at some point in the future he/she is no longer able to make decisions for him/herself due to psychiatric illness. For example, a PAD may specify treatment, such as which type of medications or treatment facilities they prefer, or a PAD may designate an HCP for mental health care, or preferences for a guardian if they are deemed incapacitated due to a psychiatric illness.

B. ***Guardianship***

Many of the conditions discussed in this book can result in an individual being incapacitated either temporarily or can lead to long-term or permanent physical, cognitive, and/or functional impairment. When the severity of impairment jeopardizes an individual's health or safety, the court may appoint a guardian. The following highlights issues relevant to medical rehabilitation settings. More detailed information is provided by the National Guardianship Association, Standards of Practice [6].

1. **Difference between guardianship and HCP/POA**
   a. In the case of HCP or POA, the Principal is mentally competent to make and communicate decisions at the time the HCP/POA is created. In contrast, guardianship is appointed only *after* an individual has become incapacitated.
   b. For HCP or POA, the Principal retains the right to elect an Agent, or conversely, the Principal can revoke HCP or POA. For guardianship, the court appoints a guardian. Anyone can petition the court to remove a guardian if there is concern that the guardian is not acting in the best interests of the protected person.
   c. There is more oversight from the court for guardianship. Guardians must file a report with the court on a yearly basis and notify the court if there are any major changes (e.g., a change in living arrangement).
   d. Guardianship is a more involved legal process than HCP and can therefore take more time and incur more legal fees compared to HCP or POA.

2. **Who is appointed as guardian**?

   The court may appoint a family member, a friend, or a local agency as the guardian. The decision as to who will be the guardian depends on who is available and most suitable to act in the best interests of the incapacitated person. More than one person can be appointed as guardian, in which case the guardians act as coguardians and both are responsible for managing the affairs of the incapacitated person.

   Sometimes, the decision is straightforward as to who may be the best person to be appointed as guardian. In situations when family members or other individuals are in disagreement as to who will be the guardian, the clinician must be aware that his/her chart notes may be used in guardianship proceedings. Chart notes should stay objective, yet detailed enough to make the patient's wishes known.

3. **Temporary vs. Permanent Guardianship**
   a. ***Temporary Guardianship*** can be appointed in an emergency situation when there is not enough time to wait for appointment of a permanent guardian. For example, if there is an acute debilitating illness, such as a traumatic brain injury, an individual may need a guardian to quickly assist in making important medical decisions. Temporary guardianship may also be granted if the appointed guardian is suddenly unable to act as guardian (also known as substitute guardianship). Temporary guardianship will

terminate after a specified time (e.g., after 60 days), or after a specific task is accomplished (e.g., to assist in making a specific medical decision).

   b. ***Permanent Guardianship*** is granted indefinitely (i.e., permanently) when an individual has a condition that is not expected to improve in the future. This type of guardianship could be revoked or modified by the court if the protected person regains capacity, or if the appointed guardian is no longer able to serve as the guardian.

4. **Limited vs. Unlimited Guardianship**
   a. ***Limited guardianship*** is restricted to specific areas of need. This allows the protected person to maintain independence over certain areas of life, yet receive assistance in other aspects of life that he/she is not able to manage. For example, guardianship may be limited to health care decisions, residential placement decisions, or financial decisions (e.g., designation as Social Security Representative Payee).
   b. ***Unlimited or full guardianship*** allows the guardian to manage all aspects of the protected person's affairs.
5. **Guardianship vs. conservatorship**

   A guardian may or may not also be a conservator. Both guardianship and conservatorship are legal proceedings that appoint someone else to manage the protected person's affairs. However, a conservator manages the protected person's **assets**, whereas a guardian has responsibility for an individual's **health and welfare**. A conservator in some jurisdictions is also referred to as a guardian of estate, property guardian, or financial guardian.
6. **Clinical Example**

   Mrs. Smith is a 68-year-old female. She was in a motor vehicle accident, resulting in a severe traumatic brain injury. One year postinjury she remains unable to manage her basic activities of daily living, she has persisting language deficits that limit her ability to understand or communicate, and her treating providers do not believe she will have much more improvement. She has been at a rehabilitation hospital for the past several months and is now ready for discharge. Her daughter, Mary, had POA when the accident happened, so was able to manage her affairs in that capacity. However, Mrs. Smith insists on being discharged back home without assistance, to her house where she previously lived alone. Mary petitioned to become her mother's guardian so she can have more authority to manage her mother's residential placement decisions and to manage her other affairs. The judge granted Mary unlimited guardianship due to the severity, breadth, and chronicity of Mrs. Smith's deficits.

Tips

A. ***Role of Clinicians***
   1. ***Informed Consent***. All medical treatments require informed consent by the patient or a surrogate if the patient cannot consent him/herself.
   2. ***Assent***. Even if an individual is deemed incapacitated, he/she can still be involved in his/her treatment decisions by providing assent. For example, someone who is unable to make decisions for him/herself due to a medical or psychiatric illness may need a guardian to provide consent for treatment, yet the treatment team can engage the incapacitated person in his/her own health care by obtaining assent. By evaluating whether or not an individual is in agreement (i.e., assent) with certain health care decisions, the treatment team will go a long way toward recognizing the dignity of an incapacitated person, regardless of his/her inability to make or communicate decisions. Readers are encouraged to consult state and local guidelines or institutional review boards (IRBs) for a more complete definition of *assent* as it applies to specific populations and settings.

3. ***Staying alert to a person's level of capacity at all times*** *to* comprehend, appreciate, and make or communicate decisions about his/her personal affairs, including health care, living arrangement, food, clothing, etc., is essential.
   - ***Decision-making capacity can flux***. A person's decision-making capacity can fluctuate (i.e., not be permanent and can change over time) and may be context dependent (e.g., only during a urinary infection). Clinicians may be the first to recognize that an individual's ability to make or communicate his/her own decisions has declined or become compromised. The treatment team has the responsibility to monitor and identify whether there is an elected HCP, or if not, to determine who is the appropriate health care surrogate. In either case, the clinician's role in documenting competency is an important step in the process of determining when HCP or POA goes into effect, or whether guardianship will be appointed by the court.
   - ***Decision-making capacity domains***. Different domains of capacity determination exist (e.g., medical decision-making capacity, financial capacity, driving capacity, testamentary capacity, or capacity to live independently). The attending physician should consider whether he/she can evaluate the patient's decision-making capacity, or whether another specialist needs to perform a capacity evaluation. For example, if a patient is suspected to have cognitive impairment and poor judgment, but performs well on brief cognitive screening, the attending physician may make a referral for a more comprehensive neuropsychological evaluation by a neuropsychologist trained in capacity evaluations for the particular domain.
   - Refer to the separate chapter in this book regarding details about determination of decision-making capacity and competency.
4. ***Expert Witness***. The clinician may be called upon by an attorney as an expert witness to give his/her clinical opinion regarding the patient's cognitive or functional impairment.
5. ***Consent for ordinary* vs. *extraordinary medical treatment***. Who can provide informed consent for medical procedures for an incapacitated person? An appointed guardian, health care proxy, or POA can provide consent for **ordinary medical treatment**. However, a guardian has limited authority to consent for extraordinary health treatment, such as admission to a nursing home facility, admission to a mental health facility, authorization for use of antipsychotic drugs, or other medical treatments that are considered extraordinary. The guardian must ask the Court for approval to manage **extraordinary medical treatment**.
6. ***Documentation*** in a clinical report or chart notes should assert the following:
   i. ***Cause/etiology of incapacity***. What is the known or suspected etiology of cognitive or functional impairment? For example, is there a medical condition that is known to be the cause of cognitive impairment, such as a recent history of a stroke? Upon clinical evaluation, are the clinical course, lab results, and cognitive testing consistent with a cortical neurodegenerative process, such as Alzheimer's disease?

   ii. ***Extent of incapacity***. Which domains of cognition or functional impairment are affected? Is the condition affecting multiple cognitive domains, or isolated to specific cognitive domains (memory, executive function, language, visuospatial, or sensorimotor)? Which aspects of daily living are impacted by the condition—cooking, cleaning, self-care, driving, financial management, health care and medication management, social function, communication, etc.?

   iii. ***Areas of preserved function***. It is important to document areas of preserved function. This can help an HCP or guardian understand which tasks the incapacitated person can be expected to handle independently and enhance the person's overall well-being by giving him/her a sense of independence and agency in his/her life. For example, after summarizing areas of cognitive or functional deficit, be sure to include an assessment of the patient's strengths, including cognitive strengths, functional abilities that are preserved, or general personality features that will help them adapt to their environment.

iv. ***Likelihood they will regain capacity***. If the condition is reversible or partially reversible, when should the patient be re-evaluated to determine whether cognition or function has improved?

v. ***Concurring determination*** of incapacity, or a second opinion, is required in some cases. Please refer to local jurisdiction for details on whether this is required in the specific case, and who is able to make the concurring determination.

vi. ***Relevant forms***. Requirements for different forensic issues vary by state. Consult state and local guidelines for specific forms or criteria that may be needed from treating providers.

B. ***<u>Other team members and local resources</u>***

1. ***Social work*** may be familiar with family dynamics or other life situations that have a bearing on certain forensic issues. They may also be familiar with the procedures that are needed for handling certain forensic issues.
2. ***Neuropsychologists*** are skilled at assessing a patient's cognitive functioning. They can provide a comprehensive neuropsychological evaluation or help the treatment team understand how cognition affects a patient's decision-making capacity.
3. ***Forensic psychologists/neuropsychologists*** may be needed for complex legal issues. For example, if there is a dispute among family members, or if there is a criminal investigation that affects the incapacitated person, a forensic psychologist or neuropsychologist may be helpful.
4. ***Legal services***. A patient may need legal representation, depending on the forensic issue. Local attorneys or legal advisors for your local institution can help you determine local laws for your jurisdiction, or whether or not the patient would benefit from legal representation.
5. ***Local organizations*** can be a good resource for providers and their patients. For example, local support and guidance are often available for individuals with disorders such as dementia, stoke, TBI, multiple sclerosis, or cancer.

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Part II

Populations, Problems and Procedures

Traumatic Brain Injury

12

Mark Sherer

Topic

TBI is "damage to brain tissue caused by an external mechanical force as evidenced by medically documented loss of consciousness or post traumatic amnesia (PTA) due to brain trauma or by objective neurological findings that can be reasonably attributed to TBI on physical examination or mental status examination. Penetrating wounds fitting the definition listed above are included. This definition of TBI excludes several conditions when the criteria above are not met: Lacerations or contusions of the face, eye, or scalp, without other criteria listed above; Fractures of skull or facial bones, without criteria listed above; Primary anoxic, inflammatory, toxic, or metabolic encephalopathies which are not complications of head trauma; Brain infarction (ischemic stroke); Intracranial hemorrhage (hemorrhagic stroke) without associated trauma; Airway obstruction (e.g., near-drowning, throat swelling, choking, strangulation, or crush injuries to the chest); Seizure disorders (grand mal, etc.); Intracranial surgery; Neoplasms" [1].

Importance

Epidemiology of TBI. Surveillance data provided by the Centers for Disease Control and Prevention [2] indicate that:

- Approximately 1.7 million persons sustain TBI each year in the U.S.
- Of these, 52,000 die, 275,000 are hospitalized, and 1.365 million are treated and released from emergency departments. The number of persons who sustain mild TBI and fail to seek medical care is unknown.
- TBI is a contributing factor to almost 1/3 of all injury-related deaths.
- Most frequent for children aged 0–4 years, older adolescents aged 15–19 years, and adults aged 65 years or older.
- Incidence of TBI is greater for males than females in every age group.
- Falls are the most common cause of TBI followed by being struck by an object and motor vehicle incidents.

Practical Applications

A. ***Classification of TBI Severity***. Severity of TBI is most commonly classified based on level of responsiveness at arrival to the Emergency Department.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_12

1. **Glasgow Coma Scale (GCS)**

   Measures eye opening, motor movement, and verbal communication. Scores range from 3 to 15 so that a person with a score of 3 has no eye opening even to pain, no movement, and no vocalizations while a person with a score of 15 has spontaneous eye opening, follows commands, and is able to answer questions to indicate that he/she is oriented.

   - **Severe TBI**: GCS scores ranging from 3 to 8. Note: Sometimes this group is divided between extremely severe (3–5) and severe (6–8).
   - **Moderate TBI**: GCS scores ranging from 9 to 12.
   - **Mild TBI**: GCS scores ranging from 13 to 15.
   - **Complicated Mild TBI**: Persons with GCS scores indicating mild TBI but who have positive CT scan findings or focal neurologic findings. Outcomes for this group are similar to outcomes for persons with moderate TBI.

2. **Duration of Loss of Consciousness (LOC)**

   Another index of TBI severity with longer intervals associated with more severe injuries and poorer eventual outcomes.

   - Also known as time to follow commands (TFC), is the interval from injury till the patient regains the ability to follow commands.
   - Note: Some persons with mild TBI may never lose the ability to follow commands.
   - Unfortunately, there is no empirically supported, commonly agreed upon scheme for translating LOC durations to severity categories roughly equivalent to GCS categories.

3. **Duration of Posttraumatic Amnesia (PTA)**

   Another index of TBI severity that refers to the inability of persons early after TBI to store and later recall new memories.

   - Persons in PTA are disoriented and may exhibit a range of other neurobehavioral deficits.
   - **Galveston Orientation and Amnesia Test** (**GOAT**) or the **Orientation Log** (**O-Log**) are common scales used in clinical practice and in research to assess duration of PTA through frequent administrations.
   - As with LOC, greater duration of PTA is associated with greater injury severity and poorer outcome.
   - The period of LOC, if present, is included in the PTA duration.
   - There are empirically derived classification schemes for PTA such as that provided by Nakase-Richardson et al. [3].
   - Nonetheless, different psychologists may use different classification schemes making comparison between studies difficult and complicating communication between clinicians.

LOC and PTA have advantages over GCS as indices of TBI severity as they can be influenced by various secondary causes of injury such as brain swelling, biochemical and physiologic changes in the brain, neurosurgical interventions, infection, etc. that occur after initial GCS scores are recorded. However, these factors also complicate comparison between indices of severity as persons given one classification based on one index may receive a different classification based on a different index. See Sherer et al. [4] for a discussion of this issue.

B. ***Recovery from TBI***

- **Unconsciousness at the time of injury** occurs in all persons with severe TBI, most persons with moderate TBI, and some persons with mild TBI.
- In some cases, unconsciousness can be brief, but for those with severe injuries it can persist for days.
- **Coma** is persistent unconsciousness lasting more than a few minutes. Persons in coma have no eye opening even to pain and show no evidence of conscious awareness of self or the environment. By definition, all persons with severe TBI are in coma at the time of presentation to the

Emergency Department and no persons with moderate or mild TBI are in coma at presentation.

- **Vegetative State**. A small percentage of persons in coma (10 % or fewer) recover to a vegetative state.
    - Some brainstem function recovered permitting eye opening at times and evidence of a sleep/wake cycle.
    - However, no evidence of conscious awareness of self or the environment persists.
- **Minimally consciousness state**. Persons in the vegetative state may recover to the minimally consciousness state.
    - It is thought that a substantial portion of patients make this transition, but the number is not known.

C. ***Prognosis***

- **Vegetative state.** Survival can persist for years; however, such persons are medically fragile and can expire due a variety of complications such as pneumonia.
- **Minimally conscious state** offers a more favorable prognosis. Most persons in coma transition directly to the minimally conscious state.
    - Characterized by inconsistent responses to the environment such as command following, yes/no responding, visual pursuit, object manipulation, and others.
    - Emergence from the minimally conscious state is indicated by functional use of objects and/or functional (i.e., accurate) yes/no responding [5].
- Posttraumatic confusional state (PTCS). Persons who emerge from the minimally conscious state are in PTCS. Some persons move directly from coma to PTCS. Persons in PTCS have a favorable prognosis for substantial additional recovery.
    - PTCS is a form of delirium caused by trauma.
    - The disorientation component of PTCS is essentially the same as PTA.
    - Patients with four or more symptoms (disorientation, cognitive impairment, fluctuation in presentation, restlessness, nighttime sleep disturbance, decreased daytime arousal, and psychotic-type symptoms) meet diagnostic criteria for PTCS.
    - Patients with three of the above symptoms meet diagnostic criteria if one symptom is disorientation.
    - PTCS resolves as the number of symptoms decreases. Usually persons become oriented when PTCS resolves and show other improvements. Persons with TBI who have just emerged from PTCS have fairly severe cognitive and other neurobehavioral impairments that continue to improve over time.
    - For a description of PTCS and diagnostic criteria, see Sherer et al. [6].
- **Many persons with severe TBI and some with moderate TBI** will not make full recoveries.

NOTE: ***Diverse presentations***. Some persons with mild TBI may never meet PTCS criteria, and only have a brief period of PTA. While at least a brief period of PTA has been the minimum threshold for diagnosis of TBI historically, some published criteria [cf., 7] indicate that even a transient alteration in mental state such as feeling dazed, disoriented, or confused following an accident could indicate mild TBI. It is unclear whether such a mild injury with not even a few seconds of PTA could be clinically important or whether a person with a transient alteration of mental state or a healthcare provider who examined such a person after the alteration resolved could determine whether this subjective state was due to brain injury as opposed to surprise, fear, shock, pain, or some other emotional or physical response to an accident or other trauma

D. ***Emotional, Physical, Cognitive, and Behavioral Effects of TBI***. Persons with TBI may experience a wide range of physical, cognitive, and other neurobehavioral deficits as a direct result of the injury.

- **Secondary emotional responses**. As with any traumatic, life-changing event, injured persons may experience anxiety, depression, anger, and other emotional responses.

- **Physical symptoms** of TBI can include lateralized weakness, incoordination, decreased balance, slowed motor responses, easy fatigability, spasticity, decreased vision, decreased hearing, and decreased sense of smell.
  - Persons with very severe or penetrating injuries can have persistent physical symptoms.
  - However, most injured persons have favorable physical recovery so that by 1 year postinjury, physical deficits are rarely the limiting factor for personal independence or employment.
  - An exception to this pattern of favorable physical recovery for many persons is residual increased fatigability.
- **Cognitive impairments** can range from attention deficits to aphasia.
  - Impairment on attentional tasks, slowed cognitive processing speed, decreased memory, and executive dysfunction are the most frequent findings in group studies.
  - **Prognosis** for cognitive recovery is related to initial severity.

    Severe TBI: By 1 year postinjury, virtually all persons with very severe TBI (initial GCS 3–5) have some degree of residual cognitive impairment that can range from profoundly severe in some persons to moderate in others. A substantial portion of persons with severe TBI (initial GCS 6–8) also have cognitive impairment, but the degree of impairment is generally less than for persons with very severe TBI and ranges from profound impairment to mild impairment.

    Moderate TBI: (initial GCS 9–12) persons show a very wide range of cognitive outcomes ranging from severe impairment to no impairment.

    Mild TBI (initial GCS 13–15) manifests substantial overlap in functioning at 1 year with noninjured persons. However, some group studies show minimal impairment for persons with mild TBI.

    A recent systematic review of the literature on cognitive outcomes for persons with TBI concluded that there was insufficient evidence to determine whether or not mild TBI is associated with any cognitive deficits that persist 6 months or longer post-TBI [8].

    When cognitive deficits appear to be persistent after mild TBI, possible causes such as preinjury learning disability, substance use, or psychiatric condition and postinjury adjustment issues or poor performance validity on testing should be ruled out [9].

E. ***Neurobehavioral effects***. In some cases, these can be even more limiting for injured persons than cognitive impairment.

- Neurobehavioral disorders may reflect directs effect of injury due to structural lesions and altered brain biochemistry, or they may reflect difficulties in adjusting to the injury or preinjury issues that are now attributed to the injury. Often these problems are comorbid.
- Depression and anxiety are the most common neurobehavioral problems experienced by persons with TBI.
  - Prevalence varies a good deal from one study to another, but it is safe to assume that 30–40 % of persons with TBI experience significant depression or anxiety at any given time point postinjury.
  - Restlessness (agitation), irritability, decreased interpersonal skills, and impaired self-awareness are other common neurobehavioral disorders. This latter problem may be particularly vexing as it can result in persons with great rehabilitation potential having poor outcomes due to poor goal setting and/or poor compliance with treatment [10].

  - Family members and other caregivers find these neurobehavioral changes to be quite stressful and this can result in depression in the caregiver.

Tips

- **<u>Psychological Services for Persons with TBI</u>**:
  - **Brief Assessments**. While we often think of the comprehensive neuropsychological evaluation when considering assessments for persons with TBI, briefer assessments can be provided early in recovery and provide value to the person with injury, family/close others, and healthcare providers.
  - **Early Assessment**. Key issues in early assessment include whether the patient has any conscious awareness (i.e., has the patient transitioned from the vegetative state to the minimally conscious state), is the patient able to give valid yes/no responses (critical to early assessment of pain and allowing the patient to express preferences), has the patient emerged from the minimally conscious or posttraumatic confusional states, is the patient depressed, anxious, or experiencing other emotional reactions to injury.
  - **Bedside assessments**. Frequently these issues can be addressed at the bedside with procedures requiring 30 min or less.
  - **Communicate with the team**. Completing these assessments in a standardized manner and communicating the results in a way that is useful to the treatment team can be a great value to early medical management or rehabilitation.
- **Scales** such as the **Coma Recovery Scale-Revised** can be used to determine whether the patient is vegetative, minimally conscious, or emerged from the minimally conscious state.
- The **Confusion Assessment Protocol** can be used to determine whether the patient is in PTCS and to track progress as the patient recovers.
- Cognitive measures such as those included in the **NINDS Common Data Elements for TBI** [11] can be used to assess early cognitive deficits.
- The **Patient Health Questionnaire-9** (**PHQ-9**) and the **Generalized Anxiety Disorder-7** (**GAD-7**) can be used to assess depression and anxiety, respectively.
- Information for some of these measures as well as other scales useful in assessment of persons with brain injury and be accessed at the **Center for Outcome Measurement in Brain Injury** website [12].
- For a detailed review of **brief beside evaluation procedures,** see Sherer and Giacino [13].
- Defer **comprehensive neuropsychological evaluations** until the patient has emerged from PTCS. Such assessments should include a detailed review of original medical records of the patients medical care at the time of injury, interview with the person with injury, interview with a family member or close other who knew the patient well before the injury and has interacted extensively with the person after the injury, a comprehensive battery of cognitive tests, questionnaires or tests to measure emotional distress and personality issues as indicated, and tests of symptom validity (effort) as indicated.
  - Areas of cognitive function to assess include attention/concentration, cognitive processing speed, memory, complex language and discourse, executive functions, and others as indicated by the patient's clinical and behavioral status. See Sherer and Novack for a review [14].
- **Clinical management** of persons with TBI. Early interventions are often directed toward managing agitation and increasing compliance with rehabilitation therapies. Such interventions involve education of family/close others and healthcare providers in addition to direct interaction with the patient.
- **Cotreatment** with the healthcare provider who is having difficulty managing the patient's behavior is very effective for behavioral management.
- A basic Antecedent-Behavior-Consequences analysis will usually reveal options for treatment. Fortunately patients in early recovery

are often progressing rapidly so behavioral issues present on Friday may be resolved by the time the psychologist is back on the unit the following Monday.

- As the person with TBI becomes oriented and more self-aware; anxiety, depression, grief, anger, and other emotional responses to trauma, loss, and uncertainty may arise. These issues can be addressed with cognitive behavioral therapy or mindfulness therapies though these may need to be modified depending on the patient's cognitive capabilities.
- Finally, cognitive rehabilitation therapies for patients with residual cognitive deficits. Evidence indicates that therapies geared toward compensation for deficits (e.g., memory notebook and electronic reminders) are generally much more effective than therapies geared toward restoration of lost abilities (e.g., repetitive computer-based memory training). See Cicerone et al. [15] for a comprehensive, evidence-based review of the effectiveness of cognitive rehabilitation therapies.

Acknowledgment Preparation of this chapter was partially supported by U.S. Department of Education National Institute on Disability and Rehabilitation Research (NIDRR) grants H133A070043, H133B090023, and H133A120020.

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13

Stroke

William Stiers

Topic

Stroke, also known as cerebrovascular accident (CVA), is an injury to the central nervous system that occurs due to problems with the vasculature (blood vessels). Stroke can occur anywhere in the central nervous system, including the brain, spinal cord, and retina. This chapter will focus on strokes occurring in the brain.

Stroke can be classified as ischemic (restricted blood flow) or hemorrhagic (bleeding). However, an area of the brain damaged by an ischemic stroke may also subsequently begin to bleed (hemorrhagic conversion).

About 87 % of strokes are ischemic, and about 13 % of strokes are hemorrhagic. Hemorrhagic strokes have greater incidence of sudden death than do ischemic strokes, but often better recovery for those who survive the immediate onset.

Almost all ischemic and hemorrhagic strokes are due to problems in the arterial system that supplies blood to the brain. However, ischemic and hemorrhagic strokes can also occur due to restriction of the venous system that drains blood from the brain, although this is not common.

A. ***Ischemic Strokes***

Ischemic strokes are due to restrictions of the blood flow in the vessels inside the brain. The restriction of blood flow deprives the brain tissue of oxygen and glucose. Restrictions in blood flow may be caused by:

1. **Embolus**

   An embolus is a blood clot, fat globule, air bubble, or other obstruction that travels in the blood stream and lodges where the vessels narrow, blocking blood flow.

2. **Thrombus**

   A thrombus is a plaque deposit that accumulates on the wall of a blood vessel and restricts blood flow.

3. **Venous Clot**

   A venous clot can restrict or block blood out-flow from the brain, resulting in a limitation of blood in-flow to the brain tissue.

B. ***Hemorrhagic Strokes***

Hemorrhagic strokes are due to bleeding from the blood vessels inside the brain itself (intraparenchymal). Bleeding may be caused by:

1. **Hypertension**

   Hypertension weakens the blood vessel walls due to excessive blood pressure.

2. **Arterio-Venous Malformation (AVM)**

   AVMs are a congenital condition where the arteries and veins in a specific area of the brain grow together in a tangle of poorly formed vessels that can subsequently leak or rupture.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_13

3. **Amyloid Angiopathy**

   Amyloid angiopathy is a weakening of a blood vessel due to amyloid deposits within the arterial walls. Amyloid deposits in the brain tissue itself are associated with Alzheimer's dementia, but amyloid angiopathy (amyloid deposits in the blood vessel walls) is not correlated with Alzheimer's dementia (amyloid deposits in the brain tissue).

4. **Venous Clot**

   A venous clot can restrict or block blood out-flow from the brain, resulting in an increase in blood pressure in the brain leading to hemorrhage.

C. ***Hemorrhage External to the Brain***

There are additional types of hemorrhage affecting the brain but not in the brain itself. Although these are not strokes, they are mentioned briefly here.

1. **Epidural Hematoma**

   Epidural hematomas (sometimes called extradural hematomas) involved bleeding outside of the dura but inside the skull. These are associated most commonly with trauma involving skull fractures. They are usually localized, and affect the brain by causing pressure on it. Epidural hematomas can become dangerous within a few hours.

2. **Subdural Hematoma**

   Subdural hematomas involve bleeding in-between the dura and the arachnoid layers of the meninges that surround the central nervous system. These most often result from trauma, but not necessarily skull fracture. They are usually localized and affect the brain by causing pressure on it. Subdural hematomas can progress over hours, but sometimes over many months before becoming symptomatic.

3. **Subarachnoid Hemorrhage**

   Subarachnoid hemorrhage (SAH) is due to bleeding from the blood vessels on the surface of the brain. This is most often associated with cerebral aneurysms that abruptly rupture. SAH is usually diffuse as the blood disperses in the cerebrospinal fluid and affects the brain by the toxic effects of blood on the brain tissue. SAH is sometimes classified as a hemorrhagic stroke, but this is a nontraditional classification.

D. ***Transient Ischemic Attack (TIA)***

TIA is defined as a transient episode of neurological dysfunction caused by focal brain, spinal cord, or retinal ischemia, without acute infarct. Older definitions specified that symptoms lasted less than 24 h, but one-third to one-half of individuals with traditionally defined TIAs exhibit new infarct on advanced imaging procedures. Therefore, it is impossible to define a specific time cutoff that can accurately distinguish whether a symptomatic ischemic event will result in brain injury. Rather, imaging is needed to differentiate a symptomatic ischemic event with infarct (stroke) vs. a symptomatic ischemic event without infarct (TIA). It is suggested that the term *acute neurovascular syndrome* be used until diagnostic imaging is completed or if diagnostic imaging is not performed all.

Importance

A. ***TIA***

Approximately 240,000 TIAs occur in the U.S. annually [1]. For people who have a TIA:

- 5 % develop stroke within 2 days [2]
- 10–15 % develop stroke within 90 days [2]
- 20 % increased death rate (above usual mortality rate) within 5 years [3]

B. ***Stroke***

Approximately 795,000 Americans experience a stroke each year. Over the course of a lifetime, 4 out of 5 American families will be touched by stroke. There are an estimated 6.8 million adult stroke survivors in the U.S. The estimated national direct and indirect cost of stroke is $62.7 billion annually [4].

For individuals with stroke, 8 % of ischemic strokes and 38 % of hemorrhagic strokes result in death within 30 days [5]. Stroke is the fourth leading cause of death in America and a leading cause of adult disability [6].

Stroke complications at 1 month:

- cognitive impairments 65 %
- Urinary incontinence 54 %
- Malnutrition 49 %
- Dysphagia 47 %
- Pulmonary 40 %
- Urinary tract infection 40 %
- Depression 30 %
- Pain 30 %
- Bowel incontinence 25 %
- Falls 25 %

For stroke survivors [5]:

- 10 % recover almost completely
- 25 % recover with minor impairments
- 40 % experience moderate to severe impairments requiring special care
- 10 % require care in a nursing home or other long-term care facility

For people who have had a stroke who survive 30 days [7]

- 10 % die within 1 year
- 40 % die within 10 years

Practical Applications

A. ***Acute Inpatient Medical Care***

Public health campaigns providing education and advice about stroke have focused on using an acronym to help people recognize and respond to stroke:

FAST

Face—ask the person to smile; is there unilateral facial weakness?

Arm—ask the person to raise their arms; is there unilateral arm weakness?

Speech—ask the person to talk; is there language disturbance or slurred speech?

Time—time is of the essence; seek emergency medical help immediately!

Time is of the essence because most strokes are ischemic, most ischemic strokes are embolic, and most embolic strokes are caused by blood clots. Blood clots have the potential to be addressed in the early stages of a stroke before extensive damage occurs.

On presentation to a hospital emergency department, after any needed initial stabilization, a head CT is performed. This quickly shows whether there is a hemorrhage in the brain, as acute blood is quite bright on CT. However, if there is an ischemic stroke, CT will usually not show any abnormalities until 24 h later. This rapidly differentiates ischemic from hemorrhagic stroke. If the patient has clear stroke-like symptoms, and the CT shows no bleeding, a clot embolus is presumed.

Tissue plasminogen activator (*t*-PA) can be injected within the first four hours following ischemic stroke to dissolve blood clots. However, if the stroke occurred more than four hours previously, *t*-PA can increase the risk of hemorrhagic conversion, and is not recommended. However, recent research [8] indicates that the increased risk of hemorrhage is due to damage to the blood–brain barrier (BBB) in the area of the stroke in some patients. A new MRI sequence has been shown to differentiate those patients who had stroke involving damage to the BBB, and therefore should not be given anticoagulant treatment, from those patients who had stroke without damage to the BBB, and therefore may be given anticoagulant treatment even beyond the 4-h time window [8].

An additional procedure, performed only at a few centers, is thrombectomy, where a catheter is introduced through the femoral artery, through the aorta, heart, and internal carotid artery, into the brain to the site of the blockage, and then the clot is mechanically grabbed and pulverized or pulled out.

Following immediate treatment, work-up includes evaluation of the heart. Since most strokes are caused by blood clots in the arterial system, evaluation of the heart is logical:

- Venous (deoxygenated) blood returns to the heart and is pumped to the lungs for gas exchange (drop off CO_2 and pick up O_2). Clots in the venous system result in pulmonary embolus as the clot lodges in the capillary beds of the lungs.

- Arterial (oxygenated) blood returning from the lungs to the heart to be pumped out in the arterial system is clean, and any arterial clots have likely originated in the heart itself.

This can be due to heart disease with low ejection fraction (inefficiency resulting in blood pooling in the heart chambers and forming clots), patent foramen ovale (a hole between the left and right sides of the heart during fetal development that normally closes during infancy, but in some individuals fails to do so), or other heart complications.

Individuals who survive the initial stroke and have impairments that preclude immediate discharge home, but have the potential to eventually return home, are usually transferred to inpatient rehabilitation once they are (mostly) medically stable. This is important because stroke patients who receive organized inpatient multidisciplinary rehabilitation have better outcomes than those who do not (30–50 % lower odds of dependency, institutionalization, and death—Langhorne and Duncan [9]).

B. ***Inpatient Rehabilitation Care***

In many comprehensive inpatient rehabilitation facilities, stroke survivors will encounter a psychologist. Psychological assessments and interventions with stroke patients and their families may include:

- Cognitive functioning, including decision-making capacity
- Emotional and personality functioning, including resiliency
- Behavioral functioning, including health behaviors and recovery engagement.

These will be considered separately. Additional assessments and interventions focused on understanding of stroke and stroke-related impairments, sexual functioning, substance use, pain, and academic, vocational, and recreational functioning are not discussed in this chapter, but are discussed elsewhere in this book.

1. **Cognitive Functioning, Including Decision-Making Capacity**

a. *Assessment*

Basic assessment of orientation to time and place and memory for recent events is important.

- Can the patient answer orientation questions, including age, year, season, month, and time of day? Minor errors in date and day of week are likely of little significance during a period of acute stress and changes in routine. If the patient is unable to spontaneously answer orientation questions, choices can be given, first starting with broad categories, and then focusing on specifics. For example, regarding age: “Are you in your 50s, 60s, 70s, or 80s?” And then, “Ok, 60s—60 what? Regarding year: “Is it the 1980s, the 1990s, or the 2000s?” And then, “Ok, 2000s—2000 what?” Similarly, the patient is asked to identify the current location, and, if unable, choices can be provided. Patients who are mildly to moderately aphasic may be able to point to written choices—again, first to the broad category, and then to the specific response.
- In regard to recent events, can the patient tell you a logical sequence of events leading up to your encounter with him or her? “What happened? When was that? What happened next?” “Now, how long have you been staying here?”

Additional assessments may examine:

- Simple and complex attention (the latter often referred to as “working memory”)
- Language-based processing (receptive language, including the ability to answer simple yes/no questions and the ability to follow 1-, 2-, 3-, and 4-step commands; expressive language, including conversation and confrontational naming; and repetition)
- Visual-spatial processing (clock drawing and figure copy)

- Episodic memory (list and/or story memory, including recall and recognition)
- Reasoning/problem solving (“what would you do if…”, e.g., from the Repeatable Battery for the Assessment of Neuropsychological Status).

Assessment of decision-making capacity may also be necessary. Adequate decision-making capacity requires the ability to:

- Understand and communicate the available choices.
- Understand and communicate the consequences of the available choices.
- Express a consistent choice preference that makes logical sense, even if others do not think it is the best course of action.

Impaired orientation to time and place and confused memory for recent events likely means that the patient does not have adequate decision-making capacity to manage their own affairs, since they cannot accurately remember events from yesterday (e.g., “The doctor told me to…”) or anticipate events of tomorrow (e.g., when is the rent due), and cannot place events in a time-and-place context.

Decision-making capacity is context dependent. Patients with severe aphasia cannot use language-based processing to make decisions. Patients who are confused and disoriented have very limited decision-making capacity and cannot manage their own affairs. However, patients may be able to identify who they want to function as a surrogate decision maker, even in the presence of significant aphasia or confusion and disorientation. Patients without confusion and disorientation may have greater decision-making capacity, and the specific decision in question will need to be explored to ascertain understanding of choices, understanding of consequences, and the ability to consistently express a logical choice.

b. *Intervention*

Interventions may include the following:

- Patients with confusion and disorientation may benefit from frequent reassurance, reorientation, and reminders of recent events (e.g., “You had a stroke about 6 days ago; you were taken to X hospital; you were transferred here and have been staying in this room now for about 3 days; we are working to help you get better”).
- Patients with attentional impairments may benefit from reduced competing stimuli, including turning off the television in their rooms, and private treatment areas for PT and OT interventions.
- Patients with language-based impairments may benefit from simple active-voice sentences (subject–verb–object), focused on one idea at a time, without qualifiers and embedded clauses, and without adjectives and adverbs, in combination with gestures and other contextual cues.
- Patients with visual-spatial impairments may benefit from repeated spatial reorientation and assistance with organizing his/her body and other objects in space, and with path-finding. Spatial neglect may present significant difficulties in spatial awareness and safety.
- Patients with episodic memory deficits may benefit from a memory book; however, many memory books are ineffectual because they are simply given to the patient with the instructions to “write things down.” In order for memory books to be useful, the patient must be systematically trained through

structured, sequenced practice and repetition to consistently and correctly record relevant information in specific sections of the book, and then to consistently refer to the information. Memory books can include sections on personal information (autobiographical data and names of important others), log of hourly/daily activities, calendar/appointment book, "to-do" list, and task-specific directions (e.g., how to send/receive text messages, how to call someone, and how to operate the television remote control). Patients have to be trained to identify the appropriate section for each type of information, to write the information down in that section, and then to refer to that section to find specific types of information.

2. **Emotional and Personality Functioning**
   a. *Assessment*

In assessing emotional functioning, it is important to keep in mind the following analogy: "Mood is to affect as climate is to weather." Mood is the prevailing emotional tone (the overall emotional "climate"). Affect is the moment to moment emotional variation (the current emotional "weather"). Affect and mood must be clearly distinguished.

Affect syndromes include emotional lability and pseudo-bulbar affect. Emotional lability involves rapid changes in subjectively experienced emotions, from feelings of sadness to anger to irritability, or, less commonly, euphoria. Pseudo-bulbar affect (PBA) describes emotional behaviors without subjective emotional feelings. Individuals may laugh or cry or yell angrily without the subjective experience of these emotions. These uncontrollable outbursts of emotional behavior lack an appropriate environmental trigger and are incongruent with the underlying emotional state. Rather, brain stem and cerebellar damage results in disinhibition of the facial and vocal behavioral expressions of emotions. Although many people now commonly refer to "pseudo-bulbar affect" to describe any lability of emotional expression, it is important to recognize that in true PBA these behaviors occur without subjective emotional feelings, and, because of the brain stem and cerebellar involvement, are almost always associated with dysphagia, dysphonia, dysarthria, and impaired facial and tongue movements.

Mood syndromes include anxiety, irritability, and depression, depression being the most common in stroke. Approximately one-third of stroke survivors experience poststroke depression [10]. Depression is differentiated from emotional lability in consisting of sustained low mood (greater than 2 weeks for major depressive disorder) and decreased pleasure and enjoyment, and is often accompanied by self-blame and self-criticism, and hopelessness and wish for death. However, it is important that psychological depression not be confused with physiological depression involving lack of initiation, decreased responsiveness, and blunted affect due to brain injury, metabolic or electrolyte imbalance, infection, or other physiologic compromise.

In evaluating depression, one should examine moods, thoughts, and behaviors. Moods related to depression may involve sadness, anxiety, or irritability. Thoughts related to depression may involve catastrophizing, negative memory bias, and pessimism. Behaviors related to depression may involve avoidance and self-defeat/lack of perseverance. Two questions, derived from the Patient Health Questionnaire have good sensitivity and specificity in assessing depression [11]:

- During the past 2 weeks, have you felt down, depressed, or hopeless?
- During the past 2 weeks, have you had little interest or pleasure in doing things?

  One could also ask about the additional factors often accompanying depression:
- Over the past 2 weeks, have you felt bad about yourself, or thought that you are a failure or have let yourself or your family down?
- Over the past 2 weeks, have you felt hopeless or thought that it would be better if you were dead?

  More detailed evaluation of suicide should follow, if indicated:
- Thoughts—"Have you thought about killing yourself?"
- Plans—"Have you thought about how you might kill yourself? What have you thought about?"
- Actions or near actions—"Have you ever done something to try to kill yourself, or come close to doing something to try to kill yourself? What was that?"
- Intent—"Is that what you want? Do you want to be dead?"

In regard to personality functioning, aspects of self-image, self-esteem, locus of control, and resiliency are important. Stroke results in changes in physical functioning, task functioning, and social role functioning. The inability to perform usual activities and roles disrupts established psychological, family, social, and vocational systems—norms, obligations and responsibilities shift. Self-esteem and social status related to role functioning may be disrupted. Social interactions may be reduced. If a crucial role is disrupted and the person lacks alternative sources of self-worth, depression can occur.

One important factor is the complexity and variety of different roles from which an individual derives self-esteem. Individuals with more different kinds of involvements have greater ability to feel pride from a variety of activities and abilities. They are more likely to be able to identify intact skills and abilities from which to draw satisfaction when some skills and abilities don't work anymore.

Family assessment of emotional and personality functioning is also important. In relation to stroke, stroke survivor depression is related to caregiver's emotional distress. However, caregiver emotional distress is not related to the stroke survivor's physical disability and level of assistance needed, but is related to the interference a caregiver experiences with their ability to participate in valued activities. Thus, it is important to consider both the patient's and the caregiver's abilities to continue to participate in valued activities following stroke.

b. *Intervention*

Treatment for depression is important, because research shows that depression keeps people with strokes from improving as much as they can [12]. For example, persons with stroke who are not depressed make more improvement while in the hospital than persons with stroke who are depressed. In addition, persons with stroke who are depressed may lose function after leaving the hospital, and also make less recovery from their stroke over the next few years.

Treatment of depression involves:

- Interventions for sad mood
  - Psychopharmacology and supportive psychotherapy
  - Increase social support
- Interventions for depressive cognitions
  - Cognitive-behavioral therapy
- Interventions for depressive behaviors
  - Behavioral activation
  - Increase pleasant experiences

- Compensatory and adaptive techniques to increase social role functioning

Family interventions to assist in maintaining involvement in valued activities are also important.

2. **<u>Behavioral functioning, including health behaviors and recovery engagement</u>**

a. *Assessment*

Behavioral functioning in stroke treatment settings, as well as in home and community settings, results from an interaction of person, task, and environment factors.

In regard to health behaviors, one can evaluate adequate hydration and nutrition, appropriate sleep, regular physical activity, weight management, substance use, preventive health care, and medication adherence. These are broad issues in all types of health conditions, not specific to stroke, and will not be discussed further here.

In regard to recovery engagement, this is a relational process. Disengagement (or failure to engage) is commonly portrayed as a patient "problem" and responsibility. This ignores the role of the healthcare provider, therapeutic process, and environment in disengagement.

There are not "unmotivated" or "noncompliant" patients. Rather, engagement is an interpersonal interaction involving the patient and clinician and is related to patient perceptions of the relevance of the activities to their needs, and patient perceptions of clinician engagement.

Thinking about engagement as a relational process may promote a reflective, approach to the rehab process. Because engagement comes about through interpersonal interactions, rehab staff must think about their structures and processes, as well as their team and individual engagement, in addition to thinking about the patient and family characteristics and preferences.

Recovery engagement involves attendance, participation, and effort. One measure of recovery engagement is The Hopkins Rehabilitation Engagement Rating Scale [13]:

- The patient regularly attended therapy.
- The patient required verbal or physical prompts to actively participate in therapy.
- The patient expressed a positive attitude toward therapy.
- The patient acknowledged a need for therapy and the benefit of therapy.
- The patient actively participated in therapy.

Higher engagement is related to greater Functional Independence Measure efficiency and higher level of functioning at three months postdischarge.

b. *Intervention*

Ways to increase recovery engagement include:

- Ask and listen empathically to identify the patient's valued end goals.
- Describe the intermediate steps and the expected time frame to reach these end goals.
- Explain how specific therapy activities contribute to the intermediate steps necessary to reach the end goals.
- Provide graded task activities from easier to more difficult to allow for success.
- Point out gains and improvement over time and praise these.
- Point out areas needing continued work and normalize these, reminding about the expected time frames.

C. ***<u>Outpatient Rehabilitation Care</u>***

Stroke recovery lasts a lifetime, and the focus of outpatient rehabilitation is to return to valued activities. Quality of life is not related to strength, range of motion, or activities of daily living—quality of life is related to social role participation, including family, community, spiritual, educational, vocational, and recreational roles [14]. Albeit, social role participation may be changed after stroke, but the challenge of outpatient rehabilitation is to help the patient and family develop new ways to achieve their valued goals.

The psychologist can work with the patient and family to identify these valued goals and social role participations and to develop ways to achieve these. However, it is also critically important that the psychologist work with the other members of the outpatient rehabilitation multidisciplinary team to help them focus on eliciting these goals, and then brainstorming how to achieve them:

- “Tell me what your garden is like, and let’s think about how you can work in it.”
- “How can we arrange things at home so that you can get back to cooking?”
- “I know you have trouble talking, but let’s work on singing so you can get back to the church choir.”
- “Let’s talk with your employer about reasonable accommodations so you can return to work.”
- “I know you can’t play third base on the softball team, but maybe you could be the score keeper, and go out for pizza after.”

Tips

- Stroke results in an acute crisis for the patient and family. It is important to explicitly point this out to them that these events are unanticipated, unwanted, and uncontrollable, with initially difficulty anticipating what comes next, and they can expect to experience stress from this disruption and uncertainty. The psychologist should emphasize that there is a process of recovery that involves many stages, that they will have ongoing rehabilitation assistance throughout this process, and that they should pay attention to helping themselves cope and adapt through these difficult times (sufficient sleep and nutrition, soliciting assistance from others, asking questions, telling the team about needs, etc.).
- Staff and family members have difficulty differentiating between emotional lability vs. psychological depression vs. physiological depression, and it is important for the psychologist to help clarify these differences. Emotional lability involves episodes of tearfulness interspersed with times of pleasure and enjoyment, and is not worrisome unless it is so strong as to be uncomfortable for the patient. (Selective serotonin re-uptake inhibitors can be helpful with emotional lability.) Psychological depression involves sustained low mood with decreased pleasure and enjoyment and should be treated. Physiological depression may mimic the vegetative signs of depression, but lethargy, abulia, psychomotor slowing, decreased initiation, blunted affect and the like cannot be considered indications of psychological depression in a physiologically compromised patient.
- In patients with aphasia, it is easy to appreciate the patient’s expressive language difficulties, but it is common for staff and families to underestimate the patient’s receptive language difficulties. People will almost always talk at the patient and say “He’s understanding me pretty well.” This is based upon the patient’s perception of postural and gestural cues, tone of voice, and facial expressions; however, these do not help in the understanding of complex verbal information. It can be helpful to demonstrate to staff and family members what the patient’s true receptive language ability is, for example, with simple yes/no questions (“Is fire hot? Is fire cold?) and commands (“Touch your nose and point to the ceiling”).
- One of the more challenging aspects of inpatient rehabilitation is when patients are not fully engaged, or actively disengaged, from the ongoing therapy activities. Often this can be helped by carefully listening to the patient’s goals, wishes, needs, and fears, and helping them reframe these in a more “rehab centered” way. It is also important to be an advocate for the patient, such as solving problems (scheduling and food preferences) and

helping communicate the patient's situation to the team in a way that helps the team to be empathic, supportive, and encouraging. However, in some cases patients may be more actively noncompliant, and they may need to be told that there are requirements for therapy participation, and that if those requirements are too demanding, then they can choose to transition to a less-intensive level of care such as a subacute rehabilitation unit in a nursing home.

- Patients and families may resist the transition from inpatient rehabilitation to subacute rehabilitation facilities or to home-health or outpatient care because they want to get "more." It is important to discuss continuums of care and appropriate transitions. Patients and families may be helped in this process by comparing the transition to "graduation" due to successful completion of the current level of care.

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Neurological Tumors

14

Rachel L. Orr

Topic

Neurological tumors belong to two broad groups: **primary brain tumors** and **secondary, or metastatic, brain tumors**. Primary brain tumors are those that arise from abnormal growth of the brain, while metastatic brain tumors originate elsewhere in the body and metastasize to the brain. Malignancy of tumors varies greatly and generally depends on several factors, including tumor location related to accessibility for treatment, vascular/endothelial proliferation, mitotic features, nuclear atypia, and necrosis. The World Health Organization developed a **grading system** (I–IV) in 1993 (revised in 2000 and again in 2007 [1]) to classify tumors according to biological potential, with higher grades (grades III and IV) associated with greater malignancy.

Some *fast facts* about primary and metastatic brain tumors [2–6]:

A. ***Primary brain tumors***
- More common in children and elderly adults
- Less common overall than metastatic brain tumors
- Typically do not metastasize to other areas of the body
- Categorized according to histology
- Some more common subtypes include:
  - Gliomas—originate from glial cells.
    Astrocytomas—develop from astrocytes, can be quite benign (pilocytic astrocytoma, grade I) or quite malignant (glioblastoma multiforme [GBM], grade IV).
    Ependymomas—develops from ependymal cells.
    Oligodendrogliomas—originate from oligodendrocytes.
  - Meningiomas—originate from the meninges, the membranes that surround the brain and spinal cord.
  - Pituitary tumors—originate from pituitary gland (e.g., adenomas, craniopharyngiomas, and carcinomas).
  - Primary cerebral lymphomas—originate from lymph tissue within the brain.
  - Medulloblastomas—a type of embryonal tumor that originates in posterior fossa, generally high grade, more commonly occurs in children than in adults.
  - Germ cell tumors—originate from immature germ cells in pineal or suprasellar regions of the brain.

B. ***Metastatic brain tumors***
- More common overall than primary brain tumors.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_14

- Occur more often in adults than in children.
- Typically arise from lungs, breasts, skin, colon, kidney, or genitourinary origins.
- Lung and breast cancers and melanomas are most common origin, primarily because they are more common cancers overall.
- Typically affect cerebral hemispheres at the gray and white matter junction, and cerebellum metastases are common also.
- Metastatic brain tumors are highly malignant; life expectancy is less than 6 months for most patients with brain metastasis, but most die of systemic, not intracranial, involvement.

Importance

Brain tumors affect a significant number of children, adults, and elderly individuals each year, given the following statistics [2]:

- In 2014, there were 343,175 incidents involving brain and central nervous system (CNS) tumors (primary and metastatic combined).
- It is estimated that 68,470 new cases of primary brain tumors will be diagnosed in 2015, while an estimated 13,770 individuals will die of primary malignant brain and CNS tumors the same year.
- The five-year survival rate following diagnosis of primary malignant brain and CNS tumor is only 34.2 % (according to data from 1995 to 2011), with rates decreasing with age.

Increasing medical advances have dramatically improved the survival rate for individuals affected by brain tumors. However, survivors of all ages often live with significant rehabilitative needs and lasting physical, cognitive, and emotional problems. Eighty percent of brain tumor survivors have cognitive deficits, 78 % have residual weakness, and 53 % have visual and perceptual deficits, among other problems [7]. More than 75 % have three or more areas of deficit [7]. Notably, rehabilitative needs are neither significantly different in those with malignant versus benign tumors, nor among those with primary versus metastatic brain tumors [8]. The lasting impact for brain tumor survivors can occur either as a direct result of the tumor or as a result of the brain tumor treatment.

A. ***Treatments and Their Impact***

The three primary means of treatment for brain tumors are (1) **neurosurgical resection** (gross total resection [GTR]; near total resection [NTR]; or subtotal resection [STR]), (2) **cranial radiation therapy (CRT)**, and (3) **chemotherapy**.

1. **Neurosurgical resection**

   The possibility of neurosurgical resection varies depending on the tumor location. Tumors within deep subcortical regions are more difficult to operate on because of access. When resection is possible for a brain tumor, the extent of resection (i.e., GTR, NTR, and STR) depends on location and how clearly defined the borders are; that is, it depends on the invasiveness of the tumor on surrounding brain tissue and whether the brain tissue is amenable to being removed (i.e., some functions may be too important and thus spared in the resection). It is more challenging to achieve total resection of tumors with anaplasia, extensive vascular proliferation, and/or necrosis, making tumors with these qualities characterized as malignant (grades III and IV, e.g., anaplastic astrocytoma and GBM). Regardless, neurosurgery, when warranted, is a significant medical procedure that brings with it an array of potential complications (e.g., craniotomy, hydrocephalus, and need for shunt placement).

2. **Cranial radiation therapy**

   Radiation can be delivered in varying doses, as well as to the whole brain or to more focused regions [9]. There is an abundance of literature to suggest that CRT is associated with significant cognitive deficits across various domains, including attention, learning, memory, processing speed, visual-spatial skills, and higher-order executive functions [9]. Greatest risk for cognitive impairment has been found when CRT is administered in higher fractionated doses (i.e., greater than 2 Gy), in higher total dosage overall, with larger brain volume treated, for longer duration of treatment, in combination with chemotherapy, when used in patients under 7 years old or older than 60 years old, or used with individuals with vascular risk factors [10–12]. Radiation therapy is thought to damage cognitive function by means of metabolic and white matter changes, necrosis, and by affecting neuronal function and synaptic plasticity [13]. Radiation therapy can also result in encephalopathy, which can be acute (less than two weeks after treatment), early delayed (one to four months after treatment), or late delayed (more than 4 months after treatment), and can result in lethargy, cognitive and behavioral changes, as well as changes associated with tumor/CRT location [6]. Importantly, suspected encephalopathy must be distinguished from tumor recurrence. Radiation therapy can also induce brain edema, thus corticosteroids are often administered prophylactically [6] and come with their own set of potential side effects.

3. **<u>Chemotherapy</u>**

   Many chemotherapy agents for brain tumors are delivered intrathecally (directly into cerebrospinal fluid) or by intraarterial means, and the protection of the blood–brain barrier makes an effect on brain tumors difficult in many instances. Many adverse effects have been identified following chemotherapy treatment, including alopecia, fatigue, nausea, constipation, headache, and cognitive deficits [6]. In addition, chemotherapy can result in neurotoxicity and brain edema, which often warrants close monitoring and prophylactic corticosteroid treatment [6], similar to CRT. Cognitive impairment is hypothesized to result from direct neurotoxic damage, injury to glial cells, damage to neuroprotective hormones, DNA damage due to oxidative stress, and/or immune dysregulation [14]. Similar to CRT, damage following chemotherapy is associated with cumulative dose, intensity of individual doses, and duration/quantity of cycles of treatment [14].

Practical Applications

A. ***<u>Discovery of Brain Tumors</u>***

   Often, brain tumors are discovered prior to psychology involvement, the latter of which is warranted for emotional reasons as well as for neuropsychological assessment. First symptoms are often **focal** in nature and consistent with dysfunction in the brain region where the tumor resides, such as headaches, behavioral and personality changes (frontal), visual symptoms or hallucinations (occipital), perceptual or proprioceptive effects (parietal), language or emotional symptoms (temporal), endocrine dysfunction (pituitary involvement), or balance problems, incoordination, and dysarthria (cerebellar) [4]. Cortical tumors often present with **seizure activity** in the affected region, and this is the presenting complaint in 15–20 % of patients with brain tumors [6]. Symptoms consistent with **mass effect** and **edema** can also arise, such as focal symptoms at the region of mass effect or more general symptoms of edema, such as nausea, vomiting, and fatigue [4]. **Cognitive complaints** are also common, thus it may be important for a neuropsychologist to refer for neuroimaging if no clear etiology of cognitive impairment is otherwise identified from assessment.

B. ***<u>Diagnosis</u>***

   Once symptoms are identified, a referral to a neurologist for assessment is warranted. Means of identifying brain tumors include: a thorough neurologic exam, neuroimaging scans, laboratory tests (i.e., of blood and/or cerebrospinal fluid), and/or biopsy, the latter of which is completed at resection for histological identification, tumor classification, and prognosis estimation [4].

C. *Cognitive Impairment and Neuropsychology Involvement*

Cognitive impairment as a result of brain tumor and/or treatment is common, as noted previously. Possible reasons for a patient to be referred for neuropsychological assessment include [4, 6]:

- To establish a baseline of cognitive functioning before treatment.
- To assess for language dominance if temporal regions are affected and neurosurgery is considered.
- To assess cognitive status after treatment (typically compared to baseline, if baseline scores are available).
- To assess cognitive functioning after tumor recurrence.
- To acquire specific recommendations given remission/success of treatment.

1. **Cognitive and Behavioral Deficits**

Neuropsychologists will often uncover decreased IQ scores (particularly among children affected early by brain tumor and treatment, given negative impact on learning), poor academic achievement, as well as deficits in attention/short-term memory, processing speed, learning and long-term memory, and higher-order executive functions [15]. Comprehensive assessment may also reveal social dysfunction and emotional effects [15]. Children are often removed from school for extended periods of time for treatment, resulting in difficulties with re-integration, social alienation, and incomplete academic instruction, among other problems. Childhood brain tumor survivors' areas of difficulties often persist into adulthood [6] with generally poor follow-through across health care systems, as many patients transfer physicians upon becoming adults. Further, adult survivors of brain tumors are less likely to acquire employment than the general population and are more likely to require assistance with activities of daily living [6].

2. **The Neuropsychological Assessment and Report**

A neuropsychologist should always consider the referral question when designing a test battery and composing the report. If previous testing has been completed, it is often most helpful to repeat tests where possible, calculate reliable change indices to determine progression/change since last assessment, and administer tests with careful consideration of their reliability and validity characteristics with repeat testing/comparison now or later in mind. Furthermore, the neuropsychologist should assume that there will be future assessments completed; thus, it is important to include raw scores within the report for future comparison whenever possible. Regardless of the reason for referral, however, recommendations are of utmost importance for this population; parents and teachers of children with brain tumors consistently rate the recommendations section as most helpful [15]. A good neuropsychological assessment report will typically identify cognitive and behavioral strengths and weaknesses as well as strategies to capitalize on strengths and accommodate or compensate for weaknesses [15]. In addition, recommendations that include factors for future consideration (i.e., how to access services, how to deal with/manage new life milestones, prognosis of cognitive recovery/dysfunction, etc.) will be helpful. The neuropsychologist's role is to educate others involved with the patient in a way that is easily understandable to all potential audience members [15].

3. **Cognitive Rehabilitation**

Cognitive rehabilitation is an emerging field that holds a wealth of potential for individuals recovering from brain tumors, and the provision of these interventions holds important roles for neuropsychologists, psychologists, speech and language pathologists, and other specialists within the oncology team. Cognitive rehabilitation entails identification of strengths and weaknesses, typically following neuropsychological assessment, and intervention to capitalize on strengths and address weaknesses via remediation (with the goal of improvement) and/or compensatory strategies (with the goal of better functioning when improvement may or may not be possible). Interventions may be provided either during one-on-one sessions with a therapist or within group (typically disorder-specific) settings.

4. **Medication for Cognitive Deficits**

   There is a large body of literature investigating the utility of pharmacologic treatment for cognitive deficits, with some evidence suggesting that methylphenidate may yield performance improvements in some cognitive areas, including attention, memory, reasoning, and verbal fluency, as well as in motivation [6]. Additional research has focused on donepezil, modafinil, and ginkgo biloba, but with little benefit, highlighting the need for more research in this area.

5. **Common "Side Effects" of Brain Tumors**

   Individuals with brain tumors present with a variety of problems, sometimes specific to the focal region of tumor mass and other times more generalized. Some common problems of which providers should be aware [6]:

   - **Seizures** occur in 20–40 % of patients with high-grade tumors and about 50–85 % of patients with low-grade tumors. Antiepileptic drugs are often prescribed for management but demonstrate little prophylactic help.
   - **Headache** is present in between 50 and 70 % of patients with brain tumors, often of the tension subtype. Highly persistent headaches should be investigated as potentially recurred tumor.
   - **Fatigue** is common, directly from the tumor or as a side effect of treatment. Psychologists may provide support to patients through education regarding detailed exploration of triggers and mitigating techniques for fatigue such as pacing strategies and sleep hygiene.
   - **Mood** dysregulation can result from direct tumor effects or the complicated sequelae of life changes related to tumor occurrence. There is an important role for psychology in supporting the adaptation of individuals after diagnosis and throughout the treatment and recovery process.

6. **Family and Caregivers**

   Families and caregivers of patients with brain tumors often experience challenges such as emotional responses to having a sick loved one, changing relationships and family roles, caregiver burden, financial difficulties, and interaction with medical systems and medical providers [6, 16]. Review of the extensive literature on family functioning after a child or loved one has been diagnosed with a brain tumor reveals significant impact on family functioning via the aforementioned factors as well as from the impact of neurocognitive impairment (i.e., impaired communication due to neurocognitive issues) [16]. Theoretical models have been developed to incorporate family functioning in the conceptualization of how late effects impact individuals with brain tumors and their families, suggesting that treatment type, intensity, and other variable factors may affect families' adaptation to illness, which in turn, may affect patients' adaptation and overall outcome factors [16, 17]. Qualitative exploration into patient and family functioning after brain tumors (via case studies) reveals drastically different family members' attitudes toward illness, treatment, recovery, and level of burden [16]. Additionally, case studies suggest that family members' adaptation to illness and its complicated sequelae may influence the family's allocation of resources toward the survivor and may affect how well the family functions after brain tumor survival [16]. Overall, family and caregivers should be considered essential components of a patient's "team" and warrant attention and support also, particularly from a family systems perspective and given potential impact on the patient.

7. **Palliative Care**

   Patients with malignant tumors may find themselves with a terminal prognosis, facing end-of-life care. Palliative care from a prepared, cohesive oncology team is crucial at this time to manage neurological deterioration, medical issues, and psychosocial complications [18], with the goal of assisting the patient and his/her family in being most comfortable and supported. For example, medications such as midazolam may be used to facilitate sedation and manage symptoms such as delirium, agitation, refractory seizures, or death rattle, and corticosteroid use is typically reduced to decrease wakefulness and promote rest [18]. Patients and families who receive more support in preparation for death report significantly less distress when looking back upon their family member's end-of-life period [18]. Psychologists can take an important role in supporting and helping patients explore reflective thoughts about life as well as thoughts about impending death.

Tips

- Given that cognitive complaints may be a first identified symptom of brain tumors, neuropsychologists should always consider referrals for neuroimaging to assess for brain tumors. Recurrent tumor should also be considered if headaches, seizures, or other symptoms are not resolved or mitigated following intensive treatments.
- It is essential for psychologists to become familiar with the various types, origins, malignancy levels, treatments, and treatment side effects/late effects of brain tumors if they are to be working with this population.
- Psychologists have the unique role of providing psychoeducation for the patient and caregivers/family regarding prognosis and the impact of brain tumor on functioning (physical, cognitive, emotional, etc.). An empathic psychologist can serve as an integral member of a rehabilitative and treatment team with the role of translating difficult medical jargon into information that the patient and caregivers/family can understand and appreciate.
- Neuropsychological evaluations for brain tumor patients should include provision of raw scores, given that repeat testing is often warranted to monitor neurocognitive change. If prior testing is available, results should include discussion of changes (e.g., which may include statistical analysis of change via reliable change index).
- A neuropsychological evaluation is most useful if its recommendations are useful. This means creating recommendations that are highly applicable and relevant to the particular patient, that are understandable to the layperson and those who will be most involved with the patient, and that can be implemented successfully by the family, caregivers, teachers, neurologists, rehabilitation therapists, and other professionals who may read it. Targeted reports with careful consideration of the audience are warranted.
- Family and caregivers are essential members of the patient's team and should be treated as such. Family adaptation is important for

patient adaptation and recovery, thus appropriate attention and care should be provided to both parties.

- Psychologists play a key role in palliative care overall, regardless of malignancy. The emotional adjustment is difficult, from the receipt of diagnosis to end-of-life hospice care, and psychologists have unique and important training in this area that can be invaluable to a patient and his or her caregivers/family during an incredibly challenging time.

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Spinal Cord Injury

15

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Topic

A **spinal cord injury** (**SCI**) is damage to any part of the spinal cord or nerves extending from the spinal cord that often results in permanent changes in motor and/or sensory abilities and other body functions below the point of the injury. The physical impairments from SCI vary as a function of the level and completeness of the injury. Nearly every aspect of a person's life—physical health, work, personal relationships, and recreation—may be affected following SCI. Adjustment involves learning new adaptive behaviors and attitudinal change, so psychologists play a crucial role in assisting the rehabilitation process.

A. ***Key concepts***

1. **Neurological level of injury**

   In 1982, the American Spinal Injury Association (ASIA) published an international classification of SCI that is still widely used to document motor and sensory impairments after SCI. The ASIA Impairment Scale (AIS) is determined by neurological responses of touch and pinprick sensations tested in each dermatome (area of skin supplied by a single spinal nerve) as well as the strength of key muscles on each side of the body corresponding to the neurological level of SCI. Research on prediction of outcomes has focused on the relationship between AIS classification within the first week and later recovery of function in traumatic injuries. In addition, AIS rating helps guide the rehabilitation process by identifying expected degree of physical independence for a given injury level:

AIS A/Complete	**No motor or sensory function** is preserved in the sacral segments S4-S5. The person has **no rectal/anal sensation**, sphincter contraction or other motor function below the neurological level, which is the lowest segment with nor mal sensory and motor function
AIS B/Sensory Incomplete	**Sensory** (but **no motor** function) is preserved below the neurological level; **includes** the sacral segments S4-S5. The person *has* anal sensation but no motor function below the neurological level. AIS B can be a transitional stage toward AIS C or D when some motor abilities recover below the neurological level.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_15

ASIA C/ Motor Incomplete	**Sacral sensation** and **motor function is preserved** below the neurological level with **less than 50 %** of the key muscles below the neurological level having a **muscle grade of 3 or greater** (muscle grade 3 = active movement with full range of motion against gravity)
ASIA D/ Motor Incomplete	**Motor function** is preserved **below** the neurological level, and **more than 50 %** of the key muscles below the neurological level have muscle grades of 3 or more
ASIA E/ Normal	**Motor and sensory functions are normal**. Essentially a person can have an SCI and neurological problems that are not detectable on a neurological examination of this type. **Note**: AIS classification may not be sensitive to subtle weakness, spasticity, pain, and some forms of dysesthesia that could be a result of spinal cord injury, which would then be classified AIS E

The neurological level may change over time in some cases and does not always correspond to the site of initial vertebral injury. For example, a C4 bone injury may start with a C4 neurological level and then recover function at C5 and C6, resulting in a neurological level of C6. Approximately 45 % of individuals with AIS A injuries gain at least one neurologic level in the first year. Among people with AIS A injuries, only 3 % regain functional strength for ambulation. Prognosis is more favorable for AIS B, C and D classifications, with 50 % or greater chance of ambulation [1].

2. **Tetraplegia**
   - Replaces the term “quadriplegia” to denote four limbs are involved, maintaining consistency with Greek derivation (tetra = 4; para = 2).
   - Cervical segments of spinal cord are affected, with impairment or loss of motor and/or sensory function below this level.
   - Primary impairment of function in arms, trunk, legs, and pelvic organs.
   - Does not include brachial plexus lesions or injury to peripheral nerves outside neural canal.
3. **Paraplegia**
   - Thoracic, lumbar, or sacral segments of spinal cord, with impairment or loss of motor and/or sensory function below this area.
   - Arm function intact, trunk, legs, and pelvic organs may be affected.
   - Refers to cauda equina and conus medullaris injuries, but not to lumbosacral plexus lesions or injury to peripheral nerves outside the neural canal [2].
4. **Complete SCI vs. Incomplete SCI**
   - “Complete SCI” refers to an injury resulting in complete loss of function below the neurological point of injury. “Incomplete SCI” refers to an SCI in which partial sensation or movement is evident below the point of injury.
5. **Traumatic SCI vs. Nontraumatic SCI**
   - Traumatic SCI is the direct result of trauma to the spinal cord from sudden application of physical force or movement that injures the cord by stretching, bruising, or displacement. Nontraumatic SCI designates injuries that occur because of medical conditions such as ischemia, spinal stenosis, infection, congenital disease, or tumor.
   - Nontraumatic SCI represents a significant portion of patients in rehabilitation, and some studies suggest similar incidence and prevalence as traumatic SCI [3, 4].
   - Rehabilitation needs are the same for all etiologies of SCI [5].
   - Individuals with traumatic SCI often achieve greater overall functional improvement, possibly due to younger mean age at injury [6].
6. **Autonomic Dysreflexia (AD)**
   - “Dysreflexia” refers to the abrupt onset of excessively high blood pressure caused by overactivity of the autonomic nervous system, triggered by a noxious stimulus below the level of injury. Individuals with SCI at T-6 or higher are most at risk.

- AD can be potentially life-threatening if not treated promptly and thus constitutes a medical emergency. AD occurs as a result of disconnection between the sympathetic and parasympathetic branches of the autonomic nervous system (ANS). For example, an overfull bladder sends sensory impulses toward the brain but is blocked by the lesion at the level of injury. The impulses evoke a reflex that increases the activity of the ANS, resulting in spasms, narrowed blood vessels, and an increase in blood pressure.
- Symptoms of AD include pounding headache, sweating above the level of injury, cold clammy skin below level of SCI, goose bumps, flushed face, slowed pulse (<60 beats per minute), blotching of the skin, and nausea.
- AD is caused by anything that would have been painful, uncomfortable, or physically irritating before the injury. Common causes of AD include blocked urinary catheter, bowel problems (e.g., distention and impaction), skin irritation or injury (e.g., an object in shoe/chair, overly tight clothing, wounds, and broken bones), and sexual activity (e.g., overstimulation, menstrual cramps, and labor and delivery).
- Persons with SCI at risk for AD need to learn to recognize symptoms and how to implement interventions (e.g., keeping head elevated, loosening clothing, checking for urinary blockage, and monitoring blood pressure).

7. **Spasticity**
    - Spasticity refers to sustained, involuntary muscle contractions and heightened muscular reflexes that occur below the neurologic level of injury. The majority of persons with SCI experience some degree of spasticity, which can limit function, cause contractures, and contribute to pain. Spasticity management often entails a long-term daily program of stretching exercises to maintain range of motion and the use of muscle relaxants such of baclofen or tizanidine.
8. **Neurogenic Bowel and Neurogenic Bladder**
    - Involves loss of voluntary bowel and bladder control caused by disconnection of sacral segments from the brain. Teaching strategies for maintaining bowel and bladder continence represents a major focus for rehabilitation.
9. **Bladder Catheterization**
    - Managing neurogenic bladder usually necessitates some form of catheterization (i.e., using a tube to allow the bladder to drain). An indwelling catheter (“Foley”) remains in the bladder for continuous drainage, whereas intermittent catheterization (IC) entails inserting a catheter every 4–6 h. The use of IC is generally preferable because it is associated with a lower incidence of urinary tract infections, a common secondary complication of SCI. Suprapubic catheterization requires a surgery (cystostomy) to insert a catheter into the bladder through the abdominal wall. Advantages include prevention of damage to the urethal/sphincter tissue, maintenance of access for sexual activity, and reversibility.
10. **Bowel Program**
    - Includes techniques for enabling the bowel to empty in a regular fashion and to prevent stool incontinence. A bowel program involves the use of suppositories, enemas, laxatives, stool softeners, digital stimulation of the rectum to trigger colonic reflexes, or manual removal of stool. Regulation of diet, especially fiber intake, also plays a role. The combination of techniques that is effective varies from person to person.

11. **Pressure Injury**
    - People with SCI, especially AIS A injuries, have impairments in sensation and movement that interfere with spontaneous weight shifts while sitting or lying down. Prolonged pressure from stationary positioning causes compression and ischemia of soft tissue that can lead to deep tissue injury and open wounds over bony prominences, including the ischium, trochanter, and sacrum. Approximately 80 % of persons with SCI will develop a pressure injury at some point in the course of their disability, and 30 % will have more than one pressure injury [7].
    - Pressure injury risk factors include completeness of SCI, time since SCI, age, and nutritional status. Individuals with SCI need to develop new skills for skin care, such as turning in bed every two hours, and deliberately shifting weight while seated several times per hour.
    - Specialized wheelchair cushions and air mattresses are often prescribed for skin maintenance.
    - Behavioral factors such as psychiatric disorders, cognitive impairment, substance abuse, and smoking may increase risk for pressure injuries.
12. **Functional Independence Measure (FIM)**
    - **FIM** is a rating technique for describing a person's level of independence with respect to the motor and cognitive abilities required for basic activities of daily living, such as mobility, grooming, dressing, bathing, and toileting. FIM is based on a scale ranging from 7 (complete independence with no helper or assistive device needed) to 1 (helper or is needed for 100 % of task completion). FIM is the mostly widely utilized measure for tracking progress and measuring outcome of acute SCI rehabilitation.

Importance

- **Incidence and Prevalence**. SCI is a relatively infrequent but highly visible and costly disability, with an incidence rate of approximately 40 cases of traumatic SCI per million people annually, with a prevalence of approximately 270,000 persons in the United States. SCI mainly affects younger adults, with half of injuries occurring between the ages of 16 and 30; most (approximately 80 %) are male. African-Americans are overrepresented relative to the U.S. population as a whole, comprising around 23 % of injuries.
- The most common causes of traumatic SCI include moving vehicle crashes (36.5 %), falls (28.5 %), violence (14.3 %), and sports (9.2 %). Violent causes of SCI are much more common among ethnic minority groups. For example, violence accounts for about 44 % of injuries among African-Americans, compared to just 7 % for Caucasians [8]. Lifetime medical costs of having an SCI are high, ranging from 2.1 to 5.4 million dollars, depending on age at injury and injury level [9].

Practical Applications

A. ***Biopsychosocial Model***

Biopsychosocial models are helpful to understand the effects of physical impairments, psychological well-being, and social variables (e.g., community access, independent living, relationship role changes, and vocation) that are interrelated. Specialized knowledge about biological, psychological, and social aspects of SCI enhances rapport with persons served and helps optimize interventions for mental and physical outcomes. The goal is to formulate an individualized rehabilitation plan, collaborating with the person served in the context of the physical environment, social supports, and life values.

- Common social stereotypes promote the notion that people with SCI lead miserable lives, especially if they are completely paralyzed. However, a large body of research shows most that level of SCI has limited or no effect on a person's psychological well-being, anxiety, depression, or quality of life [10, 11]. Variations in pre-injury personality, coping styles, cognitive appraisals, and social supports appear to play a larger role in adaptation than the level/extent of SCI, *per se*.

1. **Biological Aspects**
   - **Early intervention** and mobilization is crucial for recovery. Initiating rehabilitation efforts as early as possibly, even during critical care, may lead to better outcomes.
   - **Determine the ASIA Impairment Scale classification** from initial chart review and the associated functional expectations for a given level of injury, based on clinical practice guidelines. Understanding the degree of physical independence that the person served can reasonably achieve helps to guide expectations for recovery and define behaviors to target in rehabilitation. For example, a person with paraplegia may be able to attain complete independence with self-care using the right compensatory strategies, whereas someone with tetraplegia may need to focus on learning to direct care provided by others. Persons with AIS D injuries may recover a great deal motor function over time, whereas this is less likely for AIS A injuries. In addition, medical comorbidities and age may modify expected outcomes.
   - **Evaluate pain**. Although prevalence estimates for pain vary from study to study, a high proportion of persons with SCI experience acute and/or chronic pain that may interfere with effective engagement in rehabilitation. Acute pain that is undertreated can set the stage for development of chronic disorders. Neuropathic pain at or below the neurologic level of injury is common, typically described as diffuse burning, tingling, or band-like sensations that are relatively constant and worse at night for some people. Musculoskeletal pain occurs frequently as well, as a result of acute traumatic injury or as a consequence of overuse of the upper extremities for transfers and wheelchair propulsion. A 10-point numeric rating scale is the most widely accepted metric, with 0 indicating "no pain" and 10 indicating "worst pain imaginable." Standard assessment explores current pain level, worst and best levels, acceptable or bearable level, aggravating/alleviating factors, and interference with life activities.
   - **Assess for co-occurring Traumatic Brain Injury** (**TBI**). Many people with traumatic SCI also sustain a TBI, particularly in high-speed moving vehicle crashes or falls. Incidence estimates vary anywhere from 16 to 59% [12]. A review of medical records may indicate severity parameters: any documented loss of consciousness, initial Glasgow Coma Scale performance, neuroradiologic findings, and duration of posttraumatic amnesia. However, this information may not be available, particularly in less severe injuries. Lifetime exposure to TBI can be gauged through structured interview techniques [13]. It is helpful to incorporate cognitive screening into early assessment and consider neuropsychological evaluation for individuals who present with impairment.
2. **Psychological Aspects**
   - **Evaluate Depression**. Most people (roughly 70%) do *not* become depressed following SCI, reflecting the widespread resilience of human beings under challenging circumstances. Nevertheless, depression is the most commonly reported psychological disorder following SCI.

The occurrence of severe depression is associated with longer hospitalizations, less functional independence after discharge, and potentially preventable secondary complications such as pressure injuries and urinary tract infections. In addition, persons with SCI have increased suicide risk. Recognizing and treating depression represents a major priority in the rehabilitation setting.

  - **Assessment**: Some common tools to assess depression are **Beck Depression Inventory** (**BDI-II**) and the **Patient Health Questionnaire-9** (**PHQ-9**). The latter instrument has been validated in the SCI population and is likely preferable. The PHQ-9 quantifies the core symptoms of major depression, with scores of 10 or above suggesting probable mood disorder. The **SIGECAPS** mnemonic (**low mood** plus changes in **S**leep, **I**nterests, **G**uilt, **E**nergy, **C**oncentration, **A**ppetite, **P**sychomotor changes, and **S**uicidal thoughts) can aid in making a thorough appraisal within an interview context. When examining depression in an SCI setting, it is important to consider shared qualities inherent in both conditions that may affect self-reported symptoms. (e.g., people with SCI may have problems sleep due to need to reposition in the night or pain, reduced energy related to medication, weight changes, and occasional down days).
  - **Intervention**: Recent research suggests that depression in SCI is vastly undertreated. For example, a large-scale study found that less than 12 % of persons with probable major depression received psychotherapy or an effective dose of antidepressant in the prior 90 days [14]. Traditional treatment strategies for depression appear effective in the context of SCI [15].

- **Screen for Substance Use Disorders**. Studies suggest a high rate of alcohol intoxication at time of injury for persons with SCI, ranging from 29 to 40 %, and intoxication with other substances is frequently seen as well. Contrary to stereotypes, having an SCI likely does not cause people to start using substances as an avoidance mechanism. Instead, substance use after injury usually involves gradually resuming preinjury patterns of use after active rehabilitation has ended. One large-scale study of people with SCI living in the community found that 14 % of participants described problematic alcohol use and 11 % endorsed use of illegal or nonprescribed drugs.
  - **Assessment**: Routine substance use screening is essential for the SCI population. Instruments, such as the Alcohol Use Disorders Identification Test-Condensed (AUDIT-C) or CAGE Questionnaire, offer a systematic means for identifying people at risk [16].
  - **Intervention**: Many people experience readiness to change when faced with a radically altered situation. Individuals with substance dependence may have gone through withdrawal in the intensive care unit prior to rehabilitation, with remission in a structured setting. Major treatment efforts for substance use disorders typically cannot occur during acute rehabilitation because of time constraints. However, brief interventions focused on motivational interviewing, education, and reducing barriers to treatment can be effective [17].

- **Explore Adaptation to disability**. Traditional "stage theories" of adjustment to disability have not been validated by clinical research. Although normal responses to disability may encompass shock, denial, depression, anger, anxiety, acknowledgement, and acceptance, coping appears to be nonlinear, and each person's experience is unique. Some disability theorists prefer the term "adaptation" over "adjustment," because adapting implies an ongoing process with inherent fluctuations rather than an idealized endpoint with successful achievement or failure [18]. Contemporary models of adaption emphasize personality factors and individual differences, environmental and social characteristics, and cognitive appraisals [19]. Current research has examined individual coping patterns over time, identifying trajectories of resilience, recovery, and distress. The majority of people with SCI present with a pattern of resilience or recovery [20]. Understanding attitudes toward disability is crucial because such beliefs are potentially modifiable.

  - **Assessment**: There is no simple method or questionnaire for evaluating adjustment to disability. Measures of cognitive appraisals, self-efficacy, self-esteem, and optimism have been correlated with well-being, but none are universally accepted as a standard of practice [21]. In the acute rehabilitation setting, willingness to engage in therapies and learn new strategies for self-care often becomes the proxy definition of adaptation; individuals who refuse or avoid treatment are usually referred for psychological services. Rehabilitation-oriented assessments typically combine traditional distress screening along with exploration of attitudes toward disability.
  - **Intervention**: Psychotherapeutic intervention usually focuses on processing emotions, modifying negative appraisals about SCI, enhancing social skills/assertiveness related to disability, practical problem-solving, and increasing disability-specific knowledge for both the person served and family members. It is extremely important for the team as whole to provide behavioral activation and to orchestrate experiences of mastery, enjoyment, and community integration such as recreational outings.

- **Address Quality of Life**. Most people living with SCI report having an acceptable quality of life (QOL). Level and severity of injury do not predict self-reported negative QOL. Correlates of increased life satisfaction and positive affect include higher education, employment, longer time since injury, better physical health/absence of secondary complications, social support, having a spouse/partner, transportation/community access, absence of chronic pain, and having a subjective sense of purpose or meaning [22].
  - **Assessment**: The **Satisfaction with Life Scale** (**SWLS**), a five-item, Likert scale instrument that measures perceived life satisfaction, is the measure employed by the SCI Model Systems and the Department of Veterans Affairs Spinal Cord Injury System of Care. **The Short Form** (**36**) **Health Survey** (**SF-36**), which evaluates quality of life/life satisfaction in eight different domains, is another widely used quality of life measure.
  - **Intervention**: With individuals who report a lower quality of life, it is helpful to explore their perceptions of what barriers exist using **open-ended questions** (i.e., "What would have to change for you to feel happier?"—"What's missing for you?," etc.). Interdisciplinary interventions should address medical problems, equipment needs, untreated depression, or other modifiable factors, tailored to the individual case.

- **Discuss Sexuality and Sexual Health**. Regardless of age and health status, people have a need to express their sexuality in some form, despite stereotypes that tend to portray persons with disabilities as asexual. SCI usually affects physiologic aspects of sexual response (erectile function for men and lubrication/vaginal contractions for women), creating an altered experience that necessitates experimentation to learn what is satisfying. Studies suggest that individuals with SCI potentially can have similar levels of sexual satisfaction as those without an injury.
  - **Assessment**: People often do not spontaneously inquire about sexual concerns due to embarrassment or social inhibitions, so it is essential for providers to

raise this topic in a nonjudgmental fashion as part of care. Direct questioning is essential, such as "Has anyone talked to you about sexuality since your injury?" or "After a spinal cord injury, most people have questions related to sexuality and sexual activity; can you tell me about your concerns?" It is common for individuals in the acute stage of SCI to focus on overall general physical recovery during rehabilitation.

- **Intervention**: Identify one or more individuals from the treatment team to consistently address sexual health needs. A widely accepted intervention approach is the **PLISSIT model**, which characterizes levels of intervention based on readiness and individual needs [23]. **P**ermission-giving refers to openly encouraging people to talk about and engage in sexual activity. **L**imited **I**nformation entails education about general aspects of sexuality following SCI. **S**pecific **S**uggestions offer prescriptions for positioning or other techniques based upon the person's unique situation. Finally, **I**ntensive **T**herapy may be required for people with preexisting sexual dysfunction or complex sexual histories. Referral to a specialist in sex therapy may be warranted.
- Biological interventions for erectile dysfunction include medications, vacuum pumps, and penile implants, needing medical evaluation and physician orders. Reproduction and fertility are highly possible but warrant specialized supports in many instances. For example, men with spinal cord injury can have reduced sperm quality and difficulty ejaculating, so methods such as electrical stimulation or vibration may be helpful. Women who become pregnant following SCI need prenatal and delivery care that takes injury characteristics like risk for pressure injuries or dysreflexia into account.

3. **Social Aspects**
   - **Involve families and significant others in the rehabilitation process**. Involvement of family and friends is a critical variable in recovery and community integration for person with SCI. Persons with SCI may develop new needs for instrumental and emotional support that families are in the best position to provide, so family members need specific education and support to facilitate the caregiving role. Stress associated with the catastrophic nature of SCI may activate unhealthy family dynamics and conflicts that can complicate rehabilitation. Psychological intervention is frequently helpful for understanding and reducing emotional barriers to family adjustment. Over the long term, caregivers may benefit from support services aimed at reducing burden and burnout.
   - **Attend to cultural and diversity issues**. Diversity variables—gender, ethnicity, cultural background, sexual orientation, language, and religious beliefs—can greatly affect individual experiences of rehabilitation. Health care systems tend to embody mainstream culture and authority, which may create fear, mistrust, and misunderstanding for diverse consumers. It is important for interventions to incorporate active efforts to learn about and respect cultural preferences and thereby reduce the risk of alienation from the rehabilitation team. At the same time, certain values may be gently questioned. For instance, in some religious belief systems, the occurrence of disability signifies a moral flaw or wrongdoing of the person, and it might be helpful for the team to carefully offer alternative perspectives.

- **Facilitate vocational interests and employment**. Research suggests that competitive employment is associated with better quality of life following SCI, yet the rate of unemployment is high in this population. Instilling the idea that people can and should work if they wish constitutes a priority in care. Supported employment has been shown to be an effective strategy for increasing successful job placement [24]. Educational pursuits represent another desirable means of social participation.
- **Provide instruction about disability rights**. Persons with SCI may experience social discrimination and marginalization because of their disability status. Ideally, the rehabilitation process enhances awareness of social barriers and encourages self-advocacy for civil rights. In the United States, the Americans with Disabilities Act (ADA) of 1990 prohibits discrimination with respect to employment, transportation, and public accessibility. The ADA is a productive focal point for education.

Tips

- ***Language matters***. Focus on the person first Avoid outmoded and value-laden language such as “wheelchair bound,” “confined to a wheelchair,” “unfortunate” individual who “suffered” an injury, and so on.
- ***Normalize stress and intense emotional reactions to disability***. In the ideal situation, the psychologist sees every person admitted for rehabilitation, integrating mental health into the overall plan of care and enabling psychological understanding for the team and persons served. Even when psychology is only consulted for problematic cases, it facilitates acceptance to introduce psychological services as a means of addressing quality of life concerns and stress management, rather than as a traditional treatment for mental disorders.
- ***Embrace openness to experience***. Some people perceive SCI as a gift while others view it as a fate worse than death (indeed, one individual might have both responses at different times). Cultivating flexibility in yourself may assist you in allowing others to approach tasks and goals in a different way.
- ***Consult with your team***. Gathering team perspectives on care helps build cohesion and enhances assessment.
- ***Be aware of boundaries***. It is critical to respect boundaries of confidentiality in the rehabilitation setting. Employ informed consent as well as circumspection in sharing sensitive information about the person served with family members and the team, in order to strike an ethical balance between collaborating with other professionals and minimizing intrusions on privacy. For example, if you meet separately with a family member to discuss family functioning or provide education, assume that the substance of your interactions will be disclosed and discussed with the person in rehabilitation.

Acknowledgment Special thanks to Charles Patten who edited and commented on this work.

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Multiple Sclerosis

16

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Topic

Multiple sclerosis (**MS**) is a chronic and progressive central nervous system disease characterized by immune-mediated demyelination and neuronal damage within the brain, spinal cord, and optic nerves. While the exact cause of MS is unknown, it is thought to result from a combination of one or more environmental triggers and genetic vulnerability [1]. MS is characterized by significant variability in the type and severity of symptoms, as well as the pattern and rate of progression.

Individuals with MS experience a constellation of symptoms and co-occurring conditions, including sensory problems, cognitive difficulties, weakness, spasticity, paresthesia, pain, visual disturbance, heat intolerance, fatigue, bowel/bladder dysfunction, and emotional changes. However, the specific symptoms and their severity differ widely among individuals:

A. ***Key Concepts***

1. **Diagnosis**

   Diagnosing MS is challenging: there is no one test that definitively diagnoses MS, and many of its symptoms are nonspecific and/or suggestive of other CNS disorders. Diagnosis of MS is often based upon the revised **McDonald criteria** [2] which specifies characteristics of the medical history, neurologic exam, and MRI that are indicative of MS. Occasionally, other tests, such as evoked potentials and spinal fluid analysis, are instrumental in differentiating MS from other conditions. Given that the individual symptoms experienced by a person with MS are not unique to MS specifically, diagnosis also involves ruling out other potential etiologies.

2. **Disease course**

   MS is conceptualized in terms of four types of disease course [1]:

   a. **Relapsing-remitting MS** (RRMS) is the most common course, affecting an estimated 85 % of people with MS at time of initial diagnosis. RRMS is characterized

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_16

   by distinct attacks or exacerbations of neurologic symptoms (relapses), followed by a return to prior function or partial recovery (remissions).
   b. The majority of individuals with RRMS eventually progress to **secondary progressive MS** (SPMS), at which point their disease may progress with or without relapses. The prevalence of this conversion is unknown given the recent advances in disease management, as described below.
   c. **Primary progressive MS** (PPMS) affects approximately 10 % of people with MS and is characterized by steady progression of neurologic symptoms from the onset of the disease.
   d. **Progressive-relapsing MS** (PRMS) is the least common disease course and involves a steady progression of disease from onset with episodic exacerbations (which may or may not result in some recovery).

Data on the natural history of MS suggest that at 15 years' postdiagnosis, approximately 50 % of people will require an assistive device to walk, and 20 % will require a wheelchair. However, current disease-modifying therapies are used in an effort to slow the onset of these symptoms.

3. **<u>Management of underlying disease</u>**
   a. Although there is no cure for MS, a number **of disease-modifying therapies** (**DMT**) are used to decrease disease activity and slow progression in individuals with relapsing forms of MS. To date, there are no approved DMTs for PPMS. Current medications come in three forms (oral, injectable, infusion,) and each comes with a profile of benefits and side effects. For the average patient with RRMS, early intervention with DMTs is associated with less disability over time relative to patients who do not take DMTs.
   b. To combat the inflammatory process that causes acute relapses and reduce their duration, patients are often prescribed 3–5 day infusions of high-dose corticosteroids. Alternatives, such as oral steroids and an injectable gel (ACTH) are also emerging as alternatives to infused corticosteroids.
4. **<u>Symptom management</u>**

   The remainder of medical treatment primarily focuses on managing symptoms and improving health-related quality of life via a range of interventions, including medications, behavioral interventions, and rehabilitation:
   a. **Medications** are available to alleviate the severity of many MS symptoms, such as pain, fatigue, and bladder/bowel dysfunction.
   b. **Cognitive and behavioral interventions** are recommended for the management of MS symptoms in an effort to maximize the individual's ability to engage in the activities that promote highest quality of life:
      i. Rehabilitation psychology is frequently consulted to address questions related to adjustment to disability, depression, anxiety, cognitive assessment, cognitive rehabilitation, health behavior change, relationship conflict, and sexual functioning.
      ii. Rehabilitation interventions, such as physical therapy, occupational therapy, and speech and language pathology, are prescribed when there are opportunities to improve or maintain physical or cognitive functioning.

B. ***<u>Terminology</u>***
1. **<u>Exacerbation or relapse</u>**
   - Episode of new symptoms or a worsening of existing symptoms.
   - To be considered an exacerbation, the symptoms must experience a minimum of 24 h and not occur within 30 days of a prior attack.
   - Severity of exacerbations can vary in terms of severity, symptoms experience, and length.
   - Individuals with MS also experience *pseudo-relapses*, which are temporary

worsening of symptoms due to physical and psychological stressors that resolve when the stressor is resolved. The variability in presentation of relapses, along with the presence of pseudo-relapses, makes the identification of relapses difficult.
   - Relapses are followed by recovery, but the individual may or may not return to his or her prior level of functioning.
2. **Lesion**
   - Hallmark characteristics of MS on MRI
   - Areas where the myelin has been damaged (*demyelination*)
   - May be present in the brain or spinal cord
   - Sometimes quantified in terms of *lesion load*, such that individuals with more lesions are said to have higher lesion load.
3. **EDSS**
   - The **Kurtzke Expanded Disability Status Scale** (**EDSS**) [5] is the most commonly used measure used to describe disability in individuals with MS.
   - It has two forms, a provider-administered form [3] and a self-report form [4] which is highly correlated with the provider-administered form.
   - The EDSS is scored on a 0 to 10 ordinal scale in 0.5 increments, with higher scores suggestive of greater disability.
   - Individuals with scores <5.0 are fully ambulatory.
   - Despite its frequent use, the EDSS has psychometric limitations; for a discussion of these, see http://www.nationalmssociety.org/For-Professionals/Researchers/Resources-for-Researchers/Clinical-Study-Measures/Functional-Systems-Scores-(FSS)-and-Expanded-Disab.
4. **Other**
   - For a list of additional terms commonly used in MS care, see http://www.nationalmssociety.org/Glossary.

Importance

- **Incidence and prevalence**: MS is the most common acquired neurologic disability found in young adults [5]. The estimated worldwide prevalence of MS is more than 2.3 million people, including more than 400,000 individuals in the USA [1]. MS is more prevalent among women (2–3 times more prevalent than in men), Caucasians, and individuals from northern latitudes [5].
- **Onset**, **duration**, **and lifespan**: The onset of MS is typically between the ages of 20 and 50 years [5], although it also occurs in children and older adults. As the lifespan of people with MS is only 5–10 years shorter than healthy adults [6], the typical person with MS faces many years of managing the disease and its effects.
- **Impact on functioning and quality of life**: Individuals living with MS often must make a number of lifestyle and behavioral changes to manage not only the effects of the disease but also its treatments (e.g., adapting to physical or cognitive impairments, adhering to disease-modifying therapies). As a chronic neurologic condition, many daily activities can be affected by MS, including physical functioning, activities of daily living, vocational functioning, role functioning, and leisure pursuits. The course, specific symptoms, and severity of disease progression vary considerably between and within individuals, making it an unpredictable chronic condition to manage. Health-related quality of life is significantly lower in patients with MS relative to healthy controls, the general population, and patients with other chronic diseases such as diabetes, hypertension, arthritis, and epilepsy [7].
- **Financial impact**: MS has been associated with substantial costs to individuals, their families, and society. As many as two-thirds of adults with MS are unable to maintain employment [8]. Uncertainty about the future, decreased independence, and financial hardship are common [9, 10]. Given that MS often occurs during child-rearing years, it may

affect parenting and performance of other family roles [11]. At a societal level, the economic costs attributed to MS in the USA have been estimated to be as high as $13 billion per year [9]; costs include both direct costs for medical care and indirect costs such as lost wages, lost productivity (including sick leave), and caregiving costs.

Practical Applications

A. ***Assessment and management of MS symptoms and associated concerns***

As with all medical conditions, the biopsychosocial model serves as a useful basis for the assessment and management of MS symptoms. Individuals with MS present with a constellation of symptoms that are primarily managed (versus eliminated). Treatment focuses not only on symptom severity but also symptom interference with functioning and quality of life. The following are common symptoms and associated concerns experienced by individuals with MS, along with recommendations for the assessment and management of those symptoms:

1. **Fatigue**

   As many as 90 % of people with MS experience persistent fatigue, and 40–60 % report it as their most incapacitating symptom [12]. In MS, fatigue involves a lack of physical and/or mental energy; fatigue negatively affect activities of daily living, participation in valued roles, and quality of life [12].

   - **Assessment**: The severity and impact can be obtained using a 0–10 numerical rating scales or by measures such as the Fatigue Severity Scale [13] and Modified Fatigue Impact Scale [14].
   - **Interventions**: Medications such as amantadine hydrochloride and modafinil are sometimes used for fatigue; evidence of their benefits is mixed. Rehabilitation approaches including energy conservation [15], heat management, and physical activity [16] have some evidence for decreasing fatigue and its negative impact in MS. Treatment of comorbid factors that may exacerbate fatigue, such as depression or insomnia, is also indicated.

2. **Pain**

   Approximately 50–65 % of adults with MS experience chronic pain [17–19]. Although pain can be widespread, it is most commonly found as affecting the legs, hands, and feet. Pain may be musculoskeletal, neuropathic, or both. In MS, chronic pain has been associated with poorer health-related quality of life, including greater interference with daily activities, vitality, emotional health, and social functioning [20]. Pain-related cognitions and coping behaviors and social variables have been strongly associated with pain intensity, physical functioning, and psychological functioning in MS samples [21]. (Individuals may experience acute pain, particularly during an exacerbation, but the more commonly experienced pain in MS is chronic.)

   - **Assessment**: Pain intensity is typically measured via 0–10 numeric rating scales. Pain interference can be measured simply with a similar 0–10 scale or via the interference scale of the Brief Pain Inventory [22]. Assessment of potentially modifiable behaviors impacting pain such as activity level, pain catastrophizing (unhelpful thoughts about pain), and coping skills is also recommended for treatment planning.
   - **Intervention**: Anticonvulsants such as gabapentin or pregabalin are commonly prescribed for neuropathic pain; nonsteroidal anti-inflammatory medications and antidepressants such as duloxetine may also be used. Behavioral interventions—including cognitive behavioral therapy, hypnosis, and mindfulness—are recommended to

decrease pain and its negative effects on functioning, mood, and quality of life [23].

3. **Cognition**

   Cognitive deficits are observed in 43–70 % of individuals with MS [24]. Cognitive problems are variable in presentation, severity, and impact. Most commonly, individuals with MS present with difficulties in attention, learning/acquisition of new information, speed of information processing, and executive functioning; however, there is some variability in presentation related to MS disease course [24]. Individuals can have cognitive impairment in the absence of or minimal physical disability. As with most symptoms of chronic disease, cognitive concerns are often noted when symptoms begin to interfere with functioning, often in the work, school, or home setting.

   - **Assessment**: Historically, the primary modality for assessment has been the comprehensive neuropsychological evaluation, which focuses on functioning across commonly effected cognitive domains (e.g., memory, processing speed, attention), as well as the intelligence, academic achievement, and personality domains. More recently, MS-focused researchers have focused efforts on shorter batteries, such as the Minimal Assessment for Cognitive Functioning in MS [25] that focuses specifically on processing speed, working memory, learning and memory, executive function, visual-spatial processing, and word retrieval.
   - **Interventions**. The most common interventions for areas of cognitive weakness focus on the identification and implementation of compensatory strategies to accommodate deficits in the context of the patient's life (e.g., memory notebooks, organization systems, reminder prompts). Recent preliminary evidence suggests certain skill training practices (teaching imagery and story context) may also improve deficits in memory [26]. Such "cognitive rehabilitation" interventions are most commonly provided by rehabilitation psychologists, neuropsychologists, or specially trained speech-language pathologists.

4. **Depression**

   The lifetime prevalence of concurrent depressive disorders and MS is 25–50 % and 2–3 times that of the general population and other chronic diseases [27]. Biologic (e.g., brain pathology, immunologic) and psychosocial (e.g., stressors) factors contribute to depression [28]. Major depression is associated with fatigue, poorer neuropsychological functioning, pain, lower quality of life, vocational disruption, social disruption, poorer health, and possibly greater disease progression [29]. Depression is too often underdiagnosed and undertreated in MS mood [30].

   - **Assessment**. Ideally, all patients with MS should be routinely screened for depression as part of their specialty or primary care. Screening measures validated for use in MS include the Patient Health Questionnaire-9 [31], Hospital Anxiety and Depression Scale, and the Beck Fast Screen for Medically Ill Patients. No one measure is clearly superior to the others, however [32].
   - **Interventions**. Multimodal treatment is typically recommended, particularly for moderate or severe depressive episodes [28]. Antidepressants are commonly used and presumed to be beneficial, although they lack evidence refuting or supporting their use in MS [33]. Research supports the use of cognitive behavioral therapy delivered in person or by phone in people with MS and depression [33].

Other behavioral interventions used for treating depression in other populations (e.g., behavioral activation, mindfulness-based interventions, acceptance, and commitment therapy) have not been studied in MS depression but merit consideration in treatment planning.

5. **Anxiety**

   Anxiety disorders are present in as high as 40 % of individuals with MS [34]. and may take many forms, including generalized anxiety disorder, health-related anxiety, or injection phobias. In MS, in particular, anxiety often centers around the uncertainty that is central to the condition, as the perceived uncontrollability often becomes a focus for worry. The implications of anxiety are significant, as anxiety has been associated with poorer medication adherence [35], higher pain intensity and interference [36, 37], lower quality of life [38], and suicidal intent [34].

   - **Assessment**. Measures such as the HADS-A and the GAD-7 are validated measures of anxiety symptoms in MS [39, 40]. More formal measures, such as the SCID or MINI, are available to provide diagnostic assistance. Clinical interviews are effective in identifying the cognitive, behavioral, and physiologic correlates of anxiety.
   - **Interventions**. There are a number of effective anxiety interventions that are well known to mental health professionals, but relatively little has been done to evaluate these interventions for anxiety experienced by individuals with MS. Commonly used interventions include cognitive behavioral therapy, exposure therapy, and acceptance and commitment therapy. In some cases, medication may also be helpful.

6. **Adherence to DMTs**

   Despite the importance of DMTs in slowing MS progression, nearly one-half of individuals who begin a course of DMT discontinue at some time, and overall past-month adherence has been estimated at roughly 75 % [41, 42]. Numerous medical and psychosocial factors, including side effects, depression, social support, perceptions of medication efficacy, and cognitive difficulties impact adherence over time [35, 43–45].

   - **Assessment**. Self-report of missed doses over a fixed time period retrospectively or with medication diaries, electronic pill container devices, or administrative reviews of pharmacy data.
   - **Intervention**. Motivational interviewing and care coordination promoting self-management have been shown to improve adherence over time [46, 47].

7. **Exercise/Activity**

   Levels of physical activity among individuals with MS are generally low [48]. However, mounting evidence suggests that physical activity has substantial benefits for individuals with MS, including improvements in physical health (e.g., strength, balance, endurance, and ambulation) [49, 50] and mental health (e.g., fatigue, depression, and quality of life) [51–53].

   - **Assessment**. Exercise testing (e.g., VO2 max), physical activity monitoring (e.g., accelerometer), global functional tests (6 min walk), and self-report (e.g., 7-day physical activity recall).
   - **Intervention**. Group-based exercise programs and individual counseling delivered in person [52], via telephone [51], or with web-based education support [54] have all demonstrated improvements in physical activity levels and corresponding physical and mental health outcomes.

8. **Alcohol use**

   Current rates of hazardous alcohol use among individuals with MS typically range from 14 to 18 % [55, 56].

Hazardous consumption may compound MS-related disability by impairing sleep, exacerbating fatigue and cognitive difficulties [57, 58], and contributing to depression, anxiety, and suicidal ideation [55, 59].

- **Assessment**. Assessment typically addresses use and use-related problems. The Alcohol Use Disorders Identification Test (AUDIT) is one of the many brief and well-validated options [60].
- **Intervention**. Individual brief advice, cognitive behavioral therapy, motivational interviewing and group-based cognitive behavioral treatment, and 12-step programs as well as pharmacologic interventions including acamprosate, naltrexone, and disulfiram under supervision have all been shown to reduce hazardous alcohol use [61]. Little is known about the efficacy of specific interventions among individuals with MS.

9. **Smoking**

Current rates of smoking among individuals with MS typically range from 18 to 36 % [62]. In addition to being the leading cause of preventable death among the US population in general [62], smoking also provides specific challenges for individuals with MS. Smoking is associated with a greater likelihood of developing MS [63]—possibly even by second-hand exposure [64]—disease progression [65, 66], increased CNS lesion activity, and in some studies increased disability over time [42, 66].

- **Assessment**. Current use. Readiness to quit. Past quit attempts. Dependence [60].
- **Intervention**. Brief advice during a medical appointment (5 or 10 min), motivational interviewing, nicotine replacement therapy, tobacco quit lines, and smoking cessation classes have all been shown to reduce smoking [67]. Little is known about the relative effectiveness of smoking cessation interventions among individuals with MS.

10. **Additional important symptoms and concerns**

- **Sleep disorders**, as well as **sleep interrupted due to disruptive symptoms**, are more common in MS than in the general population and warrant assessment and treatment.
- Common changes in physical functioning and sensation include **sensory changes** (e.g., numbness or tingling, heat sensitivity), **spasticity** (**e.g.**, **involuntary muscle contractions**, **stiffness**), **weakness** (**neurologic and deconditioning**), mobility impairment, and **falls**.
- A high percentage of patients experience **bowel** and/or **bladder dysfunction** (retention or incontinence), as well as **disrupted sexual functioning**, all of which may be underreported due to embarrassment, but all of which can be highly interfering with quality of life
- In a portion of patients, **visual changes**, including changes in visual perception, may occur
- As MS often presents during the prime years of **employment**, **childbearing**, and **family/relationship building**, it is common for patients to have concerns in one or more of these areas
- While onset of MS symptoms most commonly occurs in early to middle adulthood, an estimated 2–5 % of individuals with MS have an onset of symptoms prior to age 18. According to the National MS Society, most individuals with **pediatric MS** have relapsing-remitting disease course. Given the relatively low prevalence and difficulty distinguishing pediatric MS from other childhood medical conditions, research on pediatric MS is relatively sparse; more research is needed to understand prognosis and treatment for this subpopulation.

Tips

a. ***Focus on improved management of symptoms and reduced interference***. MS is largely a disease that requires effective management of multiple symptoms, as opposed to a focus on the elimination of symptoms.

b. ***Acknowledge the discomfort associated with uncertainty***. A hallmark symptom of MS is the constant presence of uncertainty regarding prognosis, progression of symptoms, and impact on quality of life. Patients can learn to cope effectively with the presence of uncertainty, but it is a source of discomfort for most patients.

c. ***Normalize fears of disability***. Patients often have fears of increased disability, including requiring a wheelchair for ambulation, given the progressive nature of MS. This is a real, understandable, and common fear of individuals with MS.

d. ***Utilize community resources***. A positive for individuals with MS is that there is a strong support network provided by national organizations, including the National MS Society (NMSS). They provide opportunities for community support, assistance with case management, and reliable educational resources about MS.

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17 Deaf and Hard of Hearing

Amy Szarkowski

Topic

Reduced hearing sensitivity cannot be perceived as a singular disorder. It does not result in a particular set of factors that impact functioning. Rather, the influence of reduced hearing sensitivity depends on its etiology, characteristics, timing, and the role that these all play in an individual's development. For example, a child with congenital profound deafness that limits access to spoken language will be largely shaped by the condition, with impact on educational, social, and familial functioning. An older adult with an age-related progressive hearing loss will not have been influenced by hearing status throughout development but may experience emotional, social, and familial effects associated with more limited ability to communicate.

In summary, physiological, developmental, and environmental factors are significantly shaped by a person's hearing status. Reduced hearing sensitivity alone may, but not necessarily, impact intellectual, neuropsychological, emotional, social, or behavioral functioning. Appropriate supports and accommodations that maximize access to language and communication can substantially mitigate the negative consequences that are sometimes associated with reduced hearing.

The role that hearing status plays for the patient, and understanding of that on the part of their health-care providers, will influence the interactions between them in significant ways. Knowledge of key concepts can help in the understanding of the nature of reduced hearing sensitivity, hearing loss, being deaf or hard of hearing, Deaf culture (defined below), and the role of hearing status:

A. ***Physiology***

Several physiological characteristics of hearing influence an individual's functioning and also inform specific types of needed interventions and accommodations. These include degree of hearing, site of hearing loss, time of onset, and benefit from assistive devices [1]:

1. **Degree of hearing loss**

Normal	0–20 dB
Mild	21–40 dB
Moderate	41–55 dB
Moderately severe	56–70 dB
Severe	71–90 dB
Profound	>90 dB

a. ***Mild to moderate range***. Most individuals who experience reduced hearing in the mild and moderate ranges are able to

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_17

access sufficient auditory information so that their hearing does not significantly impact their ability to develop linguistic competence or to perform academically. Yet, even a mild hearing loss can make it difficult for individuals to attend, to alert to their surroundings, and to appreciate what is happening around them. A mild to moderate hearing loss can influence one's communication abilities and impact social relationships.

   b. ***Severe and profound range***. Hearing status in the severe and profound ranges often limits access to spoken language and influences educational and communication options. Individuals with hearing in this range may communicate using a visual language (e.g., American Sign Language (ASL) as used in the USA and Canada or another formal signed language used elsewhere in the world). Alternatively, a person may have varying degrees of ability to use spoken language with the aid of hearing aids or cochlear implants.

2. **Cause of hearing loss**

Conductive hearing loss	Disruption of sound waves caused by a physical blockage, typically in the middle ear, that limits hearing. Most frequently, conductive hearing loss is temporary and can be caused by otitis media (ear infections), "fluid in the ears" as a result of a sinus infection, or excessive cerumen (earwax). In such cases, removal of the blockage can restore hearing. Anatomical anomalies can also result in conductive hearing loss, which may be more permanent
Sensorineural hearing loss	Structural alterations to the nerves in the inner ear, most commonly in the hair cells of the cochlea or the auditory nerve (i.e., VIII cranial nerve) resulting in reduced hearing. Sensorineural hearing loss is permanent and can be progressive (i.e., it can worsen over time). The majority of individuals who are considered deaf or hard of hearing have this type of hearing loss
Mixed hearing loss	Hearing loss that has both conductive (blockage) and sensorineural (nervous system) components is referred to as a mixed hearing loss
Auditory neuropathy/ auditory dyssynchrony	This type of hearing loss, often referred to as "AN," is a result of improper transmission of sound from the inner ear to the auditory nerve or to the brainstem. This type of hearing loss often results in inconsistent hearing abilities, with periods of normal or near-normal hearing and periods of significant loss, making access to sound highly unpredictable

3. **Time of onset**

   The timing of the onset of reduced hearing has significant implications for the individual's functioning and life experience. Typically, onset is characterized as *congenital*, *prelingual*, or *postlingual*, referring to whether the reduced hearing is present at birth, before a child has developed spoken language or after spoken language has been established. Congenital and prelingually acquired hearing loss may interfere with an individual's ability to develop spoken language abilities. Hearing loss that is acquired postlingually is less likely to have as significant of an impact of the development of spoken language skills. Once a child has developed a solid foundation in spoken language, experiencing a reduction in hearing abilities will not necessarily inhibit further development of speech and language.

4. **Benefit from assistive devices** [2]:

   a. ***Hearing aids***. Many individuals with mild and moderate levels of hearing are able to access auditory information with the use of hearing aids. Typically, these amplify sound, but do not necessarily clarify the sounds that are heard. For many people, hearing aids allow for some, but not perfect, understanding of what is happening in their environment and can reduce the social isolation that can accompany progressive hearing loss.

   b. ***Cochlear implants***. Individuals with more profound levels of reduced hearing may qualify for a cochlear implant. This is a device with electrodes that are inserted directly into the cochlea that sends an electrical impulse to the auditory nerve. In the USA, candidacy for cochlear implant surgery is largely determined by the Federal Drug Administration (FDA). New technologies, such as hybrid cochlear implants, which function as a cochlear implant in the frequency ranges in which a person has a profound hearing loss and function as a hearing aid in the ranges in which a person hears better, helping to preserve some "natural hearing," are now available.

c. ***Hearing assistive technologies (HAT)***. Many deaf and hard of hearing individuals benefit from additional supports to promote their auditory access. Personalized listening frequency modulation (FM) systems are like individualized radio stations that operate on special frequencies. For example, personal FM systems can be used to target a speaker's voice directly to the microphones of an individual's hearing aids. Small, wireless, personalized microphones are another example of technology for amplification. These look similar to a writing pen and can be used discretely to improve hearing in loud environments or over a distance (such as across a large room). In group settings, these "smart devices" can detect the direction from which speech is coming and enhance the listener's access to that sound, over the background noises in the room.

d. ***Visual technologies***. For individuals who cannot hear certain environmental sounds, visual supports can be employed to ensure they are aware of their surroundings. Doorbells can be connected to a lamp, for example, which will flicker when a guest has arrived; fire alarms can be linked with flashing lights, and alarm clocks can be attached to vibrating devices that can wake a person who is deaf or hard of hearing from a deep sleep.

B. ***<u>Terminology</u>***

The terms used to describe and understand individuals with reduced hearing vary depending on the context of the hearing status. Individuals with reduced hearing sensitivity are typically referred to as hard of hearing, deaf, or Deaf [3]:

1. **<u>Hearing loss</u>**

   The phrase "individuals with hearing loss" has been commonly used, yet increasingly this has changed to "individuals with reduced hearing" to reflect the understanding that not all individuals with limited auditory access have experienced a "loss" of hearing (e.g., when an infant is born with reduced hearing, she may not have ever had a full range of hearing).

2. **<u>Hard of hearing</u>**

   Typically, an individual who identifies as *hard of hearing* has some degree of reduced hearing yet can still access sound and spoken language. Audiologically, this term often refers to a person whose hearing loss is in the mild or moderate range.

3. **<u>deaf</u>**

   When the hearing status is further reduced, and a person's auditory input is minimal such that there is limited functional access to spoken language, the term *deaf* may be used. From an audiological perspective, the person may have reduced hearing sensitivity in the severe to profound or profound range.

4. **<u>Deaf</u>**

   When an individual has significantly reduced hearing sensitivity, he may identify as Deaf and belong to the Deaf community, a recognized linguistic and cultural group. For those who self-identify as members of the Deaf community, the use of a uniform signed language and the incorporation of Deaf cultural norms are common. For "capital D (Deaf)" individuals, reduced hearing sensitivity is not perceived as a loss but rather as Deaf gain, the recognition by members of the Deaf community that being Deaf has added numerous benefits to their lives.

5. **Hearing impairment**

   This a term that has historically been applied to individuals with reduced hearing. However, this term is not accepted by members of the Deaf community and is perceived as disrespectful.

Importance

A. ***Incidence*** **and** ***prevalence*****:**

1. **At birth**

   The incidence of children born with profound hearing loss is 1 in 1000 births; the number of children born with reduced hearing sensitivity of any degree is 3 in 1000 [4].

2. **Children 12 years of age and younger**

   Recurrent otitis media (ear infection) is the leading cause of mild hearing loss for children. One in eight children under the age of 12 experiences some degree of hearing loss [5].

3. **Adults over the age of 18**

   A study conducted in the USA revealed that, in adults over age 18, 15 % experience reduced hearing [6]. The prevalence of reduced hearing increases substantially in older members of the population.

4. **Adults 70 years plus**

   Nearly two-third of adults age 70 and older experience significant hearing loss that impacts their functioning, particularly in the social realm [5].

5. **Worldwide**

   Five percent of people, or 360 million individuals, experience a “disabling hearing loss” (defined by the WHO as hearing loss greater than 40 dB in the better ear for adults and greater than 30 dB loss for children) [7]. The majority of people who have disabling hearing loss live in low- and middle-income countries. Reduced access to primary healthcare, as well as follow-up specialty services, has a negative effect on the overall health of deaf and hard of hearing individuals, in resource-rich countries as well as those with fewer resources [8].

B. ***Etiologies of reduced hearing*****:**

1. **Hereditary conditions**

   Some etiologies of hearing loss are a result of genetics [9]. These can present as particular syndromes that include reduced hearing along with other physical conditions. Common syndromic conditions include Waardenburg syndrome, Usher syndrome, Pendred syndrome, and mitochondrial DNA mutations. With the exception of the mitochondrial mutations, many syndromes do not necessarily result in implications for cognitive, psychiatric, or neurological functioning. Non-syndromic etiologies of hearing loss, as the phrase implies, involve reduced hearing in the absence of other symptoms. A person with non-syndromic hearing loss is considered to be “just D/deaf.” Examples include otosclerosis (more common in older adults and results in conductive hearing loss) and the GJB2 gene mutation (also known as Connexin 26), the most common genetic cause of deafness, accounting for up to 50 % of all non-syndromic sensorineural hearing loss.

2. **Non-hereditary conditions**

   Nonhereditary causes of reduced hearing are numerous [9]. The most common congenital cause of nonhereditary deafness is cytomegalovirus (CMV). Additional congenital causes include in utero exposure to rubella, toxoplasmosis, syphilis, and herpes simplex virus. Hearing loss that occurs after birth can be caused by a multitude of factors including exposure to bacterial meningitis, measles, mumps, hypoxia, and ototoxic medications. Hearing loss in older adults often results from extended exposure to noise and presbycusis (age-related hearing loss). The differential impacts of the nonhereditary etiologies of hearing loss make it difficult to succinctly state the cognitive, psychiatric, and neurological impacts of each.

Practical Applications

A. ***Cultural vs. medical perspectives***

Working in rehabilitation, the aim of many professionals is to help patients to improve and "get better." From the medical perspective, it follows that restoration of hearing could, or even should, be the goal. Yet, this is in conflict with cultural perspectives on what it means to be a person who is Deaf. Practitioners are encouraged to consider the cultural competence that might be required in working with deaf and hard of hearing individuals, as they might with other minority groups [3]. Resources and information about how to create hospital-based [10] and psychotherapeutic services that support the cultural perspectives of being Deaf [11, 12] are available.

B. ***Health literacy***

Owing to reduced access to health-related information and barriers in accessing health-related services, deaf and hard of hearing individuals are at risk for marginalization in health-care systems [13]. Rehabilitation specialists should be cognizant of possible gaps in global health knowledge and check to ensure that information imparted to deaf and hard of hearing patients is understood. Professionals should also be aware that gaps in knowledge of health-related content is not suggestive of reduced cognitive ability; it is more likely attributable to reduced exposure to health content.

C. ***Psychological functioning and quality of life***

Outcomes and daily functioning for a patient who is deaf or hard of hearing are significantly influenced by attitudes toward hearing held by the patient and attitudes held by the important people in the patient's life. The role of communication with family members and significant others is likely to impact a deaf or hard of hearing person's social-emotional functioning, identity formation, and quality of life [14].

The type and degree of hearing loss, and the benefit from assistive listening devices, will influence the role that reduced hearing plays on social-emotional functioning at the individual level [15]. In broad terms, we will highlight particular challenges that frequently occur for individuals across four categories:

1. **Progressive hearing loss**

Progressive hearing loss requires frequent readaptation to changing levels of hearing. This can result in extended periods of grieving over lost abilities and fear of further loss. As a result, many people with progressively worsening hearing, primarily older adults who have age-related hearing loss, experience negative impacts on their social interactions and relationships with loved ones. They are at risk for feelings of social isolation, frustration, and depression.

2. **Hard of hearing**

Many persons who have moderate hearing levels feel that they are neither hearing nor Deaf. This experience of not fitting into either group can negatively impact identity formation as well as quality of life; indeed, studies of the latter show that hard of hearing individuals struggle more than individuals with typical hearing or those with much more significant hearing loss. Further, because a person who is hard of hearing can "sometimes hear things and sometimes not," the role that hearing plays in their social relationships can be confusing.

3. **Cochlear implants**

The goal for many parents of young children who receive cochlear implants is to be able to verbally communicate with their child. When parents and their children can use similar communication modes (e.g., the same spoken language or the same signed language), perceived family quality of life is improved [12, 14]. Some cochlear implant users adapt relatively well to the hearing world and view their "ear gear" similar to eyeglasses, i.e., with the appropriate supports, they are able to function without limitations. In fact, for cochlear implant users who have good auditory access and strong language-based skills, quality of life is comparable with those in the general population. Yet, individuals who benefit from cochlear implants vary widely in their ability to use and understand spoken language. Many cochlear implant users struggle to "fit in" and, similar to their hard of hearing counterparts, may feel that they are not entirely *hearing* and yet not truly *deaf* [14].

4. **Deaf sign language users**

Reduced social opportunities and lack of understanding of the experience of being Deaf by members of society can lead to Deaf individuals feeling marginalized, left out, or lonely [15]. This can increase the rates of depression and anxiety in this population. However, Deaf individuals who have adequate social networks, as are often fostered through the Deaf community, report quality of life comparable with individuals in the hearing population [14].

D. ***Cognitive and neuropsychological functioning***

Overall cognitive function in deaf and hard of hearing individuals is distributed similarly to that of hearing individuals, with some differences in specific areas [16]. There are many factors that influence measurement and development of cognitive and neuropsychological functioning including etiology, timing and degree of hearing loss, access to early language, and educational opportunities. Children with neurological risk factors beyond hearing loss tend to have greater difficulties, while children without additional risk factors perform similar to their hearing peers.

1. **Attention and executive functioning**

Studies of attention and executive function offer mixed and task-dependent results: children with hearing loss perform like their hearing peers on tests of planning, impulse control, and cognitive flexibility when tasks are appropriate and accessible for both groups [17]. Language ability seems to be significantly positively correlated with executive functioning in both hearing and deaf children; this may have important implications, particularly in understanding the executive functioning skills of deaf or hard of hearing individuals who have had reduced access to language [18].

2. **Visual processing**

While there are subtle differences in visual processing skills for deaf individuals who sign, these are not typically observable in neuropsychological evaluation [19]. Studies of perceptual abilities in deaf individuals have documented both a deficiency of skills, as well as supranormal visual processing abilities [20]. The field continues to struggle with understanding the role of cross-plasticity of the brain in the presence of reduced sensory input.

3. **Working and short-term memory**

Memory and working memory vary in deaf and hard of hearing individuals; deaf signers have been shown to have an advantage on visual working memory tasks [21] but a disadvantage for linguistic working memory tasks [22]. Some of the differences documented in working memory between deaf and hearing individuals can be attributed to the types of information presented (e.g., recall for numbers is more "automatic" in deaf signers than is recall for letters) [23]. Yet, there do seem to be some consistent differences in span for serial recall, even in conditions that are known to "maximize span" for deaf individuals [24].

4. **Academic achievement**

Among deaf and hard of hearing individuals, the ability to attain a high level of academic achievement is influenced in large part by the extent to which educational information is accessible and appropriate educational opportunities are provided. The belief that the use of a signed language will "stunt" a deaf person's ability to learn to read has been disproved [25], although, unfortunately, this false belief continues to be held by many professionals in Deaf education.

5. **Motor functioning**

   Depending on the etiology of reduced hearing, motor functioning in deaf and hard of hearing individuals can be, although it is not necessarily, negatively impacted in individuals who are deaf or hard of hearing [26]. Although "motor deficits" cannot be generalized in this population, given the vital role of the inner ear structures in aiding with balance, it is perhaps not surprising that balance is reduced in many deaf and hard of hearing people. Interestingly, cochlear implants may enhance balance by granting greater access to auditory information that is used by the brain to foster balance; alternatively, the cochlear implantation surgery may cause trauma to the vestibular system, thereby increasing balance issues. At present, the jury is still out regarding the longitudinal impact that cochlear implants will have on balance and motor functioning.

E. ***Communication***

Communication and access to information is a primary concern for individuals with all degrees of hearing loss. Many children with mild hearing loss or unilateral hearing loss readily gain spoken language skills, althoughit is still possible that their language levels may be below their hearing peers. Functional imaging studies show that brain organization for language is differently distributed for deaf individuals who sign [27] and that deaf children exposed to early sign language can develop strong language skills. The availability of cochlear implants has increased the potential for developing spoken language in profoundly deaf children, though language outcomes even after early implantation are variable; many children who received implantation early show age-appropriate language skills, although a much smaller group of children show little development of spoken language despite access to sound [28]. Explaining the remaining variability in outcomes is an important area of current research.

Tips

- **Inquire about the individual's perspective on his hearing loss**. For any given patient, reduced hearing may be "detrimental" or "no big deal." Some young people may exhibit pride at being members of the Deaf community, while others may have never met another deaf or hard of hearing person and may feel painfully isolated. Older adults may see age-related progressive hearing loss as a natural aspect of aging that must be accepted, while others may resent the impact that changes in hearing status have had on their relationships. Knowing what being Deaf or hard of hearing means to a particular patient will allow health-care providers to best meet that individual's needs.
- **Know that reduced hearing has differential impacts**. Depending on etiology, some individuals are "just deaf," whereas others experience reduced hearing combined with additional physical limitations, reduced cognitive abilities, or psychiatric syndromes. Deaf individuals may have had exposure to Deaf culture, full of rich opportunities to communicate and interact with others similar to themselves, or they may have experienced painful loneliness and been cut off from interactions with others, or been perceived as being "less than smart," because of communication challenges. You cannot know the impact that reduced hearing has had on a particular patient without exploring some of these issues.
- **Recognize that for Deaf persons, spoken/written language may not be their primary language**. Many people assume that, if a patient is unable to talk, written exchanges are a valid substitute. For some this is true. Yet, for many, written language is a second language. Written exchanges of information with a patient who is deaf or hard of hearing will not be sufficient in many cases.

- **Ensure access to communication and information**. Interpreters should be secured if communicating with a patient who uses a signed language. In the USA, the Americans with Disabilities Act (ADA) necessitates that healthcare providers utilize interpreter services in order to promote communication with patients [29]. All patients, regardless of hearing status, should be granted access to information that is pertinent to their health. Involving family members as interpreters is not adequate and is discouraged. Using interpreters in psychological testing is also not advised.

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Spine, Back, and Musculoskeletal

18

Ellen H. Zhan

Topic

Musculoskeletal pain can be caused by disorders of bones, joints, muscles, tendons, ligaments, bursa, or in combination. The human spine is formed by 30 vertebrae including: 7 cervical, 12 thoracic, 5 lumbar, 5 sacrum (fused together), and 1 coccygeal vertebrae along with intervertebral discs. The spine protects the spinal cord, which issues 31 pairs of spinal nerves that innervate trunk and all extremities. The brain and spinal cord comprise the "central nervous system" and both innervate the whole body.

The cervical and lumber spines are quite mobile with less support compared to thoracic and sacrococygeal spine. Therefore, the cervical and lumbar spine are particularly predisposed to injury and degenerative changes (e.g., arthritis, mal-alignment, and dislocation). This chapter will then review some common neck and back anatomy and some problems that frequently present for medical rehabilitation.

A. ***Neck Issues: Introduction, Prevalence, and Causes***

Cervical spinal problems have been described by Egyptian physicians in ancient times, more than 5000 years ago [1]. The neck is the most mobile portion in the whole spine and is only supported by ligaments and neck muscles.

1. **Anatomy**

   The cervical spine comprises seven vertebrae and intervertebral discs. The joint between the occiput and the first cervical vertebra (the atlantooccipital joint) allows for approximately one-third of flexion and extension and one-half of lateral bending of the neck. The C1-C2 cervical vertebrae (the atlantoaxial joint) allows for 40–50 % of rotational range of motion. The C3-C7 joints allow for approximately two-thirds of flexion and extension, 50 % of rotation and lateral bending but the more lateral bending occurs at C3-C4 and C4-C5; the greatest amount of flexion is at C4-C5 and C5-C6 [1]. The normal cervical spine has a shallow lordosis, maintained by the neck muscles and this lordosis can be decreased in patients with degenerative changes.

2. **Range of Motion (ROM)**

   The cervical spine can rotate about 90°, laterally bend at 45°; forward flex to 60° and extend backward 75°.

3. **Eight Cervical Spine Nerves**

   Each spinal nerve arises from the spinal cord by two roots, the ventral and dorsal spinal roots. The ventral root carries

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_18

motor fibers and the dorsal root carries primary sensory fibers, both of the spinal roots combine to form the spinal nerve.

4. **Prevalence of Neck Pain**

   With or without upper limb pain occurs from 9 to 18 % in the general population. One out of three individuals report at least one incidence of neck pain in their lifetime [1].

5. **Causes**
   - The etiologies of neck pain can be varied and could be due to systemic or local causes as listed partially as below:
   - Some systemic diseases, such as rheumatoid arthritis, spondyloarthritis, polymyalgia rheumatica, or bone metastases.
   - Some focal problems can include cervical strain, sprain, internal disc disruption (discogenic pain), or cervical spinal degenerative change, cervical "whiplash" syndrome, and myofascial pain.
   - Cervical degenerative changes are the most common cause of acute and chronic neck pain.
   - The main cause extremity symptoms and neurological dysfunction include cervical radiculopathy and cervical spondylotic myelopathy.
   - The most severe injuries and greatest wear and tear occur between C4 and C7 [2]. The foraminal narrowing is a common cause of cervical radiculopathy [3].

B. *Neck Injuries and Conditions*

1. **Cervical Sprain and Strain**

   A sprain is an overstretching or tearing of ligaments and/or tendons with microscopic contusion or hemorrhage or both.

   A strain may result from an injury to the neck muscle and ligaments with associated spasm of the cervical and upper back muscles. The cervical strain can also be caused by accumulated physical stresses of everyday life, including poor posture and poor sleeping habits.

   The typical symptoms are experienced as pain, stiffness, and tightness in the upper back or shoulder, and can last for up to 4–6 weeks.

2. **Cervical Whiplash Syndrome**

   The diagnosis of cervical strain is based on the patient's history of having a traumatic incident with the acute onset of pain on neck and upper back muscles without abnormal neurological dysfunction.
   - Caused by a traumatic event with an abrupt flexion/extension movement to the cervical spine.
   - Whiplash injury is a typical example of cervical sprain and strain.
   - Symptoms of whiplash include severe neck pain, spasm, range of motion loss in the neck, and occipital headache.
   - Pain can be persistent with little identifiable abnormality seen on MRI, CT, X-ray, or bone scan imaging.
   - Often multiple structures can be injured including soft tissues, spinal nerve, intervertebral disc, posterior longitudinal ligament, interspinous ligaments, facet joints, or other osseous structures.
   - After the traumatic incidence, 60 % of the patients can get better within the 1st year, 32 % on 2nd year, 8 % have permanent problems [4–6].
   - Eight risk factors are identified: female, young age, prior history of neck pain, rear collision, stationary vehicle, severity of collision, not being at fault, and monotonous work [7].

3. **Cervical Spondylosis**
   - Caused by degenerative changes and/or inflammation in the intervertebral disc and vertebral body.
   - Degenerative changes in the cervical spine are apparent on radiographs of many adults over the age of 30 but the degree of radiographic change is poorly correlated with the presence or severity of pain [8].
   - The degenerative process that occurs in the intervertebral disc is thought associated with an inability to effectively distribute pressures between the disc, vertebral endplates, and facet joints.

- Usually axial pain is more severe than extremity pain in cervical discogenic pain. Symptoms are often exacerbated when the neck is held in one position for prolonged periods, such as occurs with driving, reading, or working at a computer.
- Factors that contribute to degenerative changes of the spine: aging, trauma, work-related activities and genetics.
- Usually causes osteoarthritis in the zygapophyseal (facet) and unconvertebral joints.
- Caused osteophytes formation along the vertebral bodies, facet joints, and laminal arches, resulted in foraminal stenosis and central spinal canal stenosis.

4. **Cervical Radiculopathy**
    - Cervical radiculopathy refers to dysfunction of the spinal nerve root that may manifest with pain, weakness, reflex changes, or sensory changes.
    - Multiple conditions can cause cervical radiculopathy, including cervical foraminal stenosis, cervical herniated disc, herpes zoster, lyme radiculopathy, diabetic polyradiculopathy but degenerative changes in the spine are overwhelmingly more common than the other causes, accounting for 70–90 % of cases.
    - Spurling's maneuver can reproduce the patient's radicular pain, which is a sudden electric shock like paresthesia extending down from neck to the ipsilateral arm with flexed neck, this illustrates a positive Lhermitte's sign.
5. **Cervical Spondylotic Myelopathy**
    - Defined by degenerative changes narrowing the spinal canal, resulting in cervical spinal cord injury or dysfunction.
    - Consider when patient presents neck pain with following neurological complaints: tingling, numbness, weakness, coordination impairment, gait disturbance, bowel or bladder retention or incontinence, and sexual dysfunction.
6. **Cervical Facet Syndrome**
    - The zygapophyseal joint is commonly called the facet joint and can cause axial pain.
    - The most common cause of whiplash-related neck pain and headaches.
    - Patients often have a history of trauma with an abrupt flexion–extension type injury, or an occupation which leads to repeatedly positioning the neck in extension.
    - There is no specific examination, or imaging finding, that provides confirmatory diagnosis.
    - A fluoroscopically guided intra-articular injection with anesthetic drug into the innervation of the joint resulting in relief is considered the definitive diagnostic tests.
7. **Cervical Myofascial Pain**
    - Regional pain with associated trigger points, taut bands, and pressure sensitivity.
    - Myofascial pain can be a nonspecific manifestation of any pathologic condition that causes pain from the neck to the shoulder and can also be associated with muscle sensitivity, depression, anxiety, insomnia, and likely represents a less generalized variant of fibromyalgia.
    - Chronic muscle overuse or direct trauma may play a role in the development of myofascial pain and trigger points [9].

C. ***Low Back***

1. **Anatomy**

The spine of the "low back" comprises five lumbar vertebrae and intervertebral disc, which consists of internal nucleus pulposus (gelatin-like material) and the outer of annulus fibrosis, as well as supporting muscles, ligaments, and joints. It permits lumbar spine flexion, extension, lateral bending, and twisting. About 90 % of spinal flexion and extension occurs at the L4-L5 and L5-S1 level, which explains the high incidence of disc problem at these levels.

2. **Range of Motion (ROM)**
   - Flexion: 40–60°
   - Extension: 20–35°
   - Lateral Flexion: 15–20°
   - Rotation: 3–18°
3. **Prevalence of Low Back Pain (LBP)**

   Studies have shown a lifetime prevalence up to 84 % [10], most of the patients have short attacks of mild to moderate pain and usually the pain is self-limited and does not limit daily activities. Most episodes of LBP can be resolved within 1–3 weeks but can recur over the years. "Chronic" LBP occurs in 10 % patients and 1 % of patients become permanently disabled by LBP [1].
4. **Causes of LBP can be Varied**
   - Mostly caused by disc degeneration or arthritis.
   - Back pain associated with leg pain, numbness, or weakness can be due to a herniated disc or spinal stenosis.
   - Some back pain are due to muscle strain or spasm or ligament sprain.
   - Some are caused by serious spinal condition, such as infection, fracture inflammation, tumor, or specific disorder called cauda equina syndrome which causes weakness and bowel or bladder dysfunction as well as back pain.
   - Less than 5 % will have serious systemic pathology.

D. ***Common Low Back Problems***

Some terms are used to describe conditions related to the low back, based upon radiological findings (spondylosis, spondylolisthesis, spondylolysis) and physical findings (kyphosis, scoliosis), and clinical or neurologic features (neurogenic claudication, radiculopathy, sciatica, cauda equina syndrome).

1. **Degenerative Disc Disease**

   Wear and tear condition along with our aging. The disc can be broken down, with small cracks or tears or loss of fluid in the discs. This can lead to formation of bone spurs. Many people have degenerative disc disease seen on X-rays or other imaging studies but have no pain or other symptoms.
2. **Facet Joint Arthropathy**

   Arthritis in the joints connecting the vertebrae to one another (facet joints). This can cause bone spurs around the joint and may cause low back pain. Very common with aging and may experience no symptoms.
3. **Herniated Disc**

   Described as disc material (nucleus pulposus) that is "squeezed" beyond the intervertebral disc space. Based on displaced disc material, it can be classified as a *bulge* (no annulus defect, disc convexity is beyond vertebral margins), a *protrusion* (nuclear material protrudes into an annulus defect), an *extrusion* (nuclear material extends to posterior longitudinal ligament), and *sequestration* (nuclear fragment free in the canal), identified in a range from mild to severe.

   Over 95 % of **lumbar disc herniation** occurs at L4-L5 and L5-S1. Most common occurrence is within 30–40 years of age.

   Herniated discs are frequently seen MRI, even in people with no low back pain.However, herniated discs can cause back pain with radiated to leg or weakness if the disc presses on a nerve root.

   Herniated discs usually heal over time, ¾ of these injuries will resolve with conservative treatment in 6–12 months.
4. **Spondylolisthesis**

   Describes an anterior slippage of the upper vertebral body on the lower vertebral body, most commonly occurred at L4 on L5 and L5 on S1.
5. **Spondylolysis**

   A stress fracture and defect on the pars interarticularis, mainly occurred at L5. Common cause of back pain in children and adolescents.

6. **Lumbar Spinal Stenosis**
   - Described the narrowing of the spinal canal, usually <10 mm in diameter.
   - Symptoms include back and leg pain, transient tingling in the legs, and ambulation-induced pain localized to the calf and distal lower extremity.
   - Some caused neurogenic claudication; however, some people may have no symptoms.
   - Symptoms will be resolved with rest and spine flexion.
7. **Scoliosis**

   A lateral curvature of the spine in which the spine curves to varying degrees in "S" shape.
8. **Sacroiliac Joint Dysfunction**

   A term to describe pain in the region of the sacroiliac joint due to malalignment or abnormal joint movement. The sacroiliac joint may be a referred site of pain, including from a degenerative disc at L5-S1, spinal stenosis, or osteoarthritis of the hip.
9. **Sciatica**

   Evidence of nerve root irritation typically manifests as sciatica, a sharp or burning pain radiating down the posterior or lateral aspect of the leg, usually to the foot or ankle. Pain radiating below the knee is more likely to represent true radiculopathy than proximal leg pain [11]. Sciatic nerve pain is often associated with numbness or tingling and can be due to disc herniation in which the pain increases with coughing, sneezing, or performance of Valsalva maneuver.
10. **Lumbosacral Radiculopathy**

    The clinical presentations of lumbosacral radiculopathy vary according the level of nerve root or roots involved. The most frequent are the L5 and S1 radiculopathies. Patients usually present with pain, sensory loss, weakness, and reflex changes consistent with the nerve root involved.
11. **Cauda Equine**

    A **medical emergency** that can present with bowel or bladder dysfunction, including urinary retention, saddle anesthesia, bilateral sciatica, and leg weakness. The cauda equina syndrome is most commonly caused by tumor or a massive midline disc herniation.

Importance

A. ***Neck Issues***

The neck is the most mobile portion in whole spine and is only supported by ligaments and neck muscles. Although the most common cause of acute and chronic neck pain is due to cervical spine degenerative change, some neck pain may indicate more serious pathology warranting additional diagnostic and therapeutic steps.

B. ***Low Back Issue***

Low back issues are one of leading musculoskeletal complaints (second) that contributes to impairment and disability. A costly burden to society with total costs in the USA exceeding $100 billion per year [12]. Up to 84 % of adults have LBP at some time in their lives [13, 14]. For many patients, the episodes of LBP is self-limited and resolved without specific treatment but for other patients, back pain is chronic and recurrent issue, the pain can persist with a negative impact on quality of life and/or with employment.

The potential risk factors for the onset of back pain include smoking, obesity, older age, female gender, physically strenuous work, sedentary work, emotionally demanding work, low educational attainment, Workers' Compensation insurance, job dissatisfaction, and psychological factors such as somatization disorder, anxiety, and depression [15–17].

Practical Applications

A. ***Differential Diagnosis***

1. **Neck Pain**

   Broad. Although the majority of neck pain complaints are related to musculoskeletal causes, numerous other conditions can present with a constellation of symptoms that include neck pain. While the differential these diseases should be kept in mind in evaluating the patient with neck pain, diagnosis of these conditions is usually evident from accompanying symptoms (i.e., fever, neck stiffness, diffuse joint pain). A negative neurological examination indicates a low likelihood of root compression.

The following are some of the "**red flags**" that need to be watched closely:

- Neck pain associated with headache, shoulder or hip girdle pain, or visual symptoms in an older person may suggest rheumatologic disease (e.g., such as polymyalgia rheumatica or giant cell arteritis).
- Neck pain with a history of fever, chills, intravenous drug use should raise suspicion for infection.
- Neck pain with unexplained weight loss, immunosuppression should raise suspicious for tumor or cancer.
- Neck pain with neurological signs or symptoms (arm clumsiness, gait difficulty, bowel or bladder dysfunction, Babinski's sign) may suggest cervical myelopathy.
- A shock-like paresthesia occurring with neck flexion (Lhermitte's phenomenon) suggests compression of the cervical cord by a midline disc herniation or spondylosis but may also be a sign of intramedullary pathology such as a multiple sclerosis.
- Patients with a recent history of a major fall or trauma should be immobilized, stabilized, and transported by ambulance to an emergency department.
- The differential diagnosis for cervical spondylotic myelopathy includes multiple sclerosis, syringomyelia, tumor, epidural abscess, and amyotrophic lateral sclerosis.
- Distinguishing cervical spondylotic myelopathy from other causes of neck pain is critical because optimal neurological recovery depends on early surgical decompression.

2. **Low Back Pain (LBP)**

   Most of LBP is caused by disc degeneration, however, the importance of imaging findings associated with disc degeneration (i.e., osteophytes, disc narrowing, and herniation) remains unclear. Muscular and ligamentous sources of pain can be equally important. Although the differential diagnosis of LBP is broad, the vast majority of patients seen in primary care will have nonspecific LBP, meaning that there is no neoplastic, infectious, or primarily inflammatory cause. Less than 5 % will have serious systemic pathology. Generally speaking, imaging studies in the first 4–6 weeks are not recommended unless there are neurologic deficit findings or high suspicion of systemic etiology.

   Patients with back pain and psychological distress may display anatomically "inappropriate" signs of pain amplification, it is referred to as **Waddell signs** or called nonorganic signs of LBP:

   1. Tenderness-superficial, nonanatomic
   2. Simulation-axial loading, rotation
   3. Distraction-straight leg raising
   4. Regional-weakness, sensory
   5. Overreaction

   The presence of *three or more Waddell's signs* may suggest a behavioral component to a patient's pain and may require detailed psychological evaluation.

B. ***Assessment***

Note: ***In addition to detailed history and careful physical examinations***. The choice of test varies with the clinical features of the patient:

1. **Neck Pain**
   - **Plain radiographs** are usually considered as the 1st step of work-up for non-traumatic chronic neck pain
   - May consider **MRI** or **CT scan**, **electromyography/nerve conduction studies** (**EMG/NCS**) and **blood tests** if the patient has some red flags and/or

indications. For example, to rule out bony fracture or spinal cord injury or cervical myelopathy or disc herniation or osteomyelitis, epidural abscess or root compression or the like.

2. **Low Back Pain**
   - **Clinical Evaluation**: the physical examination should include observation of walking, changing positions, and spinal motion; peripheral pulses (in older patients with leg symptoms); a focused neurologic examination based on history, with testing of L5 and S1 nerve roots in patients with leg symptoms; and an appropriate detailed examination related to any red flags found in the history.
   - **The Straight Leg Raise Test** may be useful to help confirm radiculopathy. Straight leg raising is conducted with the patient in supine position. The examiner raises the patient's extended leg with the ankle dorsiflexed. The test is considered positive when the sciatica is reproduced between 10 and 60° of elevation. For patients suspected of having a disc herniation, neurologic testing should focus on the L4-5 and L5-S1 nerve roots, since 98 % of clinically important disc herniations occur at L4-5 and L5-S1 [18].
   - Consider a **plain lumbosacral X-ray** if the LBP is not improved after 4–6 weeks conservative treatment.
   - **CT or MRI** is indicated for progressive neurologic deficits, high suspicion of cancer or infection, or after 12 weeks of persistent low back pain. However, bulging discs are seen in more than 50 % of asymptomatic patients.
   - **Serology**: **blood test that can include CBC**, **ESR**, **CRP**.

C. ***Interventions***

- **Relative** rest is recommended. However, strict bed rest is ***not recommended***.
- **Spinal Stabilization**
  - **Cervical spine**: provide soft or hard cervical or cervical thoracic orthoses to support cervical spine based on patient's medical condition
  - **Lumbar spine**: provide thoracic lumbar or thoracic lumbosacral brace or lumbar corset to support lumbar spine-rehabilitation: patient education, ROM, stretching, and strengthening program with focus on specific weak muscles.
- **Pain Control**
  - **Medication**: Tylenol, NSAIDs, analgesics, TCA, muscle relaxant, etc.
  - **Other**: Epidural steroid injection under fluoroscopically guided procedure
  - **Modalities**: thermotherapy (heat, cold), electric stimulation (e.g., TENS unit)
- **Rehabilitation**

  Patient education, ROM, stretching, strengthening program with focus on specific weak muscles. Home exercise program to promote independence, to intensity rehabilitation efforts, and/or to continue intervention after formal treatment discharge.
- **Surgical Intervention**

  Consider surgical referral for patients with progressive or severe neurologic deficits, persistent sciatica, sensory deficits, weakness, unremitting pain, or reflex loss after 4–6 weeks
- **Urgent Referral** is indicated if patients are suspected to have cauda equina syndrome or spinal cord compression or progressive neurologic deficits such as persistent sciatica, sensory deficits, or reflex loss.

D. ***Prognosis***

1. **Neck Issues**

   The majority of the patients with neck pain improve quickly, only a few with neck pain lose time from work and less than 1 % develops neurologic deficits.

   Pure sensory radiculopathy often results with a good prognosis for patients and respond to a combination of rest, exercise, and occasionally medication or corticosteroid injection.

   In contrast, patients with **sensorimotor involvement** have a less predictable prognosis than patients with only sensory or only motor impairment.

2. **Low Back Pain**

   The long-term outcome of low back pain is generally favorable. Patients who themselves have high expectations for recovery have better outcomes. One longitudinal study of 973 primary care patients with recent onset low back pain found that 83 % had mild or no pain and 86 % had minimal or no disability at one-year follow-up; however, only 72 % had completely recovered [19].

   Psychosocial variables are stronger predictors of long-term disability than anatomic findings found on imaging studies. In a systematic review of 20 prospective studies in patients presenting with acute low back pain, predictors of disabling chronic low back pain at 1 year follow-up included maladaptive pain coping behaviors, functional impairment, poor general health status, presence of psychiatric comorbidities, or nonorganic signs [20].

Tips

Although most causes of neck pain and LBP are due to degenerative changes (wear and tear) and can respond well to conservative treatments, the “red flags” must always be considered and may indicate surgical referral.

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Amputation

Aaron P. Turner, Rhonda M. Williams, and Dawn M. Ehde

Topic

Amputation (or limb loss) is the removal of a limb or portion of a limb. It can be the result of many causes including chronic disease (predominantly diabetes mellitus and peripheral vascular disease), infection, trauma, malignancy, or the surgical correction of congenital limb deficiency. Over 90 % of amputations affect lower limbs and over 75 % are secondary to chronic illness such as diabetes and vascular disease.

A. ***Terminology***
- **Amputation level**: amputations are commonly referred to by the level at which the amputation occurred. They include:
  - *Transfemoral amputation*: above knee amputation (often abbreviated as "AKA").
  - *Transtibial amputation*: amputation that occurs below the knee (often abbreviated as "BKA").
  - *Transhumoral amputation*: amputation that occurs above the elbow amputation (often abbreviated "AE").
  - *Transradial amputation*: amputation that occurs below the elbow (often abbreviated "BE").
  - *Disarticulation*: *the surgical separation of two bones at their joint. Examples include hip disarticulation and shoulder disarticulation.*
  - *Syme amputation*: *disarticulation of the foot at the ankle.*
  - *Major* (*proximal*) *amputation*: *through and proximal to the foot and*/*or hand.*
  - *Minor* (*distal*) *amputation*: *amputation of finger and*/*or toe.*
  - *Forequarter amputation*: *amputation of the arm*, *shoulder*, *scapula.*
- **Residual limb**: the portion of the limb that remains after an amputation; it is sometimes referred to as the "stump."
- **Contralateral limb**: the limb opposite of the amputated limb.
- **Phantom limb pain**: pain in the missing portion (phantom) of the limb.
- **Phantom limb sensations**: non-painful sensations in the missing portion (phantom) of the limb.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_19

- **Revision**: surgical modification of the residual limb includes amputations to a higher level (e.g., from a BKA to an AKA).
- **Prosthesis**: an artificial substitute or replacement of part of the body, designed for functional or cosmetic reasons or both.
- **Orthosis**: a support, brace, or splint used to support, align, prevent, or correct the function of movable parts of the body.
- **Limb Salvage**: Limb salvage refers to a number of procedures used to preserve a diseased or damaged/injured limb. Limb salvage broadly refers to the process by which a limb is restored to a state of reasonable functionality after severe injury or disease process that might otherwise result in amputation.
- **Activities of Daily Living**: routine activities that people normally do such as feeding, bathing, dressing, toileting, and walking.

For a list of other terms commonly used in amputation care, see http://www.amputee-coalition.org/resources/limb-loss-definitions/

B. ***Key Concepts***

1. **Characterization**

   Limb loss is characterized by amputation etiology (e.g., traumatic, dysvascular), by the limb(s) affected (e.g., arm, leg) and by amputation level (e.g., below knee amputation (BKA), above knee amputation (AKA)). The context of amputation is often important. In traumatic amputations, the loss of the limb may be one of multiple injuries and may occur after attempts to salvage the injured limb are unsuccessful. In the context of diabetes and peripheral dysvascular disease, amputations may be required to manage non-healing wounds or infections. In such planned amputations, the underlying medical conditions that require the amputation often have a significant impact on other areas of health and functioning (e.g., renal and vision compromise). For planned major amputation surgeries necessitated by chronic disease, the anatomic level of amputation is determined on a case-by-case basis, considering demographic and health factors. Health care teams must balance the probability of survival and healing from the surgery (which is generally better if the amputation is at a higher anatomic level, often because an additional revision surgery to a higher level is less likely to be required) with the potential for good mobility/function (which is improved with a lower anatomic amputation level [1]).

2. **Amputation**
   - *Perioperative period*. Amputation surgery is associated with significant morbidity and mortality [2]. In a study of 229 Veterans requiring major lower extremity amputations, 30-day mortalities for BKA, AKA, and BK to AK revision surgeries were 12 %, 17 %, and 7 %, respectively. A key component of postsurgical management is wound healing and prevention of complications [3], such as ulcers, sepsis, and infections in the residual limb (all of which can require revision surgery to a higher amputation level). In the previously mentioned sample, 30 % eventually required revision surgeries [3].
   - *Postoperative period*. Recent amputees who are elderly or medically complicated may participate in inpatient rehabilitation post-surgery to facilitate wound healing and improve self-care. Those who participate typically have better outcomes (e.g., lower 12-month mortality, fewer subsequent amputations) than similar individuals who do not [4].
   - *Beyond the postsurgical period*. Later, amputation management involves strategies to improve/restore mobility and ADL independence, prevent further complications, and support self-management of pain and chronic medical conditions. Rehabilitation therapies (offered via inpatient or outpatient modalities) can address skin/wound care, prosthetic fitting and management, and

gait and balance training. Individuals admitted to inpatient rehabilitation are more likely to regain pre-amputation levels of function such as mobility [5].

3. **Prostheses and Orthoses**

   Prostheses are frequently used by persons with limb loss either alone or in combination with orthoses or aids (e.g., crutches, canes). Prosthesis use is an option for many individuals with amputations, including those with hemipelvectomy or hip disarticulation. Close collaboration with a certified Prosthetist/Orthotist is essential to identify, fabricate, and adjust equipment in an ongoing way. Many prosthesis choices are available; decisions about specific prostheses are related to function, comfort, appearance, cost, and insurance coverage. Individuals may require a range of prostheses for different activities (e.g., some prostheses are designed for certain sports or for use in water). Ongoing management is required to maintain a functional prosthesis and factors like weight gain or loss, postural changes, and comorbidities may necessitate ongoing prostheses adjustments.

4. **Demographic Considerations**

   Because amputation is one of several surgical options for managing lower level ischemia, lower extremity wounds and infections, and other dysvascular conditions, there is some level of discretion and variation in clinical practice. Several large studies have identified disparities in the rate and type of amputations performed, with women, non-whites and individuals with lower income being more likely to receive amputation instead of a revascularization procedure [6–8], and more likely to have transfemoral amputations than amputations at a lower level [6]. There is also evidence that variations in regional practice and institution type influence amputation decisions; for example, there is elevated risk of amputation compared to revascularization based on non-teaching status of the institution [7]. For the rehabilitation psychologist, these socioeconomic status and hospital factors are important contextual contributions that influence functional outcomes, quality of life, and our understanding of the amputee's experience.

5. **Limb Salvage vs. Limb Amputation**

   Long-term functional outcomes after limb salvage are comparable to those with limb amputation, but tend to involve more hospitalizations and surgeries [9]. In a study of military veterans with serious lower extremity injuries, those with amputation within 90 days of injury had significantly fewer mental health problems and received more outpatient care compared to individuals who underwent salvage or amputations more than 90 days after injury. In the Military Extremity Trauma Amputation/Limb Salvage study [10] participants with amputation had better scores in all domains than those whose limbs had been salvaged, as well as lower likelihood of PTSD and higher likelihood of engagement in vigorous sports.

Importance

- ***Incidence and Prevalence***

  In 2005, 1.6 million persons in the USA were living with the loss of a limb. Of those with major amputations (excluding toes or hands) over 90 % were of the lower extremity and over 75 % were related to dysvascular disease. Due to an aging population and increasing rates of diabetes, the number of people with amputations is estimated to more than double by the year 2050 to 3.6 million [11].
- ***Impact on Life Span***

  Morbidity and mortality associated with dysvascular amputation are particularly high. Over half of individuals with limb loss due to dysvascular disease and diabetes will die within 5 years of their initial amputation and approximately half will require amputation of the contralateral limb [12].

- ***Impact on Quality of Life***
  In addition to impacting morbidity and mortality, limb loss is associated with varying levels of impairment in functional mobility, independence, the ability to complete activities of daily living, pain, and psychosocial challenges.

Practical Applications

A. ***Acute pain***

In addition to the postsurgical pain common after amputation surgery, acute pain, including phantom limb pain, is common. Phantom pain is often described as shooting, stabbing, burning, squeezing, and throbbing—a neuropathic pain resulting from disruption of the nervous system at the peripheral, spinal, or cortical level. It is most common in the distal portions of the amputated limb. Acute pain in the residual limb is also common and, for many, resolves with healing. Management of acute pain is important given it is a risk for chronic pain [13].

B. ***Chronic pain***

Although phantom limb pain typically diminishes in its intensity and frequency in the first year after surgery, between 60 and 85 % of adults with limb loss experience chronic phantom limb pain [14]. Phantom limb pain tends to be episodic, with episodes of pain lasting anywhere from a few seconds to hours or even days. Phantom limb pain is typically described as mild or moderate in severity although in one community-based sample, approximately one fourth with lower limb amputation reported phantom limb pain that was severely limiting. In addition to acute pain, the level of pre-amputation pain is also a risk factor for experiencing chronic pain [13]. Chronic residual limb pain is also quite common, with approximately half or people with limb loss reporting episodic and nearly a fourth continuous residual limb pain [15, 16]. Chronic pain in other sites such as the neck or shoulders (in upper limb amputation), contralateral limb, or back is also common [15, 16].

1. **Assessment**: Similar to other types of pain, pain intensity (sometimes referred to as severity) is typically measured via 0–10 numeric rating scales (0 meaning "no pain," 10 as "the worst pain imaginable"). Pain interference with usual activities can similarly be measured with a 0–10 scale or via the interference scale of the Brief Pain Inventory (BPI) [17]. Assessment of potentially modifiable behaviors impacting pain such as activity level, fear avoidance of movement, pain catastrophizing (unhelpful thoughts about pain), and coping skills is also recommended for treatment planning [14].
2. **Intervention**: Ideally, nonpharmacological pain management strategies should be taught and encouraged in the postoperative and rehabilitation settings as a "first-line" intervention, given the high risk of developing some form of chronic pain. Such strategies may augment other medical and rehabilitation interventions for pain. Anticonvulsants such as gabapentin or pregabalin are commonly prescribed for neuropathic pain; nonsteroidal anti-inflammatory medications and antidepressants such as duloxetine may also be used for pain, including musculoskeletal pain. Interventions such as self-management training, cognitive behavioral therapy, hypnosis, and mindfulness are recommended to decrease pain and its negative effects on functioning, mood, and quality of life. An emerging, promising treatment for painful and nonpainful phantom sensations is mirror therapy, which involves the use of a mirror to create the illusion of movement of a removed limb [18].

C. ***Cognition***

Individuals with amputation have an elevated risk of cognitive impairment [19]. Contributing factors include frequent comorbidity of vascular disease and diabetes as well as the increasingly older age at which amputations are conducted. During the perioperative period cognition may be impacted by transient factors (e.g., postoperative/anesthetic recovery, medications, anxiety, pain, and infection). Cognitive impairment has been associated with poorer medical outcomes such as developing foot ulcers [20], and poorer functional outcomes such as ambulation. Cognitive impairment is also associated with poorer prosthetic outcomes, including a lower likelihood of wearing a prosthesis after it has been issued [21, 22]. Similarly, amputees with significant cognitive impairment are less likely to participate in inpatient rehabilitation or maintain independent living [22, 23], and are more likely to have poorer community integration [24].

Although the majority of literature has focused on the global presence or absence of cognitive impairment, several studies have noted difficulties in specific domains, including memory, visuospatial ability, language, attention, and problem solving, though samples were often small [19]. Cognitive screening can inform decisions related to suitability for rehabilitation, and tailoring rehabilitation to patient's strengths to optimize mobility and independence. Consider a stepped approach to assessment that may start with brief, routine assessment of mental status (e.g., Short Portable Mental Status Questionnaire, Mini-Mental Status Examination) to identify significant impairment. A brief neuropsychological screening (e.g., Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)) may be appropriate about 6 weeks or later after amputation and prior to prosthetic fitting and before or as part of acute rehabilitation. Administration that occurs within 6 weeks of amputation surgery is not recommended because cognitive abilities can be impacted by transient factors around the time of surgery [25].

D. ***Depression***

Depression is common following amputation, with estimates ranging from 13 to 58 % during the first 2 years following surgery. After 2 years, rates typically return closer to population norms although some studies have seen elevated rates of depression 10–20 years postamputation [26].

- Poorer mood and adjustment outcomes are associated with social isolation, lower satisfaction with prostheses and medical care, and higher levels of pain [26]. Higher level amputation and, more importantly, higher levels of corresponding activity limitation and participation restriction are also associated with poorer mood and adjustment outcomes [26, 27].
- Depression plays an important role in the management of medical conditions contributing to amputation outcomes, such as diabetes. Depressed diabetics have poorer glucose control [28], more frequent complications [29], and greater likelihood of foot ulcers [30, 31].
- Depression among amputees has been associated with less active problem solving [32], public self-consciousness [33], less use of a prosthetic [34], and lower quality of life [35].
- There is robust evidence that depression can be treated effectively, ideally with a combination of psychotherapy and medication.
- Group based self-management skill development following limb loss with a professional facilitator and an amputee peer(s) has also been shown to improve psychosocial outcomes including depression [36].

E. ***Posttraumatic Stress Disorder (PTSD)***

Amputation can be perceived as a traumatic event that it may be associated with PTSD. Unsurprisingly, traumatic amputations are associated with higher rates of PTSD than disease-related amputations. Amputation-related PTSD symptoms tend to increase in the first year following amputation for individuals with both traumatic and disease-related amputations [37]. There are two main empirically supported treatments for PTSD: Prolonged Exposure and Cognitive Processing Therapy. Each of these manualized treatments can be done in about 3 months of weekly sessions.

F. ***Health Behaviors***

Patient activation (engagement in care) and self-efficacy are increasingly linked to positive health outcomes among individuals with amputation and individuals with medical conditions leading to amputation such as diabetes [30, 38]. Diabetic monitoring, wound healing, reduction of risk behaviors, and the use of prosthetic components are important aspects of amputation self-management and require ongoing and proactive engagement in care to achieve and sustain positive outcomes in physical and psychological functioning over time. Active patients recognize the value of participating in care, are confident in their ability to understand and act upon health challenges, make needed lifestyle changes, and work to sustain those changes over time [39].

1. **Alcohol**

   Misuse is associated with a host of medical disorders that contribute to limb loss and poorer recovery following limb loss including cardiovascular disease, obesity, diabetes, and hypertension [40] and has also been identified as a risk factor for foot ulceration and failing to receive or make use of a prosthetic following amputation [41, 42]. Alcohol also reduces the likelihood that an individual will return to pre-amputation levels of mobility [43].

   - *Assessment*. Assessment typically addresses alcohol use and related problems. The Alcohol Use Disorders Identification Test (AUDIT) is one of several options that is brief and validated [44].
   - *Intervention*. Brief advice, cognitive behavioral therapy (administered individually or in groups), motivational interviewing, 12-step programs, and pharmacologic interventions (e.g., acamprosate, naltrexone, and disulfuram under supervision) have all been shown to reduce hazardous alcohol use in broader medical settings [45].

2. **Cigarette Smoking**

   An important and potentially modifiable risk factor that has been associated with several amputation-related outcomes [41]. Smoking is a risk factor for initial amputation in general and for amputation as a specific result of foot ulcer [46]. Smoking is associated with poorer healing and a greater risk of revision surgery after amputation [47, 48]. Smokers have poorer prosthetic outcomes including shorter walking distances and times compared to non-smokers [49]. As a result, it is not surprising that smoking is associated with greater overall disability [9] and mortality [50] and lower satisfaction with life [51] among amputees.

   - *Assessment*. Typical assessment includes information on current use, readiness to quit, past history of quit attempts and symptoms of dependence [52].
   - *Intervention*. Brief advice during a medical appointment (5 or 10 min), motivational interviewing, nicotine replacement therapy, tobacco quit lines, and smoking cessation classes have all been shown to reduce smoking in broader medical populations [53].

3. **Obesity** (defined as body mass index >30)

   Risk factor for poorer outcomes following amputation including poorer wound healing, prosthetic fitting, prosthesis use, and mobility. Weight gain and corresponding decreases in physical activity may contribute to a vicious cycle that results in deteriorating functioning over time [54]. Exercise is not only beneficial for general health, but also improves performance in amputation-related tasks such as walking speed and endurance necessary for community access.

   - *Assessment*. Physical activity monitoring (e.g., accelerometer), global functional tests (6 min walk) and self-report (e.g., 7 day physical activity recall) are all examples of brief physical assessment measures.
   - *Intervention*. Group-based exercise programs and individual counseling.

4. **Diabetes and Vascular Disease**

   Amputation related to dysvascular disease and/or diabetes is associated with greater mortality, a greater likelihood of subsequent revision to a higher level of amputation, greater use of medical services, and younger age of initial amputation [3, 4].

G. ***Body Image***

New amputees frequently report increased self-consciousness in social settings and, in more extreme instances, embarrassment and shame about body appearance and functioning. Individuals with new limb loss also frequently report increased vulnerability to crime or exploitation. These perceptions may contribute to social isolation and detract from quality of life [55].

H. ***Social Support***

About half of individuals with amputations perceive a high level [37] of social support. The degree to which individuals are integrated in their social networks may decrease over time, particularly among older amputees and among individuals with amputation due to disease. Being married appears to be a protective factor in maintaining social integration. Having amputation related to disease tends to be associated with lower levels of social support than amputation related to trauma, although it appears that those who undergo amputation secondary to trauma have more social support in the first 6 months following the event, but these elevated levels are not sustained over time.

1. Some kinds of support are helpful—like providing a ride to an appointment or companionship—but it is important for the type of support to match the need for support. In other words, what is perceived as helpful may differ between people and situations. When assessing social support, it is important to understand what support is needed, and the degree to which those needs are met. It is also useful to assess the degree to which support is reciprocal.
2. Some kinds of support, called "aversive social support," can undermine amputee's mood or the ability to function. These may be obvious (e.g., criticism), subtle (e.g., avoidance), and hard to detect (e.g., overly solicitous responses that are well-intentioned but may undermine independence) [56].
3. Overall, social support can bolster mood, facilitate independence, improve engagement in self-management activities.

I. ***Amputations in the Military***

With the advent of new armor, vehicles, and protective equipment, more combat veterans are surviving with amputation than in previous conflicts, and more individuals have multiple limb amputations (i.e., 30 %). There are, to date, about 1700 amputees from conflicts in the middle east occurring since 2003. These individuals may represent a unique population [57] and while they often have increased functional challenges associated with multiple injuries, they often have high expectations for recovery of vocational, leisure, and athletic function and high interest in assistive technology and advanced prosthesis options.

Tips

A. The use of the term "amputee" is common among people living with limb loss/amputation. Given that this is not "person-first" language, it is suggested that you ask each patient for his or her preference regarding terminology.

B. Encourage patients to utilize the Amputee Coalition. The Amputee Coalition (www.amputee_coalition.org) is a nonprofit organization that offers multiple excellent resources for individuals with amputation. Available resources include publications and informational materials, available in booklets and electronic form, tailored for different situations (e.g., seniors undergoing initial amputation, individuals undergoing amputation due to diabetes, new amputees). Many resources are available in Spanish as well as English.

C. The Amputee Coalition also has a network of support groups across the USA, and a network of trained peer mentors, who are themselves amputees who are trained and available to meet with new amputees to offer support, advice, and facilitate access to resources. The Amputee Coalition also hosts a national conference annually and supports events such as children's camps.

D. Psychologists should educate medical teams on how to identify patients in need of psychological consultation or intervention.

For many patients with limb loss, rehabilitation, education, and community resources such as the Amputee Coalition will be sufficient in meeting their psychosocial needs. Patients whose distress, pain, or behavior interfere with rehabilitation progress, functioning, medical adherence, role participation, or quality of life should be referred to a rehabilitation psychologist for assessment, triage, and treatment.

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Suggested Reading

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VA/DoD Clinical Practice Guideline: Rehabilitation of Lower Limb Amputation. http://www.healthquality.va.gov/guidelines/Rehab/amp/

Pediatric Rehabilitation Psychology

20

Heather F. Russell

Topic

Working with children in medical rehabilitation requires consideration of important elements to facilitate optimal outcomes. Rehabilitation management of children involves identifying the child's physical and mental functional capabilities. An interdisciplinary team then selects interventions that are appropriate over the course of the disability/problem with consideration of the child's developmental age and continuum of care across professionals. Sometimes approaches should be modified for children who are born with a disability ("congenital") and for those who acquire it and can recall "before" and "now." Some general concepts applicable for those working in pediatric rehabilitation are listed below:

Family-Centered Care

- Psychology, social work, and other counseling staff should provide both individual and family counseling as needed.
- The child should be included in and provide assent for (when appropriate) every aspect of the treatment. Siblings should be included in the treatment planning and in the provision of support services, as appropriate.

Anticipatory Guidance as Good Prevention

- Inform parents/guardians and the child (when appropriate) about physiologic and other issues likely to occur in the future as the child grows and matures when known (e.g., fertility issues).
- Educate parents/guardians and children about relevant developmental features of the child's issues. For example, a large percentage of children with spinal cord injury (SCI) who have not finished growing may develop scoliosis of the spine. Targeted education may help with compliance when a physician may delay or limit the development of this complication through the use of a back brace. Counseling to identify coping and behavioral strategies to enhance wearing compliance can be helpful at the time of recommendation.
- Social boundaries and expectations of the child should be maintained and encouraged when possible.
- Accountability such as doing chores should be maintained and encouraged.
- Belief of "normalcy" should be promoted in the idea that the child can grow up, play sports, complete school, date, have a family, and be a productive member of society as any other child may also desire, as applicable.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_20

Developmental Issues

- Attachment—There should be protected time in the young child's day (especially up to the age of 5 years) to simply be with and bond with his or her caregivers, usually parents. develops between the ages of 2–5 and helps the child to be able to trust and love. This emotional bond stimulates brain growth, affects personality development, and enhances the child's ability to form stable and trusting relationships later in life [1].
- Sleep—The child's rehabilitation schedule needs to allow for the recommended amount of sleep for his or her developmental level, including daytime naps.
- Cognition—According to Jean Piaget, children progress through a series of four stages of cognitive development (see Table 20.1) [2]. Knowing which stage a child is in can guide how best to teach him or her new skills or information. For example, you should not rely solely on showing a child under the age of 12 pictures of pressure ulcers to encourage him or her to conduct pressure reliefs, as this requires more reasoning and abstract thinking.

Table 20.1 Piaget's stages of cognitive development

Stage	Age (in years)	Description
Sensorimotor	0–2½	Infants and toddlers acquire knowledge through sensory experiences and manipulating objects
Preoperational	2½–6	Youth learn through pretend play, but still struggle with logic and taking the point of view of others
Concrete operational	6–12	Youth begin to think more logically, but their thinking can also be very rigid. They tend to struggle with hypothetical and abstract concepts
Formal operational	12+	Youth develop the ability to use deductive reasoning and an understanding of abstract thinking

Transition to Adult Care Starts Early

- Transitioning from one developmental stage to the next may require time-sensitive support (i.e., early childhood to Kindergarten, middle school to high school, then to college/vocational training, then to work).
- Starting at age 14, the team should begin the transition process to adult care.
- Vocational rehabilitation services can be a valuable resource as the child approaches young adulthood.
- The child should assume increasing responsibility for his or her own care as he or she ages.

Importance

The field of pediatric psychology rehabilitation applies to a variety of childhood conditions. There are congenital and chronic conditions such as cerebral palsy, spina bifida, and developmental delay which often require various rehabilitation services across the entire life span. Then, there are acquired traumatic conditions which require an acute inpatient rehabilitation stay followed by outpatient chronic management, such as burns, limb deficiency, traumatic brain injuries, and spinal cord injuries. Some of these pediatric conditions are reviewed below:

Cerebral Palsy (CP) [3]

- In the developed world, CP occurs most often in youth who were born prematurely and affects approximately 2 in 1000 children. CP can also be caused by infection in the womb, prenatal insults, or genetic conditions.
- CP describes a group of chronic disorders with limitations in mobility and hand use and with commonly associated impairments in sensation, cognition, communication, and behavior. These children can have involvement in only one side of their bodies (hemiplegia) or bilaterally (quadriplegia). The most common form of CP involves an abnormal increase in muscle tone called spastic CP, but other forms can involve jerky or slow and

writhing movements (dyskinetic CP), and uncoordinated movements (ataxic CP).

- Approximately 50 % of children with CP have intellectual deficiency and many those with more typical cognitive skills demonstrate some level of learning disability. Academic support and social skills development often provide some benefit. Vision, hearing, and speech and language impairments are also rather common in this population resulting in the need for ongoing multidisciplinary therapies to address all of the child's needs and to enhance quality of life.

Spina Bifida (SB) [3]

- SB is the most common form of neural tube defects which results from malformations of the brain, spinal cord, and vertebrae in utero.
- In the United States, approximately 3 per 10,000 infants were born with some form of SB (not including terminated pregnancies).
- The causes of SB remain complex and unclear. It is known that both environmental and genetic factors can play a part. Specifically certain genetic mutations, maternal exposure to certain medications (certain antiepileptic and acne medications), maternal alcohol abuse, maternal exposure to hyperthermia, and maternal diabetes and obesity have been shown to result in increased occurrence of SB.
- The malformation leading to SB affects the entire central nervous system. The primary neurological abnormalities are paralysis and/or loss of sensation below the level of the spinal cord defect, bowel and bladder issues, learning disabilities, and Chiari type II malformation with associated hydrocephalus.
- Psychosocial issues such as body image issues, depression, social difficulties, self-esteem issues, lack of motivation, decreased participation, difficulties dealing with sexual changes and feelings. It is important to note that one's level of distress is not necessarily related to his or her level of function.

Burns [4]

- Approximately 1.5–2.0 million people sustain burn injuries every year resulting in about 70,000–100,000 hospitalizations of which 50 % of them are children and adolescents.
- Burns are the fifth leading cause of accidental death in children with 5500 deaths per year. Children under 5 years old account for over half of all pediatric burns.
- Etiology varies according to developmental level. Toddlers are susceptible to liquid and food spills; preschoolers and school-age children tend to sustain injuries during experimental play with lighters, matches, and kitchen devices; and adolescents tend to get hurt outside the home.
- Burns range from first degree to the more serious third degree in nature and can affect varying amounts of body surface area.
- Common psychological consultation issues in this population in the acute phase have to do with mental status, behavioral support for nutritional intake, body image issues, behavioral interventions for intense itching sensations, post-traumatic stress disorder/anxiety/depression concerns, disruptive behaviors, adherence to treatment demands, family issues, and pain management.
- These psychological concerns can continue into the rehabilitative stage of treatment and can benefit from continued support and intervention from all members of the treatment team.

Traumatic Brain Injury (TBI) [3]

- Each year, approximately 119 per 100,000 children under 18 years of age sustain a TBI.
- The most popular etiology in young children (ages 0–4) is falls (65 %), while the largest contributor in the oldest children (ages 15–17) is motor vehicle accidents (26 %).
- TBI ranges from mild to severe and require differing levels of rehabilitation. Mild injuries, including concussions, often require only rest and time and most children are expected to have a full recovery. Whereas moderate and severe injuries come with motor, sensory,

communication, and cognitive impairments and feeding disorders which often require ongoing multidisciplinary therapy interventions.

- Following TBI, the child can also demonstrate behavioral and emotional changes including adjustment difficulties, psychiatric disorders (including anxiety and/or depression), disinhibition, impulsivity, poor safety awareness, social withdrawal, and inappropriate social behavior.

Spinal Cord Injury (SCI) [4, 5]

- Approximately 3–5 % of all cases of traumatic SCI (or about 600 of the just over 12,000 new cases per year) occur in children younger than 15 years of age and in 20 % of all cases (or about 2400) when including all those up to 20 years of age.
- Motor vehicle accidents are the most common etiology of SCI in children, with falls, violence, and sports being the next most common causes. Unique etiologies of SCI in children include lap-belt injuries, birth injuries, child abuse, SCIs without radiologic abnormalities (SCIWORA), upper cervical injuries, and transverse myelitis.
- SCI is described by the level of the injury as measured by the International Standards for Neurological Classification of SCI (ISNCSCI). Studies of this measure in pediatric populations have found the reliability of the motor and sensory examinations to be good in children aged 5 years and older. It is important to note that the anorectal examination has questionable reliability when conducted on a child who had never been toilet trained before his or her injury.
- Common reasons for psychological consultation during acute rehabilitation of a child or adolescent with SCI are depression, anxiety, lack of appetite, trouble sleeping, irritable/aggressive behavior, social withdrawal, noncompliance in therapy or with medical treatment, engagement in self-destructive behavior, and suicidality. Any or all of these issues can continue after rehabilitation as adjustment to the injury occurs over years.
- Youth with SCI seem to experience lower levels of participation and quality of life when compared with normative data [6, 7].

However, children with SCI report experiencing similar levels of anxiety and depression when compared with normative data [8]. Youth with SCI appear to be emotionally resilient. Parent/caregiver mental health is a stronger predictor of how parents rate their child's quality of life than the child's own mental health [9].

Ethical Issues [10]

- Ethical issues can range from disagreements between the child and the parents/treatment team, between the two parents, between parents and the treatment team, and between treatment team members regarding the treatment plan and can lead to very serious issues with legal ramifications.
- In addition, ethical issues can arise concerning prenatal diagnosis, genetic testing and screening, withholding of treatment, end-of-life issues, and human subjects research.
- These issues can often be made more clear as a result of consulting the facility's Ethics Committee.

Legal Issues

- Children are protected by legal tenets in all US states.
- Child abuse includes four types: emotional, sexual, physical, and neglect.
- All professionals working in health care settings have a civil mandate, called mandatory reporting, to follow when a child is suspected of being abused. This mandate applies even when there is no direct clinical relationship with that patient.
- Individual state laws differ on how they define child abuse and on how to report child abuse.
- Laws dealing with the "emancipation" of minors; that is, laws that specify when and under what conditions children become legally independent of their parents/guardians vary by state. Parental/guardian consent to provide medical treatment for a child is required until

age 18 (or younger if the child is an emancipated minor).
- Obtaining the assent of the minor child is highly encouraged for any medical procedure.
- After age 18 (or younger if he/she is an emancipated minor) the child must consent to providing the parent/guardian with information related to his or her physical health.
- With regard to mental health, each state defines the age of consent differently. For example, a 14-year-old living in Pennsylvania has the right to consent to his or her own mental health treatment and may or may not give permission to share this information with the parent/guardian.

Practical Applications

Several elements must be considered in order to provide appropriate family-centered care that is mindful of the developmental transitions, anticipatory guidance, and relevant cognitive stage of development. These are:

Appropriate Physical Environment

- Cribs, high/low tables, lower beds, sinks and toilets, etc. must be provided as appropriate.
- Environment should provide for play and social spaces to meet differing needs of young children, school aged children, and adolescents including play equipment for all sizes and ages.
- Enough storage space for all sizes of equipment should be available.
- Adequate financial resources to purchase the appropriate equipment should be available.

Security Needs

- The unit must be set up to protect the safety of the minor patients including child-safe environment, supervision, secure access, etc.

Communication Needs

- Should facilitate open communication between the staff and the family regarding who is responsible for what aspects of the child's care while he or she is inpatient. It is important for both the staff and the parents/guardians to be aware of the various stages of development and of the regression in these stages that the child may demonstrate during a hospital or rehabilitation stay.
- Parents/guardians should be encouraged that in addition to learning their child's care, they will need to take care of themselves (i.e., naps, day trips, meals out, periods of respite) throughout the rehabilitation period in order for them to be good caregivers.

Education Needs

- In addition to teaching the child his or her own care, at an age appropriate level, in order to optimize independence and safety at every developmental stage at least one caregiver must be trained in the care of the child.
- Should educate the patient at an age appropriate level and the family members that the child with an SCI is at a higher risk for abuse.
- Should work with other staff members as appropriate to provide the patient at an age appropriate level and with parental permission and the parents/guardians with sex education including the areas of performance, fertility/infertility, pregnancy, etc.

Sexual Education

- Sometimes difficult to determine, but one should aim to conduct sexual education at an age appropriate level with parental/guardian consent. Youth often benefit from hearing if they are expected to be able to have sexual relationships and children in the future.

Additional Staffing Needs

- Recreation therapy and/or Child Life staff should be present in order to provide an environment for the child to play during rehabilitation and to provide information about play, sports, and travel opportunities after discharge.
- Certified teacher should be present during rehabilitation stays lasting longer than 2 weeks in order to facilitate the child's learning and educational progress.

- A pediatric speech and language therapist should facilitate developmentally appropriate speech and eating habits as much as possible.
- A pediatric neuropsychologist should be present to assess for any changes in cognitive and/or executive functioning in order to facilitate the rehabilitation process and reintegration into the school system upon discharge as needed.

Accommodations

- Accommodations in the facility must be provided for at least one parent/caregiver to stay with the child while in rehabilitation. Furthermore, accommodations for two parents/caregivers should be provided during the acute rehabilitation so that the two caregivers can provide support for each other and take turns being with the child during this difficult time.
- Daytime visits from siblings should be encouraged as much as possible during the acute rehabilitation process.

Assessment of Biopsychosocial Needs

It is often helpful to quantitatively measure certain aspects of the biopsychosocial process in order to provide a diagnosis or to track changes over time. Often commonly used pediatric measures have not been formally validated with each specific patient population. However, they continue to be used with caution as they have demonstrated acceptable levels of reliability and validity when applied to the general population.

Pain

- *Observational Scale of Behavioral Distress* (*OSBD*) is a scale which can be used for infants and describes 11 observed behaviors on a 4-point likert scale.
- *Faces Pain Scale/Visual Analog Scale* are 10-point pain scales are used to assess pain intensity in youth ages 3–8 and 9–18, respectively [11, 12].

Depression

- *Behavior Assessment System for Children*, *Second Edition* (*BASC-2*) is a Parent-report assessment of youth depression for children 2½ years and older. The BASC-2 can be completed by parents of children under the age of 7 [13].
- *The Children's Depression Inventory* 2nd *Edition* (*CDI 2*) is a widely used reliable and valid measure of self-reported depression in youth. This measure was developed for youth ages 7–17. Scales assess emotional problems and functional problems while subscales assess negative mood/physical symptoms, negative self-esteem, interpersonal problems and ineffectiveness [14].

Anxiety

- *Behavior Assessment System for Children*, *Second Edition* (*BASC-2*) is a Parent-report assessment of youth anxiety for children 2½ years and older. The BASC-2 can be completed by parents of children under the age of 6 [13].
- Revised Children's Manifest Anxiety Scale: Second Edition (RCMAS-2) is a self-report measure designed to assess the level and nature of anxiety in youth ages 6–19 years old. Subscales assess physiological anxiety, worry, social anxiety, defensiveness, and inconsistent responding [15].

Quality of Life

- *Pediatric Quality of Life Inventory* (*PedsQL*) is a parent- and child-report versions of the general core scales are used to assess four areas of children's health-related QOL including physical, emotional, social, and school functioning. Parents can complete the proxy-report version for youth ages 2–4, and both parents and youth can complete versions for youth ages 5 and up [16].

Coping

- *Kidcope* is a self-report measure designed to assess positive and negative coping strategies used by children and adolescents ages 7–18 in response to a particular negative event. The measure yields a frequency and efficacy score for each of the ten coping strategies [17].

Participation

- *Assessment of Pre-school Children's Participation* is a parent-report assessment of participation for children 2–5 years. The measure assesses participation in four types of activities: Play, Skill Development, Active Physical, and Social [18].
- *Children's Assessment of Participation and Enjoyment* (*CAPE*) is a self-report measure of participation in activities outside of class time for children ages 6–21. The CAPE includes subscales assessing formal and informal participation, and participation in recreational, social, physical, self-improvement, and skill development activities [19].

Tips

- Talk directly to the child.
- Imagination is your limit.
- Children are resilient: get out of their way.
- Encourage parents to take care of themselves.
- Be genuine/don't be afraid—children can sense fear.
- Children tend to be in the moment and generally do not think of the future in the same way that adults do.
- Have rewards/consequences be immediate and relevant.
- It's hard to have consequences in the rehabilitation setting.
- Facilitate open communication between family members—family members tend to attempt to protect each other by withholding information often resulting in miscommunication and increased distress. Youth often already know what is going on before parents/staff tell them. Help parents/guardians, family members, and the patient to communicate with each other—especially in cases of divorce or relationship strife.
- It is tough being a child/teen even without having a disability.
- Last, but not least: remember to have fun!!

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Geriatric Rehabilitation Psychology

21

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Topic

Older adults are frequently seen in rehabilitation settings and bring with them unique life experiences, wisdom, and often greater complexity of medical problems. Typically the term "older adults" describes those age 65 and older. However, there is much diversity across late life and within each cohort of older adults. As the saying goes, "If you've seen one older adult, you've seen one older adult."

A. ***Key concepts***

1. **Geropsychology**

   A specialty of clinical psychology focused on assessment, intervention, and consultation with older adults. A competency-based model of geropsychology training has been developed to assess knowledge and skills in geropsychology practice, known as the Pikes Peak Geropsychology Competencies, and in 2013 APA updated its Guidelines for Psychological Practice with Older Adults [1–3].

2. **Life span development**

   It is advantageous to utilize a developmental perspective when working with older patients. Gathering a history is critical. Personality characteristics and long-standing behavior patterns are important to note. Think about how these may (or may not) have changed over time. Often older adults present with issues related to role transition, grief, retirement, illness, or loss of functioning that are common to old age but not due to the aging process in and of itself. Be aware of health disparities among some underserved populations of older adults (particularly racial/ethnic minorities and lesbian, gay, bisexual, and transgender older adults) and address them in your setting.

3. **Myths of aging**

   Providers working with older adults in rehabilitation should be prepared to challenge commonly held misperceptions of aging. For example, "old dogs can't learn new tricks", or "I would be depressed if were in that situation." Some colleagues or trainees may shy away working with older adults, misperceiving older people as unpleasant or unappealing. This often says more about one's own fear of mortality than it does about older people themselves. When these myths arise, they allow for an opportunity to educate patients and colleagues about late life.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_21

Importance

The number of older adults in the United States is expected to increase exponentially as the generation of baby boomers becomes older adults (known in the literature as the "graying of America"). These individuals, born between 1946 and 1964, began turning 65 in 2011 [4]. This is also a global concern as the population of adults over 60 worldwide is expected to double from 11 to 22% and reach two billion by 2050 [5].

- **Mental healthcare**: Older adults cope with myriad mental health concerns. Anxiety and depression are the most common and are frequently comorbid in older people. Often older adults present with physical rather than psychiatric symptoms. Encourage your interdisciplinary colleagues to be attuned to signs of mental health disorders and refer for further evaluation and treatment.
- **Suicide**: There is an elevated suicide risk in older adults, with white males over 85 having the highest rate of suicide of any age group. Attend to warning signs of suicide, particularly: recent losses or change in social support (including widowhood), access to lethal means of self-harm, substance use, and impulsivity.
- **Abuse/neglect**: Working with older adults means being aware of signs of elder abuse and neglect (including physical abuse, verbal abuse, and financial exploitation). Self-neglect is more common than abuse and neglect by others. It often goes unrecognized and can be difficult to address. Many states require licensed professionals to act as mandatory reporters of elder abuse and neglect.

Practical Applications

A. **Reasons for Consult**

Psychology or mental health services can be helpful in rehabilitation settings for many reasons, including assessment, intervention, or consultation.

1. **Assessment**

   Mental health providers can assess issues such as decision-making capacity (i.e., level of independence to make financial, medical, or appropriate discharge decisions), functional capacities (e.g., being able to safely live alone), cognitive functioning (e.g., ability to effectively manage medication regime independently), mood and psychodiagnostics as modifiable factors, pain as a potential barrier to quality of life, and assess level of suicide risk.

2. **Intervention**

   Psychology can provide treatment for things like depression, difficulty coping with losses such as medical debility or decline; grief following deaths of spouses, children, family, and other loved ones; issues of motivation or treatment compliance; reducing the interference with pain on engaging in goals and life values; fears related to medical issues or end-of-life concerns; and other mental health diagnoses that may be impacting the patient's rehabilitation stay.

3. **Consultation**

   Mental health providers can offer useful suggestions for more beneficial interactions with patients and families, strategies to reduce challenges during difficult discussions, and advice about legal or ethical concerns such as elder abuse or neglect. They can alwo recognize when it is appropriate to involve a psychiatrist to address psychopharmacological issues

B. ***Geriatric Assessment***

Brief, bedside screening evaluations offer additional information on patient functioning but are not designed to be diagnostic (i.e., cannot diagnose dementia based on a cognitive screening instrument). Quick screens, however, can help identify areas in need of further evaluation. Geriatric assessment requires attention to the following unique considerations:

1. **Tests**

   Should be designed for and normed on the age of the older adult

2. **Administration**

   Account for sensory loss (i.e., insure that patients use their glasses and hearing aids, use larger print materials, use versions of tests modified and normed for those with visual impairment, speak in a deeper tone, and use a pocket talker or similar device to amplify sound)

3. **Brief**

   Due to physical and mental fatigue in rehabilitation setting

   A proper review of patient's medical history, labs, and medications can also distinguish between potential contributions to the geriatric patient's presentation. When evaluating the patient, strive for an environment with reduced distractions (e.g., beeping machines, nurse interruptions, roommates) and plan ahead (e.g., ensure the patient is not in a physical therapy appointment or with another doctor). You may need to allow for extra time for interacting with the patient and for increased complexity in your chart review [6] (Table 21.1).

C. ***Differential diagnosis—depression, dementia, and delirium***

Table 21.2 offers distinguishing characteristics of common geriatric syndromes. Differentiating between these conditions is vital in offering the most appropriate treatments. Several common causes of dementia are listed in Table 21.3. Consult with a specialist in geriatric mental health and medicine if needed. See also separate chapters in this book on delirium (Rudolph and Budd), dementias (Stiers and Strung), and depression (Schechter and Bentley).

1. **Delirium**

   Delirium is a common and costly problem among older patients in medical settings. Episodes of delirium are known to increase length of stay, increase morbidity and mortality, and decrease the likelihood of returning home after rehab. About 25 % of geriatric patients on medical wards will develop delirium [7].

   a. ***Signs and symptoms.*** Delirium is acute brain failure characterized by sudden onset of confusion, disorganized thinking, fluctuation throughout the day, inability to pay attention, and altered alertness.
      - **Subtypes**
        - **Hyperactive (25 %):** predominant agitation and confusion
        - **Mixed (50 %):** waxing and waning mental status
        - **Hypoactive (25 %):** somnolent and difficult to arouse

Table 21.1 Common tests for geriatric patients

Test name	Use	Length (min)	Features
Montreal cognitive assessment (MoCA)	Cognitive screen	10	Normed on geriatric population, multiple forms, free to use
St. Louis University Mental Status Exam (SLUMS)	Cognitive screen	7	Normed on geriatric population, free to use
Cognitive status exam (Cognistat)	Cognitive screen	15–20	Normed on geriatric population, includes brief screen for judgment, must purchase from publisher
Geriatric depression scale (GDS)	Depression screen	3–10	Created for geriatric population; brief (five items), short (15 items), and long (30 items) versions; free online forms and free downloadable phone app
Cornell scale for depression in dementia (CSDD)	Depression in dementia screen	30	Screen for patient and semi-structured interview with caregiver
Geriatric anxiety scale (GAS)	Anxiety screen	10–15	Created for geriatric population; available free online; follows DSM-IV criteria
CAGE	Alcohol screen	<5	Brief screen for problematic drinking; all ages; free to use
Confusion assessment method (CAM)	Delirium screen	5	Designed for detection of delirium, wide use on geriatric population, free to use

Table 21.2 Differential diagnosis in geriatric patients

	Delirium	Depression	Dementia
Onset	Acute	Gradual or episodic, may be exacerbated by admission to hospital	Varies depending on cause; can be gradual (Alzheimer's) or sudden (stroke)
Features in rehabilitation setting	Inattentiveness, fluctuations, disorganized thought, hypo- and/or hyperactive, may have visual hallucinations	Low mood, loss of interest, lack of positive emotions, suicidal ideation, lack motivation for rehab, subjective complaints about cognition	Difficulty with memory, change in behavior, impairment in language, lacking awareness of deficits or nursing safety precautions
Contributions	Dehydration, metabolic, medication toxicity, septic, encephalopathy, malnutrition, dysregulated labs	Organic (vascular health, stroke, Parkinson's, etc.) or psychosocial (physical limitations, life transitions, etc.)	Varies depending on the cause of the impairment
Treatments	Improve sensory input, lab work, address underlying medical condition	Supportive psychotherapy, refer to outpatient when discharged	Consult geriatric specialists, manage problematic behaviors in rehab setting
Rehabilitation resources	Physician, psychiatrist, neurologist, psychologist, nurse	Psychologist, psychiatrist, clinical social worker, licensed mental health provider, recreation therapist, psychiatric nurse	Psychologist, neurologist, psychiatrist, geriatrician, nurse

Table 21.3 Common causes of dementia

Cause of dementia	Average age of onset	Early features
Alzheimer's disease	65 and older	Insidious onset, progressive nature, impaired immediate recall, learning, and short-term memory early in the process, followed by language, executive functioning, and visuospatial abilities
Vascular	70 and older	Varies according to cause of impairment (i.e., stroke, microvascular ischemic changes, vascular risk factors), deficits may be focal or diffuse, impairment in executive functioning, may have an abrupt onset, diagnosis is also supported by neuroimaging
Lewy bodies	70 and older	Hallucinations (often detailed visual hallucinations), delusions, fluctuations in cognition, parkinsonism, progressive nature, REM sleep behavior disorder
Frontotemporal	50–60	Changes in personality, executive functioning, disinhibition, language impairment, and social functioning; various subtypes (i.e., behavior, language, etc.)

- **Risk factors.** Age, premorbid cognitive impairment, medical factors (e.g., fracture, infection, acuity), dehydration/malnutrition, sensory deficits, poor sleep, and the use of certain medications all increase risk for delirium.
- **Prevention.** Improve sensory input, provide cognitively stimulating activities, get the patient up and moving, maintain a consistent sleep-wake cycle, ensure adequate hydration and nutrition, and reduce use of deliriogenic medications when possible [7].

2. **Dementia**
   a. ***Dementia Behavior Management.*** The term dementia describes a number of conditions responsible for cognitive and functional decline, which vary from relatively stable to progressive in nature. Table 21.3 offers a brief outline of some of the common causes. One major challenge in the rehabilitation setting is managing behaviors that may impede care or cause harm to self or others (i.e., refusing nursing care, hitting, wandering, elopement). Problematic behaviors are generally the result of

patient discomfort (e.g., pain, isolation), perceived intrusion, or structural changes in the brain. Consultation with a geriatric mental health specialist can assist in managing these behaviors to optimize quality of care.

b. ***The CANDLES approach offers basic behavioral management techniques***
   - Communication—Use basic words (“sugar” vs. “blood glucose level”) and short phrases (“come,” “sit”), limit options offered to patient (“tea or water”), and incorporate tactile and visual cues.
   - Approach—Approach from the front, go slow, get down on the patient’s level, and use a non-threatening stance (i.e., don’t lean over the patient).
   - Needs—Be proactive in anticipating unmet needs such as thirst, hunger, warmth, pain, and need to toilet.
   - Distraction—Attempt to get the patient’s attention, offer an emotional reflection (“you sound upset”), provide gentle distraction by discussing their interests, pictures, or enjoyable activities, and move them away from upsetting environmental stimuli.
   - Leave for later—When not an immediate safety issue for the patient or others, avoid forcing activities or compliance to a hospital routine; many activities can wait until later.
   - Environment—Create a setting that matches the patient’s needs (i.e., more or less stimulation); use aromatherapy, calming music, or recreational therapy activities.
   - Sensory—Promote optimal functioning by ensuring patients have their glasses and hearing aids (if applicable), good lighting, and an environment with an appropriate amount of stimulation—not too much or too little.

c. ***Decision-making capacity***

   Psychologists in rehab settings are often called upon to provide evaluations of decision-making capacity. For those performing these assessments regularly, an essential and free tool “Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists” is available at the APA website [8]. For more information please consult an entire chapter in this handbook dedicated to decision-making capacity (Triebel, Niccolai, and Marson).

   - ***Competency vs. capacity***. Sometimes the question is to “evaluate competency.” The two terms are often confused. **Competency** is a legal term that is decided in court by a judge. **Capacity** in a clinical setting is a determination that a person lacks the ability to carry out the function in question.
   - ***Clarify the referral question, first step.*** Capacity to do what? Consent to a medical procedure? Live independently? Manage finances? Drive? Capacity is domain specific, not a global ability.
   - ***Evaluate the individual’s***
     - **Understanding** of the problem at hand.
     - **Appreciation** of personal or environmental parameters and consequences for decision to be made.
     - **Reasoning** or ability to weigh risks and benefits of a decision.
     - **Ability to express a choice** or state a preference about their care. Ideally this should remain relatively consistent over time.
   - ***Typical battery.*** Obtain informed consent, cognitive assessment, mental health screening, functional measures (e.g., independent living scales), semi-structured vignettes (e.g., Hopemont Capacity Assessment Evaluation), and clinical interview that includes values assessment.

- ***Caveats and myth busters***. A diagnosis of cognitive impairment or dementia does not automatically mean a lack of decision-making capacity. A patient who disagrees with the treatment recommendations also does not necessarily lack capacity. In addition, capacity can fluctuate, so if a delirium was the source of impaired decision-making, it should be reassessed after the mental status clears. Think about what can be put in place to enhance capacity, such as selecting a money manager to help a person avoid court-ordered conservatorship.

D. ***Interventions***

Older adults may be less familiar with mental health treatment than younger people and may not know what to expect from your interventions. Rapport building cannot be overemphasized. Take time to help the patient feel comfortable with you. Address their perception of mental health treatment, avoid jargon, and explain your role. Older adults often prefer talk therapy to psychopharmacology, and the effects of psychotherapy can be longer lasting than use of a pill. Best practice for most mental health problems is to use both modalities.

1. **Psychoeducation**

Admission to a rehabilitation setting can be overwhelming for the geriatric patient and family. Providing basic information on the hospital setting, rehabilitation expectations, importance of goal setting, and awareness of a team effort can often ease anxiety and best prepare the patient for recovery. Psychoeducation is equally important for the healthcare team. Team members can offer information on diagnoses, family dynamics, and recovery goals to foster the team's effort in providing consistent care with awareness of what may facilitate or hinder the patient's progress.

2. **Behavioral activation**

Encouraging physical activity can improve mood and facilitate patient recovery goals. Activities should consider the patient's current cognitive (i.e., does the patient need supervision) and functional level and existing safety precautions (i.e., the use of rolling walker, transfer assistance). Most settings offer recreational therapy activities that promote cognitive, social, and physical activity.

3. **Evidence-based psychotherapy**

Use evidence-based psychotherapy interventions that have been validated with older adults—some examples include cognitive behavioral therapy for depression, interpersonal psychotherapy, and problem-solving therapy. A recent comprehensive text provides an overview of these and additional EBTs that may be appropriate in an acute rehab setting [9].

Modifications to evidence-based therapy should be considered to best fit the patient's needs and preferences. Utilize repetition, break up complex topics into smaller chunks, and teach them more slowly. Consider using multiple sensory modalities in your work, like a dry erase board to list a brief outline of a session before you start. For better understanding and retention of the material, provide a written summary in print large enough for them to read it or audiotape sessions for the patient to listen to later.

Be attuned to transference and countertransference issues that may arise in treatment (both in your own work and those that may arise with other team members). Finally, network with outpatient geriatric mental health providers to ensure patients receive follow-up after returning home.

E. ***Multidisciplinary and interdisciplinary teams***

Work in a rehab setting virtually guarantees work on an interdisciplinary or multidisciplinary team. Teamwork is especially important when working with older adults who tend to be medically and psychologically complex, often needing many disciplines to weigh in on their care and rehab plan [10]. Given the reality of working on teams, the role of the psychologist often extends beyond care of the patient. Mental health professionals can help support and improve team functioning by helping improve the efficiency of meetings, facilitate more effective communication between team members and between the team and the patient, attend to team process and staff morale, and being available for consultation on team issue or concerns. Working with a team is hard work and takes a lot of patience and willingness to listen and work together, but effective teamwork has also been shown to improve patient care and reduce healthcare costs.

Tips

- ***End-of-life preferences.*** Be aware of a patient's advance directive and code status. Psychologists can assist with healthcare planning, establishing personal goals and clarifying patients' values, and helping all team members become aware of the patient's wishes and desires.
- ***Mental health stigma.*** Some elders may be hesitant to meet with psychologist, believing they are being seen as "crazy" or incompetent. Take time to educate the team about your role so they can help address any patient discomfort. Have a provider they are already familiar with introduce you, with the goal to be seen as just another member of the team. Including psychology as a regular part of all patient-team interactions can help normalize the experience.
- ***Talk with frontline staff.*** Nurses and nursing aides spend the most time with the patients and can offer a wealth of information on the geriatric patient's functioning and adaptation to the rehabilitation setting. They may also be able to inform you of when family member/friends typically visit and any relevant content or context of these visits (e.g., visit after physical therapy when patient is exhausted and family has been observed to be over stimulating).
- ***Collect collateral information.*** Consult with other members of the healthcare team for useful information on cognitive, affective, and physical functioning. In addition, reach out to family members and other important persons in the patient's life who can offer valuable information on patient preferences, values, and background. Be sure to check for release of information documents or other healthcare planning documents for guidance (i.e., healthcare proxy, guardian, etc.).

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Transplants

22

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Topic

Organ transplantation is the last line of treatment for patients with end-stage organ failure. The wait for an organ and recovery from the transplant procedure involves substantial changes to patients' physical health, psychological well-being, occupational abilities, social relationships, and self-care. Patients are at great risk for both medical and psychiatric illness and require substantial adjustment and adaptation in their lives. It is therefore necessary for transplant teams and interdisciplinary care teams to be aware of these risks in order to intervene to improve functioning and long-term outcomes.

Importance

Approximately 28,000 transplantations are performed annually in the United States. This includes an estimated 12,000 kidney transplants, 4500 liver transplants, 2100 heart transplants, 1000 pancreas transplants, and 850 lung transplants. However, the number of candidates added to the wait list exceeds the number of those receiving transplants with an estimated 15 patients dying on waiting lists each day [1]. For major surgeries, candidates in the United States wait 2 or more years for an organ and 10–18 % of candidates die while waiting [1]. The number of living donor donations has increased over time but has not kept pace with the increasing rate of patients in need. Organ shortages create pressure for appropriate allocation of organs to assure optimal utility, with priority to provide organs to those who are able to care for them. Attention to the needs and difficulties facing patients—including adjustment, substance use, and psychological distress—are important to ensure optimal outcomes.

A. ***<u>The following are the most commonly transplanted organs:</u>***
   1. **<u>Kidney (“Nephric” = “Renal” = Region of the kidneys)</u>**
      - End-stage renal disease can be secondary to various disease processes, including diabetes with renal manifestation, polycystic kidney disease, hypertension, and *nephrotoxic* (kidney damaging) drug use.
      - *Uremia* co-occurs with renal failure, which is a metabolic disturbance when waste products in the urine are retained in the blood that can also interfere with optimal cognitive functioning.
      - Dialysis is common while waiting for a viable organ, an energy- and time-consuming procedure that interferes

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_22

with day-to-day functioning and flexibility [2].
  - Kidneys can be donated from both deceased (cadaveric) donors or living donors; humans can live with one kidney.
  - Survival rates following cadaveric kidney grafts 1-year post surgery is 91.9 %, and 5-year survival is 72.0 % [1].
  - Living donor donation improves survival rate, with 95.9 % at 1 year, and 84.9 % at 5 years [1].
2. **Liver**
   - Liver transplants are most commonly performed for cirrhosis secondary to chronic viral hepatitis or alcohol abuse, though there are a multitude of diseases that can bring about the need for transplantation, including abnormalities and malformations, drug toxicity, cirrhosis, and early-stage cancers [2, 3].
   - Patients with liver disease can be lethargic and may become encephalopathic. They may demonstrate global cognitive deficits that may or may not be reversible.
   - Livers can be acquired from living or cadaveric donors.
   - Donation survival at 1 year is 87.7 %, and at 5 years is 74.3 % [1].
3. **Heart**
   - Heart transplantation is performed for patients who have been identified as having symptoms of Class IV heart failure (e.g., inability to carry on any physical activity without discomfort, with symptoms of heart failure present even at rest), and who are unresponsive to other medical therapies or procedures.
   - Heart failure can be due to ischemic disease, familial variables, viral, idiopathic, and postpartum cardiomyopathies [2].
   - One-year survival rates after a first-time heart transplantation is 87.7 %, and 5-year survival is 72.5 % [1].
4. **Pancreas**
   - Pancreas donation is typically considered for patients with advanced insulin-dependent diabetes.
   - More than 90 % of pancreas transplants are completed simultaneously with a kidney, often for diabetic patients with both renal manifestation of the disease and other diabetes-related complications [2].
   - One-year graft survival for pancreas transplant is 78.2 %, and 5-year survival is 53.2 % [1, 4].
   - Pancreas survival is typically greater in the context of simultaneous kidney–pancreas transplant compared to pancreas-only procedures, with a 91.6 % survival rate at 1 year, and 76.3 % survival rate at 5 years for those receiving the double transplant [1].
5. **Lung**
   - Lung transplant can be a treatment option for patients with chronic obstructive pulmonary disease (COPD), cystic fibrosis, pulmonary fibrosis, and pulmonary hypertension.
   - This procedure is often recommended *with* a heart transplant for patients with combined pulmonary/cardiac diseases, though this is *rarely* performed because of the reduced availability of both organs, and prioritization over patients who require only one organ [2].
   - Pulmonary rehabilitation programs can improve patients' quality of life but typically does not halt disease processes.
   - One-year survival for these patients is 83.8 %, and 5-year survival is 47.5 % [1].
   - Combined heart and lung transplant survival is 67.5 % at 1 year and 39.7 % at 5 years [1].
6. **Bone Marrow and Stem Cell**
   - Most stem cell transplants use the patient's own cells (autologous transplantation).
   - Most bone marrow transplants originate from living donors (allogenic transplantation).
   - These procedures are most often used to treat leukemias and lymphomas, aplastic anemia, and occasionally, cancers [5].

Practical Applications

The risks facing candidates emphasizes the importance of assessment and treatment of medical and psychiatric conditions, management of risk factors, and implementation of treatment at all stages.

A. ***<u>Psychiatric Disorders and Psychological Distress</u>***

1. **<u>Before transplant</u>**

   Adjustment disorders, anxiety disorders, and depression are prevalent among transplant candidates. The pretransplant period may involve significant anxiety, including fears about the procedure and mortality risk. Many patients and their families report that the wait period is the most stressful part of the transplantation process [6] with the waiting period often resulting in frustration and increased uncertainty**.**

2. **<u>After transplant</u>**

   Following transplantation, psychiatric distress, depression, and anxiety disorder rates are higher compared to the general population, regardless of organ systems and time posttransplant [7, 8]. Furthermore, postoperative depression, anxiety, and hostility have been associated with elevated levels of medical nonadherence and reduced posttransplant survival in some populations [9–11].

   - ***Mood symptoms***
   - Medications (i.e., immunosuppressants) and medical conditions (i.e., electrolyte imbalances, thyroid disorders, and nutritional deficiencies) may impact mood [6].
   - Even patients with successful transplantation procedures carry an ongoing risk of organ rejection and illness, which increases anxiety.
   - Body image changes often occur due to weight gain and surgical scarring [12]. Loss of libido and sexual activity can also occur, often secondary to poor body image.
   - ***Be aware of risk factors***
   - Psychiatric, behavioral, and psychosocial risks—are crucial to minimize posttransplant complications and improve outcomes [13]. Early identification of risks allows a treatment team to address psychological needs to optimize patient readiness for transplant [14].
   - Patients are at an increased risk for psychiatric disorders if they have a pretransplant psychiatric history, are female, have impaired physical functioning, lack social support, and have prolonged hospitalization [12, 15].
   - ***Assess Coping Skills***
     Many patients experience poor posttransplantation coping. The quality of coping skills should be examined, including ability to deal with lifestyle changes.
   - ***Be aware of mixed feelings about the transplantation process***
     Candidates may have conflicting feelings of hope, excitement, fear of surgical risk, and pondering the meaning of living with someone else's organ(s). Patients may also fear being ineligible for transplantation [12].
   - ***Psychological Screening***
     Various screening measures for mood symptoms are currently available. Commonly used depression instruments include the Beck Depression Inventory (BDI-II) and Patient Health Questionnaire (PHQ-9). An assessment of risk factors should consider comorbid psychiatric conditions, health behaviors that may influence posttransplant morbidity and mortality (i.e., tobacco use, poor eating, or exercise habits), and the patient's ability to modify health behaviors over the long term. Coping strategies can be examined with the brief COPE and the Ways of Coping Scale.

B. ***<u>Psychological Assessment and Intervention</u>***

Treatment for ongoing and emerging mood symptoms, as well as monitoring risks and changes in presentation across the transplant wait and recovery periods, is essential.

1. **<u>Medication</u>**

With the exception of autologous bone marrow recipients, organ transplantation recipients require life-long immunosuppressant therapies to prevent organ rejection.

- **Many medications have side effects.** In addition to increasing vulnerabilities to infections and other disease processes, immunosuppressant medication can cause mood swings, sleep disorders, cognitive dysfunction, gastrointestinal problems, fever, sexual dysfunction, tremors, headaches, and hallucinations, though most diminish over time [2, 16]. Newer medications have reduced prevalence of negative side effects, though pharmacokinetic interactions may occur when immunosuppressant medications are used with others to treat comorbid illnesses [17].
- **Assess the ability to adhere to the prescribed treatment**, as medication nonadherence ranges from almost 25 % to over 50 % [8, 9]. Poor adherence to medical regimens can impair life expectancy and quality of life. Up to 25 % of postoperative deaths have been related to nonadherence [9, 18]. Compliance is particularly problematic among lower socioeconomic groups, minorities, young patients (ages 20–30), and females [12].
- **Psychopharmacological treatments for mood disorders are complicated.** Many transplant patients are already on a complex regimen of medications and are at a greater risk for drug interactions when new medications are introduced. The implementation of psychotropic medication must be carefully weighed with changes in pharmacokinetics, drug interactions, and side effects [19].
- **Medication Assessment:** Monitor medication use and confirm that patients understand the importance of adherence. Monitor for both physiological and affective side effects. It is also important to be aware of over-use of pain medications to reduce potential for addiction.
- **Medication Intervention:** *Selective serotonin reuptake inhibitors (SSRIs)* have traditionally been first-line treatment to manage affective symptoms due to good efficacy and low to minimal drug interaction risk. Sertraline, escitalopram, and citalopram typically have the lowest drug interactions for these patients [9]. Mirtazapine has few drug-interaction consequences and may also benefit patients with insomnia, anorexia, and nausea [9]. Bupropion is more vulnerable to interactions and is not recommended for patients whose electrolyte abnormalities and polypharmacy leaves them more prone to seizure activity. Venlafaxine has a reduced drug interaction risk, though may increase blood pressure at higher doses. *Tricyclic* and *monoamine-oxidase inhibitors (MAOIs)* are generally not recommended due to significant pharmacokinetic and pharmocodynamic concerns [9]. *Benzodiazepines* are effective, to reduce acute anxiety symptoms, though the use should be time-limited to reduce the risks of tolerance, dependence, and cognitive compromise.

2. **Cognitive impairment**

One-third of patients with end-stage organ failure have some degree of measurable cognitive impairment, which can occur in transplant candidates before transplantation due to the medical consequences of the diseased organ, or after a procedure due to iatrogenic effects from surgery, including infection following transplant or hypoxia during surgery. Impairments can also result from other comorbid conditions (e.g., vascular disorder and diabetes), previous substance abuse or exposures, medications, or head trauma [6].

- **Assess, Understand, and Track Cognitive Functioning.** Cognitive deficits range from subtle to severe on neuropsychological testing, but even if undetectable can nonetheless impact postoperative quality of life. Cognitive difficulties can be a sign of encephalopathy, which is especially concerning in liver and kidney disease prior to transplant. Early identification of cognitive symptoms is essential in treatment monitoring and planning.

Clinicians should be mindful of medical decompensation or medication toxicity as potential causes of cognitive dysfunction so appropriate treatment can be applied. It is important to be aware of a patient's capacity to understand the transplant process and to provide informed consent. Consider establishing baseline measures of functioning in order to be able to monitor postoperative changes [2, 13].

Cognitive reductions can often be misdiagnosed as depression or anxiety, but can impact a patient's ability to comprehend and comply with treatment.

- **Be aware of delirium.** Postoperative delirium is common, and most patients typically show good cognitive recovery within a week of transplant [2, 20]. Patients may need to be reoriented to time and place, and reminded of why they are hospitalized.

  It is important to differentiate between potentially reversible delirium, which is characterized by fluctuating cognitive impairments, and more persistent cognitive deficits [6].
- **Cognitive assessment:** Psychological evaluations can offer a description of neurocognitive functioning to guide clinical management of the patient. A patient can be referred for an abbreviated or comprehensive neuropsychological assessment to establish a baseline of cognitive functioning.
- **Cognitive Intervention:** For delirium, environmental treatments are most helpful (e.g., improve sensory input, cognitive stimulation, and promote sleep). Antipsychotic medications (high-potency and atypical classes) are considered to be the first line of pharmacological treatment, with the exception of benzodiazepine use in alcohol withdrawal delirium [9]. Clinicians should be prepared to distinguish depression or anxiety from cognitive difficulties by tracking mood over time.

3. **Physical Adjustment**

   Many who undergo transplant must adjust to reduced physical capacity. Adjusting to reduced physical capacity may be especially challenging for patients who were previously active and fit individuals. For example, those with heart transplants are easily fatigued and may experience shortness of breath after short exertions. Patients with lung transplants have limited tolerance for physical exertion, and often require continuous oxygen.
4. **Adjustment to Financial, Social, and Occupational Losses**

   Patients can spend years waiting for an organ and then recovering from transplant, often sacrificing occupational accomplishments, social opportunities, and physical health.

   Transplants bring about financial hardships related to costly procedures and medication regiments. The long-term care can create a financial burden for those who remain underinsured, and those who cannot afford regiments are at greater risk for graft rejection for not complying with medication [2].

   Most patients can return to work within 9–12-months posttransplant [2]. Nonetheless, career derailment can alter financial security, and patients must adjust to the reduction or loss of this role.
5. **Substance Abuse**
   - **Be aware of patient substance use histories**, as well as their recovery and ability to maintain long-term abstinence. Many patients who are in need of transplant—especially liver—have a history of alcohol abuse or intravenous drug use. Substance use presents a challenge for

treatment teams, and it is their responsibility to allocate organs wisely and responsibly to those who will ensure the best possible outcome [9]. Treatment teams typically expect prospective transplantees to remain abstinent for a period of time, often for at least 6 months, prior to being eligible for surgery [21]. However, there is little evidence to suggest that carefully selected patients experience different rates of relapse. Current relapse estimates are as low as 3–6% of patients per year among those who had alcohol or illicit drug use histories [6, 22].

The greatest risk factors for relapse are:

- ○ Previously heavy drinkers (>17 servings daily)
- ○ Alcohol consumption for more than 25 years
- ○ History of failed rehabilitation [23]

- **Substance use assessment:** Patients at risk can be identified using standardized instruments. For example, the Alcohol Use Disorder Identification Test (AUDIT-C) can be easily administered [24]. It will also be important to collaborate with family members to be aware of substance use not disclosed by patients.
- **Substance use intervention:** **Motivational interviewing** is an effective technique in moving patients to change harmful behaviors, such as substance use, that may impede their transplant goal [25]. This technique involves aligning with patient interests, explicitly outlining their reasons for and ambivalence toward changing behaviors, and has been shown to help patients move in the direction of making positive changes.

C. ***Identify Supports***

- **Assess the patient's support structure.** Higher levels of psychological support have been shown to improve adherence and sense of control [9]. The quality of a patient's support system at both pre- and posttransplant phases should be understood to determine a patient's needs and treatment priorities.

  Support from others often include:

  - ○ Mobility and flexibility to attend appointments
  - ○ Assistance with medication dispensing and monitoring
  - ○ Aid in patient care as necessary
  - ○ Provision of emotional support
  - ○ Reliance for adjunctive care of family, children, etc.

- **Identify family and caregiver stressors.** Organ disease and transplantation also puts a burden on family members of patients, especially as family and significant others are left to manage the tasks that cannot be accomplished by the patient (e.g., child care, financial contributions, and management). Caregivers may also have to terminate employment to provide care [12]. Increased stressors on the caregiver may reduce the quality of the support available to the patient that may inadvertently impact patient adjustment and outcomes.
- **Consider psychotherapy.** Psychotherapy has many goals and benefits to maintain patient psychological health and improve outcomes. Benefits include instillation of hope for candidates, reduction of unrealistic expectations or confusion about the process, encouragement of compliance through patient empowerment, assistance with facilitation of dialog between patient and his/her transplant team [12], and reduction of body image concerns and sexual dysfunction.

  Many therapy modalities can be used:

  - ○ **Brief problem-solving** and **solution-focused** treatments can help with medical decision making, facilitate adjustment, and address any discord between patients and supports [12].
  - ○ A **cognitive-behavioral approach** is a psychotherapeutic approach used to reduce maladaptive behaviors and thought processes through goal-directed

procedures. This can be effective for transplant patients if they have unrealistic expectations of the recovery process, or when negative thought patterns threaten emotional stability [2]. Treatments can range from muscle relaxation, systematic desensitization, to visual imagery in order to reduce anxiety during the medical processes.

- ○ **Psychodynamic approaches that** rely on interpersonal relationships to reveal unconscious motivations have been used to aid in adjustment, as well. Both group therapy and individual therapy modalities have both been shown to have positive outcomes [26, 27].
- ○ **Educational interventions** might include learning and practicing healthy lifestyles and can be used to teach and encourage adherence and self-care.
- ○ **Support groups** can offer patients information about transplant recovery, an opportunity for commiseration and socialization, and support [12]. Groups can increase quality of social functioning, assist in adaptation to return to work, and increase medication compliance [2]. Groups have been shown to reduce depression and anxiety, improve coping skills, and aid in adjustment [12].
- ○ **Adjunctive therapies and tools** can be included to tailor approaches. For example, one transplant center uses yoga to encourage patients to attend to their health through physical and meditative practice [12].

D. ***<u>Graft Failure, Retransplant, and Death</u>***

- **Plan for graft failure and end of life.** Graft failures can be life-threatening, and often retransplantation may be the only treatment option. Unfortunately, many transplant recipients are not referred for retransplantation because of advanced medical status, high demand of organs, the high cost of the procedure, and evidence of poor maintenance of the first organ.

  Death is imminent for many patients with end-stage organ disease. Despite the risks, patients and family members may delay end-of-life care planning, including living wills, powers of attorney, palliative care, and do-not-resuscitate orders [6, 28, 29]. The hesitation may be in part due to denial of the disease process.

Tips

- Timely identification and treatment of psychiatric complaints and psychiatric disorders in transplant candidates and recipients is essential to optimize the outcome. Failure to treat these conditions risks patient's mortality and morbidity, as well as quality of life and self-care.
- Be aware of affective and somatic symptoms that are not attributable to the disease process itself. Thorough medical and psychiatric evaluations and follow-up are encouraged for patients to minimize psychiatric distress [6].
- Be sure to have up-to-date medication list and anticipate negative interactions before they occur.
- Monitor medication compliance for early intervention.
- Track cognitive changes over time.
- Transplant treatment teams can best prepare patients by offering support and treatment at all stages of the transplantation process, as mood disorders and psychiatric distress are common.
- Do not delay end of life planning, as the risk of graft failure, rejection, and death persists despite an initially successful transplant procedure.

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23

Intensive Care Patients

Jennifer E. Jutte

Topic

Patients participating in medical rehabilitation often come from an intensive care unit (ICU) environment and are recovering from critical illnesses or traumatic injuries. During ICU hospitalization patients can experience difficulties including lost autonomy, fear/anxiety, depressive symptoms, confusion/delirium, sleep/wake cycle dysregulation, or pain. These issues not only affect ICU and acute care hospitalization, but also can affect the rehabilitation process and recovery.

To be admitted to an ICU requires a severity of illness or injury that cannot be addressed on an acute care hospital floor. Patients often cannot breathe independently; thus their breathing is assisted via invasive or noninvasive mechanical ventilation. Patients admitted to an ICU are particularly vulnerable to psychological issues, both during their ICU stay and hospitalization, as well as longer term. Regardless of the reason for hospitalization, the ICU experience can affect patients emotionally and cognitively during their hospital stay and for years afterward.

Intensive care unit environments are characterized by high nurse-to-patient ratios and include the burns ICU (BICU), medical ICU (MICU), medical cardiac ICU (MCICU), trauma ICU (TICU), surgical ICU (SICU), and postanesthesia care unit (PACU) among others. And there are also pediatric-focused intensive care units including the neonatal ICU (NICU) and pediatric ICU (PICU). While each of these can be considered a critical care environment, for the purposes of maintaining chapter brevity, we focus solely on the MICU, MCICU, and TICU environments.

Key concepts in understanding the complexities of some common intensive care diagnoses, psychological issues experienced during intensive care hospitalization, and outcomes associated with critical illness are outlined below:

A. ***Terminology***
   1. **ABCDE Bundle**
      A coordinated effort across disciplines for management of critically ill patients. It includes: (A) AWAKENING trials for ventilated patients; (B) Spontaneous BREATHING trials; (C) COORDINATED effort between respiratory therapist and nurse; (D) A standardized DELIRIUM assessment program; and (E) EARLY mobilization and ambulation.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_23

2. **Acute Respiratory Distress Syndrome (ARDS)**
   Within 1 week of a known clinical insult or new/worsening respiratory symptoms, ARDS is a type of acute, diffuse inflammatory lung injury characterized as respiratory failure not fully explained by cardiac failure or fluid overload and with clinical features including hypoxemia and bilateral opacities identified through chest radiograph or CT scan [1]. ARDS is further differentiated by level of severity as follows [1]:
   Mild [PaO_2/FiO_2 between 200 and 300 mmHg with PEEP or CPAP $\geq$5 cmH_2O];
   Moderate [PaO_2/FiO_2 between 100 and 200 mmHg, with PEEP $\geq$5 cmH_2O]
   Severe [$PaO_2/FiO_2 \leq 100$ mmHg with PEEP $\geq$ 5cmH_2O].
3. **Acute Stress Disorder**
   The diagnostic criteria are similar to those for posttraumatic stress disorder (PTSD—see below), though there are two key differences (1) diagnosis is only made within the *first month* following a traumatic event and (2) there is greater emphasis on *dissociative symptoms* (e.g., numbing, reduced awareness, depersonalization, derealization, or amnesia). ASD is found to be highly predictive of development of PTSD. Risk factors include prior PTSD diagnosis, premorbid psychiatric dysfunction, and exposure to prior trauma.
4. **Atelectasis**
   Complete or partial collapse of a lung or lobe of a lung.
5. **Bacteremia**
   The presence of bacteria in the blood.
6. **Bronchoscopy**
   A visual or invasive examination of the breathing passages of the lungs. Involves placing a thin tube-like device (bronchoscope) through the nose or mouth and down the airways. The bronchoscope has a camera on the end of it. It is used for visual examination as well as biopsies and sample collection.
7. **COPD (Chronic Obstructive Pulmonary Disease)**
   Includes chronic bronchitis or emphysema or a combination of both. COPD is a preventable and treatable disease that makes it difficult to empty air out of the lungs and can lead to shortness of breath and fatigue.
8. **CPAP (Continuous Positive Airway Pressure)**
   Term is used interchangeably with PEEP (see below). Air is delivered to the lungs with slight pressure in an effort to prevent the airways from narrowing or closing. CPAP also is administered through a mask and often is used for treatment of obstructive sleep apnea (OSA).
9. **Critical illness**
   Condition in which life cannot be sustained without invasive therapeutic intervention. It is characterized by acute loss of physiologic reserve and can last hours to months depending on the underlying pathophysiology and response to treatment [2]. Critical illnesses often affect multiple organ systems including pulmonary, cardiovascular, renal, gastrointestinal, neurologic, and endocrine. Underlying reasons include a variety of factors such as infection, major trauma, burns, inhalation of noxious fumes, embolism, poisoning, radiation, and cancers. Although high morbidity and mortality are associated with critical illnesses, more and more people are surviving which, in turn, can lead to a host of long-term physical, cognitive, and emotional complications.
10. **CF (Cystic Fibrosis)**
    A life-threatening genetic disease in which a defective gene and its protein product cause the body to produce unusually thick, sticky mucous that clogs the lungs making it difficult to breathe. CF can result in death from lung infections.
11. **Delirium**
    A reversible, acute-onset syndrome that typically develops suddenly over a short period of time and results in transient

global cognitive dysfunction that represents a change from baseline. Delirium has a waxing and waning clinical course marked by periods of confusion and lucidity.

a. ***Three types: hyperactive, hypoactive,*** *and* ***mixed delirium***.
b. ***Four core features***:
    (1) Fluctuations in level of attention and orientation
    (2) Reduced awareness and/or perceptual disturbance (e.g., hallucinations [mostly visual])
    (3) Changes in psychomotor behavior (e.g., agitation/restlessness and lethargy/slow reaction time)
    (4) Changes in cognition (e.g., high distractibility, reduced ability to focus, sustain, or shift attention)

    Note: There are several terms often used in error to describe delirium including: intensive care unit (ICU) psychosis, acute brain failure, acute brain syndrome, and reversible dementia. You should avoid using these terms because they misrepresent the typical causes of delirium and because they overemphasize psychosis that does not always occur (e.g., hypoactive delirium).

12. **Early Mobility**
    Mobility that occurs within 24–48 h after ICU admission. Mobilizing patients who are critically ill, and often mechanically ventilated, in the ICU has been shown to be important for reducing complications such as neuromuscular weakness, though it is not common practice across ICUs [2, 3].
13. **Extubation**
    Removal of an endotracheal tube (i.e., breathing tube).
14. **F_iO_2**
    Fraction of inspired oxygen.
15. **FEV (Forced Expiratory Volume)**
    Measures how much air a person can exhale during a forced breath.
16. **Healthcare Associated Infections (HAIs)**
    Infections that people acquire while receiving treatment for another condition in a healthcare setting. HAIs affect approximately 1 in every 20 patients in a hospital setting. They cost the U.S. healthcare system billions of dollars annually and are associated with mortality, though they are preventable.
17. **Hypercapnic**
    A condition of abnormally elevated carbon dioxide (CO_2) levels in the blood. Also termed hypercarbic.
18. **Hypothalamic–Pituitary–Adrenal (HPA) Axis**
    A collection of structures involved in the regulation of the stress response. These structures include the periventricular nucleus of the hypothalamus, the anterior lobe of the pituitary gland, and the adrenal gland.
19. **Hypoxemia/Hypoxemic**
    A state in which there is low arterial oxygen supply.
20. **Hypoxia/Hypoxic**
    A state in which oxygen supply is limited in the tissues. Can be generalized or localized.
21. **ICU-Acquired Weakness**
    Diffuse, symmetric, generalized muscle weakness detected by physical examination and meeting specific strength-related criteria (namely, inability to overcome resistance on manual muscle strength testing) that develops after critical illness onset without other identifiable cause [4].
22. **Intubation**
    Endotracheal intubation is a procedure in which a tube is inserted through the mouth down into the trachea. The purpose is to allow air to flow freely into and out of the lungs to facilitate breathing. Intubation also permits use of a mechanical ventilator when patients are unable to breathe on their own.
23. **Invasive Mechanical Ventilation (MV)**
    A life-saving procedure for persons with respiratory failure. A mechanical ventilator is a machine that makes it easier for patients to breathe until they are able to breathe on their own.

- ○ ***<u>MV satisfies a couple of functions</u>***: (1) improvement of pulmonary gas exchange during acute hypoxemic or hypercapnic respiratory failure with respiratory acidosis and (2) redistribution of blood flow from working respiratory muscles to other vital organs thus aiding in the management of shock from any cause. Although life-saving, MV also can be toxic and, thus, should be removed as early as it is feasible to do so.
- ○ ***<u>Process of MV:</u>***
  - ▪ Successful intubation of the trachea
  - ▪ Endotracheal tube placement
  - ▪ Select ventilator settings
  - ▪ Ventilator mode (determines how the ventilator initiates a breath, how the breath is delivered, and the breath is terminated)
- ○ ***<u>There are several types of MV including:</u>***

1. **<u>Assist-control (AC):</u>** The tidal volume (V_T) of each delivered breath is the same whether generated by MV or the patient. AC is a patient- or time-triggered, flow limited and volume-cycled mode of ventilation. If the patient does not initiate a breath within a predetermined time interval, then the ventilator will deliver a determined V_T—this is referred to as *time-triggered*. If the patient does initiate a breath, then the ventilator will deliver a determined V_T—this is referred to as *patient-triggered*. Regardless of type of initiation, the breaths are limited to a particular flow rate and pattern.
   a. <u>Benefits:</u> low work of breathing because every breath is supported and tidal volume is guaranteed.
   b. <u>Concerns:</u> Tachypnea could lead to hyperventilation and respiratory alkalosis.
2. **<u>Synchronized intermittent mandatory ventilation (SIMV):</u>** Similar to AC except that the breaths triggered by the patient are supported with pressure instead of set volumes (see PSV described below). The volumes are determined by the patient's strength and lung abilities. Pressure support may be added to these breaths to supplement their volumes. With SIMV, ventilator-assisted breaths are different than patient-triggered breaths. If the respiratory rate on the ventilator is high, it allows for very little spontaneous breathing, whereas low respiratory rates allow for more opportunities for the patient to breathe spontaneously.
   a. <u>Benefits:</u> Allows spontaneous breaths and less ventilator support, thus allowing the patient to "exercise" their respiratory muscles.
   b. <u>Concerns:</u> May increase the work of breathing and cause respiratory muscles to become fatigued, perhaps delaying extubation and weaning.
3. **<u>Pressure support ventilation (PSV):</u>** PSV can be used alone or in combination with SIMV. In PSV, inspiratory pressure is added to spontaneous breaths, which can be helpful for overcoming the resistance of the endotracheal tube or to increase the volume of spontaneous breaths. With PSV, patients can control the rate but not depth of breaths. When added to SIMV, PSV is added only to those spontaneous breaths that occur in between volume-guaranteed breaths. When PSV is used alone, all breaths are spontaneous; the patient determines respiratory rate and V_T.

<u>Note:</u> For patients who are heavily sedated, paralyzed, or otherwise unable to breathe on their own—AC and SIMV are identical.

24. **<u>Neuroleptic Malignant Syndrome</u>**

Signs include severe muscle rigidity, elevated temperature, and other related findings (e.g., diaphoresis, incontinence, decreased level of consciousness, mutism, elevated or labile blood pressure, and elevated creatine phosphokinase) developing in association with the use of neuroleptic (i.e., antipsychotic) medication.

25. **<u>Noninvasive Mechanical Ventilation (NIV)</u>**

Assisted ventilation that is offered through a mask. Patients with hypercapnic forms of respiratory failure are more likely to benefit, though those with hypoxic respiratory failure may also benefit. NIV allows patients to take deeper breaths with less effort.

26. **PaO_2**
    Partial pressure of arterial oxygen.
27. **PEEP (Positive-End Expiratory Pressure)**
    Refers to pressure that is applied at the end of expiration to maintain alveolar recruitment. It is a term that is used interchangeably with CPAP.
28. **Personal Protective Equipment (PPE)**
    Specialized clothing or equipment worn by a hospital employee for protection against infection. In the ICU setting these include gloves, gowns, mask/respirator, goggles, and face shields.
29. **Phrenic Nerve**
    A nerve that originates in the cervical region (C3–C5) and passes through the lungs and heart to reach the diaphragm. It is important for breathing function. Damage to the phrenic nerve has been associated with prolonged hospitalization and duration of mechanical ventilation.
30. **Postintensive Care Syndrome (PICS)**
    A term used to describe "new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalization" [4]. Given the high frequency with which patients experience multiple issues across domains (physical, psychological, and cognitive) following critical illness, the Society for Critical Care Medicine (SCCM) coined the term Postintensive Care Syndrome (PICS) in 2010.
31. **Posttraumatic Stress Disorder**
    According to the DSM-V, PTSD is diagnosed when an individual directly experiences a traumatic event (e.g., physical trauma, war exposures, and sexual violence). However, PTSD symptoms also can occur after critical illness and injury and is being recognized as a common consequence of ICU hospitalization. ICU-related risk factors include longer duration of sedation; memories of adverse ICU experiences; and delirium [5]. Note: As in other treatment settings, PTSD is not diagnosed until the duration of symptoms (intrusion symptoms, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity) is *at least 1 month*.
32. **Respiratory acidosis**
    Refers to body fluids, especially blood, becoming too acidic when the lungs are unable to remove all the carbon dioxide the body produces.
33. **Respiratory alkalosis**
    A condition of low levels of carbon dioxide in the blood due to excessive breathing.
34. **Respiratory Failure**
    A syndrome of inadequate gas exchange due to dysfunction of one or more essential components of the respiratory system. May be acute, chronic, or acute on chronic. There are two main types (1) *Hypoxemic* which involves failure of oxygen exchange and (2) *Hypercapnic* which involves failure to exchange or remove carbon dioxide. *Type I* includes pneumonia, pulmonary edema (ALI, ARDS), atelectasis, and pulmonary fibrosis. *Type II* includes hypoventilation, asthma, and chronic obstructive pulmonary disease (COPD). Type I and Type II can occur separately or together.
35. **Sarcoidosis**
    A disease in which inflammation causes tiny lumps of cells to infiltrate a variety of bodily organs, in particular the lungs, but also can appear in the eyes, lymph nodes, skin, and other areas. It is most common in individuals between the ages of 20–40 who are of African-American descent as well as German, Irish, Scandinavian, Puerto Rican, and Asian ancestry.
36. **Sepsis**
    A potentially life-threatening systemic inflammatory response syndrome (SIRS) caused by severe infection that causes millions of deaths annually. Severe sepsis is complicated by organ dysfunction.

37. **Septicemia**
    This is a term that you may come across that is no longer used by the American College of Chest Physicians/Society of Critical Care Medicine Committee. Instead, the term "sepsis" is used.
38. **Serotonin Syndrome**
    Occurs when patients take serotonergic medications and is associated with new serotonergic medication or increased dosage of a serotonergic medication. Signs can include agitation/restlessness, confusion, dilated pupils, muscle rigidity, diaphoresis, high fever, seizures, irregular heartbeat, and unconscious.
39. **Spontaneous Breathing Trials (SBT)**
    Used to determine readiness for withdrawal of MV.
40. **Tachypnea**
    Elevated respiratory rate (i.e., breathing more rapidly than "normal").
41. **Tidal Volume**
    The volume of gas inhaled and exhaled during one respiratory cycle.
42. **Tracheostomy**
    A surgical procedure to create an opening through the neck into the trachea for patients who are unable to breathe on their own.

Importance

Millions of patients are admitted on a yearly basis to an intensive care unit (ICU) in the United States, accounting for nearly $80 billion in hospital expenditures and 1 % of gross domestic product [6, 7]. The number of survivors of critical illness is rapidly growing due to: the aging population, which increases ICU demand; and improving ICU mortality rates due in large part to advances in medical and surgical interventions [8–12]. Despite these advances, survival from critical illness comes at a substantial "cost" in terms of common and long-lasting physical, psychological, and cognitive outcomes and associated impairments in quality of life [12–17].

Critical illness survivors often suffer impairments associated with critical care hospitalization including muscle weakness, lingering respiratory compromise, psychoemotional difficulties (e.g., general anxiety, panic, acute stress/posttraumatic stress, and depression), cognitive impairment, and poor quality of life. In addition, survivors can experience changes in their family roles, lifestyle, ability to return to work, and overall life expectancy [12, 18–20].

Rehabilitation providers are in a unique position to provide care during ICU hospitalization that can positively affect engagement in rehabilitation therapies and longer-term physical, psychological, and cognitive outcomes.

Practical Applications

A. ***Common Issues***
   1. **Anxiety** is a typical reason for rehabilitation psychology consults in the ICU. Up to 50 % of ICU survivors experience clinically important anxiety symptoms at 1 year after hospital discharge [5], which is much higher than the US general population's 18 % prevalence for any anxiety disorder [21]. Anxiety symptoms experienced during ICU hospitalization can have an adverse impact on post-ICU psychological function and may also impact physical function due to patient's limited ability to engage in early mobility while in the ICU and/or afterward. Patients and staff alike often experience fear and anxiety particularly related to mobilizing while on a ventilator, though many studies have shown that early mobilization not only is feasible, but also is important, during ICU hospitalization [2, 3, 22].
   2. **Depressive symptoms** also are commonly experienced by persons who are critically ill in the ICU. It has been shown that depressive symptoms can be persistent or long-lasting, and they also are independently related to impairments in physical function up to 2 years following

ICU hospitalization [15]. Early intervention is thought to be key for enhancing emotional and physical function and thus, may also enhance the rehabilitation and recovery processes among survivors of critical illness.

3. **Delirium** is very common in the ICU setting with incidence as high as 60–80 % in a medical ICU [23]. This compares to 15–18 % on acute medical/surgical floors and 1–2 % in the general US population [23]. Incidence is higher in the elderly and has been associated with increased mortality. Among survivors, there is an increased likelihood of death within 1 year as compared to hospitalized patients who have not experienced delirium [23]. Some common causes for delirium include infection, medication, general anesthesia (especially among persons aged 65 and older), and toxic exposure. It is very important to identify and treat delirium early, as it has been associated with a host of complications including morbidity, mortality, and psychiatric sequelae (e.g., PTSD).
4. **Pain** is a common issue faced by critically ill and traumatically injured patients. Some reasons for pain can include physiological trauma as well as endotracheal intubation, suctioning, and other ICU-related causes. Critically ill patients often are unable to accurately communicate their pain to their providers and they experience sleep/wake cycle dysregulation and psychological complications (e.g., anxiety, depressive symptoms, and delirium) that can exacerbate their pain experience.

B. ***Assessment Instruments***

(1) **Biopsychosocial**

As with any other treatment setting or patient population, there are three key components of an individual patient that comprise the basis of a thorough rehabilitation psychology assessment: physical, psychological, and cognitive functioning. These areas of assessment are based in the biopsychosocial model that highlights the multidimensionality of individual patients as well as characteristics (state and/or trait), which may facilitate or hinder the rehabilitation and recovery processes. Assessment must consider the interplay between the person, situation, and environment. The environment in which the individual patient presently "resides" is of utmost importance in determining the choice of assessment tools.

(2) **Communication**

Patients who are critically ill often are unable to communicate via "traditional" means. Therefore, the mode of communication can become significantly important in providing a true assessment of the person's needs, as well as for identification of facilitators and barriers to treatment and recovery. Assessment measures must be feasible to administer in this setting and they must be easily understood and very brief. In addition, the majority of assessment measures are those that can be used by other providers (e.g., physicians, nursing staff, physical/occupational therapists, and speech and language pathologists) especially because the ICU setting often does not include a psychologist. And, it is of utmost importance to ensure decision making capacity when obtaining consent from a patient to engage in an assessment, intervention, or research study.

a. ***Decisional capacity assessment*** (regarding treatment decisions) must include the following key questions:
   (1) What is your present condition?
   (2) What treatment is being recommended to you?
   (3) Do you believe you still need treatment?
   (4) What do you and your medical provider think might happen if you receive treatment?
   (5) What do you and your medical provider think might happen if you do not receive treatment?
   (6) What are the alternatives available and what are the probably consequences of each?

   (7) Have you decided whether or not to go ahead with your medical provider's recommendation?
   (8) Tell me how you have reached a decision to accept/reject the recommended treatment.

b. ***Documentation*** must include the following key elements:
   (1) Ability to *communicate choice* and maintain choice over time.
   (2) *Understanding* of relevant information regarding admission and treatment.
   (3) *Appreciation* of the situation and its consequences.
   (4) Ability to *rationally manipulate* information.

Note:

- A patient who has decisional capacity may make a choice that differs or conflicts with what his/her providers [or family] recommend.
- Decisional capacity must be assessed with each different question that arises (e.g., questions pertaining to medical decisions, discharge planning, etc.).
- Decisional capacity must be assessed more than once and ideally on multiple occasions to ensure that (1) the patient is lucid when making decisions and (2) the patient's decision does not change over time (it is within the patient's rights to change his/her mind when full decision-making capacity is present).

Some of the instruments used for common referral questions are listed in Table 23.1. In order to maintain chapter brevity, these measures are not described in detail here and the reader is referred to the referenced articles.

C. ***Interventions***

Investigating psychological issues has been identified as a critical research priority for critically ill patients by the Multisociety Strategic Planning Task Force for Critical Care Research [6]. Despite this, there are limited studies that have investigated nonpharmacologic psychological-based interventions for management of psychological issues typically occurring in the ICU (e.g., anxiety, PTSD, and depressive symptoms). Thus, the intervention recommendations that follow are used or recommended, but are in need of confirmatory research. Like assessment practices, interventions must be brief and communication constraints must be considered. Typical psychological interventions in the ICU often last no longer than 30 min.

1. **General Anxiety**

   In the ICU, symptoms of anxiety are commonly managed with short-acting anxiolytic medications that have important unintended side effects including delirium [24], prolonged hospitalization [25], and anxiety symptoms after hospital discharge [5]. At this point, there are few published studies of nonpharmacologic treatment approaches tested in the ICU. Among these are (1) randomized trials of nurse-administered music therapy to reduce anxiety in mechanically ventilated patients [26, 27] and (2) a before–after observational study of nonspecific psychological management in a trauma ICU [28]. Although these interventions have shown good results in anxiety management during ICU hospitalization, in other settings music therapy has not been efficacious in anxiety management and we are unsure of any long-term benefits to this type of intervention because the studies did not evaluate outcomes after hospital discharge. The second study was observational and did not specify the role of the psychologist in the ICU or the exact treatment components that were used. These studies suggest that a nonpharmacologic anxiety management intervention is feasible in the ICU and may be effective in reducing anxiety in critically ill patients residing in an ICU setting, although, further intervention research is needed.

   a. *Modified cognitive-behavioral treatment* which may include anxiety psychoeducation; reflective listening and supportive statements; normalization of difficulties; establishment of a sense of hope; exposure to anxious thoughts/feelings; cognitive restructuring; relaxation training; problem-solving and provision of coping strategies. Additional interventional tools that may be helpful for **anxiety management** in the ICU include:

  b. *Environmental modification* including moving monitors so patients can more easily or less easily see them; relocating patients so they are closer to the nursing station; asking nursing staff to check on patients at predetermined intervals; placing "reminders" or "cues" for patients in the room where they can easily see them—for example, positive statements, cues for relaxation or distraction, etc.
  c. *Operant conditioning* approaches (e.g., provision of verbal or nonverbal rewards/reinforcement for "good" behavior to encourage further occurrence of that behavior). For example, providing the patient with a positive reward that is meaningful to him/her when he/she engages in an early mobility task.
  d. *Motivational interviewing* strategies can be useful for enhancing engagement in early mobility and also for adhering to treatment recommendations (e.g., for anxiety management).

2. **Acute Stress/PTSD**
   Patients in ICU care often experience symptoms of acute stress and depending on how long they have been hospitalized, PTSD. Risk factors include premorbid psychiatric diagnosis, high-dose sedative and opioid medications during hospitalization, and memories of delirious experiences.
   a. *Medications* considered evidence-based treatment for PTSD include sertraline (Zoloft) and paroxetine (Paxil). And there have been several studies to suggest that Prazocin also may be used for treating nightmares and improving sleep or for reducing the severity of PTSD.
   b. *Nonpharmacologic treatment* for acute stress/PTSD during ICU hospitalization is very different from outpatient treatment that often relies on exposure and narrative accounting. Managing symptoms is a priority. First, normalize symptoms and then provide psychoeducation along with reassurance that we expect symptoms to decrease in frequency and intensity over time. Symptom management may also involve providing education to staff members caring for patients so symptoms are not inadvertently exacerbated.
   c. *PTSD Prevention* may include symptom management as well as the implementation of ICU diaries, which are gaining popularity in Europe and are beginning to be trialed in the US. An *ICU diary* is a chronological narrative account free from medical jargon, the purpose of which is to fill in memory gaps and provide an understanding of what happened during ICU hospitalization. The diary is written by clinicians (especially nurses) and family members. For more information, the reader is directed to http://www.icu-diary.org.

3. **Depressive Symptoms**
   Like anxiety management interventions, there are limited studies published to date that have examined nonpharmacologic treatment of depressive symptoms in an ICU setting. One study is the aforementioned before–after observational study of nonspecific psychological management in a trauma ICU [28] that showed benefits when strategies included relaxation and other CBT-based elements. There is only one randomized controlled trial that was effective in improving physical function and depression following critical care hospitalization, although the trial was not a designed to be a depression intervention [29]. In addition, early mobilization and engagement in physical activity or exercise also may be beneficial for mood enhancement. Interventions that have been found useful in other settings also can be used in the ICU, keeping in mind communication

constraints, respiratory demands and the need for brevity due to co-occurring procedures and patient fatigue.

4. **Delirium**
   Various psychological, behavioral, and environmental interventions for delirium have been associated with improved safety, shorter length of hospitalization, and reduced complication rates. Helpful interventions include: reduced/moderate stimulation; quiet, well-lit surroundings during daytime; closed window coverings and reduced lighting at night; windows to help with time of day; quiet, uninterrupted sleep; frequent orientation, cueing, and reassurance; placement of the patient near the nursing station; clustering patient care activities; use of large clocks and calendars; large print boards; provision of glasses, hearing aids; placement of familiar objects in the room; the presence of familiar faces and use of collateral support; avoidance of restraints and preference for one-on-one observers; and pain management (pre-emptive analgesia and/or nonpharmacologic interventions [e.g., relaxation] for procedural pain and taking care not to overprescribe opioid medications). Ambulation, exercise, and range of motion also have been associated with reduced duration of delirium [3].
5. **Pain**
   Sometimes patients believe that activity will further exacerbate their pain, whereas some activity is often helpful. Therefore, provide psychoeducation about pain and activity level (what may be possible, and perhaps even beneficial). Pain management interventions that have been useful in other settings (e.g., relaxation, distraction, hypnosis, and other CBT strategies) also are helpful in the ICU, keeping in mind communication constraints, respiratory demands and the need for brevity.
6. **Family/Caregiver Considerations**
   Like patients, family members also seek security, stability, and predictability. It can be the role of the rehabilitation psychologist to fully explain procedures, routines, and delays in everyday language. Patients and family members typically only retain ~50 % of presented information in a critical care setting and, therefore, it is important to repeat information, summarize information, and utilize overlearning in a calm and direct manner.

   Recent studies have shown that *psychological issues* typically affecting critically ill patients also can affect family members and caregivers (e.g., anxiety, depressive symptoms, and difficulty adjusting to their family member's critical illness). These issues may compromise surrogate decision-making capacity and lead to long-term complications (e.g., PTSD). It is important to provide support to family members when possible to prevent deleterious complications associated with their loved one's critical illness. ICU diaries are one strategy that has been used to prevent PTSD, for example.
7. **Staff Considerations**
   One of the main areas of intervention can be with staff members. It is very important to remain mindful of the stress that staff can experience in the context of caring for critically ill patients who often wax and wane between wellness and death moment to moment. As such, staff can experience burnout and compassion fatigue. Some signs of burnout include emotional exhaustion, withdrawal, increased cynicism/negativity, reduction in empathy, and depersonalization. Rehabilitation psychologists are in a unique position to provide support to staff members not through individual counseling (due to dual roles), but rather through informational and/or didactic sessions, provision of materials and resources, and active and consistent guidance in working with complicated patients.

Tips

Isolation/Infection Control: It is highly important for all providers working in the ICU to be familiar with isolation and infection control practices. Before working in an ICU setting, you must be knowledgeable about the common infectious agents found in an ICU setting, how those agents can be transmitted, and how to protect yourself and your patients from infection.

Although ICUs account for a relatively small proportion of hospitalized patients, infections acquired in these units account for >20 % of all hospital-acquired infections (HAIs). This patient population has increased susceptibility to infection for a variety of reasons including underlying disease, invasive procedures used in their care (e.g., catheters and mechanical ventilators), and frequency of contact with healthcare personnel, prolonged length of stay, and prolonged exposure to antimicrobial agents [30].

- *Transmission of infections* requires three elements (1) a source, (2) a susceptible host with a viable portal of entry, and (3) a mode of transmission.
- *Common modes of transmission* include people (patients, providers, other healthcare workers and hospital staff, and family/friends/caregivers), environmental vectors (e.g., pens and clipboards), and intestinal gut flora already present in compromised patients.
- *Special patient groups* in the medical ICU include those with cystic fibrosis (CF). Persons with CF require additional protection, especially from contaminated respiratory equipment and because they are highly susceptible to infections.

<u>Things to keep in mind:</u>

(1) **Check signage** before entering any patient's room to determine whether any *personal protective equipment* (PPE) may be needed/required. If PPE are required:
   a. *Before entering* patient's room, PPE are put on in the following sequence (1) gown (with opening in the back and secured at the neck and waist), (2) mask/respirator (adjust to fit), (3) goggles/face shield (adjust to fit), and (4) Gloves (extended over the gown cuffs).
   b. Keep gloved hands away from face and limit contact with other PPE, items, and surfaces.
   c. *PPE removal* should occur carefully ideally at the doorway prior to exiting the patient's room (except respirator which should be removed immediately outside the patient's room) in the following sequence (1) gloves, (2) face shield/goggles, (3) gown, and (4) mask/respirator.
   d. *Immediately perform hand hygiene* which includes alcohol-based hand rub or washing with hot soap and water. If hands are visibly contaminated, hot soap and water should be used. Hot soap and water also must be used depending on suspected type of infection present (e.g., *Clostridium difficile*).

(2) When in doubt, **consult** with your infectious disease hospital representative.

<u>Communication:</u> Persons who are critically ill in the ICU often have difficulties communicating in the "traditional" ways. This can leave them feeling isolated, misunderstood and frightened. They often worry that their needs will not be met by staff members who do not understand what those needs may be. There are several ways in which we enhance communication with patients who are critically ill:

* Work closely with other providers. Including a speech and language pathologist, respiratory therapist, nurse, and other staff during a clinical interview or follow-up can be instrumental for ensuring that a patient's needs are understood and met.
* Provide the 'gift of time.' In other words, provide the patient ample time to get his/her point across. Summarize your understanding of their needs (verbally and nonverbally). And ask for their confirmation through a variety of means including head nods/shakes, thumbs up/down, alphabet board, iPad.
* Eye gaze equipment is becoming more popular in the ICU. It enables patients to communicate with eye movements who otherwise would be unable to do so via voice, head, or hand movements.
* Sip and Puff technology enables people with limited or no motor function to operate

switch-operated devices such as computers and augmentative communication devices.

- * A "talking trach" (portex blue line ultra suction aid with talk attachment) can be used and patients also can begin to communicate verbally with the use of a speaking valve (e.g., passy-muir valve).
- * Specialized "call bells" can be located close to a patient's hand, arm, or head for those persons who are unable to "call" out to the nurse or other providers.

Differential Diagnosis: Patients who are critically ill often appear nervous and agitated and refuse to engage in treatments including early mobility. These can be related to a variety of "diagnoses" including anxiety/panic, delirium, behavioral issues or premorbid personality, or other psychological disturbance. Although patients can experience delirium superimposed on dementia; a diagnosis of dementia should never initially be made while a patient is critically ill in the ICU because the patient may be experiencing "signs of dementia" for other reasons, such as delirium. It is important to meet with patients knowing the referral question, but as free from a biased impression as possible until a full assessment has been completed.

Transfer Out of ICU: Patients and family members can experience fear and anxiety when the patient is transferred from the ICU to the acute care medical floor. To some, this may seem counterintuitive—the patient's medical status has improved enough to transfer out of the intensive care setting, so why would not he/she feel better emotionally? It can feel daunting to leave an environment where the nurse-to-patient ratio is high, the patient has become accustomed to all the providers and the pace of the ICU, and the acute care medical floor is a great unknown. Some hospitals have social workers or nurse liaisons that can help to facilitate this transition. A rehabilitation psychologist can help to facilitate patient transfer by (1) asking open-ended questions for patients/family members to describe their thoughts pertaining to transfer; (2) ascertain what type of information might be helpful to them; (3) providing imaginal exposure to the acute care medical floor; (4) perhaps introducing one of their providers prior to transition; and (5) meeting with the them immediately following the transition (and beyond if necessary).

Teamwork: The ICU environment is one of acute care medicine in which there are multiple providers from a variety of specialties all working with one patient, but not necessarily with each other. When multiple providers from a variety of specialties provide information to patients, it can be confusing and patients often are left feeling that they have received mixed messages. The rehabilitation psychologist can play an instrumental role as liaison between these various teams and the patient and can help to develop a unified and understandable message that can help to alleviate patient anxiety.

Team building is extremely important, especially given the often ill-defined role of the rehabilitation psychologist in the ICU. Some of the ways in which you can do this is through:

(1) *Attending Rounds:* As often as possible, ideally on every occasion regardless of whether you are a "consultant" or member of the team. Your role is not only to discuss the particular assessment/intervention you may have done, but also to provide guidance to treatment team members for working with patients.

(2) *Attend Team Meetings:* This is an opportunity not only to discuss your patients, but also to provide guidance regarding patients you may not have seen yet—based on team members' descriptions of issues that may be occurring. This also is an opportunity to begin to be viewed as an integrated member of the team.

(3) *Didactics:* You are in a unique position to provide didactics to medical residents, therapists, and staff on a variety of topics important to them including anxiety, depression and delirium assessment and management; enhancing communication with ICU patients; boundary setting; and engaging patients who are deemed "difficult."

Establish Your Value: The vast majority of ICU settings do not have a psychologist consultant, or integrated team member, to address psychological needs in ICU settings. Thus, if you aspire to become part of a critical care unit in this capacity, then you must begin to establish your value. This can be accomplished in a variety of ways including:

(1) Provide tangible data: There is no literature regarding the financial benefits for inclusion of a psychologist in, or psychological consultant to, the ICU. However, you can cite the literature that states that nonpharmacologic psychoemotional intervention provided in the ICU is associated with improved physical and mental health [26–28] and that implementation of an early rehabilitation program in the ICU can result in cost savings across a variety of areas while improving patient outcomes including reduced length of stay, improvements in physical function and quality of life, reduced mortality, and reduced hospital readmissions [31, 32].
(2) Do your own small study—for example, to show patient acceptance of psychological intervention pre- and post-intervention. NOTE: Consult the hospital's IRB for guidance.

Boundaries: The clinician–patient relationship by definition is one of unequal status. Patients and clinicians in the ICU are especially vulnerable. Patients often are minimally clothed and compromised from physical, communication, emotional, and cognitive standpoints. While it can be appropriate to touch a patient who is lying in a hospital bed, as this can be a gesture of support, there are some key questions the ICU providers must ask him/herself with regard to any verbal or nonverbal behaviors during the clinician-patient interaction:

(1) Is this in my patient's best interest?
(2) Whose needs are being served?
(3) How will my behavior impact the intervention?
(4) How would I feel telling a colleague about this?

Conclusion: Critical illnesses expose patients to a host of physical and psychological stressors, and the resulting ICU hospitalization also can be particularly stressful both physiologically and psychologically. All providers in ICU, and specifically rehabilitation psychologists, are in a unique position to provide care to ICU hospitalized patients and guidance to their treatment teams; the ICU also is a challenging environment for ICU providers in terms of the complexity of diagnoses and interventions as well as high mortality rates despite improved practices.

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Cardiovascular Disease: Medical Overview

24

Melisa Chelf Sirbu and John C. Linton

Topic

This chapter introduces coronary anatomy, terminology, and common cardiac conditions. Common medical treatments for cardiac problems are delineated.

Importance

Cardiovascular disorders are the leading cause of mortality and morbidity in the industrialized world. In the United States alone, more than 14 million people have some form of coronary artery disease (CAD) or its complications, including congestive heart failure (CHF), angina, and arrhythmias. Many will undergo medical and surgical procedures to address their CAD, and hundreds of thousands are candidates for cardiac rehabilitation [1]. Cardiac events can be life-changing experiences that involve not only alterations in physical functioning but also challenges to adaptation in both the patient and the family.

Practical Applications

A basic understanding of the cardiovascular system and medical techniques to assess it are critical to evaluating a patient with cardiac disease. Key concepts in understanding cardiovascular events are outlined below:

A. ***Anatomy of the heart and coronary arteries***

The heart is a hollow muscle about the size of a fist. It pumps roughly five quarts of blood through the body each minute. To do this, the healthy heart beats between 60 and 80 times per minute. During physical exercise or under acute mental stress, the heartbeat can increase to more than 100 beats per minute to supply the organs and tissues with sufficient oxygen. The heart is made up of four chambers. A wall called the septum separates the left and right halves. Both halves of the heart have an atrium and a ventricle. The right side of the heart pumps already used, dark-red blood into the lungs. After the blood has been enriched with oxygen in the lungs, it flows to the left half of the heart. The left side of the heart pumps regenerated, bright-red blood into the main artery, the aorta, and supplies the body with oxygen.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_24

1. **Coronary arteries**

   The cardiac muscle needs nutrients and oxygen, which are delivered by the cardiac vessels, also known as the coronary arteries. The left side of the heart has coronary arteries in front and behind it; the right side relies on just one artery.

2. **Heart valves**

   Human heart valves are tissue-paper thin membranes attached to the heart wall that constantly open and close to regulate blood flow (causing the sound of a heartbeat). This flexing of the tissue occurs continually, withstanding about 80 million beats a year or five to six billion beats in an average lifetime. The heart has four valves, the **mitral valve** and **tricuspid valve**, which control blood flow from the atria to the ventricles, and the **aortic valve** and **pulmonary valve**, which control blood flow out of the ventricles.

3. **SA node—the body's natural pacemaker**

   The heart beats because the atria and ventricles contract rhythmically using low natural electrical signals that originate in the SA node, a network of nerves. From there, the signals spread through conductive tissue in the myocardium (the electrical conduction system) until they reach the heart's most remote cells. The SA node, which triggers the heartbeat and controls the regular sequence of the individual phases, is often called "the body's natural pacemaker" [2].

B. ***Terminology***

   Cardiovascular disease, also known as **coronary artery disease (CAD)** or **coronary heart disease (CHD)**, includes numerous conditions, many of which are related to atherosclerosis, a condition that develops when plaque builds up in the walls of the arteries. Other cardiovascular conditions also occur independently of the buildup of plaque. Patients in need of cardiac rehabilitation have either had a cardiac event or have had a procedure to address a cardiac condition. The following terms are applicable to understanding these disorders.

1. **Ejection fraction (EF)**

   A measurement of the percentage of blood leaving the heart with each contraction. During each heartbeat cycle, the heart contracts and relaxes. When the heart contracts, it ejects blood from the two pumping ventricles. When relaxed, the ventricles refill with blood. No matter how forceful the contraction, the heart does not empty all the blood from a ventricle. The term "ejection fraction" refers to the percentage of blood that's pumped out of a filled ventricle with each heartbeat.

   The ejection fraction is usually measured only in the left ventricle (LV), the heart's principal pumping chamber. An LV ejection fraction of 55 % or higher is considered normal. An LV ejection fraction of 50 % or lower is considered reduced.

2. **Total oxygen consumption (VO2)**

   The oxygen consumption of the whole body, representing the peripheral skeletal muscles rather than the myocardial muscles.

3. **Aerobic capacity (VO2 max)**

   Measures the work capacity of an individual. As the exercise workload is increased, the VO2 increases in a linear fashion until it plateaus even with increased workloads.

4. **Myocardial consumption (MVO2)**

   The actual oxygen consumption of the heart. It can be measured via the rate pressure product (RPP) since the heart rate and systolic blood pressure correlate well with the MVO2.

5. **Metabolic equivalent (MET)**

   A resting metabolic unit where one MET = 3.5 mL O2 consumed per kilogram of body weight per minute.

6. **EKG**

   An electrocardiogram, also called an EKG, or ECG, records the heart's electrical activity. With each heartbeat, an electrical signal spreads from the top of the heart to the bottom. As it travels, the signal causes the heart to contract and pump blood. The process repeats with each new heartbeat.

The heart's electrical signals set the rhythm of the heartbeat. The EKG shows how fast the heart is beating, whether the heart rhythm is steady or irregular, and the strength and timing of electrical signals as they pass through each part of the heart [3]

7. **Cardiac echocardiogram**

   An echocardiogram is a test that uses sound waves to create a moving picture of the heart. The picture is much more detailed than a plain x-ray image and involves no radiation exposure [4].

8. **Cardiac stress test**

   Exercise cardiac stress testing **(ECST)** is the most commonly used cardiac stress test. The patient exercises on a treadmill according to a standardized protocol, with progressive increases in the speed and elevation of the treadmill, usually at 3 min intervals. During the ECST, the patient's electrocardiogram, heart rate, heart rhythm, and blood pressure are continuously monitored. If a coronary arterial blockage results in decreased blood flow to a part of the heart during exercise, certain changes may be seen in the EKG in addition to the response of the heart rate and blood pressure [5].

9. **Thallium (nuclear) stress test**

   A thallium stress test is a nuclear imaging method that shows how well blood flows into the heart muscle, both at rest and during activity. An IV (intravenous line) is started, and a radiopharmaceutical, such as thallium, is injected into a vein. The patient reclines and waits for between 15 and 45 min. A special camera scans the heart and pictures how the radiopharmaceutical has traveled through the blood and into the heart. Patients then walk on a treadmill or pedal on an exercise machine. Blood pressure and heart rhythm via EKG are monitored, and with increased effort, when the heart is at maximal exertion, a radiopharmaceutical is again injected into the vein. After a waiting period, the camera again scans the heart and produces pictures. Comparing the initial and follow-up images allows an evaluation of potential heart disease onset or worsening [6].

10. **Cardiac catheterization**

    Cardiac catheterization (also called **cardiac cath** or **coronary angiogram**) is an invasive imaging procedure to evaluate heart function. It is used to evaluate or confirm the presence of coronary artery disease, valve disease, or disease of the aorta; evaluate heart muscle function, and clarify the need for further intervention such as stenting or coronary artery bypass graft surgery. During cardiac catheterization, a catheter tube is inserted into a blood vessel in the leg or arm. With X-ray guidance, the catheter is guided through the blood vessel to the coronary arteries. Contrast material is injected through the catheter, and X-ray films are created as the contrast material moves through the heart's chambers, valves, and major vessels. Digital photographs identify the site of any narrowing or blockage in the coronary artery.

C. ***Cardiac conditions***

1. **Angina.** The most common symptom of coronary artery disease is angina or "angina pectoris," also known simply as chest pain. Angina can be described as a discomfort, heaviness, pressure, aching, burning, fullness, squeezing, or painful feeling due to coronary heart disease. Often, it can be mistaken for indigestion. Angina is caused when blood flow to an area of the heart is decreased, impairing the delivery of oxygen and vital nutrients to the heart muscle cells.

   With **stable angina**, the pain is predictable and present only during exertion or extreme emotional distress, and it disappears with rest. **Unstable angina** pain is different from the pain that occurs while active. The angina may occur more frequently, more easily at rest, feel more severe, last longer, or occur with minimal activity. Although this type of angina can often be relieved with medication, it is unstable and may progress to a heart attack.

   Angina can occur in the absence of coronary disease. Up to 30 % of people with angina have a heart valve problem called aortic stenosis, which can cause decreased blood flow to the coronary arteries from the heart.

2. **<u>Atherosclerosis</u>** can affect any artery in the body, and when affecting the coronary arteries leads to coronary artery disease. Hardened plaque narrows the coronary arteries and reduces the flow of oxygen-rich blood to the heart causing angina. If the plaque ruptures, a blood clot can form on its surface. A large blood clot can block blood flow through a coronary artery. This is the most common cause of a heart attack.
3. **<u>Myocardial infarction (MI</u>**) is a major cause of death and disability worldwide. It is the medical term for an event commonly known as a **heart attack**. An MI occurs when blood stops flowing properly to part of the heart and the heart muscle is injured due to not receiving enough oxygen. Usually this happens because one of the coronary arteries that supplies blood to the heart develops a blockage due to an unstable buildup of white blood cells, cholesterol, and fat. The event is called an "**acute MI**" if it is sudden and serious.

   A person having an acute MI usually has abrupt chest pain that is felt behind the breast bone and sometimes travels to the left arm or the left side of the neck. Additionally, the person may have shortness of breath, sweating, nausea, vomiting, abnormal heartbeats, and anxiety. Women experience fewer of these symptoms than men but usually have shortness of breath, weakness, a feeling of indigestion, and fatigue. In many cases, the person does not have chest pain or other symptoms, and these are called "**silent**" myocardial infarctions.

   Coronary atherosclerosis is a chronic disease with stable and unstable periods. During unstable periods with activated inflammation in the vascular wall, patients may develop a myocardial infarction. Myocardial infarction may be a minor event in a lifelong chronic disease and may even go undetected, but it may also be a major catastrophic event leading to sudden death or severe hemodynamic deterioration. A myocardial infarction may be the first manifestation of coronary artery disease, or it may occur repeatedly in patients with established disease.
4. **<u>Heart valve problems</u>**. **Stenosis** occurs when heart valves don't open enough to allow blood to flow through as it should. **Regurgitation** occurs when heart valves don't close properly and allow blood to leak through. **Mitral valve prolapse** occurs when valve leaflets bulge or prolapse back into the upper chamber. When this happens, the valves might not close properly. This allows blood to flow backward through them.
5. **<u>Congestive heart failure (CHF).</u>** Sometimes shortened to "heart failure," this condition does not reflect that the heart stops beating but rather means the heart isn't pumping blood efficiently. The heart keeps working, but the body's need for blood and oxygen isn't being met. Heart failure worsens if untreated.
6. **<u>Chronic obstructive pulmonary disease (COPD)</u>** is a progressive lung disease that makes breathing difficult. The prevalence of COPD among patients with CHF is very high, with one in four high-risk elderly patients with CHF treated for associated COPD. In addition, COPD strongly and autonomously worsens survival in CHF patients.
7. **<u>Arrhythmia</u>** is an abnormal rhythm of the heart. There are various types of arrhythmias. The heart can beat too slowly, too fast, or irregularly. **Bradycardia** occurs when the heart rate is less than 60 beats per minute. **Tachycardia** occurs when the heart rate is more than 100 beats per minute. An arrhythmia can affect heart functioning, rendering it unable to pump enough blood to meet the body's needs.

8. **Nonischemic heart disease/nonischemic cardiomyopathy** is damage to the heart muscle that is not associated with interruptions to the heart's blood supply, as seen in cases of coronary artery disease. In ischemic cardiomyopathy, the heart muscle is damaged as a result of oxygen deprivation caused by restricted blood flow, while in nonischemic cases, the patient has another medical issue leading to injuries to the heart.
9. **Cardiomyopathy** refers to abnormalities of the heart muscle. Cardiomyopathies can have different causes and affect the heart in different ways. **Dilated cardiomyopathy (DCM)** is a condition in which the heart becomes weakened and enlarged and cannot capably pump blood. DCM is the most common form of nonischemic cardiomyopathy. It occurs more frequently in men than in women and is most common between the ages of 20 and 60 years.
10. **Peripheral arterial disease (PAD)** is a common circulatory problem in which narrowed arteries reduce blood flow to the limbs. In a typical presentation, the legs do not receive sufficient blood flow to meet demand. This causes symptoms, most notably leg pain when walking (intermittent claudication).

D. ***Pharmacological treatments for heart disease***

1. **Nitrates**

   Uses: Acute angina or prevention of angina. Dilates blood vessels to increase coronary blood flow, reduces hypertension.

   Examples: Nitroglycerin tablets (Nitroquick, Nitrostat), spray (Nitrolingual, Nitromist) or patches (Minitran, Nitro-Dur, Nitrek), isosorbide dinitrate (Isordil), and isosorbide mononitrate (Imdur, ISMO).

   Note: Viagra, Levitra, or Cialis should not be used if taking a nitroglycerin product. Always discuss patients' sexual functioning. Headaches, lightheadedness, dizziness, and dangerously low blood pressure are potential side effects.
2. **Antiplatelet Agents**

   Uses: Prevention of "platelet clumping" and clot formation. Used after heart catheterization to keep arteries open.

   Examples: Aspirin, clopidogrel (Plavix), and ticlopidine (Ticlid).

   Note: Patients should inform doctors and dentists that they are taking these agents. Proton pump inhibitors used for gastric acid such as Nexium, Prevacid, Aciphex, and Protonix can render antiplatelet drugs ineffective.
3. **Anticoagulants**

   Uses: Slows down the blood clotting process and can be prescribed for multiple reasons such as after a severe MI, cardioversion, atrial fibrillation, etc.

   Examples: Enoxaparin (Lovenox), fondaparinux (Arixtra), and warfarin (Coumadin).

   Note: Patients should inform doctors and dentists that they are taking these agents. Patients should carry a card or wear a medic alert bracelet or necklace stating they are taking blood thinners. Frequent blood tests will be required to determine the correct dosage. Drug and food interactions occur. Easy bruising and difficulty stopping bleeding are possible.
4. **Beta-blockers**

   Uses: Prescribed after MI or for heart failure to reduce the demand on the heart by slowing heart rate, decreasing the force of cardiac contractions, and reducing blood pressure. Also prevents chest pain.

   Examples: Atenolol (Tenormin), carvedilol (Coreg), carvedilol phosphate (Coreg CR), labetalol (Trandate, Normodyne), metoprolol succinate (Toprol XL), metoprolol tartrate (Lorpressor), nadolol (Corgard), and propranolol (Inderal, Inderal LA).

   Note: Patients can experience fatigue, weakness, dizziness, and slow heart rate with these medications.

5. **ACE inhibitors (ACEI)/angiotensin receptor blockers (ARBs)**

   Uses: Treatment of heart failure and high blood pressure and protects kidneys in patients with diabetes. Works by relaxing blood vessels and reducing how hard the heart has to beat to pump blood.

   Examples of ACE inhibitors: Benazepril (Lotensin), captopril (Capoten), enalapril (Vasotec), fosinopril (Monopril), lisinopril (Zestril, Prinivil), moexipril (Univasc), perindopril (Aceon), quinapril (Accupril), ramipril (Altace), and trandolapril (Mavik).

   Examples of angiotensin receptor blockers: Candesartan (Atacand), eprosartan (Teveten), irbesartan (Avapro), losartan (Cozaar), olmesartan (Benicar), telmisartan (Micardis), and valsartan (Diovan).

   Note: ARBs are typically used when patients have side effects with ACEIs, such as dry cough.

6. **Calcium channel blockers**

   Uses: Control rapid heart rate, prevent chest pain, and reduce high blood pressure. Works by decreasing the cardiac workload and reducing the required amount of oxygen for the heart.

   Examples: Amlodipine (Norvasc), diltiazem (Cardizem CD, Cartia, Dilacor), felodipine (Plendil), isradipine (Dyna Circ), nifedipine (Procardia XL, Adalat CC), and verapamil (Calan, Isoptin SR).

   Note: These can be used as second-line agents for patients who cannot tolerate the side effects of nitrates or beta-blockers or in addition to these medications in refractory patients.

7. **Statins/cholesterol-lowering agents**

   Uses: Lower cholesterol levels, prevent MI.

   Examples: Atorvastatin (Lipitor), fluvastatin (Lescol), lovastatin (Mevacor), pravastatin (Pravachol), rosuvastatin (Crestor), and simvastatin (Zocor).

8. **Antiarrhythmics**

   Uses: Treatment of abnormal heart rhythms. Works by stabilizing the heart to prevent unwanted heart rhythms.

   Examples: Amiodarone (Cordarone), disopyramide (Norpace), propafenone (Rythmol), and dofetilide (Tikosyn).

9. **Cardiac glycosides**

   Uses: Treatment of heart failure and controls atrial fibrillation at rest. Works by increasing the force of heartbeat (benefit in patients with heart failure) and controlling the heart rate (benefit in patients with atrial fibrillation).

   Example: Digoxin (Lanoxin).

10. **Diuretics**

    Uses: Used to remove excess fluid from the body and often referred to as "water pills."

    Examples: Hydrochlorothiazide (HydroDiuril, Hydro-Par), metolazone (Zaroxolyn), furosemide (Lasix), bumetanide (Bumex), spironolactone (Aldactone), and torsemide (Demadex).

E. ***Interventions***

1. **Angioplasty.** During angioplasty, a thin, flexible catheter with a balloon at its tip is threaded through a blood vessel to a narrowed artery. Once in place, the balloon is inflated to compress the plaque against the artery wall, reestablishing blood flow through the artery. This procedure is used to improve symptoms of angina as well as to reduce heart muscle damage after a heart attack.
2. **Cardiac/coronary stenting** is a placement of a tube in the coronary arteries to keep them open. It is used in a procedure called percutaneous coronary intervention or **PCI**. Treating a blocked ("stenosed") coronary artery with a stent follows the same steps as angioplasty procedures with a few important differences. The interventional cardiologist uses angiography to assess the location and estimate the size of the blockage ("lesion") by injecting a

contrast medium through the guide catheter to view the flow of blood through the downstream coronary arteries. The cardiologist uses this information to decide whether to treat the lesion with a stent, and if so what kind and size.

Drug-eluting stents (infused with medication to reduce blood clotting) most often come as a unit, with the stent in its collapsed form attached onto the outside of a balloon catheter. The stent is threaded through the lesion and expanded. The physician withdraws this catheter and threads the stent on its balloon catheter through the lesion. The physician expands the balloon which deforms the metal stent to its expanded size. It is critically important that the framework of the stent be in direct contact with the walls of the vessel to minimize potential complications such as blood clot formation. Very long lesions may require more than one stent, sometimes referred to as a "full metal jacket." The procedure is performed in a catheterization clinic ("cath lab"). Barring complications, patients undergoing catheterizations are kept at least overnight for observation.

3. **Coronary artery bypass grafting (CABG**, pronounced "cabbage"), often called heart bypass or bypass surgery, is a surgical procedure performed to relieve angina and reduce the risk of death from coronary artery disease. Arteries or veins from elsewhere in the patient's body are grafted to the coronary arteries to bypass narrowing caused by atherosclerosis and improve the blood supply to the myocardium (heart muscle). This surgery is usually performed with the heart stopped, necessitating the usage of cardiopulmonary bypass. Procedures are available to perform CABG on a beating heart, also known as "off-pump" surgery. The terms *single bypass*, *double bypass*, *triple bypass*, *quadruple bypass*, and *quintuple bypass* refer to the number of coronary arteries bypassed in the procedure. Hospitalization for uncomplicated CABG typically lasts about 5 days.
4. **Pacemaker.** When the heart beats too slowly, the body and brain receive insufficient oxygen. Symptoms may be lightheadedness, tiredness, fainting spells, and shortness of breath. A pacemaker is a small, battery-operated device that senses when the heart is beating too slowly or irregularly due to sinus node disease or heart blockage and sends a signal to the heart that makes it beat at the correct pace.

   Some pacemakers can be used to modify a heart rate that is too fast or irregular. Other types of pacemakers called biventricular pacemakers that match up the beating of both sides of the heart can be used in severe heart failure.
5. **Automatic implantable cardioverter defibrillator (AICD)** is an implanted device that monitors heart rate during heart failure. The device is programmed to speed up or slow down the heart rate as needed. The AICD shocks the heart if it detects life-threatening arrhythmias or an abnormally high heart rate. The therapeutic shock given by the AICD can allow the heart to start beating normally again. An AICD can also make the heart beat faster if it is beating too slowly. Some AICDs function as pacemakers.
6. **Heart valve repair or replacement**. Whether a valve(s) will be repaired or replaced can be decided only once surgery has begun. During valve repair, a ring might be sewn around the opening of the valve to tighten it. Other parts of the valve may be cut, shortened, separated, or strengthened to permit the valve to open and close correctly. If a valve cannot be repaired, it may be replaced with a prosthetic valve. Two kinds of prosthetic heart valves are available. *Mechanical valves* are created from man-made materials. Lifetime therapy with an anticoagulant ("blood thinner") is needed when these types of valves are used to prevent blood clots from forming on or around the valve. *Biological (tissue) valves* are taken from

pig, cow, or human donors. These valves don’t last as long as mechanical valves, but with the use of tissue valves, long-term use of an anticoagulant is seldom needed.

Tips

While this information may be detailed and complex, becoming as familiar as possible with the conditions experienced by patients with cardiac problems as well as the diagnostics and medical treatments for these conditions will better prepare you to understand and assist each cardiac patient you treat.

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Cardiac Rehabilitation

25

Melisa Chelf Sirbu and John C. Linton

Topic

This chapter addresses treatment considerations for cardiac conditions. Cardiac rehabilitation is described. Physical, psychological, and social implications for cardiac health are delineated, and tips for successful treatment of patients with cardiac disease are offered.

Importance

Coronary heart disease (CHD), with its clinical manifestations of stable angina pectoris, unstable angina, acute myocardial infarction (MI), and sudden death, affects more than 14 million Americans. Nearly 1.5 million Americans sustain MIs each year, of which about a half million are fatal. Fifty percent of MI occurs in those under age 65. Annually one million survivors of MI and more than seven million patients with stable angina pectoris are candidates for cardiac rehabilitation, as are patients following coronary artery bypass graft (CABG) [1].

Practical Applications

Interventions to supplement medical assessment and treatment are critical to the outcome of patients with CHD, stressing the need for coordinated and comprehensive care by a multidisciplinary team. Although several million patients with CHD are candidates for cardiac rehabilitation services, only 11–20 % participate. The mortality rate for CHD has fallen 47 % since 1963, with most decrease occurring from 1979 to 1989 due to modification in risk factors (cholesterol and hypertension management and reduced smoking), improved treatment methods, and improved prevention [2].

A. ***Patients with cardiac conditions on a general medical rehabilitation unit***

For many years patients with cardiac problems and other physical challenges were excluded from medical rehabilitation units, and low ejection fractions (EFs) were considered absolute contraindications to their participation. That has now changed since cardiologists follow their patients in the rehabilitation center and physiatrists and rehabilitation staff are properly trained for this population.

However, sufficient cardiac reserve is necessary for medical rehabilitation, mostly

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_25

due to the level of exertion required for rehabilitation therapies (e.g., physical and recreational therapies). A patient with an EF below 10 % would not be a good candidate for physical rehabilitation. The special needs of patients with cardiac conditions are better met in a cardiac rehabilitation center than in a general medical rehabilitation facility.

B. *Cardiac Rehabilitation*

For the first half of the twentieth century cardiac conditions were considered to be inevitably disabling and accounted for the majority of premature retirement from the labor force because the medical prescription for those with cardiac compromise was prolonged bed rest, often up to 6 weeks. This led not only to loss of strength and mobility but also to depression and perceived invalidism [3]. In the 1960s medical evidence reversed this course completely and found that increased physical activity and eventually attention to lifestyle factors were critical in the improvement of patients with cardiac conditions [4].

The central focus of cardiac rehabilitation is exercise, but programs have evolved to become comprehensive prevention centers where all aspects of preventive cardiology care are delivered to include nutrition, weight loss, management of lipid abnormalities with diet and medication, blood pressure control, and management of diabetes and psychological stress. Staff can comprise physicians, nurses, exercise physiologists, psychologists or counselors, and nutrition educators.

Cardiac rehabilitation has been found effective in significantly reducing hospital readmissions, lowering rates of recurrent sudden cardiac death, lessening need for cardiac medications, increasing return to work rates [5], and helping psychosocial adjustment [6] compared to standard cardiology care alone. However, the American Heart Association estimated that only 10–20 % of newly diagnosed cardiac patients each year are referred to formal cardiac rehabilitation programs [7]. Furthermore, less than one-third of referred patients participated in cardiac rehabilitation [8].

C. *Phases of Cardiac Rehabilitation*

Phase I Inpatient period. This occurs during hospitalization and as soon as the patient is stable following invasive procedures or acute cardiac events. The primary goal is increased mobilization of the patient to the level of activity necessary to carry out easy household tasks. Brief counseling is offered about the nature of the illness, home exercise, risk factor modification (including tobacco cessation if applicable), and planning for follow-up.

Phase II Immediate Outpatient period. This is the convalescent ambulatory program following hospital discharge, and the most closely monitored phase of rehabilitation. The length of this phase is partly determined by risk stratification and monitoring need, with 36 sessions of rehabilitation being covered by Medicare and many insurance programs. Some programs offer education classes to patients on topics such as heart physiology, cardiac conditions, managing risk factors, nutrition, stress management, and cardiac medication.

Phase III Intermediate and Phase IV Maintenance periods. This is an extended outpatient period that may be divided into *intermediate*, which follows immediate outpatient cardiac rehabilitation where the patient is not intensely monitored or supervised but still involved in regular endurance exercise training and lifestyle change, transitioning into *maintenance*, where the patient is not typically monitored but encouraged to maintain the changes from the previous phases.

D. *The Dr. Dean Ornish Program for Reversing Heart Disease*

The Dr. Dean Ornish Program for Reversing Heart Disease comprises four components: nutrition, stress management, moderate exercise, and group support. The diet is a plant-based, vegetarian, very low fat, whole food eating plan. Exercise consists of at least 3 h per week of moderate aerobic exercise, plus strength training at least twice per week. Stress management includes 1 h per day of stretching, deep breathing, meditation, progressive relaxation, and imagery. Participants also engage in 1 h of group support twice a week. Through group support participants address emotional distress, foster social connections, and promote behavioral change. Participants share a community meal and receive education on the lifestyle change program each visit. Being tobacco free is a requirement of the program. Studies have proven the Ornish Program an effective noninvasive strategy for improving both medical and psychosocial factors in patients with coronary disease, diabetes, and significant risk factors for cardiac disease [9–11]. Some question participants' ability to follow the program guidelines, but the Ornish program at the authors' site has been operational since 2001 and is working with its 39th cohort of participants at the time of this writing, with multiple participants from the first cohort still following the Ornish lifestyle.

E. Biopsychosocial Model

The biopsychosocial model is necessary for the rehabilitation of patients with cardiac conditions since the disease process can influence the individual's capacity for physical effort as well as having implications for one's self-image and role transition, and can have a considerable impact on social and family functioning.

1. **Biological**

a. *Exercise Training*

Patients in cardiac rehabilitation receive an individually prescribed exercise program with behavioral goals. Updates to exercise prescriptions and goals are made weekly according to patient progress. Patients are taught how to properly and safely use exercise equipment, and patient workload levels and difficulty are assessed with each piece of equipment used. A patient's MET level, or energy expenditure, is assessed early in the program, with changes noted as patients progress through the program. Staff evaluate expected outcomes on a set basis throughout the course of cardiac rehabilitation.

Patients are allowed to exercise only if they have taken prescribed cardiac medication prior to arrival at rehabilitation. Patients have their blood pressure checked by staff nurses or exercise physiologists before exercise. Patients identified as diabetic will also have their glucose levels checked. A series of warm ups occur before beginning exercise rotations. Patients are closely monitored while they exercise through the use of EKG monitors connected to patients' chests with wires and electrodes. These monitors assess patient heart functioning during exercise, ensuring patient safety and thereby increasing confidence as patients exercise within individualized, predetermined target heart ranges. After exercising and a brief cool down period, patients have their blood pressure checked again. Diabetic patients have their glucose levels checked again as glucose levels often continue to drop after exercise.

Some patients contend that they regularly engage in exercise through their jobs, yard work, and housework. However, patients receive education on the difference between aerobic activity, in which their heart rates are elevated for an extended period of time, and an active lifestyle, which may encompass a physically demanding job or household tasks.

Fears can be present among patients and family members when exercise is begun after a cardiac event or surgery. Despite medical assurance, patients report fear they will overtax their hearts with exercise, not know how to operate exercise machines, or look foolish due to being unconditioned. Concerns often fade when patients learn that the monitors will catch any problematic heart activity, and staff will inform them to slow down if they exceed their target heart limits. Cardiac rehabilitation staff are well-trained medical professionals prepared to assist in the event of an emergency. And knowing one can safely work up a sweat on a treadmill gives assurance when attempting household tasks one has been medically released to do. Patients are able to see a variety of degrees of conditioning, with some patients having bigger hurdles to cross than others despite outward appearance.

Family members are sometimes more fearful than patients themselves. The same reassurances provided to patients can help family members as they watch their loved one during exercise, to see for themselves the many controls in place to address safety. This can decrease worry about patients resuming medically cleared tasks at home, as some patients report annoyance at the overprotectiveness of family. Many of these issues can benefit from the normalization patients and families receive as they talk to staff and other patients in the rehabilitation setting.

b. *Physical activity counseling*

While a patient's physician has the ultimate say in resuming activities of daily living, some general guidelines exist based on research findings. While vigorous physical activity can play a role in the occurrence of cardiovascular events, the risk is reduced by regularly engaging in activity that involves an aerobic component [12]. Patients often wonder if they can safely resume sexual activity after having a cardiovascular event. The general rule is if they can climb two flights of stairs, they should be able to safely engage in sex. One study determined the risk of MI is increased 2 ½ times in the 2 h after sexual activity, with the risk decreased among those who were regularly physically active. However, the risk appears to be eliminated among patients who exercise vigorously ≥ 3 times per week [13]. The ability to safely watch an exciting sporting event is also a frequent concern among cardiac patients, with recent studies finding no association between major sporting events and cardiovascular mortality [14–16].

c. *Weight Management*

Waist circumference is a stronger indicator for future risk of cardiovascular disease [17, 18] and type 2 diabetes [18] than overall obesity, often expressed as BMI. In men, an abdominal circumference ≤ 40 in. is desirable, and ≤ 35 in. in women is recommended to lessen risk. The primary goal of cardiac rehabilitation regarding body composition is to have a patient finish the program in that low risk category.

d. *Nutritional Counseling and Behavioral Changes*

When a cardiac rehabilitation program has a nutrition educator on staff, individual meetings will often take place as patients advance through the program. Patients are asked to share a typical day's food intake to assist in evaluating their diet. Patients are asked what changes they want to make in their eating habits, and a nutrition educator can assist with turning these into concrete plans. Patients report eating out of stress, boredom, or habit, and a psychologist or counselor can be helpful in modifying these behaviors. Nutrition educators often teach psychoeducational classes to groups of cardiac rehabilitation patients and include topics such as label reading, diabetes education, sodium and the heart, and education about adapting national dietary guidelines to a cardiac diet.

e. *Lipid Management*

Nutrition educators educate patients with cardiac conditions about lipid management. Lipids are fats and serve as a source of fuel for the body. They include cholesterol and triglycerides, and both are necessary for the body to function. Cholesterol is transported through the bloodstream by carriers called lipoproteins made of fat (lipids) and proteins. Two types of lipoproteins carry cholesterol to and from cells: low-density lipoprotein, or LDL, and high-density lipoprotein, or HDL. LDL cholesterol and HDL cholesterol, along with one-fifth of one's triglyceride level, comprise total cholesterol count. This can be measured through a blood test, and *desirable levels of total cholesterol* are <145 mg/dL for cardiac protection. LDL, or “bad” cholesterol, contributes to plaque, which can clog arteries. *Desirable levels of LDL cholesterol* are ≤70 mg/dL. HDL, or “good” cholesterol, helps remove LDL cholesterol from the arteries. *Desirable levels of HDL cholesterol* are ≥45 mg/dL. When eating, the body converts any extra calories into triglycerides, which are stored in fat cells and released for energy between meals. If more calories are regularly eaten than burned, high triglycerides can result. High levels of blood triglycerides are associated with atherosclerosis and increase the risk for heart disease. *Triglyceride levels* < 150 mg/dL are recommended for cardiac health.

A heart-healthy diet can help manage blood cholesterol levels. Education about which fats raise LDL cholesterol is an important step in lowering heart disease risk. Weight, physical activity, and exposure to tobacco smoke also affect cholesterol levels.

f. *Blood Pressure Management*

High blood pressure, or hypertension, is dangerous because it causes the heart to work harder to pump blood to the body and contributes to atherosclerosis and to the development of heart failure. Normal blood pressure readings are less than 120 (systolic) over 80 (diastolic). Possible causes of high blood pressure include smoking, being overweight, lack of physical activity, excess salt in the diet, excess alcohol consumption, stress, and genetics. These risk factors are modifiable with lifestyle changes. Some patients are prescribed medication to lower blood pressure but side effects send many patients back to their doctors with concern. Education, monitoring, and support are important as patients adapt to the medication.

g. *Diabetes Management*

Managing diabetes is important to reducing the risk of atherosclerosis and cardiac events. A new diagnosis of diabetes can come as a shock to patients already coping with cardiac disease. Or patients with longstanding diabetes may wonder which is the lesser of the evils when trying to decide how to eat facing a new cardiac diagnosis. A team approach involving the combined efforts of dietitians, nurses, behavioral health staff, and exercise physiologists can be helpful in educating patients on proper diabetes management and providing the support necessary to make and maintain a health plan.

Two blood tests are used to determine how well diabetes is controlled. The *hemoglobin A1c* test provides an average of blood sugar, or glucose, levels over the previous 3 months. A blood glucose test measures the amount of glucose in the blood at any given time. A *fasting blood glucose level* will be most accurate. For people without diabetes, normal levels are <100 mg/dL.

h. *Alcohol Counseling*

The association between alcohol and heart disease is complex. For some people, even mild alcohol use comes with risk. Patients who have heart failure, cardiomyopathy, hypertension, diabetes, arrhythmia, a history of stroke, obesity, high triglycerides, or who take medications are recommended to check with their doctor before drinking alcohol [19]. Moderation is key for heart health if one does drink alcohol. Drinking more than two servings of alcohol per day for men and more than one serving per day for women increases the danger of high blood pressure, obesity, and stroke. Controversy exists about whether or not moderate alcohol consumption is cardioprotective for some people. Until more evidence is found, doctors do not recommend drinking alcohol specifically for better cardiac health, and the American Heart Association (AHA) cautions people *not* to start drinking if they do not already drink alcohol [19].

i. *Tobacco Cessation*

Tobacco cessation is one of the most important and cost effective of all lifestyle modifications to reduce the risk of coronary artery disease. As a matter of fact, almost 20 % of all deaths from heart disease in the United States are directly related to cigarette smoking [20]. Those who smoke have a two to four times greater chance of developing heart disease than nonsmokers [20, 21]. The risk of heart disease and heart attack increases with the number of cigarettes smoked and length of time smoking [20].

Nicotine causes heart disease by decreasing oxygen to the heart, increasing blood pressure and heart rate, increasing blood clotting, and damaging the cells that line the coronary arteries and other blood vessels [20]. Narrowing of these arteries causes reduced circulation and can also lead to peripheral vascular disease. In addition, cigarette smoking almost doubles a person's risk for stroke. Smoking is also harmful for nonsmokers since exposure to secondhand smoke increases their heart disease risk by 25–30 % and their lung cancer risk by 20–30 % [21].

Patients can receive assistance with tobacco cessation (with all types of tobacco use) in cardiac rehabilitation. Multidisciplinary staff are trained to educate about the risks of tobacco use and assist with cessation efforts where desired. It is of note that some patients are not ready to quit smoking and grow depressed or irritable due to constant pressure from others to quit, inadvertently adding to rather than reducing risk factors for cardiac disease. Motivational interviewing techniques can be useful here, as can simple empathy for patients who know what's healthy for them but aren't ready to make the commitment.

B. ***Psychological***

Behavioral health serves a vital role in cardiac rehabilitation but full-time behavioral health staff are extremely rare in cardiac rehabilitation settings. Some programs refer out for the behavioral health needs of their patients. Behavioral health staff may consist of psychologists, psychiatrists, social workers, licensed professional counselors, family nurse counselors, and other mental health professionals. Medicare requires assessment of psychosocial functioning of patients with cardiac conditions for reimbursement, and some programs have nonbehavioral health staff administer these surveys.

In addition to screening for psychosocial risk factors, behavioral health staff can consult with or treat identified patients to alleviate symptoms, meet with patient spouses or family, help patients make lifestyle modifications to decrease cardiac risk, and address issues such as adjustment to cardiac status, stress management, sleep hygiene, tobacco cessation, diet modification, and adherence to an exercise regimen. They can assist with resistance and backsliding that are common as patients attempt to modify longstanding habits. Behavioral health staff can also help alleviate depression, anxiety, and frustration that often accompany cardiac issues. They may treat issues that were present in patients' lives prior to cardiac status, such as family and work issues, and some patients use the availability of a therapist to disclose childhood traumas and marital issues. This is a dilemma for behavioral health staff as they decide where to draw the line with treatment in a cardiac rehabilitation unit. Robert Allan noted that patients do better with longer, more extensive treatment, with booster sessions being helpful in maintaining change. He also suggests that therapists provide a caring relationship that includes being readily available for crises that may arise [22]. Being available for all patients in a busy cardiac rehabilitation setting, screening for psychosocial risk factors, responding to crises, meeting new patients, and providing follow-up sessions for patients who desire them can prove challenging. This leads some mental health providers with little option but to refer out for more complex or long-standing treatment issues.

Behavioral health staff may also offer psychoeducational classes to cardiac rehabilitation patients, teaching relaxation and topics related to reducing psychosocial risk factors for cardiac disease, such as coping with depression or anxiety, anger management, conflict resolution, time management, using social support, the psychological aspects of eating, and dealing with grief.

1. **Depression**
   a. *Importance of Depression*

      Depression has been more consistently linked with the development and prognosis of cardiovascular disease than any other emotion studied [23]. Depression can both follow a cardiac disease diagnosis and increase risk for cardiac disease. The American Heart Association (AHA) issued a scientific statement recommending that depression be elevated to official risk factor status [24], with depression risk being comparable to traditional cardiovascular risk factors such as hypercholesterolemia and hypertension [25]. Depression is much more prevalent in patients with coronary heart disease (15–40 %) than in the general population (2.3–9.3 %) [26]. Patients respond well to having their symptoms normalized, since many express concern they're "going crazy" when reporting growing tearful at commercials, for example, after cardiac surgery. Learning they're not alone can lead to improvement in affect even before any interventions are implemented. Some depression may manifest as irritable mood or extreme "touchiness." Families may notice these changes before patients do. After an MI or open heart surgery, patients may report depressed mood decreasing as they feel relieved to be alive. Other patients report increased depression post-surgery as they feel vulnerable and ineffective when faced with their physical limitations. This depressed mood can improve as they get "back on their feet" and are able to resume more activities of daily living.

      Depression is the best psychological predictor of cardiac-related mortality 5 years after MI, even after adjusting for cardiac disease severity [27]. Both diagnosed depression and depressive symptoms are associated with mortality [27, 28], increased cardiac disease severity [29], and greater recurrence of cardiac issues [29]. Depressive symptoms have also been inversely related to cardiac rehabilitation attendance and positively related to failing to complete cardiac rehabilitation [30–33].

      At times it is concluded that a patient's cardiac symptoms must be due to psychosocial factors when those factors are not present. This can happen when all medical tests performed are normal and providers do not know how to categorize or treat the illness. Patients can feel they're being told "it's all in your head," or that it's implied they've caused their medical problems by not managing stressors properly. Often these patients have excellent coping skills and use resources and social support well. Some get relief when the true medical contributions to their illness are later found. Others come to therapy for assistance dealing with a medical community they view as punitive rather than helpful and supportive. And some patients shun the medical community completely, hesitant to report further symptoms due to fear of stigmatization.

      Many patients with cardiac disease feel guilt over "causing" their illness. They lament, "If only I'd eaten better/quit smoking/or exercised more." In these situations, bring patients back to the present and point out that if they continue their present trajectory, they could become depressed. Tell them that given what we know at the present time, we can make choices about our health in the hopes that our futures will be better as a result. Patients have responded well to this mindset and have been able to set goals and move forward in their recovery, although it is not surprising for the guilt to resurface periodically, making booster sessions helpful.

b. *Assessment of Depression*

   1. Many therapists use the **Beck Depression Inventory (BDI)** [34] to assess depression in patients with cardiac conditions [35]. The BDI-II, the revised version, is a self-report measure with 21 items that correspond to the Diagnostic and Statistical Manual of Mental Disorders (DSM) [36] depressive symptoms.
   2. The **Zung Self-Rating Depression Scale** [37] is a 20-item self-report questionnaire that assesses both affective and somatic symptoms of depression. It is easy to score, and both the instrument and scoring instructions can be found on the internet: http://healthnet.umassmed.edu/mhealth/ZungSelfRatedDepressionScale.pdf.
   3. **Caution with Interpreting.** A potential issue with the measures listed above is that positive results on somatic items such as insomnia and fatigue could be caused by medical symptoms rather than by depression [23]. Discerning the cause of these symptoms requires further inquiry with patients and disentangling physical concerns or the after effects of cardiac surgery from depressive symptoms.
   4. The **Cardiac Depression Scale (CDS)** [38] is a 26-item self-report measure designed to assess a range of depressive symptoms specific to cardiac patients. Cutoff scores to indicate varying levels of depression were not provided by the original authors of the CDS. However, cutoff scores of 90 for mild and 100 for more severe depression were later suggested [39].
   5. The **Psychosocial Risk Factor Survey (PRFS)** eliminates ambivalence regarding causes of elevated depression scales and provides well validated assessment of depression, anxiety, anger/hostility, and social isolation [40]. It also includes an emotional guardedness scale that helps determine if patients are minimizing symptoms or hiding things they don't want others to know. The PRFS was specifically designed to measure the primary psychosocial risk factors of patients in cardiopulmonary programs, and as such contains 70 self-report items tailored to this population. It provides cut off scores that alert providers to patients requiring further evaluation. It can be ordered from the Web site http://prfs1.com, which also contains free patient handouts explaining the psychosocial risk factors assessed in the survey. It can be administered both at the beginning of a patient's treatment in cardiac rehabilitation and at the end to assess for outcomes and improvement in patient symptoms.

2. **Anxiety**

   a. *Importance of Anxiety*

   Substantial data exists supporting anxiety as a risk factor for CHD [23, 41]. Before CABG operations, 28–55 % of patients have symptoms of anxiety, with about one-third still exhibiting clinically relevant symptoms 3 months later [42]. After MI, 36 % of women and 19 % of men were positive on anxiety screening [43]. Diagnosable anxiety is also common among patients with heart failure (18 %) [44], and among patients with ICDs (13–38 %) [45]. A meta-analysis conducted in 2010 examined risk of first incident CHD in people with anxiety. Anxious persons were at increased risk of CHD regardless of other biological risk factors, health behaviors, or demographic variables [46].

   Panic attack presents a dilemma in cardiac conditions. Panic attack symptoms often mimic cardiac symptoms such as palpitations, accelerated heart rate, sweating, trembling, shortness of breath, choking, chest pain or discomfort, nausea, dizziness or lightheadedness, fear of losing control or going crazy, fear of dying, numbing or tingling sensations, and chills or hot flushes [36]. Less than 4 % of people in the general population have diagnosable panic disorder, while 15–20 % of emergency room patients with chest pain are diagnosed with panic disorder [25]. Patients who have both cardiac disease and panic attacks must decide whether to go to the emergency department when they have symptoms that could be attributable to either condition. Patients report embarrassment when they go to the emergency department with chest pain only to be told they're physically fine, and might hesitate to seek help for symptoms in the future. Medical staff can be helpful in teaching such patients how to distinguish nuances in their symptoms. Behavioral health staff can also assist with anxiety about this dilemma.

Some patients demonstrate "cardiac denial" or the failure to recognize cardiac symptoms (chest pain, shortness of breath) as heart related [23]. Sudden cardiac death is often predictable, but many people have symptoms of cardiac disease they don't recognize, either through cognitive distortion or in an unconscious effort to reduce anxiety [23]. The fact that cardiac symptoms are not always clear, particularly in women, complicates the issue. Even with more "classic" cardiac symptoms (i.e., chest pain and pressure), individuals believing they're in good health often assume indigestion rather than cardiac symptoms, going to the hospital for treatment only after symptoms don't remit with gastrointestinal remedies.

Approximately 15 % of MI and cardiac surgery patients develop posttraumatic stress disorder (PTSD) in the year after their cardiac event, and adverse medical outcomes in patients with cardiac conditions have been linked to PTSD [47]. PTSD often goes undiagnosed, leaving patients with poor quality of life that could be improved with psychotherapy and pharmacotherapy. Some patients with cardiac disease recognize but downplay their PTSD symptoms assuming others have had worse trauma, and some patients retrigger past traumas through the experience of MI or cardiac surgery. Patients may also think of loved ones who have died as they consider their own mortality and realize they too could have died. Some are told by medical professionals that they're very lucky to be alive, and some report stories about coming back from death and their experiences "on the other side."

Patient fears may include being alone in case they have cardiac symptoms or traveling away from home or far from their doctor or hospital. They report fear of sleeping at night in case they have an MI in their sleep and don't awaken. Some are afraid of exercising or doing activities of daily living in fear of triggering cardiac events. Patients with automatic implantable cardioverter defibrillators fear being shocked by their medical device. And many patients become hypersensitive to body cues, particularly any emanating from their chests, and report worry over whether or not body sensations may be cardiac related and require intervention. Other patients learned they had cardiac issues by chance, perhaps receiving cardiac clearance for an unrelated surgery or during a yearly physical. These patients may worry they will have further issues develop and not know due to lack of symptoms again. Patients feel they cannot trust that their internal organs are working properly and feel vulnerable and out of control. They can lose their former identities as spouses, parents, friends, and coworkers and become "cardiac patients." The cardiac rehabilitation staff can help patients regain their identities and sense of control, viewing cardiac problems as just part of their history to be addressed through health-conscious behaviors but not the defining factor of their identities.

Worry can decrease with time and with gradual increases in exertion under monitored exercise. If a patient feels comfortable walking on a treadmill at a brisk pace, knowing that a heart monitor will alert staff to any adverse cardiac occurrence, he or she is more likely to feel comfortable doing yard work at home. Some patients feel hesitant despite medical assurance they are safe to resume normal activities, and behavioral health staff can be instrumental in addressing these fears.

Some anxious patients will appear overtly anxious but others will appear overly compliant. They might say, "I'll be the best patient you've ever seen!" out of fear they'll face certain death if they fail to follow every medical directive perfectly, over restricting caloric or sodium intake, or afraid to eat anything but salad, worried they'll cause further cardiac damage. Some patients exercise too much, logging in hours daily, afraid their arteries will begin to harden the moment they sit still. Education by the rehabilitation team is key in these situations.

b. *Assessment of Anxiety*
   1. The trait form of the **State-Trait Anxiety Inventory** [48] is a 20-item self-report questionnaire that assesses trait anxiety, cognitive symptoms that remain relatively stable despite external events. This form can be more helpful in a cardiac population than the state form, which can capture physical symptoms and mistake them for anxiety [23].
   2. The **PRFS** [40] (detailed under "Assessment of Depression") is a well-validated tool that assesses anxiety, as well as other psychosocial risk factors, in a cardiovascular population.

3. **Anger/Hostility**
   a. *Importance of Anxiety*

Anger, hostility, and aggressiveness have been found predictive of CHD in numerous studies [49–51]. People have been found nine times more likely to experience an MI in the hour after an episode of anger than during other times [52], and anger has also been linked to more rapid restenosis after angioplasty [53].

Despite the knowledge that the experience of anger is bad for their cardiac health, many patients feel stuck in situations that are likely to continue eliciting angry responses and report feeling justified in their anger. "The hook" is a tool that can prove very useful in these situations. The hook was originally developed for the Recurrent Coronary Prevention Project [54] by Lynda H. Powell and was later modified by Robert Allan [55]. It encourages patients to visualize themselves as fish "swimming through the sea of life." As will happen with fish, "hooks," with "tasty looking bait," representing "good reasons" for anger, will appear in front of them. The categories "injustice" and "incompetence" catch most anger seen as justifiable, or most of the bait. If a fish learns to spot the bait it can choose to swim on by rather than becoming angry, thereby preserving its freedom and perhaps its life. When one takes the bait and becomes angry at injustice or incompetence freedom is lost by having a *reaction* rather than getting to choose a *response* to a situation.

b. *Assessment of Anger*

The **Aggression Questionnaire** (AQ) is a 29-item self-report questionnaire that taps four domains of anger: physical aggression, verbal aggression, anger, and hostility [56]. It has been used extensively in cardiac populations and provides specific examples of behaviors and attitudes that can be addressed therapeutically [23].

The PRFS [40] (detailed under "Assessment of Depression") is a well-validated tool that assesses anger, as well as other psychosocial risk factors, in a cardiovascular population.

4. **Sleep**

Sleep problems are common after open heart surgery or a cardiac incident. Some patients report difficulty getting comfortable due to pain at the incision site, and sleep much better propped up in bed. Many sleep in recliners initially until able to transition back to their beds. Patients may also have other physical pain unrelated to cardiac surgery. Some patients benefit from basic education in sleep hygiene, and some benefit from the use of relaxation techniques to fall asleep if ruminating about worries keeps them awake. Rule out depression and/or anxiety with sleep disturbance if physical discomfort is not the cause. Patients may also benefit from sleep aids prescribed from a physician.

5. **Postperfusion Syndrome**

Also called "pump head," this is the term used to describe the cognitive decline and depression thought to result from use of a heart–lung machine during on-pump CABG, where the heart is temporarily stopped and a heart–lung machine takes over the function of the heart and lungs. This syndrome was found to typically resolve 1-year post-surgery [57]. However, more recent findings suggest the heart–lung machine may not be the culprit of cognitive decline [58, 59]. A newer study examined why postperfusion syndrome was also found in patients who had different procedures, such as off-pump surgery and no surgical intervention at all. It concluded that coronary artery disease itself is the underlying cause of the syndrome, as people who have plaque buildup in the cardiac vessels likely have plaque buildup in the arteries leading to the brain [58, 59].

6. **Vocational Issues**

The risk of a first cardiac event is increased by job strain and an imbalance between the effort and rewards of a job [60]. After an MI, job strain is associated with higher risk of recurrent CHD in men [61, 62]. Men and women post-MI with an imbalance between effort and job rewards have a higher risk of CHD recurrence [63]. Many patients readily state that their job is the reason they had an MI and report worry that they'll have another one if they don't make changes. Many patients feel financial pressure to return to work even if not medically cleared to do so. And some say that they can't return no matter what because "that job will kill me."

C. ***Social***

1. **Importance of Social Support**

Lack of social support has been linked to poor cardiac prognosis [23]. People without social support are more at risk for initial CHD incidence and subsequent mortality, and high levels of social support buffer the effects of the cardiac event [23]. Social isolation and lack of support also predict death after MI [64, 65].

People in a patient's support system can help activate and maintain lifestyle changes in the areas of diet, exercise, and stress management. Patients often begin cardiac rehabilitation because of pressure from their families. At times family members make lifestyle changes with a patient. Eating healthy food is easier if family members are not eating unhealthy food one craves. Others can unintentionally undermine patients' efforts by suggesting that "a little won't hurt" or "you can skip exercise for just today."

Patients may have access to multiple sources of support (e.g., family, friends, coworkers, neighbors, church), but hesitate to ask them for help. They may worry about appearing weak or vulnerable to others if they request assistance. Often, people with cardiac conditions are used to being the ones helping others with everything, and this unexpected role reversal can be uncomfortable. People like to feel the scales are balanced regarding the giving/receiving of help and hesitate to ask for help when they don't know for sure when or if they'll be able to return the favor due to physical limitations. When recovering from open heart surgery, patients can forget about the emotional aspects of support they can still render. Patients also worry about overburdening others with their requests for assistance ("They're so busy already;" "They have their own problems to deal with") that they don't ask. Recognizing that others are often willing to help, and are not keeping a mental tally of who owes favors to whom, can be a long process that violates deep-seated societal norms. The process is complicated even more by the fact that heart conditions are not visible on the outside. While crutches with a broken leg are easily seen, if someone looks physically healthy, asking others to lift an item off the grocery store shelf that weighs more than the 10 lb they've been told they can carry is uncomfortable.

At home, a patient may have to adapt to having someone else do tasks he or she would usually do. While not all families engage in stereotypical gender roles, men can report feelings of emasculation watching their wives mow the lawn or being driven while awaiting medical clearance. Women can report feeling helpless while their husbands tend to household chores or children. If the cardiac event or surgery requires time away from work, patients have to adapt to others filling in on their jobs. Financial stress is often present due to lost income. And some patients may not return to the type of work they held prior to cardiac diagnosis, if they are able to return at all. Some patients must apply for disability or early retirement, which is particularly difficult for younger patients. Some patients and families are at the mercy of prolonged disability decisions or need financial help from family, friends, or government institutions to make ends meet. And the added burden of medical bills leads to guilt in many patients, as they feel responsible for putting their families through hard times. Some have to adapt to sitting home while a spouse provides the sole income, or watching a spouse enter the workforce for perhaps the first time.

Patients may find themselves excluded from social excursions early in their recovery, either through their own choice due to fears of overexertion or through the assumptions of others that they "aren't up to it." Events involving food can be particularly awkward if patients are new at eating more healthily and uncomfortable eating around others who are not eating healthily. Family and friends may also feel uncomfortable eating unhealthy foods around a patient they worry may feel deprived. However, patients can lead rich social lives, including lives involving food. One of the goals of cardiac rehabilitation programs is to help patients *regain* their lives, not avoid them.

Family members may have spoken or unspoken concerns about a loved one's health or ability to return to "normal" functioning. The patient may be excluded from stress-inducing situations like making important family decisions, with the unfortunate potential consequence of making the patient feel even more helpless than before. Family concerns about finances may be hidden from patients. Others may become overprotective with good intention, fearful their loved one may face sudden death with overexertion or stress, but overprotection frustrates many patients with cardiac conditions. Doing things they are medically cleared to do is vital to their self-esteem and return from invalid status. Conversely, some patients are afraid to do household chores or return to work despite a doctor's assurance they can return to normal functioning after cardiac surgery, and families can be frustrated with attempting to both support and encourage a return to normal functioning. Cardiac rehabilitation can be helpful in these situations since patients often build self-efficacy through monitored exercise.

Socialization with other patients with cardiac conditions in rehabilitation is invaluable to patients. Patients agree that while the support of family and friends is critical, being able to talk with others who have had a cardiac event is unique and extremely valuable. For some patients, cardiac rehabilitation is the only social support they have, and they grieve when their time there comes to an end. Some find the encouragement and accountability they feel from their classmates to be the motivation they need to make recommended lifestyle changes. Patients provide normalization and validation for each other about everything from hospital experiences to strange chest twinges to where to find the best turkey hot dogs.

2. **Assessment of Social Support**

   The **PRFS** [40] (detailed under "Assessment of Depression") is a well-validated tool that assesses social isolation, as well as other psychosocial risk factors, in a cardiovascular population.

Tips

A. ***Language.*** Watch use of the term "cardiac patient." Instead, use "patient/person with a cardiac condition." "Cardiac patient" feeds into the idea of an invalid or a "cardiac cripple," who is weak and vulnerable with an identity defined by the cardiac condition. This concept is the opposite of the schema we try to build through rehabilitation.

B. ***Normalize.*** Use pattern recognition to normalize emotional and physical experiences of patients when possible. If a patient gets the honest message from the rehabilitation team that whatever strange (to them) symptom they're experiencing is something that is commonly seen and treated, hope will be instilled. Normalize where possible so patients realize they're not alone and others have walked this path before them and come out on the other side of the woods.

C. ***Be approachable.*** Use good basic interpersonal skills when approaching patients, taking note of their affect and reacting accordingly. If inpatient, remember many patients will likely be fearful with thoughts of their mortality in mind. Outpatient cardiac rehabilitation units are often laidback, pleasant settings. This is an environment for healing. Match the setting and don't present yourself as an overly serious medical professional. Patients will want to come to rehabilitation if they feel comfortable and enjoy their time there. And they will want to seek your services and ask questions of you if they view you as approachable.

D. ***Some patients don't want help.*** Some patients simply do not want to meet with behavioral health staff, no matter how approachable the staff appear. Some patients are too overwhelmed with their physical recovery to view the mind and body as connected. When in the acute phases of cardiac illness, patients are often more concerned with survival than their emotional well-being. Some patients hold onto the stigma of seeing a counselor, and some are simply not interested in change or ready to change. These patients can become frustrated if repeatedly encouraged to seek emotional assistance. Sharing contact information of behavioral staff and letting patients know of their availability if desired can plant seeds that grow later. Or patients may be more comfortable with "informally" talking with behavioral health staff while exercising. If using this approach, just be sure other patients can't overhear what is said.

E. ***Teamwork.*** If you have the benefit of being part of a multidisciplinary team, *truly* act as a team. All disciplines interact with patients, and patients may mention a pertinent psychosocial tidbit to a nutrition educator or exercise physiologist they haven't told you and vice versa. Collaborate with your team on information sharing and on treatment planning.

F. ***Boundaries.*** While it is important to share patient information with other disciplines, some information is not meant to be shared. Nurses on a cardiac rehabilitation unit do not need to know that a patient cheated on his spouse 10 years ago, and if a patient knows this information will not be shared he is much more likely to be honest and continue to share with you. Patients will often disclose information simply because they're in the company of a counselor for the first time. Explaining the limits of confidentiality pertinent to any therapeutic relationship and the boundaries particular to a multidisciplinary medical setting will help relieve patient concerns. At times families will share information with rehabilitation staff and request that staff not mention this to the patient. Letting well-meaning family members know that information shared with staff is privy to being shared with the patient up front can eliminate later conflict.

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Delirium: Risk Identification, Mitigation, and Intervention

26

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Topic

Delirium is an acute change in attention and other cognitive functions, which may also include altered consciousness and disorganized thinking. Delirium is a direct result of an underlying medical condition that occurs when the brain is overwhelmed by stressors in the body and environment. While all are susceptible to delirium, the elderly and those with cognitive impairment are at heightened risk. Delirium may present as a short-term reversible condition or persist for months and is often associated with long-term negative medical and functional outcomes [1, 2].

This chapter highlights the importance of delirium risk identification and present methods for risk identification and a standardized treatment protocol to reduce the incidence or mitigate complications using an empirically studied intervention program. Delirium risk identification, prevention, and treatment can hinder the long-term medical, functional, and cost outcomes associated with this common syndrome.

Importance

Delirium is common and underrecognized in medical rehabilitation. Estimates of delirium in the general inpatient hospital population are around 20 % with an increased incidence for elderly individuals or those with prior cognitive impairments [2]. Patients with delirium have a heightened mortality rate (39 % cumulative 1-year mortality) [3, 4]. In the perioperative period, the incidence of postoperative delirium varies by type and urgency of surgery. For example, patients hospitalized due to hip fractures have one of the highest incidences, due in part to the pre-existing cognitive and physical frailty leading to the fracture, and also to the acute onset of the condition and urgency of the surgery. By comparison, elective and outpatient surgery typically results in lower incidences of delirium [2]. The reported incidence rate of delirium can be affected by the methods used for assessment.

Substantial delirium costs can include iatrogenic complications, longer lengths of stay, longer intensive care unit stay, and higher rates of discharge to rehabilitation and nursing homes. The definitions of delirium variants and methods

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_26

to assess, prevent, and treat delirium are described in the following section.

A. ***Types***

Delirium is classified as **hyperactive**, **hypoactive,** or **mixed**.

1. **Hyperactive delirium** accounts for about 25 % of cases and is often detected following a disruption in patient care. Patients with three or more of the following symptoms are considered "hyperactive": hypervigilance, restlessness, irritability, combativeness, impatience, swearing, singing, laughing, euphoria, anger, wandering, fast motor responses, easy startling, distractibility, tangential discourse, nightmares, persistent thoughts, and fast or loud speech.
2. **Hypoactive delirium** is the most common presentation (50 %), and unfortunately less detected as it may be assumed the patient is simply sleepy. Patients who have four or more of the following symptoms are considered "hypoactive": lethargy, unawareness, decreased alertness, sparse or slowed speech, staring, slowed motor responses, and apathy.
3. **Mixed delirium** is the subtype where patients exhibit both hyper and hypo active symptoms and represents the remaining 25 % of cases.

B. ***Predisposing Factors***

Predisposing risk factors for delirium include older age, male gender, existing cognitive impairment (most common independent factor), severity of dementia, sensory impairment, depression, functional dependence, immobility, alcoholism, atherosclerosis, stroke, multiple comorbidities, and metabolic abnormalities [3].

C. ***Precipitating factors***

Medications, severe illness, infection, hyponatremia, hypoxemia, dehydration, fracture, shock, pain, physical restraint, surgery, alcohol and tobacco use, duration of cardiopulmonary bypass, sleep deprivation, intensive care admissions, and a high number of hospital procedures often preclude onset of delirium [3].

Practical Applications

Delirium is a geriatric syndrome, a highly prevalent constellation of symptoms with multiple underlying factors that is more common in the elderly and is associated with increased disability. There is no treatment aside from addressing the underlying cause. Prevention strategies have shown to reduce delirium incidence up to 40 % [4]. Additional strategies can mitigate complications for patients and caregivers once delirium develops.

A. ***Prevention of Delirium***

1. **Nonpharmacological** strategies should be implemented for all patients identified as moderate and high risk for delirium. These interventions should include clinical protocols and supplies to improve preexisting vulnerabilities and avert iatrogenic complications. For example, nonpharmacological sleep protocols (i.e., dedicated time to sleep with lights off and relaxing environment), patient-centered care, and education for caregivers about delirium risk. More nonpharmacological interventions are detailed below under Interventions: Delirium Toolbox [5].
2. **Pharmacological** prophylaxis is not supported as most studies have been small and underpowered to detect a difference in delirium [6]. A study of acetylcholinesterase inhibitors as prevention was halted after less than 25 % of enrollment due to increased risk of death in those treated with rivastigmine [7]. In contrast, Dexmedetomidine, an alpha-2 adrenergic receptor agonist used for sedation, has been associated with lower incidence of postoperative delirium [8] and may be warranted in critically ill patients if the benefits outweigh potential adverse events.

B. ***Assessment/Screening***

Screening for delirium should occur upon admission and at least daily on general medical wards. In higher intensity situations (e.g., intensive care, postoperative, etc.), screening

Table 26.1 Common causes and explanations for delirium

Cause	Explanation
Medications	New or existing:
	– Anticholinergic medications; antispasmodics; benzodiazepines; steroids; opioids
	Underuse:
	– Withdrawal from benzodiazepines, antidepressants, opioids and dementia medications; undertreated pain; alcohol withdrawal
Microorganisms	Urinary tract infection; aspiration pneumonia; pressure ulcer; venous catheter infection
Metabolic	Electrolyte abnormalities; uremia
Micturition	Urinary retention; constipation; urinary catheter
Myocardial	Myocardial infarction; pulmonary embolism; congestive heart failure; hypoxia
Mind	Acute stroke; intracranial hemorrhage; brain mass/metastases; other psychiatric diagnosis

should be more frequent. Prehospitalization cognitive assessments determine delirium risk, document baseline performance, and thus, help detect delirium during acute episodes and guide delirium prevention interventions.

1. **Etiology of delirium**

   Importantly, absence of evidence for an etiology is not evidence for absence of delirium. Detecting and treating the underlying problem(s) may be determined using the following Table 26.1 [1].

2. **Assessment**

Serial assessments can help detect as well as monitor for further changes.

a. *History*—Gathering history from the patient, family, or nurse is important for identifying when changes first appear. Serial assessments such as those utilized in the CAM-ICU are helpful at identifying changes during hospitalization [9]. Additional questions include: When were symptoms first detected? Time Course? Trauma? Medications changes? Recent changes in other conditions?

b. *Standardized Mental Status Assessment*—There are many instruments that have been utilized in the literature for the diagnosis of delirium. Importantly, the sensitivity and specificity of these measures often varies depending on the performance of standardized cognitive assessment.

c. *Diagnostic Algorithms*—DSM5 criteria requires cognitive assessment of attention and other cognitive domains to detect delirium [10]. While the validity of these criteria remains to be validated, a broad interpretation of the criteria is more closely associated with past definitions of delirium [11].

d. *Operationalized Definitions*—The 4-AT is a valid diagnostic algorithm that has been validated for delirium, is available for clinical use, and has been clinically operationalized [12]. The algorithm includes attention, alertness, orientation, and alteration.

The Confusion Assessment Method is a diagnostic algorithm for delirium that has high sensitivity and specificity when accompanied by supplemental cognitive testing [13]. The CAM includes acute mental status change and fluctuating course, inattention, disorganized thinking, and altered level of consciousness [14]. The CAM ICU provides an operationalization of the CAM Criteria for nonverbal patients [15].

The Modified Richmond Agitation and Sedation Scale (mRASS) is a valid and reliable scale of consciousness [16] that has been modified for verbal patients. While a single mRASS lacks sensitivity for delirium, monitoring the mRASS for change over time is associated with increased sensitivity and specificity [17].

C. ***Management of Delirium***

Once delirium has developed, the proper treatment is to identify and treat the underlying cause. In accordance with clinical practice guidelines, nonpharmacological measures should be attempted while treating the underlying causes in an effort to reduce the agitation associated with delirium. A standardized program is described below:

1. **The Delirium Toolbox**

   A delirium risk modification program that has been associated with improved hospital outcomes and lowered costs for older patients [5]. The strategy of the delirium toolbox is fourfold:

a. ***Identify*** patients at greatest risk.
b. ***Inform*** treatment teams with clinical notes/education.
c. ***Intervene*** to reduce risk with tools to improve sensory improvement, sleep promotion, and cognitive stimulation.
d. ***Monitor*** longitudinally for changes in consciousness indicative of delirium.

The risk identification process includes screening with assessment of cognition and attention, vision or hearing deficits, and dehydration. Once completed, the clinical team is informed of delirium risk via a note in the medical record.

2. **Interventions**
   a. ***Preventative interventions*** have been summarized in systematic reviews [4].
      (1) *Cognitive impairment*
         - Reality orientation (e.g., repeated verbal reminders of the day, time, location and identity of key providers and pictures of family members)
         - Day/night orientation
         - Family members present when possible
         - Large print calendars
         - Memory games
         - Modeling clay to manipulate
      (2) *Sensory impairment*
         - Reading glasses accessible
         - Hearing aids accessible
         - Rule out cerumen impaction
         - Magnifiers
         - Hearing amplifiers
      (3) *Immobilization*
         - Early mobilization
         - Assistive devices
         - 4-prong canes or walkers
         - Early PT/OT
         - Remove restraints
      (4) *Sleep deprivation*
         - Minimize nighttime disturbances
         - Ear plugs
         - Sleep masks
         - Open curtains during day hours to facilitate sleep/wake schedule
      (5) *Dehydration*
         - Early recognition
         - Fluids at bedside
         - Monitor volume repletion
         - Straws
         - Easily grasped containers [18]

D. ***Differential Diagnosis***

Delirium is a clinical emergency and serious consequences can occur if it is not promptly identified and treated. Table 26.2 provides

Table 26.2 Differentiating delirium, depression, and dementia

	Delirium	Depression	Dementia
Onset	Acute	Subacute/chronic	Chronic
Cognitive domain(s)	Attention	Severe depression can cause deficits in cognitive function	Memory
Reversible	Potentially	Yes	No
Future vulnerabilities	Long-term care, decreased functional ability, prolonged cognitive sequelae, and death	Decreased functional ability	Long-term care, decreased functional ability, and death

differential diagnosis from other diagnoses that have overlapping features. In the hospital setting, delirium should be assumed and ruled out prior to making a diagnosis.

Tips

- Improve sensory input, cognitive stimulation, and sleep promotion.
- Provide hydration if patient is medically cleared.
- Take delirium seriously as a medical emergency.
- Educate staff and family caregivers about delirium: what it is, why it matters, and how risk can be mitigated.
- Train nurses to screen for delirium and implement nonpharmacological interventions.
- Assess patients for delirium risk 24 h prior to surgical procedures.
- Monitor for delirium throughout the hospital stay.
- Encourage the treatment of the underlying causes of delirium (labs to detect infections and medication review).
- Utilize nonpharmacological behavior management techniques when patients are exhibiting symptoms of hyperactive delirium.
- Remove physical restraints whenever possible.

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27

Suicide Risk Assessment and Intervention: Considerations for Rehabilitation Providers

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Topic

A. ***Self-Directed Violence (SDV) Classification System***

Suicide is the tenth leading cause of death in the United States (US) [1]. The **self-directed violence (SDV) classification system** provides a comprehensive taxonomy of terms and definitions that facilitates providers and researchers having a common understanding and language for suicidal thoughts and behaviors [2]. The following terms and definitions are from the SDV Classification System and Centers for Disease Control and Prevention (CDC) [2, 3].

- **Suicide** is defined as death caused by self-inflicted injurious behavior with any intent to die a result of the behavior [2]. CDC data from 2011 showed that 39,518 individuals died by suicide in the United States during the previous year, averaging approximately 108 suicides each day [4].
- **Suicidal ideation (SI)** is when people think about, consider, and/or plan for suicide [3]. Based on annual averages, data from 2008 to 2009 suggested that an estimated 8.4 million US adults aged 18 and older reported experiencing suicidal thoughts within the previous year [5].
- **Suicidal intent** refers to past or present evidence that an individual wishes to die, means to kill themselves, and understands the probable consequences of their actions or potential actions [2].
- **Preparatory behavior** is defined as acts or preparations toward engaging in SDV, but before potential injury has occurred. This

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_27

can include anything beyond a verbalization or thought, such as assembling a method (e.g., buying a gun, collecting pills) or preparing for one's death by suicide (e.g., writing a suicide note, giving things away) [2].

- A **suicide attempt (SA)** is a nonfatal self-inflicted potentially injurious behavior with any intent to die as a result of the behavior [2]. Data from 2008 to 2009 indicated that an estimated one million US adults reported making an SA in the preceding year. Further, a suicide to SA ratio of 1:25 has been reported [5].

1. **Risk factors, protective factors, and warning signs**
   - **Epidemiological research findings** support several suicide **risk factors** that are associated with SDV on the population level. Research has shown that most risk factors are **non-modifiable** and include race, ethnicity, gender, age, individual and family history of SAs, and trauma history [6–8]. However, other risk factors are **modifiable** and may be changed with intervention. Mood dysregulation, medical diagnoses, low self-esteem, and attitudes about suicide are examples of modifiable risk factors [9].
   - Based on epidemiological research, **protective factors** on the population level are characteristics that are associated with decreased likelihood of engaging in SDV. Protective factors can include access to evidence-based interventions, effective clinical care, connections with social supports, and belief systems that discourage suicide (e.g., cultural, religious, personal values) [8].
   - Research has highlighted the necessity of assessing **risk and protective factors**; however, the changing nature of these factors can make it difficult to predict behavior and to know when to intervene. For example, the breakup of a once supportive relationship that served as a protective factor may subsequently serve as a risk factor. Furthermore, because risk and protective factors are typically derived from research on a defined population, they may not be personally meaningful to any given individual. Therefore, providers should also be attuned to patient specific **warning signs** to inform immediate intervention. Rudd et al. defined a warning sign as "the earliest detectable sign that indicates heightened risk for suicide in the near-term (i.e., within minutes, hours, or days)" ([7], p. 258).
   - **Warning signs** are precipitating emotions, thoughts, or behaviors that imply acute and imminent risk. They may be new behaviors and/or increased pre-existing behaviors [7, 10]. For example, emotional distress related to changes in a relationship status may increase the likelihood of imminent SDV for one individual, while substance use relapse may serve as a warning sign for another.
   - **Comprehensive risk assessment** should include inquiry regarding research-identified risk and protective factors and personally meaningful warning signs.

Importance

- **Chronic health conditions** are known risk factors for death by suicide, as well as nonfatal SDV, likely due to their influence on physical well-being, mental health symptoms, and cognitive and psychosocial functioning.
- **Rehabilitation providers** should engage in routine suicide risk assessment and intervention. Individuals with diagnoses commonly associated with risk include cerebral vascular accidents (CVA), amyotrophic lateral sclerosis (ALS), epilepsy and Huntington's disease (HD), multiple sclerosis (MS), Parkinson's disease (PD), spinal cord injury (SCI), and traumatic brain injury (TBI) [11–42].
- **Comorbid psychological symptoms** including depression and hopelessness have been shown to be key factors associated with increased risk for suicidal thoughts and behaviors among general and rehabilitation populations.
  - **Depression** is a well-known suicide risk factor with over 50 % of those with clinical depression experiencing SI [43].
  - **Hopelessness** is also a risk factor for suicidal thoughts/behaviors, with greater

predictive power than depression itself [44, 45]. Hopelessness has been identified as a precursor to the development of SI and can also increase the risk of suicidal behavior [35, 40, 41, 46, 47]. In studies of depressed patients and those experiencing their first psychotic episode, interventions that reduced hopelessness demonstrated the potential to lower suicide risk [45, 48–50].

- **Recommendations**: Rehabilitation providers should be attuned to suicide **risk factors, protective factors,** and **warning signs** with **routine inquiry** regarding suicidal *thoughts, plans, and intent to engage in SDV*. **Routine assessment** encourages an open and active dialogue between patients and staff that may facilitate acute (e.g., utilization of safety plan) and longer-term (e.g., psychotherapy) intervention. Additional considerations are detailed below.

Practical Applications

A. ***Assessment***

1. **Clinical interview**
    - **Gather history of suicidal thoughts, behaviors, and medical treatment and/or hospitalizations** that may have resulted from SDV. Further, gathering information related to **history of others known to the patient (i.e., friends, family, peers) that have died by suicide** may help to inform the clinical picture.
    - Information regarding the **context** within which SI and/or behaviors may be presenting is helpful. Providers should work with patients to **identify times when the patient may be most likely** to experience ideation and/or engage in SDV. If the patient has difficulty with identifying patterns, consider using a tracking form on which the patient can keep a record of what they were doing before experiencing ideation or engaging in suicidal behavior. Doing so will facilitate appropriate intervention including safety planning as discussed below.
    - **Identify risk factors, protective factors, and warning signs.** Determine which factors may be modifiable and, if so, how changes in factors may increase and/or decrease SDV risk. For example, employment may serve as a protective factor, but if lost may quickly become a risk factor. Alternately, the lack of access to psychiatric medication may serve as a risk factor that when refilled may serve as a protective factor.
    - Due to the **fluid and dynamic** nature of risk over time, **assess fluctuations** in acute risk factors/warning signs. Because **acute suicidal crises are time limited**, it is important to note the presence of chronic risk factors to determine baseline suicide risk [51].
    - **Joiner's interpersonal theory of suicide** may be useful in helping the provider conceptualize aspects of suicide risk. For example, individuals may have the desire to die by suicide if they experience *perceived burdensomeness* (i.e., an individual perceiving that they are a burden on their family, friends, and/or community) and/or *failed belongingness* (i.e., an individual feeling that efforts at establishing and maintaining social connectedness have been thwarted or have failed). Additionally, an individual who has engaged in painful and provocative events (including prior SDV) may have greater levels of *acquired capability* (i.e., an individual develops the ability to engage in suicidal behavior due to fearlessness about death and dying and/or pain habituation) [52]. The presence of each of these factors may be associated with increased risk of SI and/or SDV. Therefore, providers may benefit from asking questions aimed at gathering information in each of these areas to augment risk assessment.

When conducting assessment, providers should identify:

- If patients are experiencing **acute and/or chronic *ideation*** or thoughts about suicide
- If the patient has been engaging in **preparatory behavior** and/or has a ***plan*** to engage in SDV
- If the patient has ***intent*** to carry out the plan. Providers should be sure to ask about means by which to carry out the plan, likelihood of following through with the plan, facilitators and barriers to being able to carry out the plan, and intervene as appropriate with regard to means restriction and safety planning (see Intervention section below).

2. **Formal measures**

Comprehensive and ongoing risk assessment is strengthened by the use of formal measures. Rehabilitation providers may benefit from incorporating the following measures into routine and serial assessment.

- The ***Beck scale for suicide ideation (BSS)*** is a 19-item scale that assesses severity of SI within the previous week with total scores ranging from 0 (no SI) to 38. The assessment includes items to determine wish to die, desire to attempt suicide, duration and frequency of ideation, and preparatory behavior among others [53].
- As depression is often associated with suicide risk, the ***Beck Depression Inventory-second edition (BDI-II)*** may prove helpful for symptom tracking. The BDI-II is a widely used self-report instrument measuring the severity of regularly reported depressive symptoms. Each of its 21 items are rated on a four-point Likert scale ranging from 0 to 3; total scores range from 0 to 63, with higher scores indicating greater degrees of depressive symptomatology. This measure also includes assessment of SI (item #9) [54].
- As reported above, research has shown that hopelessness is associated with suicide risk. The ***Beck Hopelessness Scale (BHS)*** is a 20-item true-false self-report scale that measures the level of negative expectations about the future held by respondents over the previous week. Scores range from 0 to 20 representing nil (0–3), mild (4–8), moderate (9–14), and severe (>14) levels of hopelessness [55]. Beck et al. found that BHS scores equal to or greater than 9 were associated with significantly elevated levels of suicide risk [45]. Of note, this measure has been found to be useful with TBI populations [35].

B. ***Intervention***

1. **Safety planning**

- A safety plan is a brief clinical intervention that allows patients to identify and list warning signs, coping strategies, supports, and emergency resources should they find themselves in crisis. The safety plan consists of **six steps** (listed below), which provide organized and stepwise strategies for the patient to utilize at onset of ideation through involving urgent care resources to ensure safety.
- **Creating a plan while calm and with support** allows the patient to think through strategies that may be most effective in a time of crisis to ensure safety. Stanley, Brown, and others created a manual for Veterans Administration (VA) providers to facilitate safety planning with veterans [56]. However, non-VA providers are welcome and encouraged to utilize safety planning with their patients.
    - **Step 1: Recognizing warning signs**
    - **Step 2: Using internal coping strategies**
    - **Step 3: Social contacts who may distract from crisis**
    - **Step 4: Contacting family members or friends who may offer help to resolve a crisis**

- **Step 5: Contacting professionals and agencies**
- **Step 6: Reducing the potential for use of lethal means**

For information regarding VA safety planning including a safety plan template, please see the safety planning manual by Stanley, Brown, and others, which can be downloaded from the address below: http://www.mentalhealth.va.gov/docs/VA_Safety_planning_manual.pdf [56].

Signoracci, Matarazzo, and Bahraini described several strategies to facilitate effective safety planning with those with TBI [57]. These strategies are designed to be inclusive and may be utilized at all levels of functioning (Table 27.1).

Table 27.1 Strategies to facilitate effective safety planning with those with TBI

Strategy	Function	Example/s
Slow pace of conversation	Facilitate learning and memory for individuals who may become overwhelmed with auditory information	N/A
Use patient's language	Reduce miscommunication while facilitating establishment of rapport	Clinician uses same language as an individual who refers to a difficult experience with a particular term or phrase (e.g., "the accident," "when I got hurt," etc.)
Take short breaks	Prevent cognitive overload	Input from individual will be helpful to determine length of breaks needed and when breaks should be implemented to be most helpful
	Increase opportunities for consolidation of information	
Write things down/draw things out collaboratively with the patient	Facilitate organization	Write down key points/information/examples when in session
	Facilitate learning and memory for individuals who may become overwhelmed by auditory information	Draw timelines to capture sequence of events that may have preceded crisis
	Facilitate understanding of circumstances and events that may precede suicidal ideation and/or engagement in self-directed violence	
Utilize visual cues	Create environmental prompts to engage in coping strategies	Posting safety plans, pictures representing protective factors, inspirational quotes in easy to see/highly used areas
Incorporate supports proactively	Consistently engage social supports to reduce isolation and increase active engagement in coping strategies	Regularly scheduled check-ins with social supports
	Educate social supports about the plan, and incorporating them in a proactive and meaningful way may increase likelihood of successful implementation of the safety plan	Appointments (medical, mental health, social support groups, community activities)
		Sharing the safety plan with social supports identified in the plan
Ask the patient to provide summaries	Provide opportunity for individuals to consolidate and articulate their understanding of information	Individual provides a summary of self-assessment (e.g., When I am by myself for long periods of time, I am more likely to hurt myself)
		Individual provides a summary of planning strategies (e.g., After I have been by myself for more than 3 h, I will call someone listed on my safety plan and make arrangements to spend time together)

(continued)

Table 27.1 (continued)

Strategy	Function	Example/s
Role-play	Practice engaging in coping strategies with support and opportunities for modification to reduce challenges/barriers and increase problem solving	Practice engaging in coping strategies
		Practice using the safety plan (calling supports, engaging in self-care activities, etc.)
Utilize patient identified coping strategies and work collaboratively to design implementation	Increase likelihood of implementation of safety plan by planning engagement in meaningful activities that facilitate coping	Provider facilitates planning for meaningful activities as identified by the patient (e.g., working out, calling a support, spending time with favorite pet)

2. **Means Restriction**
   - **Limiting access to lethal means** of SDV is an important component of suicide prevention [58]. For example, if an individual has identified a plan for SDV that includes death by self-inflicted gunshot or hanging, then limiting access to items to implement this plan serves as a critical preventive strategy. Means restriction may include removal of guns or other weapons from the home or place of easy access. For some, removing bullets or securing weapons (e.g., gunlock) is sufficient. Blister packaging medications may also facilitate risk reduction for individuals that have attempted suicide by overdosing on medications, have identified this as a potential plan for SDV, or are prone to impulsive acts of SDV. Evidence supports the use of blister packaging for medications to facilitate adherence to regimen while also serving as a barrier to lethal and/or impulsive overdose [59–65].
   - **Routine assessment of means and access is paramount** as these things can change. Also, working closely with patients and collateral contacts may strengthen efforts.
3. **Evidence-based therapies (EBPs)**
   - Little research has been conducted regarding EBPs with rehabilitation populations; however, several psychosocial interventions have been found to be effective in the reduction of suicidal behaviors. Significant treatment effects have been found across varied adult populations, using individual interventions (versus group), with **greatest reduction of suicidal behaviors within 3 months of treatment** [66]. Treatment appears to be most effective when interventions are **specifically tailored** to target aspects of suicidal behavior [66]. Studies that use some aspect of **home intervention** (e.g., outreach efforts such as phone calls or letters home) and/or specifically **target noncompliance** (e.g., missing/no show to appointments) may be particularly helpful to improving intervention outcomes [67]. The following EBPs (tailored specifically for reduction of suicidal behaviors) are highlighted to provide a general overview of possible intervention options:
     - **Cognitive behavioral therapy (CBT):** Although the form of CBT can vary across manuals and protocols, CBT for suicidal behaviors typically involves the *identification of thoughts, images, and core beliefs associated with suicidal behaviors*. Cognitive and behavioral strategies are then applied to increase adaptive coping. CBT**:** for suicidal behaviors can be used to address factors that may increase the likelihood of future

suicidal behavior and improve relapse prevention. Brown and colleagues found that a ten-session cognitive therapy intervention for suicide (versus usual care) was effective in reducing repeat SAs and levels of hopelessness in a sample of adults who had recently attempted suicide [68]. Simpson developed a treatment for suicide prevention aimed to reduce hopelessness in individuals with moderate to severe TBI called Window to Hope (WtoH) [69]. Results of a randomized control trial (RCT) of this CBT intervention showed significant decreases in hopelessness. An RCT of WtoH is currently being conducted in a moderate to severe TBI veteran sample.

- **Problem solving therapy (PST):** Individuals who have experienced a history of suicidal behaviors may have difficulty using effective coping strategies to solve a problem during a crisis. These individuals tend to approach problems with a negative orientation and may display more impulsive and/or avoidant problem solving styles, which may in turn be associated with greater vulnerability for future suicidal behaviors [70]. Cognitive interventions such as PST focus on helping the individual to develop a more positive problem orientation, in which he/she aligns with a rational style to actively identify problems, generate solutions, determine steps toward accomplishing concrete and realistic goals, improve flexibility, and monitor success [71, 72]. In a meta-analysis of RCTs of PST for deliberate self-harm, Townsend and others found that individuals who received PST showed significant improvements in reported problems, depressive symptoms, and levels of hopelessness compared to individuals who did not receive this intervention [73]. Furthermore, Salkovskis, Atha, and Storer found that individuals who received PST were less likely to reattempt suicide in the 6 months after the index event compared to individuals who received treatment as usual [71].
- **Dialectical behavior therapy (DBT):** Several studies suggest that the use of DBT is effective in the reduction of suicidal behaviors, especially in treatment for borderline personality disorder (BPD). Standard DBT treatment includes targeting a range of behaviors (including suicidal behaviors) by addressing several factors such as distress tolerance, emotion regulation, and interpersonal effectiveness. Linehan et al. found that individuals with BPD who received DBT were less likely to engage in future SAs, required less hospitalization, and were less likely to drop out of treatment than individuals with BPD who did not receive DBT [74]. DBT typically involves year-long treatment; however, greatest treatment effects are usually obtained during the first 4 months of treatment [75]. Stanley and colleagues found support for reductions in SDV, SI, depression, and hopelessness using a shorter course of DBT (6 months) in BPD, suggesting that briefer formats of DBT may be effective in reducing subsequent suicidal behavior [75].

Tips

The following may be especially helpful when working with medical populations:

- Attend to the **dynamic nature of illness and injury** (e.g., fluctuations in pain and functioning); these factors may correspond with changes in suicidal thoughts and behaviors.

- Consider **transitions** (e.g., newly diagnosed/injured, progression/remission of symptoms, increases/decreases in medical intervention and need for support) as these may be times of increased vulnerability.
- Provide **psychoeducation** on anticipating transitions, assist the patient in problem solving regarding how to cope during these times, and reinforce use of safety plan.
- Employ **modifications** (per Signoracci et al. [57] above) during safety planning and to facilitate its use. Doing so may help to address potential cognitive deficits, increase independent use of the safety plan, and increase likelihood of successful implementation of safety plan strategies.
- Incorporate **collateral contacts** to assist with the identification of behavior changes and implementation of prevention strategies.

Additional Resources

- **Self-directed violence classification system (SDVCS)**
  The SDVCS is a system that classifies suicidal and nonsuicidal thoughts and behaviors. It is comprised of 22 terms and contains two types of terms (thoughts and behaviors) which are further divided into subtypes. Thoughts are categorized as "nonsuicidal self-directed violence ideation" or "suicidal ideation." Behaviors are categorized as "preparatory," "nonsuicidal self-directed violence," "undetermined self-directed violence," or "suicidal self-directed violence." Subtypes are then modified by intent, interruption by self or other, and injury. A benefit of using the SDVCS is that the terms are theory neutral, culture neutral, and also mutually exclusive such that any example of thoughts or behavior can only be classified by one term [2]. For more information regarding the SDVCS and interactive clinical tools, please visit the Veterans Integrated Service (VISN) 19 Mental Illness Research, Education, and Clinical Center website using the link below: http://www.mirecc.va.gov/visn19/orderform/orderform.asp.
- **Safety planning smartphone application**
  For information on downloading a safety planning smartphone application, please visit the link below:
  https://itunes.apple.com/us/app/safety-plan/id695122998?mt=8.
- **National suicide prevention lifeline**
  This website provides information regarding risk and protective factors and helps consumers find care including crisis intervention. The website can be assessed at the following address: http://www.suicidepreventionlifeline.org/.

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Alcohol and Substance Use Disorders in Medical Rehabilitation

28

W. Christopher Skidmore and Maggi A. Budd

Topic

The *Diagnostic and Statistical Manual of Mental Disorders*, *5th Edition* (DSM-5) [1], broadly defines substance use disorders as occurring when an individual continues to use a substance despite the occurrence of significant problems related to it. The DSM-5 groups diagnoses by the type of substance used and specifies severity on a continuum from mild to severe based on the number of symptoms present. The prior DSM-IV categories of "abuse" and "dependence" have been eliminated. Specifiers can further clarify diagnoses, such as "in early remission," "in sustained remission," and "in a controlled environment." The DSM-5 also lists the World Health Organization's International Classification of Diseases (ICD-10) codes for each diagnosis. There are also coding resources and tip sheets available on the Internet. In this chapter, we will refer to alcohol use disorders (AUD) and substance use disorders (SUD) broadly for simplicity.

Importance

AUD-SUD are a global national problem and a particular concern for individuals in medical rehabilitation. These disorders are often present prior to injuries and medical problems, commonly involved in the onset of disabilities, and may continue after a person becomes disabled (although a small number may develop AUD-SUD post-injury). Adding to the challenge is a sense of professional unpreparedness, because many rehabilitation providers have not received specialized training in AUD-SUD treatment, and many AUD-SUD treatment providers have not had specialized training in medical rehabilitation [2]. However, because rehabilitation medicine treats the "whole person," this offers a timely opportunity to deliver the necessary comprehensive care for this population. This chapter describes key issues related to treating AUD-SUD, recommended accommodations in treatment programs, and helpful policies and practices to fully optimize biological, psychological, and social outcomes for patients.

A. ***Prevalence***

Several medical issues and injuries are associated with increased AUD-SUD. Patients with physical disabili-

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_28

ties such as spinal cord injuries and traumatic brain injuries have higher-than-expected rates of AUD-SUD [3–8]. Some explanations for this include [5, 6, 9, 10]:

- Premorbid problems with alcohol or substance use
- Self-medication (e.g., for escape, distraction, pain relief, or improved mood)
- Stigma and stress (general life stress and disability-specific stress)
- Social isolation or a lack of social skills
- Lack of work or limited meaningful and enjoyable life activities
- "Enabling" attitudes by family members, providers, or society

These factors vary across patients, medical conditions, and time and often occur in combination or sequentially.

B. ***Severity and Outcome***

1. **Physical Health Effects**

   Patients with AUD-SUD in medical rehabilitation have increased risks for various medical complications. These include: re-injury; longer hospital stays; urinary tract, kidney, and bladder infections; skin conditions and pressure ulcers; dehydration; and stomach and intestinal bleeding [3, 11, 12].

2. **Mental Health Effects**

   Problems with AUD-SUD lead to strained cognitive and emotional resources and may increase risk for depression, anger, and/or suicide. They can also lower overall quality of life and increase patients' struggles to adapt to disabilities, injuries, and rehabilitation needs. Ineffective coping skills and lack of interest in hobbies and rehabilitation therapies may also be present and associated with poorer mental health [3, 13–15].

3. **Pain Management Difficulties**

   Patients with AUD-SUD in medical rehabilitation may encounter significant pain management challenges. They may have lower pain thresholds, differential tolerance of pain medications, and higher chronic pain ratings compared to those without AUD-SUD [16]. To best serve patients, providers must actively address stigma, the risks of under- and overtreating pain, and patient-provider conflicts around treatment options and dosing. This requires frequent patient-centered discussions, regular measurement of progress and risk for relapse, and non-stigmatizing clinic culture and policies.

4. **Challenges in Social and Other Life Domains**

   Patients with comorbid AUD-SUD and rehabilitation needs may have lower functional independence scores and longer inpatient stays, resulting in further financial, educational, and employment challenges. Decreased participation in hobbies/activities and rehabilitation therapies can also increase isolation and reduce social support [3, 13–15, 17, 18].

   In summary, co-occurring AUD-SUD and physical disabilities or injuries can make an already challenging situation worse and create a vicious cycle. For example, an individual with legitimate pain may understandably use medications or alcohol for pain relief, which then makes pain management and medical treatment more difficult. Engagement in rehabilitation processes may be more limited, which increases physical problems, pain, and collective consequences of suboptimal functioning, such as increased stigma and social isolation.Optimal rehabilitation thus requires a plan that treats the whole individual. Consider each person's unique needs and aspects of identity such as age, gender identity, sexual orientation, race, and ethnicity [19].

Practical Applications

A. ***Assessment Data and Domains***

Both breadth and depth matter when assessing AUD-SUD. In general, ask in a nonjudgmental tone about alcohol and substance use and how problems developed or changed over time. Explore the functions of use and links between AUD-SUD and medical conditions. Also evaluate patterns of use, life problems, and readiness to change. For example:

1. **Ask about types of substances used and unsafe behaviors**
   - Drink/drug of choice (may not be the most frequently used one)
   - All substances used (ask about all types, such as alcohol, cocaine, marijuana, benzodiazepines, opiates, etc.)
   - Risky behaviors (e.g., unsafe or impulsive behaviors, gambling, or risky sexual activity)
2. **Clarify severity and duration**
   - Age of first use and when use first became a problem
   - Amount and frequency used, last time used, and preferred method of ingestion
   - Longest period of sobriety from each substance and from all substances
   - Evidence of dependence and withdrawal (e.g., blackouts, withdrawal seizures)
   - Legal, work, school, or relationship problems
3. **Explore interactions between AUD-SUD and rehabilitation needs**
   - Links between AUD-SUD and medical conditions and medication interactions
   - Potential deficits in self-care or awareness of rehabilitation needs
   - Potential deficits in cognition, memory, comprehension, learning, problem-solving, or visual motor/perceptual abilities and how these are impacted by use
4. **Assess motivation, goals, treatment history, and needs**
   - Perceived benefits and costs of use and current goals (e.g., full sobriety, reduced/controlled use, harm reduction)
   - Strengths, skills, and factors that helped maintain sobriety in the past
   - Past outpatient therapy, detox admissions, self-help groups, and medications for AUD-SUD; what did and didn't work, and why
   - Individuals in patients' lives and whether they are harmful (e.g., abusive, enabling, or permissive), neutral, or helpful to sobriety
   - Functional capabilities and limitations and any needed accommodations

   In addition, consider gender, race, culture, family history, and history of trauma and abuse, and how these variables impact patterns of use and adaptation to disabilities [2, 9, 10, 19]. Finally, monitor patients' motivation for change throughout and ask how important it is to change, how confident they are in their ability to do so, and how substance use relates to their personal values.

B. ***Assessment Methods and Tools***

Interviews, screening tools, and urine toxicology screens generate important data about the nature and severity of AUD-SUD. In interviews, ask concrete questions that require more than a simple yes/no response [6]. For example, ask "When did you last use (substance)?" instead of "Do you use (substance)?." Explain terms and ask for clarification if you hear an unfamiliar term. Visual cues or diagrams can also help, such as the "What counts as a drink?" calculator in the "Rethinking Drinking" booklet from the National Institute on Alcohol Abuse and Alcoholism (NIAAA). Finally, interview patients alone when possible to maximize honesty, and obtain information from collaterals when possible and with consent.

Screening tools can be used in many settings, and some offer both interview and self-report versions. Examples are listed in Table 28.1. Of note, they should be made accessible to patients with various ability and comprehension levels, such as by verbally administering pen-and-paper measures if needed.

Urine toxicology screens also provide critical data despite some limitations [26, 27]. Discuss these as a normal and nonpunitive part of assessment, weighted equally with other measures. Random and observed screens, rather than predictable and unobserved ones, are best when possible. Other methods include saliva or blood tests, although urine screens are more common due to their relative ease and lower cost.

Table 28.1 Sample tools for screening for AUD-SUD for rehabilitation settings

Title of screening tool	Description of screening tool
World Health Organization Alcohol Use Disorders Identification Test (AUDIT) [39]	Ten-item screener for problematic alcohol consumption
The CAGE Questionnaire [40]	Four-item screener that can indicate potential problems with alcohol use
World Health Organization Alcohol, Smoking and Substance Involvement Screening Test (ASSIST) [41]	Eight-item screener for problematic alcohol and substance use
Drug Abuse Screening Test (DAST-10) [42, 43]	Ten-item screener for substance use (other than alcohol) in the past 12 months with a list of substances
Ford and Moore's (1992) screening questions [44]	List of screening questions for use with patients with disabilities or injuries

C. *Signs of Problematic Use*

Signs of problematic AUD-SUD typically include more severe use, worsening symptoms, and associated problems with legal difficulties, work, or relationships. Also look for increasing problems related to rehabilitation such as worsening pressure ulcers or self-neglect.

D. *Treatment Planning Models*

Several treatment planning models can help guide the selection of specific interventions needed for AUD-SUD:

- **The American Society of Addiction Medicine (ASAM) Placement Criteria** [28] offer an empirically based evaluation of the severity of AUD-SUD on six dimensions: acute intoxication/withdrawal potential; biomedical conditions and complications; emotional/behavioral/cognitive conditions and complications; readiness to change; relapse/continued use/continued problem potential, and; recovery/living environment. An algorithm then suggests the most appropriate level of care (from medically managed intensive inpatient treatment to outpatient treatment).
- **The Transtheoretical Model of Behavior Change** describes both the stages of readiness for behavior change and processes that influence readiness [29]. The model has been applied to a broad range of difficulties and behaviors. Readiness for change impacts treatment in many ways, from participation and attendance to the ability to sustain behavior change [30]. The model also suggests how to use assessment data to inform treatment plans, such as by not encouraging change or making referrals until patients are ready.
- **Screening, Brief Intervention, and Referral to Treatment (SBIRT)** is an empirically based approach to assessment and treatment that can be used in various settings such as rehabilitation programs and primary care [31, 32]. SBIRT involves: systematic screening; brief interventions for patients at low to moderate risk of problems, and; referral to treatment for those with more serious problems. Brief interventions can include one to two meetings with normative feedback, motivational enhancement, and behavior change skills [26].

Rehabilitation practitioners and settings are well suited for any of these models with appropriate training. The choice may depend on clinic setting, system constraints, and provider preference.

E. *General Treatment Principles*

Regardless of interventions used, always incorporate the following general principles in treatment ("SCIM" is our imposed mnemonic):

- **Screen all patients.** Screen all patients in rehabilitation as a normal part of the intake process. Give small doses of therapy to all at-risk patients followed by reassessment and more intensive treatment if indicated.
- **Choose to give control.** Give patients control and choice, emphasize their autonomy, and ask permission before offering information or interventions. When they are open to it, provide information about the physical and mental health effects of AUD-SUD.
- **Integrate treatment.** Whenever possible, work on both issues, rather on either

AUD-SUD or rehabilitation needs alone. Progress in one area can support progress in the other [6, 7].

- **Measure progress**. Set specific, measurable, and attainable goals that are flexible enough to allow for changes in life circumstances or ability status [6]. Measure progress regularly using self-report measures, lab results or medical exam findings, clinician assessment of functioning, and other evidence of recovery such as improvements in mood or time spent in recovery-oriented activities.

F. ***General Treatment Practices***

Regardless of specific interventions, consider the use of the following practices [3, 6, 33]:

- Behavioral agreements or contracts that are explicit, patient-centered, and tailored to patients' capabilities and stage of recovery (see pages 71–73 in [16] for evidence, guidance, and a sample agreement)
- Repetition of concepts and information
- In-session practice of skills, such as role-playing
- More concrete and less abstract discussions and longer or shorter sessions if needed
- Social and personal skills that protect patients from victimization and help them address legal and financial problems, including learning how to say no to offers of substances, how to build healthy social support networks, and how to access local resources
- Accommodations that maximize engagement and access, such as assistive technologies, telemedicine, or provision of services at alternative accessible sites
- Treatment within rehabilitation settings when possible, or referral to external AUD-SUD programs with reasonable accommodations that reduce discriminatory policies, communication barriers, or architectural barriers

G. ***Treatment Modalities***

Use any of the following specific treatment modalities for AUD-SUD either alone or in combination:

- **Individual and group therapy** can enhance motivation to change, reduce use and/or harms associated with use, and teach skills to prevent relapse.
- **Family and couples interventions** such as behavioral couples therapy [34] can target problems in the family system that promote substance use. They can also enhance relational skills that support recovery [5].
- **Medications** can reduce cravings or make substance use less pleasurable or even highly aversive (e.g., disulfram/Antabuse for AUD) [35]. Naltrexone, methadone, buprenorphine, and Suboxone or Subutex may help with opiate dependence [35, 36]. Medications can also target underlying mood or anxiety disorders that lead to or maintain AUD-SUD. Of note, assess medication interactions throughout treatment [6, 30].
- **Vocational rehabilitation (VR)** can provide a motivator for sobriety, healthy structure, an alternative to unsafe peers, and a source of confidence or esteem [3, 6]. Work placements should consider patients' cognitive and physical capabilities, communication and stress management skills, and need for accommodations and accessibility [3, 13].
- **Case management** can provide support and assist patients with referrals, with navigating systems and barriers to treatment, and with adapting treatment practices and materials [6].

H. ***Interventions***

There are several interventions for AUD-SUD that can be applied in rehabilitation settings with appropriate training and support. For example:

- **Motivational interviewing (MI)** is both a therapeutic style and skill set. MI reinforces patients' autonomy and strengthens their motivation for and commitment to change; MI also recognizes that patients cannot be made to change and that trying to do so can undermine progress [37]. MI has been shown to help patients with disabilities and AUD-SUD [38] and has training resources, videos, and manuals to support providers.

You can find learning resources on the MI Network of Trainers website [39] and many information and demonstration videos on www.youtube.com.

- **Harm reduction** helps patients not yet ready to abstain but at significant risk for harm due to AUD-SUD. It focuses on decreasing risks related to unsafe behavior(s) and "meeting patients where they are" while minimizing the effects of stigma and keeping them in treatment [40]. For AUD-SUD, this might include needle exchange programs or giving patients skills and medications to recognize and prevent overdoses. Providers should carefully consider patients' medical diagnoses and complications to ensure this approach is appropriate.
- **Relapse prevention (RP)** is an evidence-based cognitive-behavioral treatment that helps sober patients remain abstinent by teaching problem-solving skills and ways to manage triggers and high-risk situations. For example, patients learn and practice skills to manage negative moods, interpersonal conflict, and social pressure [6, 41].
- **Contingency management (CM)** is an evidence-based treatment that targets a specific behavior, measures it objectively and frequently, and provides rewards (e.g., vouchers or prizes) when the behavior is present or absent. Rewards should increase with longer duration of abstinence and cease if a conflicting behavior occurs (e.g., substance use). CM is effective, straightforward, compatible with other treatments, and appropriate for various settings including rehabilitation programs [42, 43]. To be effective, CM must be implemented without punishing patients for problems due to functional limitations or lack of needed accommodations [6]. For example, patients may miss sessions or homework assignments due to functional or financial limitations, rather than substance use or lack of motivation to adhere to a treatment contract.
- **Self-help groups** provide support, accountability, community, and alternatives to high-risk situations and people. Printable meeting dates/times, locations, and types may be found on the Internet, and wheelchair accessibility may be noted. These groups may meet at more flexible times and locations than hospital clinics appointments. **Alcoholics Anonymous (AA)** is a 12-step program that includes a spiritual component [13]. There are different types of groups, so patients should try a few to find the best fit. There may be specific groups for women or individuals who identify as gay, lesbian, bisexual, or transgender. As an alternative, **SMART Recovery** focuses on cognitive-behavioral approaches and may appeal to some patients who find that AA is not a good fit.

I. ***<u>Pain Management: Special Strategies</u>***

Effective pain management in patients with AUD-SUD is a significant challenge, but patients with AUD-SUD also deserve equal access to pain relief. In general:

- Create collaborative teams with specialists from rehabilitation, primary care, pain management, and addiction when possible.
- Use non-opioid medications, cognitive-behavioral therapy and interventions such as progressive muscle relaxation and visual imagery, physical therapy and heat/ice, and complementary and integrative approaches such as acupuncture, biofeedback, and yoga [2, 6]. Help patients learn that these are effective substitutes for alcohol or substances.
- Do not assume that pain complaints or medication requests are solely due to AUD-SUD.
- Prescribe timed dosages vs. "as needed" dosing when possible. For longer-term opioid prescribing, sign a clear, written protocol or contract with patients that specifies appointment frequency, urine screens, no early refills, no over-the-phone prescribing, and contingency management principles (e.g., increased time between prescriptions for negative urine screens and on-time refills) [2, 6].
- Most importantly, do not undertreat pain; treat it while monitoring risk for relapse.

Be nonconfrontational and reinforce self-efficacy and optimism.

J. ***Expectations for Recovery***

As patients move forward in recovery, they may demonstrate increased motivation for sobriety, longer periods of abstinence, decreasing stigma, and improved coping skills and willingness to use them. It will likely be a long process with setbacks and steps forward. Ideally, patients will also experience improvements in underlying mental health conditions or pursue specialized treatment. They may also improve in terms of medical status, self-care, and adaptation to and acceptance of disabilities or injuries.

Tips

A. ***In Treatment***

- Remember that therapists' behaviors have a significant influence on patients' responses.
- Accept that no one can "make" patients stop using. Instead, create conditions to support autonomy and responsibility for their lives and recovery. Empathy increases motivation to change; confrontation decreases it.
- Actively ask patients about the impact of race, gender, sexual orientation, age, and socioeconomic status (SES) on AUD-SUD and on recovery, such as familial or cultural views on substance use, how substance use has helped them to cope if they see themselves as belonging to a stigmatized minority group, or how SES limits access to recovery-oriented activities and settings. Then, ask how these variables can function as strengths in the recovery process.
- Remember that denial of AUD-SUD or functional limitations can be an obstacle, but it can also help to preserve privacy or manage stigma [2, 3].
- Help patients combat stigma [44]. This could involve helping them to see a stigmatized aspect of their identity as a strength, to find social support among others with similar identities, or to do advocacy or volunteer work.
- Teach and model self-care to counter self-neglect and low self-worth. This can include doing activities and hobbies that reduce stress and improve your physical and mental health, practicing skills in your own life, and regularly accessing social support. Show your patients that you "practice what you teach."
- Refer to specialty care, a higher level of care, or alternative settings when needed, and confirm accessibility and accommodations ahead of time. This may include specialized residential or intensive outpatient treatment for AUD-SUD or another medical rehabilitation program that offers integrated AUD-SUD treatment.

B. ***In Your Professional Role***

- Challenge myths (or a lack of knowledge) that individuals in medical rehabilitation do not use alcohol or other substances or that unsafe use is more acceptable because of disabilities. However, also avoid assuming that "noncompliance" is the cause of all problematic behaviors [3].
- Monitor and counteract your own biases and assumptions about AUD-SUD, such as overly negative or positive personal judgments about substance use.
- Keep learning. The Substance Abuse and Mental Health Services Administration's website has resources for professionals, patients, and their families.
- "Support support," for your patients, but also yourself. Create a healthy, supportive treatment team whenever possible to make work more enjoyable and enhance the care you provide. This starts with organization-level policies that support providers and patients, but also comes from how you interact with other team members, disciplines, and clinics. Group activities that stimulate positive feelings among team members, such as celebrations of group accomplishments and respectful commu-

nication practices even during times of stress, are also critical.

- Most importantly, manage frustration and promote hope while expecting chronicity and complexity, often with relapses or setbacks [2, 3].

C. ***In Your System***

- Get training and train your staff on the effects of specific substances, AUD-SUD interactions with medications and medical conditions, and specialized treatments.
- Use “people first language” [6] rather than labels such as “alcoholic” or “addict” (but respect patients’ use of these terms if they participate in self-help groups that use them).
- Foster interdisciplinary and interagency collaboration. Build strong working relationships with community agencies to know their resources, accessibility, and availability. Create a referral options list and update it frequently. In addition, consult regularly and share your own expertise on rehabilitation processes.
- Engage in awareness-raising efforts, such as systematic screening for AUD-SUD, posting brochures in waiting and exam rooms and other visible locations, and regular questions about AUD-SUD with patients and families [6].
- Hire staff in your system with histories of AUD-SUD and rehabilitation needs to show an honest organizational commitment to supporting patients [6].
- Advocate for accessibility in treatment programs and self-help groups, and consult with other programs about how to increase accessibility if needed.

Much like the process of adaptation to disabilities, recovery from AUD-SUD is a complex, lifelong process with setbacks, detours, and successes. Patients with AUD-SUD in medical rehabilitation face even more significant challenges along the way. Mental and physical health, biology, and the social environment all impact the process. Lifetime abstinence may be only one potential goal; many people can have positive outcomes with moderated, safe use. Furthermore, the risks of potential abuse may be outweighed in some cases by the risks of poorly treated pain and medical conditions, which can increase risk for AUD-SUD. Regardless, be vigilant for the effects of stigma on patients’ health and providers’ clinical decision making. Have frank dialogues with patients about balancing treatment with acceptance and maintenance of functioning. Finally, remember that all patients including those with AUD-SUD deserve the best treatment. With your existing knowledge and competencies in treating the “whole person,” rehabilitation practitioners are uniquely poised to help these patients maintain or improve their quality of life.

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Serious Mental Illness

29

Christopher G. AhnAllen and Andrew W. Bismark

Topic

Serious Mental Illness (SMI) is typically defined as a diagnostic group of psychiatric disorders that include experiences *associated with psychotic symptoms* with the most common class of disorders consisting of those within the schizophrenia spectrum. SMI diagnoses include *predominant symptoms associated with information processing* that is not based in reality such as delusional beliefs and unusual perceptual experiences such as hallucinations. Additional features include *disorganized thinking or speech*, *disorganized or abnormal motor behavior,* and *negative symptoms* (such as loss of interest in activities). The illness course and associated features of SMI include psychiatric symptoms, duration of illness, functional impairment, and consideration of the role of substance or medical illness as potential causal factors. Persons with SMI experience a high degree of physical illnesses and there is a significant need for practitioners to be adept at understanding and managing SMI within the rehabilitation service center.

Key concepts in understanding the heterogeneity of SMI disorders are identified below:

A. ***Psychotic Disorder Features***

In 2013, the American Psychiatric Association published a revised Diagnostic and Statistical Manual of Mental Disorders (5th Edition, DSM5) [1], which provides the primary guidelines for practitioners in understanding the expression of psychiatric disorders within American culture. The DSM5 was developed based upon individual DSM5 work groups for each specialty including a group dedicated to the determination of criteria for psychotic disorders. This work group identified the following psychotic disorder features as key to the understanding of the illnesses within the SMI diagnostic group:

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_29

Delusions	Defined as ***unusual beliefs*** that are often held with conviction when presented with information to the contrary. The content could be *bizarre* whereby the individual believes an implausible or unaccepted idea apart from mainstream culture (e.g., thoughts being taken out of or placed into one's head against one's wishes). May include content such as being harassed or bothered by others (*persecutory*), information directed specifically about oneself (*referential*), possessing unique powers or abilities (*grandiose*), experiencing unusual bodily experiences (*somatic*) or unusual religious beliefs (*religious*)
Hallucinations	Defined as ***unusual perceptions*** that are not consistent with reality as experienced by other people. These are typically noted as *auditory* in nature (e.g., hearing voices) and are noted to be distinct from internal thoughts. Other less common forms of hallucinations include seeing images or persons (*visual*), feeling sensations about the skin or body (*tactile*), and tasting (*gustatory*) or smelling (*olfactory*) unusual stimuli
Disorganized thinking (speech)	Defined as a means of understanding ***aberrant thought processes*** from how an individual speaks. Also known as **formal thought disorder,** this includes patterns of speech of getting off track onto related ideas (*derailment/loose associations*), responding to questions in an irrelevant (*tangential*) or protracted (*circumstantial*) manner. Other examples include incoherent speech (*word salad),* illogical speech, or rhyming (*clanging*)
Disorganized or abnormal motor behavior	Defined as ***highly unusual physical presentation*** with regard to appearance or other goal-directed behavior. This includes clothing and related physical presentation, social and sexual behavior, aggressive and agitated behavior, and other features of a marked disconnection from the environment in terms of behavior and responsiveness (*catatonia*)
Negative symptoms	Defined as a reduction or ***loss of normal functions*** as evident in affective or emotional expression, loss of motivation to engage in enjoyable activities (*avolition*), reduced speech output (*alogia*), reduced ability to experience pleasure in life (*anhedonia*), and lack of interest in social activities (*asociality*)

B. *Schizophrenia Spectrum Disorders*

Brief Psychotic Disorder

- **A sudden onset of at least one psychotic experience** (e.g., delusions, hallucinations, abnormal speech or behavior)
- **Duration is 1 day to 1 month** only (consider other psychotic disorders if longer duration)
- **Return to prior level of functioning** following termination of psychotic experiences
- **No concurrent mood disorder** (e.g., depression, mania) or previous diagnosis of a psychotic disorder (e.g., schizophrenia, bipolar disorder with psychotic features)

Schizophreniform Disorder

- **Ongoing multiple psychotic experiences** (e.g., delusions, hallucinations, abnormal speech or behavior) over at least 1 month
- **Duration is 1 month to 6 months** only (consider other psychotic disorders if longer duration)
- No diagnosis of major mood disorder due to limited mood disruption or duration of problem or occurred outside period of psychotic experiences

Schizophrenia

- **Ongoing multiple psychotic experiences** (e.g., delusions, hallucinations, abnormal speech or behavior) over at least 6 months
- Impairment in at least **one major functioning domain** such as employment, relationships, or self-care.
- **No prolonged periods of major mood disorders** (e.g., depression or mania) that account for the psychotic symptoms

Schizoaffective Disorder

- **Psychotic experiences** (e.g., delusions, hallucinations, abnormal speech or behavior) that occur *in conjunction* with prolonged major mood problems (e.g., depression or mania)
- Delusions or hallucinations that occur for **periods of time apart from major mood problems** for at least 2 **weeks**

Substance/Medication-Induced Psychotic Disorder

- **Recent drug use or medication use, including intoxication or withdrawal**, which fully explains psychotic symptoms such as hallucinations or delusions

- **Psychotic symptoms did not pre-exist** the substance/medication use
- Substances may include alcohol, cannabis, phencyclidine (or other hallucinogens), inhalant, sedative/hypnotic/anxiolytic, amphetamine, or cocaine

Psychotic Disorders Due to Another Medical Condition

- Psychotic symptoms that occur and are **directly attributable** to a known medical illness or condition apart from delirium
- Evidence of medical illness or condition is established through a physical exam, laboratory results, or clinical interview including information from informants
- Conditions most commonly include temporal lobe epilepsy (olfactory hallucinations), untreated endocrine and metabolic disorders, and autoimmune disorders

Importance

Incidence: The number of new cases of a disorder within a period of time, usually 1 year
Prevalence: The proportion of the population found to have a disorder
Onset: The beginning of the disorder
Course: The progression of the disorder
Prognosis: The expected outcome of the disorder

- **Onset** and **course** of a psychotic illness can vary greatly, lasting minutes or hours to a lifetime, and reveals valuable details about likely causes and prognosis.
- **Factors that affect course and severity** include gender, age at and type of onset, familial history, and socioeconomic factors.
- **Acute onset psychosis** displays more pronounced/severe initial symptoms that rapidly decrease in severity and functional impairment with treatment. This implies a *reactive disease process* that is likely to receive treatment earlier in the course, thus predicting better outcomes.
- **Insidious illness onset** is preceded by an illness prodrome and predicts longer, more severely chronic course, treatment resistant symptoms and greater functional impairment. This type of presentation implies a much higher disease diathesis, and less time to develop relevant initial coping skills. Unfortunately, this is the more common presentation of psychotic illness.
- **Psychosis onset prior to adolescence is rare**, regardless of the cause.
- **Earlier onset** predicts more severe pathology and poorer prognosis.
- **Substance intoxication or another medical condition** causing acute psychosis displays shorter courses, minutes to hours, and remits with the treatment of substance effects/medical condition. Successful treatment results in the patient recovery to full premorbid levels of functioning. Psychotic illnesses of this nature will likely present in the course of emergency department admissions and not general nonemergency provider visits.
- **Acute stress** can precipitate onset of psychotic symptoms. Psychotic reactions due to acute stress span days to months, with a full return to premorbid level of functioning with remission of the stressor. Although not a chronic psychotic state, a psychotic stress reaction indicates an *underlying diathesis* for the development of psychosis and further reactions should be monitored. It is unknown what the long-term effects of repeated psychotic stress reactions are.
- **Insidious onset** coupled with a chronic course and debilitating functional outcomes is associated with schizophrenia. Prevalence rates for schizophrenia are in the range of 0.3–0.7 %, lifetime, with significant variation by race/ethnicity, cultural identification, and by geographic origins for immigrants and children of immigrants [1]. Age of onset for schizophrenia differs by gender, with male's peak onset during late adolescence/early adulthood, and a bimodal peak in females, first during late 20s to early 30s, and again in their early 40s. Due to the gender disparity in prevalence rates and age of onset, **estrogen** has been proposed as a protective factor and has emerged as potential adjunctive treatment in recent years [2]. The course of schizophrenia is

chronic and unremitting, characterized by periods of less intense symptomatology and relative psychiatric stability punctuated by more acute symptom exacerbations (usually of positive symptoms) leading to functional impairment and hospitalization.

- **Multicultural issues** are noteworthy, particularly when the care provider and the patient are culturally different. It is always advised to seek consultation when addressing cultural and linguistic disparities with SMI patients.

A. ***<u>Assessment: SMI</u>***

Clinical interview with emphasis on timeline of symptom development. If possible, include family members and other relevant caregivers to establish an estimate of genetic loading as well as interpersonal relationships and attitudes surrounding mental illness.

1. **<u>Medical Comorbidity</u>**

   SMI patients frequently present with multiple comorbidities, such as diabetes, heart disease, and substance abuse. Though medical concerns may range from legitimate to delusional, it is important to take their medical concerns seriously as medical complaints (even if potentially misinterpreted) may be indicative of an actual physical malady. Complicated SMI patients often present in one of three broad ways: High utilizers, complex high utilizers, or with neglect.

   - **High Utilizers:** Will present with over-interpreted viewpoints on bodily sensations (e.g., a headache denotes a brain tumor). In the absence of somatic delusions, these patients will return with frequent complaints and only temporarily be comforted by negative test results on relevant exams/labs.
   - **Complex High Utilizers:** Will present with medical concerns that are entangled with psychiatric issues, such as the case with somatic delusions. Presentations may include vague system-level concerns such as “I have cancer” or specific (potentially delusional) concerns such as “I’m having headaches, there’s a microchip in my head.” Patients with complex medical presentations should be referred to psychiatric treatment should no root medical cause be identified for their presenting medical issue.
   - **With Neglect:** These patients will present with complex medical or psychiatric neglect, will present only sporadically for treatment, and are likely to do so with acute illness severity or with advanced health issues. This neglect may be due to a delusional process, mistrust or fear of healthcare providers, real or perceived mistreatment from healthcare providers, or avolition/anergy on the part of the patient. Psychiatric referrals are warranted to address the complex medical and psychiatric neglect.

   a. ***Assessment: Medical Comorbidity.*** A careful assessment around the medical presentation(s) and the role of psychiatric diagnoses in their care (or neglect) should be undertaken. This assessment, combined with psychoeducation about the relationship between physical and mental health, using brief motivational interviewing, will help providers identify disease processes and barriers for treatment.

   Note: <u>Do not challenge delusional thinking.</u> The exploration of the individual’s thinking process and belief system is important for assessment. However, any challenge to delusional thinking is unlikely to change the delusional content or pattern, and increase the likelihood of patient withdrawal from treatment engagement.

Practical Applications

A. ***<u>Psychosis</u>***

Hallucinations and delusions can occur for a variety of reasons. This is particularly noteworthy for persons within a hospital or rehabilitative setting that involves assessment and treatment of medically ill persons. For example, persons may be administered medications for treatment of medical problems that affect their reality processing. It is important to determine a number of factors related to psychotic experiences to assist in clarifying whether the symptom is related to a known medical condition, substance use, or mental illness. Gathering data from multiple sources is encouraged particularly if the patient is known to have difficulty with reporting historical information.

- **Assessment**: Information to be gathered about psychotic experiences includes:
  - Current psychotic symptoms: Date of onset, course, and degree of functional impairment of recent psychotic symptom(s). It should be emphasized that certain psychotic symptoms may have limited effects on functional abilities within a rehabilitative setting (e.g., hearing a family member's voice on a monthly basis that is not a stressful experience). Level of impact on daily functioning or expected impact on treatment within the hospital or rehabilitative center (e.g., delusions about reasons why medical device used to support physical illness recovery).

    Delusions—Inquire about whether the patient has believed that they are being paid particular attention by others (persecutory), possess special powers or abilities (grandiose), experience messages sent to them because of who they are (referential), believe that something is wrong or unusual physically (somatic), or believe unusual beliefs that are considered unlikely according to religious doctrine (religious).

    Hallucinations—Inquire whether the patient has experienced hearing unusual sounds that others might not be able to notice (auditory), observe images while fully awake that others might not observe (visual), smell unusual scents (olfactory), taste substances that might not exist in reality (gustatory), or sense unusual sensations about one's body (tactile). Note that experiences of hallucinations other than auditory in nature may be indicative of another medical condition or substance-related psychosis.
  - Previous periods of psychosis: Historical symptom(s) and how the patient managed these are likely to indicate how they will be handled presently. Inquire about frequency of symptoms, availability of self-driven coping skills, and level of responsiveness to treatments including pharmacological and psychological.

  Clinical rating scales of psychotic symptoms are available including the Scale for the Assessment of Positive Symptoms (SAPS) [3], Scale for the Assessment of Negative Symptoms (SANS) [4, 5], and the Clinician-Rated Dimensions of Psychosis Symptoms Severity [1].
- **Intervention:** Effective treatments for psychosis include both pharmacological and psychotherapy. Skilled mental health providers in the treatment of psychotic patients to provide either treatment are recommended. Treatment types include typical and atypical classes of antipsychotic medication [6], as well as cognitive behavioral therapy for psychosis [7]. Additional effective treatments in the community include recovery-oriented care, motivational interviewing, multifamily group therapy, mindfulness, and solution-focused interventions.

B. ***Diverse Populations***

Persons from diverse backgrounds may be incorrectly determined to exhibit SMI given culturally misinformed clinical assessments. Therefore, there is a critical need to be attentive to cross-cultural assessments in order to develop an accurate understanding of a patient's presentation within the rehabilitative setting. Specifically, clinical providers are more likely to overdiagnose African-American and Hispanic persons with psychotic illnesses or incorrectly assign specific psychotic disorders compared to other ethnic minorities and Whites; estimations of a tenfold increase in diagnoses for African-Americans are reported including across inpatient and outpatient settings [1, 8, 9]. It is critical to be informative about a patient's racial and ethnic identities, religious/spiritual beliefs, cultural affiliations, and language proficiencies in order to determine whether a patient's presentation is consistent with culturally accepted practices or experiences or whether they are consistent with mental illness. In addition, should the patient be determined to exhibit a SMI, the content of the psychotic symptoms is known to draw upon the cultural environment of the individual (e.g., believing the CIA is monitoring the individual as an American vs. National Intelligence Service for a South Korean).

- **Assessment**: The first step is to engage in clinical interviewing to determine a patient's self-identified racial identity (e.g., White, Asian-American, Native-American), ethnic identity (e.g., Greek, Korean), religious or spiritual beliefs, cultural affiliations (i.e., the degree to which the patient identifies with a variety of local, regional, or national cultures), preferred language, and language learning history. Determination of this information will assist the rehabilitative clinician to ascertain how an individual's identity may influence their behavior. Consider using the ADDRESSING framework to guide cultural conceptualizations; this framework includes understanding the patient's **A**ge and generational influences, **D**evelopmental or acquired **D**isabilities, **R**eligion and spiritual orientation, **E**thnicity, **S**ocioeconomic status, **S**exual orientation, **I**ndigenous heritage, **N**ational origin, and **G**ender [10]. Use supportive interviewing to solicit important multicultural identities that are able to be understood using simple demographic questionnaires. Additional cultural concepts of distress may explain behavior of those with specific cultural identifications [1].
- **Intervention**: After determining the degree to which cultural identities affect behavior and potentially psychotic symptoms, the clinician is best able to determine strategies for intervention. Providers are encouraged to consult with community members from relevant specific cultural groups (e.g., Roman Catholic priest regarding hearing God's voices of negative content). Consultation will help determine whether treatment is indicated for a SMI. Use of interpreters is also encouraged for patients who prefer to use a language not known to the clinician.

C. ***<u>Drug/GMC-Related Assessments</u>***

Toxicology screens

SMI presentations are complex, and can be due to other medical conditions or substance intoxication. In addition to medical presentations, substance use often becomes a relevant issue of concern for providers. Providers conducting a brief interview covering substance use history/current use, medical issues, and psychiatric symptoms should attempt to disentangle the medical, from the psychiatric, from the substance related.

- SMI patients' **substance use problems** can have contributory factors to the onset of the disorder or have been used a means of coping with changes in their mental health. Either way, substance use problems among SMI populations are increasingly the rule and less the exception and should be given first assessment to rule out substance intoxication as a reason for the presenting medical or psychological complaint.
- Inquiring about patterns of current substance use is sufficient to gather the necessary information, but other tests such as breathalyzers or brief urine dip tests may be warranted to ascertain the extent to (if any) substances play a role. A word of caution about these later tests—SMI

patients may be guarded or minimize their use out of guilt, shame, or mistrust. If suspected, subjecting the patient to urine dip tests/breathalyzers after verbal denial of use may undermine an already fragile therapeutic alliance.

Assessment

Inquire about medications, drugs and alcohol, and recent health changes, with open-ended questions where possible. A quick physical examination can provide with valuable information regarding physical health. Quick behavioral observations (gait, odd speech patterns, injection scars, odors, dilated pupils, responding to internal stimuli) are useful for assessment of substance intoxication. Providers should also create a careful timeline about medical illness, SMI symptomatology, and substance use, to provide guidance to the interrelation of these domains.

Imaging

Imaging can be a powerful tool in the diagnosis of serious mental illness, but it is by no means definitive. It requires specialized equipment and technicians for valid and reliable measurement purposes.

- **MRI:** Structural Magnetic Resonance Imaging (MRI) research indicates many patients with schizophrenia display structural abnormalities including enlarged ventricles, abnormalities in mediecal temporal lobe structures, limbic structures, basal ganglia, inferior temporal regions, and prefrontal and orbitofrontal grey and white matter. These deficits are widespread but indicate subtle changes in brain structure that when compounded, contribute to psychotic phenomenology [11]. In addition to structural abnormalities, functional MRI (fMRI) research indicates deficits from basic sensory processing to more complex constructs such as decision-making, emotion, and theory of mind. The literature on these deficits is far beyond the scope of this chapter; however, both structural and functioning imaging remain incredibly useful tools in the assessment of SMI.
- **EEG/ERP:** Neural timing deficits also characterize psychotic disorders. These deficits, measured by electroencephalography (EEG) and event-related potentials (ERPs), manifest on the order of milliseconds. These tests indicate when within the information-processing stream, the information-processing deficits occur. Sensory gating deficits are one hallmark deficit of schizophrenia and are thought to contribute to hallucinations. Patients' brains with this deficit show continued processing to neutral stimuli (e.g., clicks or beeps), where healthy brains show diminished processing after the initial stimuli. As attention shifts between environmental stimuli, the significance of the previously attended stimuli should be decreased as it has already been processed and deemed irrelevant. After the brain's failure to "gate" (or tune out) irrelevant stimuli, it attempts to make sense of the experience, misinterprets it as new information, and can be experienced as auditory hallucinations. This is just one of a multitude of examples using EEG/ERPs that can be used in the assessment of SMI [12].
- **PET:** Positron emission technology (PET) is a functional imaging technique that produces three-dimensional images of a functional process in the brain. The one significant drawback of PET is the frequent use of an injected radioactive tracer, whose decay is known and measured over time. PET scans work by attaching a tracer compound to a glucose molecule that is taken up by some specific receptor in the brain. Over time, the target cell's increased activity means it will take in and use more glucose (and by association the tracer) so that when the tracer decays, the relative cell area can be extrapolated. With enough of this decay, the shape of the area of use becomes evident against the baseline glucose use of the surrounding tissue. The tracer injected is typically specifically designed to bind to a cell/receptor of interest and can provide more functional specificity than other imaging methods.

This technology, while exciting, is prohibitively expensive, and has obvious limits on the amount or radioactive exposure an individual undergoes. PET scans are more heavily used in research than clinical applications, but their readings can elucidate much about a particular receptor or neurotransmitter that may be of use in the diagnosis. Notably, PET scans have been used to test the receptor affinity for particular targets (such as dopamine) in order to shed light on brain pathophysiology [13].

D. ***Substance Use***

Persons with SMI are reported to experience comorbid substance use problems including alcohol and illicit substances (40–60 %) [14], and tobacco (60–90 %) [15, 16]. Elevated rates of substance use in those with SMI affect a number of areas of functioning including limiting financial stability, being at risk for homelessness, restricting healthy social supports, exacerbating psychiatric symptoms, and compromising physical health. Specifically, substance use in those with SMI is associated with risk for hepatitis, various cancers, HIV, and other chronic medical conditions. In addition, substance use disorders are often neglected by providers for treatment particularly in the SMI population.

- **Assessment**: Inquiring about lifetime substance use is relevant for rehabilitative providers including asking those with SMI about frequency of use, amount of money spent on drug use as well as the degree of tolerance (i.e., increasing use over time for desired effect) and withdrawal symptoms (i.e., various effects if a substance use is stopped abruptly). Inquiring about interest in quitting drug use is highly important to assist with providing referrals for treatment. Consider using a modified Fagerström Test for Nicotine Dependence (FTND) [17], CAGE questionnaire for alcohol use [18], Addiction Severity Index for multiple substance use (ASI) [19], and the Contemplation Ladder to assess readiness to quit smoking [20].
- **Intervention**: Engaging rehabilitative patients in considering abstinence from nicotine products (e.g., smoking) and other drug abuse is strongly encouraged. Pharmacological interventions to address substance withdrawal may be indicated for alcohol, opiates, and tobacco use. Use of nicotine replacement therapies (e.g., nicotine patch, gum, lozenge) while in the rehabilitative center can not only improve withdrawal symptoms but also engage patients in considering staying on these therapies following discharge from treatment. If the rehabilitative patients are receiving treatment within a setting that is already tobacco and substance free, then the person with SMI is already abstinent. Connecting patients to substance abuse services while in the rehabilitative center and following discharge are encouraged, including self-help support groups such as Alcoholics Anonymous and local telephone quitlines for tobacco use.

E. ***State/Trait Symptomatology***

SMI patients will present in one of two phases of illness: stable or acute exacerbation. Both of these phases display ideographic characteristics that are best assessed longitudinally. A useful metaphor may be seeing these patterns as a radio slightly off station. Most of the time the radio emits static, which may pose mild interferences, but on the whole this low-level "noise in the system" can be managed. However, occasionally the radio tunes a nearby station and both the station content and the static are amplified to disturbing volumes, causing significant intrusions and interferences to functioning. When treated appropriately, this radio will return to the baseline level of static noise.

- **State:** Acute exacerbation involves greater frequency, intensity, and duration of the more debilitating symptoms. This phase coincides with disorganized behavior, thought, speech, perception, and social functioning.
- **Trait:** Chronic but stable symptoms involve a subset of lower intensity, manageable

symptoms without obvious behavioral sequelae, or disturbances of thought, speech, or perception.

Assessment: The differentiation of these two phases is not always easy and that is why a good working relationship, with repeated assessments, is key to evaluating the psychiatric stability of the patient, and therefore the appropriate medical intervention and expected degree of success.

Intervention: Within the stable phase, psychoeducation and emphasis on coping skill utilization may be more effective; medication regimens will have greater adherence rates, and patients will be more receptive to alterations in medical care. The acute phase is far more unpredictable and psychiatric referral for stabilization should be the first intervention. If acute presentation raises concerns of danger to self or others, hospitalization may be required.

F. ***Insight***

Individuals with SMI will demonstrate varying levels of insight, with these levels often *fluctuating* with state and trait symptom stability. The more severely impaired patients will show deficits in insight or frame their illness as part of an ongoing delusional framework (e.g., auditory hallucinations are the voice of God and are not considered part of their illness). As illness severity increases, insight decreases. Unfortunately, decreases in insight are correlated with poorer social skills and more negative medication attitudes. While varying levels of insight with regard to mental health issues may be just as common as those with chronic medical conditions, the patient with SMI will typically underestimate the gravity of their condition compared to their nonpsychotic counterparts. Insight does seem to be independent of such factors as age, gender, education level, neurocognitive deficits, hospitalization history, number of social supports, or quality of life.

Assessment: Any assessment of insight using nonjudgmental, open-ended questions about the nature of their mental and physical health will best serve to collect the necessary information. Due to the fluctuating nature of insight, repeated assessments of SMI patients are often necessary for establishment of a baseline level of insight and any change to that level. However, structured assessments of insight are available including the Scale to Assess Unawareness of Mental Disorder (SUMD) [21].

Intervention: Psychoeducation can be a useful tool for building insight into a psychotic illness, but must be presented in a *collaborative* way, as pedantic presentation will likely be met with defensiveness or emotional withdrawal.

G. ***Violence***

Rates of violence are somewhat elevated while experiencing psychosis and in those with a history of psychosis. At the same time, persons with SMI can be inappropriately believed to be at a higher risk of violence toward other patients and staff when this is not consistent with a person's history. Paying attention to specific patient's behavior and history of violence including verbal and physical methods is important. Violence can occur toward oneself or others and is often linked to untreated symptoms (e.g., auditory commands to harm self or others). Relatedly, violence risk for those in whom there is a noteworthy history is likely to be reduced with engagement in pharmacological treatment for psychosis. Previous violence toward others within a hospital or rehabilitative center would be helpful information to guide provision of current treatment for the safety of the patient and staff.

Assessment: Paying attention to *clinical warning signs* of violence potential in a clinical setting is important. These signs include aspects of *speech* including verbal content, volume, and tone. *Behavioral* signs include pacing, threatening movements with appendages, and reduced participation in treatment. Gathering data about current illness state (e.g., acute or stable) will be helpful to determine whether to assess further. Additionally, clinical interviewing about thoughts of harming others, command hallucinations to harm others, or delusional beliefs that include a fear of being harmed by others are important to identify. Gathering data about previous risk and expression of violence toward others both within the community and within hospital settings is encouraged.

Intervention: For patients who are exhibiting acute emotional distress, consider determining whether specific needs can be met. For example, the SMI patient may be upset because they cannot smoke in the hospital. Be clear about how to address specific needs that are associated with distress and only offer options that are available. For threats of violence related to psychosis, consider a plan for pharmacotherapy intervention, therapeutic containment, or identification of alternative supports (e.g., psychiatry service, emergency responders, police).

H. ***Social Supports***

Persons with SMI experience significant impairment in their social skills, which is a problematic deficit that affects the establishment and maintenance of long-term relationships for social support [22]. Typically, psychotic disorders develop during late adolescence and into early adulthood during which social skills are refined and used to establish adulthood relationships. Given deficits in social functioning, persons with SMI may have few social supports in their adult lives. In addition, social supports that are maintained over time in adulthood may be nontraditional and include a greater frequency of professional supports (e.g., therapist, psychiatrist, case manager), community supports (e.g., AA sponsor, religious leader), and peers (e.g., friends at a group home). Collectively, persons with SMI are thought to experience deficits related to receiving, processing, and expressing socially mediated information [22].

- **Assessment**: Inquire about whom the patient has in their life that provides social support to include an extension to professional supports, community supports, and peers. Consider including these individuals in assisting the patient in making decisions regarding their care while in the rehabilitative setting as well as aftercare. Use observations of the patient to determine patient's ability to engage in eye contact, provision of social reinforcers (e.g., smiling, nodding), appropriate interpersonal distance, and conversational timing. Use reports from established social supports to clarify questions. The **Social Skills Checklist** can provide a guide to identify relative strengths and weaknesses [23].
- **Intervention:** Providers are encouraged to engage patient-defined social supports into clinical assessments, treatment, and discharge planning. Providers may also engage in modeling of appropriate social skills and communication of information. Social skills training (SST) is an effective skills training program to improve conversations, assertiveness, conflict management, friendship, dating as well as other social skills for persons with SMI [24].

I. ***Treatment***

The most effective treatment for psychotic illness is a combination of medication, psychotherapy, and stress management.

Medication

SMI patients in acute crisis will likely necessitate the use of antipsychotic medication for stabilization before any psychotherapeutic work can be undertaken. Antipsychotics are segregated into two generations: first-generation (typical) and second-generation (atypical) [6, 25].

- **First Generation:** The *typical medications* are genuinely older and produce more side effects. The most severe being tardive dyskinesia (TD), or a disorder that involves involuntary movements, especially of the lower face, lips, and tongue. TD is irreversible and arises after prolonged use of typical antipsychotics. Any patient prescribed a typical antipsychotic should be monitored closely for these symptoms using the **Abnormal Involuntary Movement Scale** (AIMS) [26].

- **Second generation:** *Atypical antipsychotics* have similar mechanisms as their typical counterparts, but produce far fewer side effects, and are thus the preferred antipsychotic choice. However, atypicals are by no means free of side effects with the most common being sedation, headaches, anxiety, sexual dysfunction, weight gain, dry mouth, and constipation. TD has also been reported with chronic use of atypicals, but at seemingly far lower rates.

Regardless of the generation, antipsychotics are most effective for **treating positive symptoms**, with little or no remission for the negative symptoms. This is, in part, why joint medication and psychotherapy treatments are most effective. Certain antipsychotic medications are also available in an injectable method of delivery.

First generation/typical (trade name)	Second generation/atypical (trade name)
Chlorpromazine (Thorazine)	Aripiprazole (Abilify)
Loxapine (Loxitane)	Clozapine (Clozaril)
Perphenazine (Trilafon)	Olanzapine (Zyprexa)
Fluphenazine (Prolixin)	Paliperidone (Invega)
Haldoperidol (Haldol)	Quetiapine (Seroquel)
Trifluoperazine (Stelazine)	Risperidone (Risperdal)
	Ziprasidone (Geodon)

- **Hormones:** Estrogen has also been investigated as an adjunctive treatment for schizophrenia. When examining gender disparity in prevalence rates, age of onset, and symptom severity for schizophrenia between men and women, it was hypothesized estrogen plays a protective role for these factors. Preliminary research indicates there is additional symptom reduction through supplementing ongoing antipsychotic medications with low dose estrogen therapy [2].

Psychotherapy:

- **CBT:** Cognitive behavioral therapy (CBT) emphasizes the interaction of thought, emotion, and behavior. CBT helps patients learn to manage psychotic symptoms as an adjunctive treatment to pharmacotherapy. Working with a therapist, SMI clients will learn to reality-test of their own thoughts and perceptions, and better understand how distortions in those may affect behavior. CBT is a skill-based therapy, including teaching social and problem-solving skills, which can help SMI patients minimize stressors that contribute to acute exacerbations. CBT can also help reduce overall symptom severity and help prevent relapse by helping to identify triggers to acute episodes [27].
- **Mindfulness**: Based on Buddhist teachings, mindfulness emphasizes awareness of experiences and physical sensations occurring within the moment, in an accepting, nonjudgmental manner. For SMI, mindfulness can be used to interrupt ruminative processes, worry, and serve to increase self-awareness. While not a direct goal, mindfulness often has relaxing and tension relieving effects that serve as a useful stress management technique [28].

Psychoeducation/Illness Management Skills/Relapse Prevention:

- **Psychoeducation:** Skills aimed at both the patient and the patient's primary caregivers. Psychoeducation's goal is to inform the patient about the nature of their illness and correct any misconceptions. Psychoeducation promotes empowerment.
- **Illness management skills:** Designed to help patients build coping mechanisms for dealing with stressful life events as well as persistent symptoms.
- **Relapse prevention:** Aimed to increase survival time, or time between acute psychotic states. Utilizing an effective medication regimen, intrapersonal coping mechanisms (i.e., mindfulness, Social Skills Training), and interpersonal supports will help prolong survival time and diminish symptom severity upon relapse. One critical aspect of relapse prevention is the management of **expressed emotion** (EE). EE refers to relationship patterns, attitudes, and quality of interactions between the SMI patient and their family

members within the family milieu. High levels of EE reflect critical attitudes, hostility, or emotional over-involvement within the family milieu and constitute a significant psychosocial stressor, and therefore a robust predictor of relapse [29]. By observing the interactions between the patient and their relevant caregivers, and assessing the attitudes and level of involvement of those individuals, one can easily assess the influence of EE on the patient's level of physical and mental health.

- **Other interventions include:** Acceptance and Commitment Therapy (ACT), Social Skills training (SST), Cognitive Behavioral Social Skills Training (CBSST).

J. ***Goal Setting***

Goal setting is one of the most important steps to achieving any desired outcome. However, expectations about those goals will differ based on the provider, the patient, and the patient's illness phase.

- **Provider expectations:** SMI patients often experience ongoing symptoms (even at baseline levels) and expecting them to respond to medical regimens like non-SMI patients may be unrealistic.
- **Collaboration:** Establish collaborative goal setting efforts that engage SMI patients at a level that matches their current level of functioning.
- **Do Not:** Lecture patients and provide their goals for them.
- **Realistic attainable goals:** In the eyes of the patient, provider-set goals may appear overwhelming, or unreasonable. This disparity of expectations can lead to patient inaction and provider frustration. Thus, it is important to use a collaborative style when setting goals, but also making those goals concrete and realistically achievable for SMI patients. Consider using shared decision-making tools.

Example: A patient presents with obesity and high blood pressure. In the absence of medication, the provider is likely to prescribe decreased salt intake, increased exercise, healthier diet, and decreased stress. To the provider, this list may seem immediately reasonable and easily achievable. However, to the patient with SMI, this may be easily overwhelming, and depending on life circumstances, untenable. This is where the collaboration comes in. These goals *are* achievable, but the timeline may need to be adjusted as well as the expectations for functional outcomes with a focus on more measured, intermediate goals set in order to achieve them. For instance, the first step in combating obesity and high blood pressure in SMI may be to decrease the amount of processed fast food eaten by the patient rather than the suggestion of dietary overhaul. This establishes intermediate, concrete, and achievable goals providing the patients with a sense of control over their own care and increasing the likelihood of meeting the provider's overall goals.

It is important to remember that in working with SMI, the expectation of functional outcome may need to be adjusted to meet the *abilities* of the patient not just the desires of the provider.

Tips

- **Be aware of and correct stigmatizing behavior.** One of the greatest levels of negative stigma in mental health is towards individuals with psychosis. Be accepting and open to those with SMI who have rehabilitative needs. Address stigma expressed by other team members verbally (e.g., “crazy,” “nuts”) and nonverbally (e.g., avoidance or neglect of patient's needs).
- **Include available social supports in care decisions.** Persons with SMI may have less close relationships with members of their nuclear family (e.g., mother, father) and are less likely to have a life partner. Importantly, alternative social supports may exist including a therapist, case manager, peers, or friends. Consider reaching out to these supports to involve them in treatment and discharge planning.
- **Assess capacity to make decisions.** Persons with SMI may experience short-term or long-term

impairments in their ability to make decisions in their lives including financially, medically, and other areas of functioning. Consult with experts in decision-making to properly determine when to invoke a proxy decision maker as needed.

- **Redirect delusional thinking to reality processing.** Challenging delusional beliefs by those who experience SMI is not recommended. At the same time, it is important to provide reality-based information. For example, if a person believes that they are Jesus Christ, consider assisting them with connecting with their faith or other personal needs instead of showing them the reasons why they are not Jesus Christ.
- **Collaborate with patients to establish shared treatment goals.** Goal setting within a rehabilitative setting for a person with SMI may be different from those without a major mental illness. Be mindful of the expectations of the treatment team and patient, considering together whether each goal is attainable while in the treatment setting as a short-term goal or rather should be conceptualized as a long-term goal.
- **Do diagnostic testing for medical problems.** A major problem for persons with SMI is that their psychiatric illness can distract providers from conducting a thorough assessment and then treatment of their medical problems. Conduct necessary laboratory, imaging, and other diagnostic tests to assist with clarification of unusual symptoms or behavior and refer for treatment of problems.
- **Respectful language.** Refer to the person as a "patient with schizophrenia" instead of a "schizophrenic." Labeling a person according to their illness is not just off-putting but inappropriate.

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Conversion Disorder

30

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Topic

Conversion disorder is defined by one or more physical symptoms that are not under voluntary control and are not thought to be caused by neurological or medical conditions. The key feature of this disorder is thus the incongruence between presented symptomology and medical conceptualizations of organic diseases. The most commonly observed conversion symptoms include blindness, psychogenic non-epileptic seizures, paralyses, unresponsiveness, anesthesia, aphonia, and abnormal gait [1, 2].

There is no unified model for conversion disorder and its conceptualization relies on psychological, social, and biological factors. The onset of the symptoms is sudden, and is often preceded by either psychological or physical trauma [1, 3]. The diagnosis of conversion disorder is often problematic. Since the presenting symptoms of this psychiatric disorder are neurological, a full diagnosis often requires collaboration between a psychiatrist and a neurologist [4]. Once the diagnosis has been made several treatment options may be considered. While there are no specific pharmacological or psychological treatments for conversion disorder, case reports suggest that a multidisciplinary approach in rehabilitation settings with an emphasis on maximizing physical function appears to be most beneficial [5, 6].

Chapter Organization: The first part of the chapter provides the reader with a conceptual understanding of conversion disorder. Current terminology and etiologies are also outlined.

The second part of the chapter discusses the importance of conversion disorder, its epidemiology, clinical presentation of conversion symptoms, issues with its diagnosis, comorbidities, and differential diagnosis.

The third part of the chapter discusses treatment options, as well as addresses possible challenges and barriers to positive treatment outcomes

A. ***Current Formulations***

The current understanding of the etiology and treatment of conversion disorders remains modest when compared to the progress made with other psychiatric disorders [5].

Despite the number of available theories, a unified model for the disorder does not currently exist; a combination of psychological,

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_30

social, and biological factors appears to drive the symptoms and should be considered in the formulation and treatment of the disorder.

B. ***Terminology***

To describe conversion disorder, the DSM-5 uses the terms:

- ***Conversion*** that is rooted in psychoanalytic models and psychogenic etiology
- ***Functional neurological symptom*** disorder that recognizes that underlying psychological factors might not be apparent (or present) at the time of diagnosis and emphasizes the importance of neurological examination [1].

Apart from conversion, most common terms that are currently used by clinicians to describe medically unexplained symptoms are:

- ***Functional,*** a term that denotes abnormal central nervous system functioning
- ***Psychogenic*****,** a term that denotes an etiology of psychological origin

C. ***Theories of Etiology***

1. **Psychoanalytic theory**

Psychoanalytic formulations of conversion disorder suggest that the medically unexplained physical symptoms represent expression of forbidden urges, unconscious drives, as well as the need to suffer or identify with a loss [7, 8]. A history of childhood sexual and physical abuse has also been associated with conversion disorder, suggesting that childhood traumatization may pose as a risk factor in some individuals [9]. While it remains unclear how stresses, traumas, or psychologically threatening or socially unacceptable thoughts translate into somatic symptoms, conversion symptoms are viewed as a consequence of a defense mechanism that occurs outside of the patient's awareness.

2. **Sociocultural theories**

Sociocultural formulations place an emphasis on gender roles, religious beliefs, and other sociocultural influences that may prohibit or dictate culturally acceptable ways to express emotion. Today conversion disorders are more commonly diagnosed in women, tend to affect individuals from lower socioeconomic status, rural communities, and individuals with limited knowledge of physiology and anatomy [10]. Differences in prevalence rates of conversion disorders across cultural groups are unclear due to inconsistent methods of assessment. However, some findings have shown that psychogenic non-epileptic seizures and loss of consciousness as more common in some contexts (e.g., Turkey, Oman, and India), while other settings have more frequently reported motor disturbances (Netherlands) or visual disturbances (Japan) [11]. Certain cultural syndromes, such as *ataques de nervios* (e.g., in Puerto Rico) may include similar medically unexplained symptoms such as loss of consciousness, faintness, convulsions, and blindness [12].

3. **Learning theory and secondary gains**

The social learning perspective emphasizes the role of the environment and reinforcement in behavior. Of particular importance in this model is the concept of ***secondary gains***—the benefits of the sick role behavior. Secondary gains, whether financial or interpersonal, act as a reinforcing consequence of the presenting symptoms and maintain the conversion disorder [13]. Positive reinforcement of the sick role behavior or the effect of secondary gains on symptoms maintenance may happen without the patient's conscious awareness.

4. **Neurobiological correlates of conversion**

The search for neural mechanisms by which psychological stressors translate into somatic symptoms is complicated by the low base rates, heterogeneity of symptoms, frequent comorbidities with anxiety and depression, as well as secondary gains and other psychological determinants of the behavior [14]. Despite the paucity and the heterogeneity of data, preliminary findings across studies point to converging mechanisms. Several investigations using functional magnetic resonance imaging and single-photon emission-computed tomography found associations between sensory and motor conversion symptoms and altered activity in the basal ganglia, as well as brain areas that are implicated in regulating and expressing emotion [14–17]. The results of these studies suggest that an abnormal pattern of activation in these regions may inhibit the activation of motor and sensory cortices, thus suggesting a mechanism by which intense emotion may override brain regions associated with sensory or motor function [18]. Future research is needed to further replicate these findings and determine their relevance for clinical practice.

Importance

A. ***Epidemiology***

- It is estimated that approximately 30 % of patients in neurology settings have symptoms unexplained by organic pathology [19, 20], and up to 18 % of these patients are subsequently diagnosed with conversion disorder [20]. The prevalence of patients with some symptoms of conversion disorder in general hospital settings is estimated at 20–25 % [21] with 5 % meeting the criteria for full diagnosis [22].[1]
- The disorder is two to three times more commonly reported in females.
- Its onset tends to be around 30 years for non-epileptic attacks and around 40 years of age for motor symptoms; however, it can also occur in young children and the elderly [1].
- The symptoms can be episodic or chronic and cause significant disability.
- It has been observed that the vast majority of patients diagnosed with conversion disorder are completely unable to work or attend school before receiving treatment. More than 50 % of patients are bedridden and require assistance with daily functioning [23].

Practical Applications

A. ***Clinical Presentation: What to look for***

Classification and diagnostic criteria

- In the DSM-5, conversion disorder is categorized under the umbrella of somatic symptoms and related disorders [1]. The first diagnostic feature, Criterion A is "one or more symptoms of altered voluntary motor or sensory function." Criterion B requires that the clinician provides evidence of incompatibility between the presenting symptoms and existing neurological or medical conditions. For example, in conversion blindness the patient might successfully avoid obstacles in his or her path without the conscious experience of sight. Criterion C states that the symptoms cannot be better explained by another medical condition or mental disorder including malingering. Finally, as per Criterion D, the symptoms or deficit cause significant impairment and distress in social, occupational, or other areas of functioning.
- Patients with conversion disorder may not necessarily exhibit "*la belle indifference*," an attitude that was thought to be unique to conversion disorder characterized by a lack of concern for alarming symptoms such as blindness or paralysis. Patients with conversion disorder may display as much concern over their symptoms as patients with organic diseases; they may also adopt a stoic attitude in the face of adversity, or feign it [24].
- Although the onset of the disorder is often thought to be precipitated by stress or trauma (psychological or physical), this requirement is no longer included in the current diagnostic criteria. Patients with conversion disorder do not always associate their symptoms with emotional distress,

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[1] It is noteworthy to mention that these statistics relied on the older diagnostic criteria that necessitated the existence of psychological factors associated with symptoms. These stricter criteria may have complicated the diagnosis and possibly led to the underdiagnosing and underreporting of the disorder.

thus the underlying psychological conflict (assuming it exists) may simply not be recognized and reported by the patient [4].

Most common symptom types associated with conversion disorder

Weakness or paralyses: paralysis of an arm or a leg [1]
Abnormal movement: tremor, dystonic movement (sustained muscle contractions causing repetitive movements or abnormal postures), myoclonus (a brief and involuntary muscle twitching), gait disorder, parkinsonism, abnormal limb posturing, ataxia (lack of voluntary coordination of muscle movements), periods of unresponsiveness resembling coma [1, 25]
Swallowing symptoms: Globus hystericus (sensation of a lump in one's throat) [1]
Speech symptoms: slurred speech, dysphonia (impaired ability to produce speech volume), aphonia (inability to produce sounds), dysarthria (impaired articulation) [1]
Attacks or seizures: psychogenic non-epileptic seizures, syncope (transient loss of consciousness) [1]
Anesthesia or sensory loss and other sensory symptoms: Altered sense of vision (blindness, double vision), reduced skin sensitivity, altered hearing [1]

The main feature of conversion disorder is inconsistency between presenting symptoms and an underlying organic pathology. Thus, the diagnosis necessitates an exclusion of medical or neurological conditions that may account for conversion symptoms. These may include simple bedside tests or muscle flexion exercises that can show incompatibility of presenting symptoms with neurological disorders. An electroencephalogram, X-ray, or imaging tests may be required to examine the organic basis for other presenting symptoms.

Examples of symptom incompatibility with neurological disease

Positive Hoover's sign: Normal pressure from the weak limb when asked to flex the contralateral hip against resistance [1]
Preserved deep tendon reflexes in the limb when presenting with complete paralysis or sensory loss [3]
Slower motor movements even when certain tests such as deep knee squat require more strength when performed slowly [26]
Resisting of manual eye opening by a physician during conversion unresponsiveness when in organically unresponsive patients a smooth and effortless glide is observed [27]
Psychogenic non-epileptic seizures: While differentiating a non-epileptic seizure from a real seizure is difficult, non-epileptic seizures do not display the characteristic electroencephalographic patterns. Their onset tends to be more gradual and may be accompanied by dramatic vocalizations, nontypical thrashing of extremities, and responsiveness to environmental stimuli (response to noxious stimuli) [28]
Tremors with inconsistent presentation; subsiding with distraction or changing in frequency after examiner's rhythmic tapping or movement of unaffected body part [1]

However, even in the presence of some of these positive signs that appear to be inconsistent with what is currently known about anatomy and pathophysiology, caution must be exercised when differentiating patients with conversion disorder from patients with organic diseases [29, 30]. First, the limitations and reliability of these symptoms in patients with motor and sensory neurological diseases has not been systematically investigated [31]. Moreover, in *functional overlay*, a situation where symptoms of conversion disorder co-occur with neurological dysfunction, the differentiation between disorders becomes increasingly complex [32]. However, the diagnosis of conversion disorder appears to have a reliable diagnostic stability, with a misdiagnosis rate of approximately 4% [33]. Given that one in 25 patients is misdiagnosed, caution still needs to be exercised to avoid jumping to false conclusions.

B. ***<u>Differential Diagnosis</u>***

When considering a diagnosis of conversion disorder, several alternatives should be investigated. As per DSM-5, the diagnosis of conversion disorder cannot be made if the symptoms are better explained by:

- **Neurological disease**
    - Progression of symptoms may signal previously unidentified neurological disease
    - Patients may present with unusual symptoms of organic illness such as myasthenia gravis (muscle weakness) [34] or with neurological and medical conditions that may appear like conversion

disorder (e.g., stroke, vocal cord dystonia, cortical-basal ganglia degeneration, multiple sclerosis) [23, 35]

- **Somatic symptom disease**
  - Most somatic symptoms (e.g., pain, fatigue) cannot be examined for incompatibility with pathophysiology. Moreover, individuals with somatic symptoms are preoccupied with excessive thoughts, emotional distress, and anxiety about the seriousness of their symptoms, and often invest excessive effort devoted to their health concerns [1]
- **Factitious disorder and malingering**
  - Feigning or simulating symptoms can occur in factitious disorder (a psychiatric disorder characterized by the motivation to receive medical care) or in malingering (external motivation to obtain a financial reward). Unlike individuals with fictitious disorder or malingerers, patients with conversion do not have conscious control over their symptoms [1]
- **Dissociative disorder**
  - Dissociative disorders are often comorbid with conversion, and both diagnoses should be made if symptoms meet criteria for both disorders
- **Body dysmorphic disorder**
  - The main characteristic of this disorder is excessive preoccupation with perceived physical defects; however, there are no sensory or motor dysfunctions
- **Depressive disorders**
  - In some individuals, depressive disorders can produce general feelings of heaviness in limbs that can resemble weakness reported in conversion disorder. The weakness in conversion disorder however is more localized, and depressive symptoms are often not the core diagnostic feature [1]
- **Panic disorder**
  - Transient neurological symptoms such as tremors and paresthesias (sensations of tingling, ticking, or burning of a person's skin without a long-term physical effect) can occur in conversion disorder and panic attacks. In panic attacks, however, the symptoms are acute and short lived with associated physical symptoms [1]
- **Cultural concepts of distress**
  - Certain cultural conceptualizations and manifestations of distress which include pseudoneurological symptoms such as *ataques de nervios* (e.g., pseudoseizures, fainting), *mareos* (e.g., dizziness, vertigo) in Latin Americans and among Latinos in the USA may need to be considered when working cross-culturally [1]

C. *Comorbidity*

Conversion disorders often coexist with other psychiatric disorders [1]. It is estimated that 10 % of patients with conversion disorder experience panic attacks, 23–50 % anxiety, 42 % phobia, 9–34 % obsessive compulsive disorder, 34–57 % depression, 22 % bipolar disorder, and 35–49 % posttraumatic disorder [9, 36–38]. Personality disorders (PD), in particular borderline and histrionic PDs, are also more common in individuals with conversion disorder [1, 9, 36, 39]. Thus, identifying and treating the comorbid psychiatric disorder may provide a resolution to psychological conflict and remove the primary gain responsible for the conversion reaction.

D. *Prognosis*

A better prognosis of conversion disorder is often associated with a briefer duration of symptoms; thus, it is of importance to consider a timely referral to a specialist to rule out an underlying medical condition and begin treatment as soon as possible [14].

E. *Diagnosing Conversion Disorder–Key Points*

If a patient presents with one or more symptoms that affect their movement or bodily senses and are not under the patient's voluntary control:

- Refer the patient for thorough neurological and medical examinations to exclude organic causes.
- Even with the lack of evidence for organic basis for symptoms it is possible that symptoms reflect undiagnosed neurological disease. If symptoms progress, reassessment for neurological or medical condition is warranted.
- Conduct a clinical assessment to:
  - Evaluate for differential diagnosis. Keep in mind that patients can have conversion and other mental or neurological disorders.
  - Examine the patient's history for psychological or physical traumas. If psychological stressors can be linked to the onset of conversion symptoms, appropriate psychological treatment can be provided.
  - Assess the patient for comorbidities: anxiety, depression, and other psychological conditions often coexist with conversion disorder. Treatment of comorbid conditions may alleviate conversion symptoms.
- Be aware of sociocultural factors that can affect symptom presentation
  - Conversion symptoms may vary between cultural contexts.
  - Women, individuals living in rural settings, and individuals with limited knowledge of physiology appear to be affected more often.
- *La Belle Indifference* or lack of concern for serious medical symptoms is not required for the diagnoses of conversion disorder. Patients with conversion disorder may be just as concerned about their symptoms as patients with neurological conditions.
- Patients with conversion disorder experience very high levels of disability.
- Timely diagnosis and treatment are crucial for successful outcome.

F. ***Treatment***

1. **Challenges and barriers**

   The absence of a unified etiological model of conversion disorder poses a challenge for proposing avenues for intervention. The clinician has to conduct a careful examination of the symptom timeline, often making inferences about the nature of factors precipitating the onset of the illness, the factors involved in symptom maintenance, as well as identifying possible comorbid psychiatric conditions and ruling out medical illnesses.

2. **Presenting the diagnosis to the patient**

   If the patient denies psychological causes for their symptoms, treat the patient with respect. Patients are often unaware that their symptoms may be psychogenic. Caution must be exercised to not imply that malingering is suspected. Questioning the legitimacy of symptoms can cause significant emotional distress and hinder therapy.

   Negative reactions from other health care providers may also be sensed. Many patients report that they feel accused of "faking" their symptoms or malingering and thus experience a sense of abandonment by their physicians [23]. Indeed, these attitudes are not uncommon among the neurologists, nurses, and rehabilitation staff [23].

   - Emphasize that the symptoms are not under voluntary control to validate the patient and normalize the nature of the disorder to treating staff who may not be cognizant of this disorder [6].
   - Suggest that symptoms may resolve spontaneously.
   - **Discuss the mind-body interconnection in illness:** Patients may wonder why they are referred to mental health therapists for a physical problem; clinicians may thus consider validating the difficulty of the symptoms to patients, and outline how physical suffering may be alleviated if "life stress" can be better managed.
   - Cultural influences related to conversion symptoms should be considered (discussed above) along with the DSM cultural formulation, and a consultation with a cultural consultant or interpreter when necessary [40].

3. **<u>Treatment Modalities</u>**
   a. ***Psychological treatments***

   The traditional approaches to treatment of this disorder were hypnosis and psychoanalysis. Such approaches, however, have not been validated and their success has been limited [14]. Cognitive Behavioral Therapy that is aimed at changing the maladaptive thinking patterns about pseudoneurological symptoms has shown to be effective in some studies (see [14] for review), but due to small sample sizes and heterogeneity of symptom presentation, replication is necessary to bolster claims about effectiveness. The success of all these treatments relies on the assumption that a psychological stressor linked to conversion exists and can be brought into the patient's awareness where it can be resolved, or that maladaptive thoughts related to the symptoms can be challenged. However, while this assumption may hold true, patients with conversion disorder are often unaware of the psychological stressors that may have caused their symptoms, and in some cases there may not be a clear stressor in the first place. Furthermore, these patients are often reluctant to acknowledge the psychological underpinnings of their symptoms and may be resistant to treatments that they construe as inappropriate and discordant with their belief of a physical basis for their symptoms [6, 41]. Hence, an approach that genuinely acknowledges the debilitating nature of the symptoms but also educates patients more generally about stress management and body–mind interrelationships in a manner that respects defenses, rather than directly challenges them, may be appropriate. The rehabilitation approach, below, is another method aimed at working with—rather than against—conversion symptoms.

   b. ***Rehabilitation approach***

   Evidence emerging from clinical cases suggests that a structured and active rehabilitation approach may be particularly effective for patients with motor conversion symptoms [6, 41–44]. These treatments are similar to those received by patients with symptoms arising from organic pathology and focus on maximizing physical function in rehabilitation settings.

   - Thus, the treatment should be geared towards the presenting symptoms and the patient should be referred to the rehabilitation setting appropriate for their physical symptoms [43].
   - This approach accomplishes several goals. Firstly, it acknowledges that presenting symptoms are not under the patient's voluntary control, thus validating the patient's dysfunction as real. Secondly, this approach is concordant with the patients' beliefs about the physical basis for their problem. Together these factors provide the patient with a non-threatening and supportive context for relinquishing the symptoms of conversion.
   - Adopting an approach where remaining in treatment is contingent on patients' improvement appears to motivate patients and minimizes manipulative behavior, thereby reducing negative interactions with rehabilitation staff [6]. Treating the problem as physical rather than emphasizing psychological causation may help "save face" and minimize stigma associated with a psychiatric condition. However, given that a large number of patients with conversion disorder present with other psychiatric conditions as well as social problems that can impact treatment, an interdisciplinary approach to management may be needed.

Tips

- Symptoms of conversion disorder are not feigned, but may represent a bodily manifestation of emotional distress.
- Psychological, sociocultural, and biological factors may be involved in conversion disorder, suggesting the need for a multidisciplinary approach to formulation and treatment.
- A non-confrontational approach that emphasizes psychoeducation of the mind-body relationship and validates the patient's suffering rather than minimizing symptoms may help build the alliance.
- Treatment aimed at maximizing physical function in rehabilitation settings appears to be promising.
- Treating the underlying psychological conflict may be challenging but beneficial in patients with identified emotional distress.
- More treatment studies are needed in identifying effective clinical management.

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31

Assessment and Treatment of Sexual Health Issues in Rehabilitation: A Patient-Centered Approach

Elisha Mitchell Carcieri and Linda R. Mona

Topic

The sexual lives and health of people with disabilities and chronic health difficulties have been under-addressed in medical and rehabilitation settings. When sexual health is addressed, it is often limited in focus to issues of sexual dysfunction or changes in functioning following a newly acquired injury, worsening chronic health condition, or disability. According to the World Health Organization, sexual health is defined as, "…a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity…[1]." This definition of sexual health is consistent with the new paradigm of disability, which describes people living with impairments as limited by social and environmental constraints that interact with their individual characteristics—physical, mental, or psychiatric conditions—to produce disablement [2, 3]. This view of disability focuses on well-being, wholeness, and thriving, and provides a framework for using a strength-based model for the assessment and treatment of sexual health-related issues [4].

An individual's sexual health is an integral part of the "whole person," and should therefore be incorporated into the process of rehabilitation for those with newly acquired disabilities, and for those coping with the chronic and ever-changing nature of any progressive disease, condition, or injury that warrants rehabilitation. Assessment and intervention related to sexual health should also involve exploration of the ways in which an individual's disability identity, self-concept, and psychosocial experiences interact with the presenting sexual health issue.

Importance

Historically, disability has been represented as a moral consequence, a source of shame, a medical anomaly, or a tragic condition associated with the need for rehabilitation. People with disabilities have experienced and continue to experience violation of rights and access of information and care. This is especially true in the area of sexual and reproductive health. Disability may affect an individual's sexual health in a variety of ways including but not limited to sexual dysfunction as a direct result of the disability, or from a related complication or issue. The American Psychological Association (APA) guidelines on

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_31

the assessment of and intervention with persons with disabilities [5] include specific reference to consideration of the sexual and reproductive rights of persons with disabilities and the responsibility of clinicians to provide culturally sensitive and sound information, assessment, and intervention in this area.

A. ***Barriers***

The multiple barriers to sexual health and expression among people with disabilities make providing information, assessment, and intervention a crucial aspect of a person's overall health care. These barriers/issues related to sexual health may include: beliefs about sexuality, sexual self-esteem, accessibility concerns, mobility, pain, concern about physical appearance, access to partners, or changes in sexual functioning. These barriers may prompt an individual to seek support or services and should be explored by the clinician providing culturally competent sexual health care [6].

B. ***Myths***

Several myths associated with disability and sexuality [7] serve to perpetuate the lack of availability and access to services related to sexual health concerns for people with disabilities: (1) people with disabilities are asexual, lack sex drive, or do not think about or enjoy sex; (2) people with disabilities are unable to function sexually; (3) people with disabilities do not have the capacity to behave in a sexually responsible manner; (4) people who are nondisabled are not interested in forming sexual or intimate relationships with people with disabilities; and (5) there are no effective interventions or methods of assistance for people with disabilities who have identified a concern related to sexual health.

The extent to which these myths are believed or perpetuated by the provider should be evaluated in the context of regular self-assessment of personal beliefs about disability, injury, and illness [6]. Providers should also assess personal beliefs and biases about sexual expression of persons with disability, disease, injury, or illness. Operating from a position of culturally competent, patient-centered care requires that providers develop an awareness of assumptions and beliefs about disability and sexual health.

Practical Applications

A. ***Assessment***

1. **Approach**

In assessing sexual health among people with disabilities, clinicians need to attend to an array of factors beyond symptomatology or diagnosis while maintaining an empowering, sex-positive stance to help to build rapport and guide assessment toward sources of resilience and creativity that may facilitate treatment [4]. The onset of a disability can result in a variety of changes that necessitate exploration to identify what factors require consideration in navigating a sexual experience (such as spasticity or positioning), and to rediscover sexually pleasing activities [8]. A brief screening assessment for the presence of questions or concern related to sexual health is appropriate for every patient presenting for rehabilitation.

2. **Inquiries**

Ask the patient, "To what extent are you currently satisfied with your sex life?," or, "What questions might you have about the ways in which your health condition, disability, or functional impairment has affected you sex life?" The clinician may also inquire about the ways in which a person's sex life has changed since the injury, disability, or onset of the disease. These screening questions communicate to the patient that sexual health is important and that it is safe to talk about sexual health. Providers should also regularly ask these screening questions at follow-up to further promote openness to and importance of the discussion of sexual health.

3. **Clinical Interview**

A thorough clinical interview to assess current sexual health and functioning should be used to clarify the referral question and ensure the most appropriate course of action for patients who identify a sexual health issue or concern. Zeiss, Zeiss, and Davies [9] describe an interview-based assessment of sexual functioning for older adults that was adapted and expanded upon by Mona and colleagues [10]. This model is comprehensive and sensitive to the intersection of diversity factors and sexual concerns. **Exhibit 1** is an adapted outline of important components of such an interview [11].

Exhibit 1: Clinical Interview Outline

I. Introduction and Presenting Issues/Goals
   A. Nature of the sexual issue and basic goals/hopes for treatment
      i. Client-identified goals; extent of match to/discrepancy with current situation
      ii. Client's perception of the effect of the injury/illness/disability on the sexual issue.

II. Sexual Functioning/Current Symptoms

   NOTE: These are specific symptoms according to the sexual response cycle. For each symptom, ask about: percentage of time this is occurring/is problematic; when during sexual encounter it occurs (e.g., foreplay and intromission); during what type of activities is this occurring (e.g., masturbation, oral sex, and intercourse); with whom it occurs; onset, duration, and frequency of the symptom(s); and what is happening when it is absent or when things go well.

   A. Desire
      i. Difficulties with sexual thoughts, fantasies, interest, and urges
   B. Excitement/Arousal
      i. Erection problems
         a. Percent of erections obtained typically and maximally; nocturnal or a.m. erections/emissions; concomitant desire problems
      ii. Lubrication/Vasocongestion problems
         a. Typical and maximal labia engorgement obtained; concomitant pain
   C. Orgasm
      i. Lack of Orgasm
         a. Typical timing if/when orgasmic; concomitant arousal issues; impact of quality of relationship with partner
      ii. Rapid Ejaculation
         a. Duration of erection until ejaculation; postejaculation behavior (self and partner)
   D. Sexual Penetration/Pain
      i. Unable to have vaginal penetration (digital, penile, etc.); in/voluntary tensing/tightening of pelvic floor muscles; pain and/or fear of pain during intercourse, masturbation, etc. Sources of pain (organic or nonorganic)

III. Sexual Well-Being Status
   A. Biopsychosocial aspects of sexual wellness
      ii. Biological—pleasure and satisfaction (for both individual and partner)
      iii. Psychological—joy; able to adapt sexual behaviors to situation/status; body image; feeling desirable; and sexual self-esteem
      iv. Social/relational—ability to pleasure a partner; sexual choices; trusting partnerships; emotional intimacy; and available partners
      v. Cultural—sexual values; sex roles; and sexual and reproductive rights

IV. Sexual history

   NOTE: Here, we are tracking sexual health and well-being across time. A collateral source of information is key, if available.

   A. Baseline sexual functioning—when was it going well and what sexual behaviors were occurring
   B. Onset of sexual concerns
      i. Gradual vs. abrupt; initial and subsequent sexual symptoms; precipitating factors (e.g., relationship challenges, physical/mental health concerns, and partner availability)
   C. Coping Strategies
      ii. Individual/couple coping strategies; attempts to resolve problem and successes; any upsetting consequences (e.g., doubt, depression, and failed relationships)

- iii. Causal Beliefs
  - a. Client's and partner's beliefs about causes of the sexual problem and openness to alternative explanations

V. Current Sexuality (Behaviors, Relationships, Attitudes, and Beliefs)

Note: *Here, we are getting a snapshot of the client's current sexuality. Collateral information is also key here, if available. Pursue topic areas as needed for specific client's situation.*

- A. Sexual scripts (typical sexual encounter)
  - i. Description of the typical sexual encounter(s) with prompt to describe in terms of beginning, middle, and end. Include details of when, where, and with whom sexual expression typically happens. Attend to influences on the sexual script such as mobility-related limitations, living situation, privacy, consent, physical assistance, and sexual initiation.
    - a. May include sexual activity with partners of other gender, same gender, and/or partners outside primary partnership. If so, follow-up topics include: experiences, fantasies and beliefs about sex within these partnership types; ground rules for multiple partner relationships; and any differences among those sexual scripts
  - ii. Safe sex practices
    - a. Beliefs/values about safe sex and sexual health; current practices; current and past sexual health history; knowledge of STIs and sexual risk; and resources available
- B. Relationship with primary partner
  - i. Perceived quality; expression of affection; emotional intimacy; impact of sexual problems; partner physical and mental health status; and communication
- C. Sexual Orientation and Gender Identity
  - i. Client's self-identification of sexual orientation and gender identity
  - ii. Value systems around same gender or opposite gender sexual behavior/activity; stigma and/or discrimination; and impact on family, social, and sexual relationships over time
- D. Beliefs/Attitudes/Values
  - i. General attitudes toward sex including acceptable sexual behaviors and in/appropriate situations for expression (e.g., outside of marriage and sex as solely reproductive)
  - ii. Attitudes and beliefs about disability and sexuality (e.g., impact of disability/functional status and persons with disabilities as asexual)
  - iii. Values about sexual expression and relationships/intimacy

VI. Medical and Mental Health Contributions/History

*NOTE: This information is often part of a general clinical interview and is collected from various resources (*e.g., *prior treatment, chart review shared information with treatment team).*

- i. Background information
- a. Life situation (e.g., age, education, work, cultural background, etc.)
- b. Physical health history/status and health behaviors
- c. Mental health history/status
- d. Cognitive health history/status (including any decisional capacity issues)

4. **Physiology**

While conducting the assessment, it is important to keep in mind that the physiological nature of a person's disability is relevant to her/his sexual experiences, but it is not essentially negative and does not inherently inhibit the potential for sexual enjoyment [12]. Differences in sexual functioning related to the person's disability may occur at any point in the sexual response cycle, and these differences vary depending on the specific nature of a person's disability. Providers should avoid making assumptions about the effect of an individual's disability on their experience, and take care to gain a thorough understanding of their unique presenting issue. The clinician should also consider the effect of additional sources of identity beyond disability to understand the context in which sexuality is experienced including age, religion, ethnicity, socioeconomic status, sexual orientation, indigenous heritage, national origin, and gender [13].

5. **Sexual Consent**
   Also of importance at the assessment phase is the notion of sexual consent capacity, the capability for sexual decision making [10, 14], as deficits in planning and problem solving abilities, communication, or social skills, and changes in behavior, such as disinhibition or apathy can affect sexual consent capacity and pose challenges to intimacy [15]. Mona and colleagues [4] recommend that clinicians maintain an awareness of the legal and ethical issues surrounding an individual's ability to consent to intimate sexual contact and the potentially fluid nature of this capacity [14].
6. **Body image, self-esteem, and sexual esteem**
   These fluid constructs should be evaluated and reevaluated on an ongoing basis as they are subject to change over the course of rehabilitation or over the course of a person's experience living with a disability at various stages of the lifecycle. This issue is especially relevant given the pervasive societal devaluation of the different body variations, which can affect body image or sexual desire for individuals with a disability [16, 17]. Sexual esteem includes one's personal evaluation of sexual competence and attractiveness [18] and can also be affected by disability-related experiences in the area of dating, relationships, and sex. Providers should also assess for the presence of abuse or trauma, as people with disabilities are at increased risk for abuse and face challenges associated with leaving abusive relationships [19]. A thorough assessment will provide the information needed to proceed with a disability culturally competent, person-centered approach to intervention.
7. **Relationship Boundaries**
   An important consideration for all members of the rehabilitation team, including the patient. Both physical and emotional closeness of care during rehabilitation may cause patients and providers to question boundaries during the course of assessment and treatment. Respect for boundaries of confidentiality and professional conduct within the context of in-person interactions and charting are critical and may require ongoing self-assessment by both patients and providers. Routine patient and staff education about appropriate boundaries within the context of assessment and treatment planning for sexual health concerns is advised [20].

Practical Applications

A. ***Referrals***

Referrals for treatment of sexual health-related issues may include: feeling asexual and undesirable, how and where to find partners, disclosure of disability status, sexual functioning, body image/appearance concerns, sexual positioning/body functioning education, communication barriers, bowel and bladder issues, and fertility [6]. Providers are encouraged to explore their level of clinical expertise and the needs of the patient prior to making appropriate triage decisions.

B. ***The "PLISSIT" model*** [21]

PLISSIT describes a hierarchical approach to the delivery of intervention including **p**ermission, **l**imited **i**nformation, **s**pecific **s**uggestions, and **i**ntensive **t**reatment, with higher levels requiring additional training and experience, ideally in both sex therapy and disability [7]. Many interventions can be implemented during the initial contact such as inviting a person to talk about sexual health, normalizing concerns, answering questions, providing referrals to medicine and subspecialties such as primary care or urology (See Table 31.1).

With regard to intensive treatments, the clinician should consult evidence-based practices for the particular presenting problem or symptom(s) while considering the unique experience of living with a disability and how that may affect therapy [22]. Mona and colleagues [4] describe specific intensive treatment approaches that are summarized below:

Table 31.1 The PLISSIT model of intervention

PLISSIT	Level of training/skill	Intervention
Permission	• No specialized training • Requires openness to talking about sex	• Normalize questions/problems/dysfunction • Validate concerns • Encourage exploration of sexual issues
Limited **i**nformation	• May require additional knowledge (e.g., anatomy or positioning)	• Dispel myths/provide factual information • Answer questions and provide education
Specific **s**uggestions	• Some experience with principles of sex therapy and disability	• Provide suggestions or exercises tailored to the patient, their history, and their disability
Intensive **t**herapy	• Specific training in sexual health assessment/treatment and disability	• Disability Affirmative Therapy • Cognitive Behavioral Therapy • Acceptance and Commitment Therapy

C. ***Disability Affirmative Therapy (DAT)***

DAT [7] provides a disability-positive context wherein specific treatment interventions can be applied. DAT encompasses several components: (a) empowerment and acknowledgement of social marginalization and environmental barriers, (b) appreciation of the dynamic nature of disability, (c) consideration of the medical realities of people with disabilities and recognition of personal coping strategies, and (d) provision of a therapeutic environment that provides affirmative goal-setting, an integrated view of the self, and encapsulates the values of flexibility and creativity that are prized in the disability community. An integrated approach would involve using established techniques in the context of a disability-affirmative framework to address the individual's symptoms (e.g., physical discomfort and distress due to lowered sexual self-esteem) as well as the facilitating social and political factors (e.g., inadequate sexual healthcare, myths, and difficulty identifying partners).

D. ***Cognitive Behavioral Therapy (CBT)***

CBT techniques are foundational to sex therapy [23, 24]. Goals and strategies may include overcoming disability/sexuality myths using psychoeducation and bibliotherapy, decreasing performance anxiety using relaxation techniques (e.g., sensate focus), decreasing maladaptive cognitions and negative sexual self-schemas using cognitive restructuring, and using stimulus control strategies [25]. Treatment goals may also include social empowerment using normalizing and validation, Socratic questioning about personal and societal sexual values, and psychoeducation about enhancing sexual enjoyment. Cognitive restructuring can also help to increase flexible thinking and behavior to facilitate sexual esteem and performance.

E. ***Third-wave cognitive behavioral therapies (ACT)***

ACT has emerged as an effective treatment for various presenting problems [26] through the use of mindfulness along with cognitive and behavioral techniques that facilitate psychological flexibility, value-driven behavior, and increased awareness and acceptance. Mindfulness is rooted in being nonjudgmental and open to all emotional experiences, and through practice can aid in accepting anxious thoughts and reducing distress and avoidance behaviors during intimacy. A sensual mindfulness approach includes sensate focus—staged practice of intimate touch—and integrates the goal of accepting any uncomfortable feelings or thoughts that might arise during intimacy, while intentionally remaining in the present moment. ACT also emphasizes engaging in behavior that reflects personal values and promotes values clarification—the process of articulating and exploring personal beliefs and core values. This approach can aid patients in identifying how their values affect their sexual experiences and intimate relationships [27], and how they might explore, change, or expand their sexual repertoire to fit their values around sexual health.

F. ***Practical Approaches***

Practical approaches to intervention may include exploring optimal sexual positioning or the use of sexual enhancement products, or "sex toys" to reduce pain and maximize pleasure. Functional or physical limitations should be considered, as well as the person's comfort level and desire to try a certain product, and whether or not assistance would be needed for that person to use the product. Exploring sexual products that can lessen or change the ways that assistance is needed—or provide additional privacy (e.g., a privacy pillow with a storage pocket for a vibrator, sex cushions for positioning, lubricating gels, and ergonomically designed extender toys) can also be helpful.

Providers may also work with patients towards the development of skills in the preparation for sexual experiences, and the need to adapt existing sexual scripts (scheduling and timing of sexual experiences, attending to bowel and bladder functioning, and making modifications in sexual positioning for catheters or other assistive equipment). Patients may need to build communication skills for involving their partner in proper planning or positioning. Self-stimulation (depending on individual beliefs and values) with or without intimate partners is also crucial for sexual exploration and can be a way of expressing sexuality that is less likely to be affected by physical and social limitations [28]. Identifying opportunities for meeting potential partners and working with clients to prepare to meet potential partners face to face with interventions such as role-playing and social skills training are appropriate practical interventions. Clients should be educated about safety precautions when meeting prospective partners given the physical vulnerability of many people with disabilities.

Conclusion: The assessment and treatment of issues related to the sexual health of people with disabilities and chronic health issues within medical settings has historically been undervalued and often focuses primarily on dysfunction related to injury, or illness. Contemporary definitions of sexual health and disability call for a more comprehensive approach that promotes the exploration of issues related to sexual health with every patient and incorporates aspects of self-concept, social context, and disability diversity into treatment.

Tips

- Do inquire about sexual health and satisfaction with every patient.
- Do regularly evaluate relationship boundaries to establish and maintain appropriate professional relationships with patients.
- Use ongoing education and/or consultation on relationship boundaries that may present in rehabilitation settings within the context of assessment and treatment of sexual health concerns.
- Do ask the patient about their sexual health even if you may not know the answer to a patient's question or concern. Tell the patient that you will find the answer or refer them to the appropriate provider, and be sure to follow up.
- Do ask the patient about sexual health and satisfaction at follow-up visits.
- Do not wait for a patient to initiate a conversation with you about sexual concerns and questions.
- Do not assume the patient will be knowledgeable about topics related to sexual health.
- Do complete a thorough sexual health assessment that is not limited to dysfunction.
- Do use a disability affirmative approach with established therapeutic modalities and make appropriate referrals to allied healthcare professionals as needed.

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Sleep Issues in Medical Rehabilitation

32

Luis F. Buenaver, Jessica Richards,
and Evelyn Gathecha

Topic

Sleep disturbance and complaints of insomnia in particular are common among hospitalized patients. Insomnia **(In)** is operationalized as difficulty initiating and/or maintaining sleep, early-morning awakening, and/or nonrestorative sleep. Insomnia complaints are typically associated with distress or impairment in different domains including occupational, interpersonal relationships, and social life. Treatment involves learning new adaptive behaviors that target the factors that perpetuate and exacerbate the insomnia; consequently, healthcare providers may play a crucial role in helping hospital inpatients/medical rehabilitation patients manage their sleep issues.

Various studies have examined sleep disturbance in hospitalized patients. The effects of sleep deprivation in patients with serious medical illness have primarily been investigated in intensive care unit (ICU) settings. Disrupted sleep is one of the primary complaints of patients following discharge from the ICU [1, 2]. Sleep for patients in the ICU is characterized by decreased total sleep time, increased non-rapid eye movement stage 1 sleep (N1), decreased non-rapid eye movement stage 3 sleep (N3), and decreased rapid eye movement sleep (R). Patients in the ICU experience fragmented sleep with 50 % of total sleep occurring diurnally [3–5].

Terminology

A. ***Insomnia definitions***

1. *World Health Organization (WHO)*

   The organization defines insomnia as a problem with falling asleep, remaining asleep, and/or nonrestorative sleep that occurs *at least three nights per week* and is associated with distress or functional impairment.

2. *American Psychiatric Association (APA)* [6]

   The association uses the diagnostic term "insomnia disorder" whether it occurs as an independent condition or is comorbid with another condition (e.g., medical, mental, or another sleep disorder). The APA specifies a duration criteria of *at least* 3 *months* and a frequency of *at least three nights per week*. The diagnosis is made when the primary problem is dissatisfaction with sleep quantity or quality related to trouble initiating and/or maintaining sleep and/or

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_32

early-morning awakening with inability to return to sleep. Further, the sleep complaint must be associated with significant distress and impairment in important areas of functioning (e.g., occupational, educational, academic, behavioral, social, etc.) and is not due to another medical, psychiatric, or sleep disorder.

3. *International Classification of Sleep Disorders (ICSD)*, *Third Edition*

   The book is published by the American Academy of Sleep Medicine (AASM) and defines insomnia as "persistent difficulty with sleep initiation, duration, consolidation, or quality that occurs despite adequate opportunity and circumstances for sleep, and results in some form of daytime impairment." The three diagnostic categories listed for insomnia, include *chronic insomnia disorder*, *short-term insomnia disorder*, and *other insomnia disorder*. In order to meet diagnostic criteria for chronic insomnia disorder, the sleep disturbance(s) and accompanying daytime impairment must be present at least three times a week for at least 3 months. Patients reporting insomnia symptoms that do not reach the frequency and/or duration thresholds, but do exhibit significant dissatisfaction with their sleep and/or waking impairment, are classified as having short-term insomnia disorder. Individuals failing to meet criteria for short-term insomnia, but with clinically significant sleep disturbance or daytime impairment, may be classified with other insomnia disorder.

B. ***<u>Older terminology for clinical descriptions of insomnia subtypes</u>***

No longer modern parlance yet useful for clinical description:

1. *Initial-/early-/sleep-onset insomnia*
   - Refers to trouble falling asleep
   - Often seen in circadian rhythm sleep disorder, phase-delay type
2. *Middle-/sleep-maintenance insomnia*

   Refers to difficulty with frequent or prolonged awakenings during sleep period
3. *Terminal/late insomnia*
   - Refers to problems with awakening earlier than desired and difficulty returning to sleep
   - Often seen in circadian rhythm sleep disorder, phase-advance type

C. ***<u>Contemporary sleep terminology</u>***

1. *Sleep-onset latency (SOL)*

   It is the length of time to transition from wakefulness to sleep at the beginning of the sleep period.
2. *Wake after sleep onset (WASO)*

   It is the total amount of time spent awake after the initiation of sleep and before final awakening.
3. *Final awakening (FA)*

   It is the time at which the individual awakens from his/her sleep period and no longer returns to sleep.
4. *Time out of bed (TOB)*

   It is the time at which the individual physically gets out of bed at the end of their sleep period which may or may not be the same as their final awakening.
5. *Time in bed*

   It is the time from when a person goes to bed with the intention of going to sleep until the time he/she gets up for the day at the end of their sleep period.
6. *Total sleep time*

   It is the amount of actual sleep time in a sleep period that is equal to time in bed minus time awake (SOL + WASO + time between FA and TOB).
7. *Sleep efficiency*

   It is the proportion of time in bed that is actually spent sleeping. Mathematically, it is calculated by dividing total sleep time by time in bed.
8. *Nap*

   It is a relatively short period of sleep generally obtained at a time separate from the major sleep period.
9. *Phase delay*

   This is a circadian rhythm disorder that is common in adolescents and young adults. Individuals have "night-owl" tendencies in which their sleep onset can be delayed until 2 a.m. or later. If allowed to sleep late (often as late as 3 p.m.), sleep deprivation does not occur. Typically, sleep deprivation occurs when there is a misalignment between the individual's desire for earlier bedtimes and wake times and their body's natural tendency for later bed- and wake times. Earlier wake-up times can lead to daytime sleepiness and impaired work and school performance.

10. *Phase advance*

    This is a circadian rhythm disorder that is common in older adults. This disorder is identified by regular early-evening bedtimes (e.g., 6 p.m.–9 p.m.) and early-morning awakenings (e.g., 2 a.m.–5 a.m.). People with advanced sleep phase syndrome are "morning larks" and often complain of early-morning awakening or insomnia as well as sleepiness in the late afternoon or early evening.

Importance

A. ***Prevalence and characteristics of sleep disturbance in acute care***

- The prevalence of insomnia in a sample ($N=299$) of medicine department inpatients was 42.1 % [7].
- Sleep disturbance is common in acute care. Polysomnography (PSG) studies indicate decreased N3 sleep (slow wave sleep) and total sleep time in acute care settings [8].
- In a small pilot study of older adults in an acute care setting in which actigraphy was used to measure sleep, subjects received an average of 3.74 h of sleep the first night, 3.61 the second, and 3.15 the third inpatient night. Across three nights of sleep, average sleep efficiencies were 46.75 %, 44.9 %, and 39.37 %, respectively [9]. Thus, inpatients' sleep duration is insufficient and sleep continuity is fragmented.
- In a PSG study of surgical ICU patients, sleep architecture was found to be abnormal. Patients were found to spend 96 % of sleep in N1 and N2, 2.29 % in N3, and 3.3 % in REM sleep [10]. Generally, sleep depth tends to be compromised in this population.

B. ***Sources of sleep disruption***

- Hospital noise puts patients at risk for sleep loss and its associated negative effects. The World Health Organization (WHO) international recommendations suggest no more than 30 dB for patient rooms. Yoder and colleagues (2012) conducted a study of 92 inpatients in which noise levels (48–80 dB) exceeded the WHO recommendations (30 dB) even at night when units were quieter. Moreover, higher noise levels were associated with clinically significant sleep loss. Sleep disturbance due to noise levels in hospital settings comes largely from preventable sources: conversations, roommates, alarms, intercoms, and pagers [11].
- Noise, light exposure, and frequent awakenings from medical personnel contribute to sleep disturbance [12]. Further, underlying medical illnesses and medications exacerbate sleep disruption in hospital inpatients [12].
- Patient care procedures including measurement of vital signs (i.e., blood pressure, pulse, temperature) can contribute to fragmented sleep [13, 14].
- Light levels in the ICU have been demonstrated to disrupt sleep by altering melatonin levels and dysregulating circadian rhythms [15].

C. ***Relevance to health outcomes***

- An estimated 68 % of closed head injury (CHI) patients evidence disturbed sleep, which is associated with longer stays in both inpatient acute and rehabilitation facilities [16]. Specifically, among CHI patients, individuals with sleep disturbances spent an additional 13 days admitted to acute inpatient care and an additional 16 days in inpatient rehabilitation, compared to patients with no evidence of sleep disturbance. Therefore, treating sleep disturbance in inpatients is critically important to reduce the cost of medical and rehabilitation care.

- Sleep disturbance in traumatic brain injury (TBI) patients is also associated with fatigue, anxiety, and depression and interferes with recovery and rehabilitation [17]. Sleep disturbance and co-occurring mood and anxiety symptoms among patients with TBI may be due to injury-related damage to the hypothalamic suprachiasmatic nuclei, which regulate circadian rhythms [17]. Sleep disturbance has been associated with altered immune function [18, 19] and an increased inflammatory response, which in turn stimulates the stress response [20–22].
- Sleep deprivation and fragmented sleep have also been shown to affect the equilibrium of the parasympathetic and sympathetic systems (e.g., increased blood pressure and heart rate) [22, 23].
- Sleep disruption is particularly pervasive in ICU patients, most commonly due to medical and diagnostic procedures (e.g., blood draws and vital sign checks) and environmental noise [1]. Sleep disruption within this population is associated with immune system dysfunction, impaired wound healing, and changes in behavior and mental status (e.g., "ICU psychosis") [12].
- In ICU patients, greater sleep disruption is associated with greater mortality and disease severity scores [19, 24].

Practical Applications

A. ***Make efforts to maximize sleep opportunity and quality***

There is a limited understanding of the importance of sleep and its role in healing, therefore:

- Clinician sleep education/training on the importance of sleep can be delivered via a clinician in-service training to educate hospital staff about sleep in the hospital [25].
- Sleep educational materials or posters promoting sleep can be displayed throughout the unit to help clinicians remain cognizant about the importance of sleep.
- Sleep should be considered a vital sign and be a routine part of clinical evaluation for all hospitalized patients using standardized sleep assessment tools.
- Enforce unit quiet time.
- Restrict noise.
- Limit light in the environment.
- Offer patients the option of tailored interventions including relaxation training.
- Teach patients good sleep hygiene habits (dietary, environmental, and lifestyle/behavioral). An example of environmental factor modification to promote sleep may include reviewing lights out, television off, using a white noise machine to screen out environmental noise, and room temperature adjustment or using an extra blanket. Regarding an example of the impact of dietary factors on sleep, patients can be taught about liquid intake and restroom usage and the impact of hunger and caffeine on sleep [25].
- Bundle patient care activities so as to minimize/eliminate nocturnal disturbances and increase uninterrupted opportunities for sleep.
- Careful consideration of roommate assignments.
- Standardize measurement of vital signs to minimize sleep disruption while maintaining adequate monitoring of patient health status.

B. ***Evaluate pain***

Sleep disturbance and pain are interrelated [14, 26, 27], and their relationship is believed to be reciprocal [26]. Sleep complaints are present in 67–88 % of chronic pain disorders [28, 29], and at least 50 % of individuals with insomnia—the most commonly diagnosed disorder of sleep impairment—suffer from chronic pain [30]. Across most medical interventions, the development of pain as a side effect coincides with the development of sleep disturbance and vice versa [31]. Further, both chronic pain and sleep disturbances are comorbid with depression [32].

- *Pain Assessment*: A 10-point numeric rating scale is the most widely accepted metric, with 0 indicating "no pain" and 10 indicating "worst pain imaginable." Typical assessment explores current pain level, worst and best levels, acceptable or bearable level, and aggravating/alleviating factors.
- *Pain Intervention*: Pain management is crucial in hospital inpatients in order to facilitate sleep. Psychosocial approaches to pain management include emotion-focused coping strategies such as relaxation training and cognitive restructuring. These interventions lower psychophysiological arousal. With pharmacological approaches, the sleep-interfering properties of analgesics should be considered.

C. ***Evaluate depression***

Recent epidemiological studies strongly suggest that not only is insomnia a typical symptom of depression but, vice versa, insomnia may be an independent risk factor for depression in the long run. Thus, the relationship between insomnia and depression constitutes a situation with evidence supporting a strong bidirectional linkage. The prevalence of insomnia in patients with depression ranges from 80 to 90 % [33]. Typically, patients suffer from difficulty in falling asleep, frequent nocturnal awakenings, and early-morning awakening. Depression, thus, is considered to be one of the most frequent and prominent causes of insomnia. Vollrath et al. (1989) published data from a long-term epidemiological study in Switzerland and reported that 25 % of the patients complaining of chronic insomnia suffered from depression [34]. Epidemiological data from patients of general practitioners showed that the likelihood of having depression was increased fourfold in patients with severe insomnia [35, 36].

- *Depression Assessment*: Some common tools to assess depression include the **Beck Depression Inventory (BDI)-FastScreen for Medical Patients** (a reliable 7-item self-report questionnaire for use in adolescents and adults that can be administered in less than 5 min) and the **Patient Health Questionnaire-9 (PHQ-9).** The PHQ-9 quantifies the core symptoms of major depression, with scores of 10 or above suggesting probable mood disorder. The *SIGECAPS* mnemonic (**low mood** *plus* changes in *S*leep, *I*nterests, *G*uilt, *E*nergy, *C*oncentration, *A*ppetite, *P*sychomotor changes, and *S*uicidal thoughts) can aid in making a thorough appraisal within an interview context. When examining depression in hospitalized patients with disturbed sleep, it is important to consider shared qualities inherent in both conditions that may affect self-reported symptoms. (e.g., people with sleep disturbance may have low mood, decreased energy, and attention/concentration difficulties due to insufficient sleep).
- *Depression Intervention*: Depression may be treated with psychotherapy or an effective dose of antidepressant medication. Cognitive behavior therapy for insomnia (CBT-I) has successfully been used to treat insomnia in patients with depression. The benefits extended beyond insomnia to also include overall well-being and depressive symptom severity including suicidal ideation [37].

D. ***Medications***

Review the dosage, timing, and administration of medications known to interfere with sleep. Consider alternative medications.

Tips

- **Normalize the experience of sleep disturbance in a hospital setting.** Acknowledging the prevalence of sleep disturbance in general and the fact that sleep particularly suffers in an inpatient hospital setting, due to the nature of the environment, is important. Some people may become concerned about their poor sleep which may in turn exacerbate their efforts at sleep. In the ideal situation, the psychologist sees every person admitted for rehabilitation, integrating mental health, including behavioral sleep medicine, into the overall plan of care and enabling understanding of the importance of sleep for the team and persons served. Even when psychology/behavioral sleep medicine is only consulted for problematic cases, it is crucial for facilitating acceptance to introduce psychological services as a means of addressing quality of life concerns and stress management, rather than as a traditional treatment for mental disorders.

- **Standardize the hospital environment to minimize disruptions and promote a good night's sleep for patients.** Often sleep disruptions are related to routine patient care within a hospital environment. Creating standardized patient care protocols allows routine patient care activities to be performed within a time frame that will minimize sleep disruptions for hospitalized patients.
- **Peer education on the importance of sleep and sleep education is an ongoing process.** Recognize the value in educating fellow healthcare professionals on the importance of sleep and its impact on health and quality of life and that it is an ongoing process. Similarly, educating fellow healthcare providers about their unique role in creating an optimal sleep environment for patients may also be a process that occurs over time.
- **Identify patients with underlying sleep disorders.** Early identification of patients who have an underlying sleep disorder at the time of admission helps to focus and tailor therapy specific for these individuals. Targeted treatment may be initiated within the inpatient setting and continued upon discharge from the hospital with the appropriate referrals.

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Fatigue

33

Connie Jacocks

Topic

Fatigue, from a biobehavioral perspective, is defined as "the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization, and/or restoration of resources needed to perform an activity" [1]. It is also referred to more briefly as a state of chronic tiredness and pervasive feeling of exhaustion [2]. Fatigue is common in both those with and without medical illness and can have a significant impact on daily life function and the rehabilitation process. Fatigue is a complex construct that exists along a number of dimensions defined below—the understanding of which is important for clinical conceptualization and etiology, clarifying patient experience and associated outcomes.

A. ***Normal vs. pathologic fatigue***
   1. **Normal fatigue**
      A state of tiredness with a rapid onset, the result of activity and overexertion, but that is relieved with rest.
   2. **Pathologic fatigue**
      A state of tiredness that is unrelated to activity level, may not respond to rest, and may have multiple potential etiologies resulting in an excessive and chronic presentation [3].

B. ***Physiological vs. psychological fatigue***
   1. **Physiological fatigue**
      It is associated with organ failure and the depletion of essential substrates required for function, further divided into peripheral and central fatigue. *Peripheral fatigue* may be regarded as muscle fatigue—a failure to sustain muscle force and contractions due to dysfunction of neuromuscular junction transmissions or metabolic conditions. In contrast, diseases which affect the central, peripheral, and autonomic nervous systems contribute to *central fatigue*, i.e., the perception of increased effort and difficulty sustaining physical and mental activities. *Psychological fatigue* occurs in situations with chronic stress and mood symptoms and includes weariness due to reduced motivation or prolonged activity [4, 5].
   2. **Primary vs. secondary fatigue**
      Simply stated, ***primary fatigue*** is that which is attributed directly to the pathophysiology of a medical or neurologic condition (e.g., multiple sclerosis). ***Secondary fatigue*** is the perception of

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_33

> tiredness or exhaustion due to comorbid syndromes either directly related to the primary condition or developing independently. Examples include fatigue due to chronic pain, mood symptoms and/or psychosocial stressors, sleep disturbance, physical debility, medication side effects, and poor health behaviors (nutrition, hydration, and exercise). From a medical rehabilitation perspective, providers seek to manage primary fatigue and prevent or mitigate the potential impact of fatigue due to secondary factors.

Distinctions are also made between fatigue and drowsiness, sleepiness, depression, apathy, and anxiety. Fatigue may present as a subordinate or comorbid presentation as well as a distinct entity and should be assessed accordingly [6].

Importance

Fatigue in patients with neurologic injury or illness is often chronic and pervasive. It is prevalent in a range of neurologic disorders including autoimmune conditions, stroke, traumatic brain injury, spinal cord injury, cancer, neurodegenerative disease, cardiovascular disease (congestive heart failure and myocardial infarction), organ failure, endocrine disorders, and vitamin deficiencies. In particular, fatigue is estimated to impact 50–80 % of patients with traumatic brain injury [7], 60–96 % of cancer patients undergoing cancer treatments (fatigue also often extends past treatment period [8]), 50–60 % in spinal cord injury [2, 9], 42–75 % of stroke patients [10], and up to 75 % of those with multiple sclerosis [11–13]. This is in contrast to a lifetime prevalence for neurologically intact individuals of 24 % [7, 14].

Not only is fatigue prevalent, but it can be detrimental to daily function and quality of life and present as a barrier to the overall recovery and rehabilitation process. Studies across neurological disorders have identified associations between fatigue and functional disability, dysphoric mood, neuropsychological problems, reduced life satisfaction, loss of hope for recovery, change in employment status, institutionalization, and mortality [2, 3, 15, 16]. Patients also often identify fatigue as one of their most debilitating symptoms [2]. Notably, the relationship between fatigue and poor outcomes is not unidirectional. Impairments following medical illness (e.g., stroke) may contribute to fatigue, which then further compounds and exacerbates existing impairment [17].

Given the significant impact of fatigue on individual function and rehabilitation outcomes, proper assessment, intervention, and monitoring are imperative. Due to the subjective nature of fatigue, validated and standardized instruments are necessary [16].

Practical Applications

A. ***Assessment***

Proper assessment of fatigue involves several steps in order to inform ongoing treatment and intervention. Comprehensive assessment includes exploration of the patient's subjective experience, consideration of underlying etiologies (through review of biopsychosocial history), quantifying fatigue using objective measures, and employing intervention. A review of helpful tools for assessment and intervention, and brief comparison of methods, is provided.

- ***Evaluate subjective fatigue experience***
  - **Brief screener** questions may be utilized including Socratic and open-ended questioning, as well as specific rating scales. For example, fatigue may be rated on a scale of 0–10, with 1–3 indicative of mild fatigue, 4–6 as moderate, and 7–10 as severe fatigue [18]. A multi-symptom screening tool may also have utility, as fatigue rarely occurs in isolation [18]. These screening questions then inform a more focused extended inquiry.
  - **Extended assessment** includes documentation of multiple important facets of fatigue including onset, duration, severity, daily pattern, environmental

Table 33.1 Selected measures for fatigue assessment

Measure	Items	Dimensions
Brief Fatigue Inventory (BFI)	9	Severity, interference
Causes of Fatigue Questionnaire (COF)	12	Mental effort, physical effort
Fatigue Assessment Scale (FAS)	10	Severity
Fatigue Impact Scale (FIS)	30	Physical, cognitive, psychosocial
Fatigue Scale (FS)	11	Mental, physical
Fatigue Severity Scale (FSS)	10	Interference
Fatigue Symptom Inventory (FSI)	13	Severity, duration, interference
Functional Assessment of Chronic Illness Therapy-Fatigue	40	Physical, social/family, emotional, functional well-being
Iowa Fatigue Scale	11	Cognitive function, drowsiness, energy, productivity
Modified Fatigue Impact Scale	21	Physical, cognitive, psychosocial
Multidimensional Assessment of Fatigue (MAF)	16	Degree, severity, distress, interference
Multidimensional Fatigue Inventory (MFI-20)	20	General, physical, mental, reduced motivation and activity
Multidimensional Fatigue Symptom Inventory (MFSI)	30	General, physical, emotional, mental, vigor
Pearson and Byars Fatigue Feeling Checklist	13	Severity
Revised Piper Fatigue Scale (PFS-R)	22	Behavior, severity, affective meaning, sensory, cognitive/mood
Schedule of Fatigue and Anergia (SOFA)	10	Nature, severity
Visual Analog Scale for Fatigue (VAS-F)	18	Energy, fatigue

Note: As reviewed by Bower et al. [18] and Whitehead [19]

influences, effects on functional activities, and quality of life [3].

- ***Consider etiology and contributing factors***
  - **Primary conditions**: Medical illnesses which contribute to fatigue are numerous and may include neurologic, oncologic, endocrine, autoimmune, infectious, and systemic etiologies.
  - **Secondary influences**: Potentially modifiable influences include medication's effects, mood symptoms, disturbance in sleep, nutrition, or hydration, substance abuse or dependence, and vitamin deficiencies.
- ***Quantify experience with outcome measures***
  - **Disease-specific vs. universal applications**: Measures may be developed and validated in a single population or meant for utilization across patient groups. Examples of fatigue measures found in existing literature are summarized below; however, the list is not intended to be exhaustive. The reader is encouraged to explore additional measures other than those listed (Table 33.1).
- **Disease-specific measures** (e.g., Functional Assessment of Cancer Therapy-Fatigue, FACT-F; HIV-Related Fatigue Scale, HRVS) and fatigue subscales of larger inventories (POMS-F, SF-36) are also prevalent. Further, alternative assessment systems including computerized adaptive testing programs such as the government-supported Patient Reported Outcomes Measurement Information System (PROMIS®) offer brief, precise, and valid measures addressing a range of constructs. Measures for assessing self-efficacy in fatigue interventions (e.g., Self-Efficacy for Energy Conservation Questionnaire) are also available and viable options for evaluation.

In general, no one questionnaire is to be used in isolation. Inventory selection should be made based on intended use, population of interest, and study characteristics and used in conjunction with other fatigue and quality of life measures to obtain a more comprehensive picture of patient function to inform treatment and intervention.

B. ***Intervention***

A **multimodal approach** to fatigue management is recommended. Interventions for fatigue across disorders include a combination of medication and rehabilitation therapies.

1. **Pharmacologic intervention**

   Common medications used to increase wakefulness include psychostimulants (e.g., methylphenidate, dextroamphetamine, pemoline), amantadine, modafinil, and also a range of antidepressants including selective-serotonin reuptake inhibitors, selective-norepinephrine reuptake inhibitors (bupropion), and tricyclic antidepressants [3]. Medications may also be aimed at alleviating sleep disturbance such as use of benzodiazepines; however, these medications are not indicated for long-term use in treating sleep disorders or insomnia and may have a number of side effects including exacerbation of daytime fatigue, reduced mental clarity, and interfering with sleep architecture [4, 20]. Additional strategies may include the use of melatonin or bright light therapy which has been found to improve daytime alertness and also increase vigilance performance, have arousing effects, and improve mood (as reviewed in Ponsford et al. [4]).

2. **Nonpharmacologic intervention**

   Nonpharmacologic interventions possess a number of inherent strength, including that they may be administered through a number of modalities and from a variety of qualified providers easing patient access and improving overall outcomes. Nonpharmacologic interventions can be divided into several approaches including education, promoting positive health behaviors, managing mood symptoms and psychosocial stressors related to medical condition, and minimizing fatigue impact.

   - **Educate!** Fatigue is an “invisible” symptom; therefore, patients often feel misunderstood and unsupported by those around them. Validating and normalizing a patient’s experience can serve to reduce distress, instill hope, and increase commitment and engagement in therapy services. Open discussion of fatigue with family members and caregivers can also increase understanding and improve their sense of self-efficacy by providing valuable tools to support the patient. Collaborative goal setting, motivational interviewing, and close monitoring of progress can be helpful in increasing confidence and self-efficacy in successful behavior change and management of disease factors. In general, it is about taking a proactive approach to maximize daily life function, in the context of fatigue and possible illness or injury.
   - **Identify and reduce factors which may contribute to fatigue**, replacing with more adaptive health behaviors.
     - **Physical activity and exercise**. Physical activity and exercise are associated with reduced fatigue across rehabilitation populations [16, 21, 22]. Common recommendations include a moderate level of physical activity, usually defined as 150 min of moderate aerobic exercise (e.g., fast walking, swimming, cycling) per week, augmented with several strength training sessions [18].
     - **Nutrition and hydration.** Eating regular and well-balanced meals, with healthy snacks, helps to ensure adequate nutritional resources over the course of a day and to stabilize physiological function [23, 24]. Hydration (specifically suboptimal hydration) has a significant impact on cognitive and physical function and emotional well-being across genders and throughout the life span [25–29]. For current recommendations for daily dietary standards including both nutrition and hydration, consult government resources such as www.health.gov. Consultation with a nutritionist

  may also help to guide and support further intervention.
  - **Sleep.** Education on basic sleep hygiene can be helpful in structuring sleep, improving sleep quality, and reducing daytime fatigue. Basic principles include:

    Providing education on circadian and homeostatic sleep rhythms and the sensitivity of the sleep cycle to physiological, behavioral, emotional, social, and environmental cues.

    Setting consistent sleep and wake times.

    Establishing sleep rituals which ready the mind and body for bedtime and sleep. This may include getting ready for bed at the same time each day, from showering, brushing teeth, to getting into sleeping clothes.

    Dimming lights and minimizing bright lights prior to bedtime.

    Using bed only for sleep. Reading or watching television occurs in other rooms. If the patient has difficulty falling asleep for more than 30 min, or wakes in the night and cannot return to sleep for more than 30 min, then they get out of bed and engaged in a calm or relaxing activity (reading, listening to music) before returning to bed when they again become tired.

    Consulting a sleep psychologist or other sleep specialist is recommended for significant sleep disturbance or disorders. Sleep evaluation may also be helpful in clarifying diagnosis and treatment.

- **Provide strategies, resources, and support for managing psychosocial stressors and mood symptoms** related to medical condition.
  - **Stress and mood**

    Explore and utilize a number of sources for patient and caregiver support. This may include individual psychotherapy, group therapy, and disease-specific support groups.

    Holistic and mind/body approaches may also be helpful, such as mindfulness meditation, yoga, and acupuncture.
  - **Chronic pain**

    Chronic pain is a significant contributor to fatigue experience. Therefore by providing behavioral strategies for managing chronic pain such as relaxation strategies, guided imagery, and promoting active coping, fatigue may also be reduced (these strategies are helpful in managing pain and fatigue both separately, and in conjunction).

- **Minimize fatigue impact**
  - **Energy conservation**. Perhaps the most common, “gold-standard” intervention for managing fatigue, energy conservation has been supported by multiple empirical studies with substantial evidence base for use in fatigue associated with multiple medical conditions. Energy conservation has been formally defined as “the identification and development of activity modifications to reduce fatigue thorough a systematic analysis of daily work, home, and leisure activities in all relevant environments” [30, 31]. It encompasses use multiple principles, tools, and strategies, including [16, 24, 30]:

    Keeping a fatigue journal or diary to identify triggers and patterns in fatigue experience.

    Pacing activity to correspond to the time of day with the most energy and spacing activities throughout the week.

    Balancing work and rest. This includes alternating between physical and cognitive tasks with high demands and those with low energy demands.

    Establishing structured and consistent schedules which incorporate time for rest. It is important for patients to not “overdo it” on a good day. Rather, the goal is to have the same activity level and energy expenditure each day. On a "good" day, they stick to a consistent schedule even though they may feel like they want to accomplish more, while on a "bad" day they also adhere to the established routine. This prevents patients from the phenomenon of "hitting a wall" and then losing productivity in following days due to an extended recovery period, while also establishing daily minimums for activity completion.

Prioritizing essential tasks, modifying activities to reduce energy expenditure, delegating tasks as needed.

Engineering spaces and employing assistive devices to conserve energy.

Scheduling periods for rest and taking short naps if needed—as long as they do not interfere with sleep architecture.

3. **Rehabilitation therapies**

   A multidisciplinary approach to rehabilitation encompassing services such as physical therapy, occupational therapy, recreational therapy, speech language pathology, and rehabilitation neuropsychology has been shown to be effective in reducing disability, improving functional status, and promoting community reintegration [32, 33]. These therapies may also support fatigue-specific interventions by providing education, increasing physical activity and endurance, and using compensatory strategies to minimize the impact of fatigue in activities of daily living.

4. **Empirical support**

   Among recommended guidelines for nonpharmacologic intervention provided by the National Comprehensive Cancer Network (e.g., exercise, restorative therapy, nutrition consultation, sleep hygiene, and psychosocial interventions), the use of exercise to manage and reduce fatigue, and also improve functional abilities, has received the most empirical support [16]. Further, rehabilitation interventions (including both exercise and education interventions) have shown stronger and more significant effects on reducing the impact or severity of fatigue, compared to common pharmacologic intervention (amantadine and modafinil [22]).

C. ***First-line treatments:*** **Nonpharmacologic rehabilitation interventions because**
   (1) Pharmacotherapy does not address coping with disability or functional status
   (2) Fatigue affects multiple components of health and well-being
   (3) Rehabilitation interventions including exercise and education (encompassing strategies such as energy conservation) have substantial empirical support

This is in contrast to historical perspectives which view rehabilitation as only an alternative or supplemental treatment option [22].

Tips

- **Fatigue interventions can be tailored to inpatient settings**. It is helpful to work with the rehabilitation team to develop an individualized schedule or "fatigue management plan." For example, therapies may be scheduled for the time of day when the patient has the most energy (often matching pre-admit preferences). At night, medical staff may "block" services to minimize sleep interference. Other aspects of energy conservation and sleep hygiene can also be augmented, e.g., opening curtains during day to maximize light exposure and closing window curtains or doors to the hospital floor at night to better regulate sleep cycle. Be creative!
- **Motivational interviewing and collaborative goal setting is a must!** Providing basic education is helpful, although aiding a patient in implementing these skills is necessary for long-term adherence and success. Motivational interviewing is helpful to move patient toward readiness for change, to identify how these tools and strategies will help them to achieve goals consistent with their personal beliefs and

values, and to increase self-confidence and efficacy in enacting behavior modifications. Collaborative goal setting instills a sense of control over the rehabilitation process and helps individualize treatment plans to improve long-term adherence and maintenance.

- **Workbooks on living with fatigue are widely available** and help complement education and intervention. They are also often printed in both clinician and patient editions.

Acknowledgment The author declares no conflicts of interest.

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Obesity: Prevalence, Risk Factors, and Health Consequences

34

Lawrence C. Vogel and Pamela Patt

Topic

A. ***Prevalence***

Overweight and obesity are both labels for ranges of weight that are greater than what is generally considered healthy for a given height. They also identify ranges of weight that have been shown to increase the likelihood of certain diseases and other health problems. Obesity has become a major problem in the United States (USA) over the past two centuries. More than one-third of US adults (35.7 %) and approximately 17 % of children and adolescents are obese. Non-Hispanic blacks have the highest age-adjusted rates of obesity (49.5 %) compared with Mexican Americans (40.4 %), all Hispanics (39.1 %), and non-Hispanic whites (34.3 %) [1].

B. ***Risk factors***

Obesity is common, serious, and costly. The estimated annual medical cost of obesity in the USA was $147 billion, which is twice that of one decade ago [2]. Obesity in adults with disabilities is 58 % greater than in adults without disabilities and 38 % higher in children with disabilities compared to children without disabilities.

C. ***Health consequences***

Obesity and being overweight are indicators of potential health risks, such as diabetes, cardiovascular disease, hypertension, liver and gallbladder disease, sleep apnea, osteoporosis, gynecological problems, and certain cancers.

D. ***Definitions of weight***

"Body mass index" (BMI) defines overweight and obesity for adults. BMI is calculated by using weight and height. For most people, the BMI correlates with the amount of body fat.

- An adult with a BMI of between 19 and 24.9 is considered normal weight.
- An adult who has a BMI between 25 and 29.9 is considered overweight.
- An adult who has a BMI of 30 or higher is considered obese.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_34

Importance

Obesity in people with disabilities is associated with the same morbidity and mortality as the general population. In addition those with disabilities have the additional burden of not being able to participate as readily in fitness activities as well as imposing a greater physical burden on their caregivers. More immediate risks are present in rehabilitation settings as obese individuals are more likely to have difficulty with transfers and therefore are at a higher risk of falling. The risk of caregiver injury is also higher. Those with obesity are more likely to develop pressure ulcers and have more difficulty with bracing and prosthetic use. One multicenter study looked at total knee replacement and BMI concluding that "An excessive BMI does not prevent gains during inpatient rehabilitation; however, these gains are made less efficiently and at a higher cost than those made when the BMI is low" [3]. They demonstrated higher pharmacy, physical and occupational therapy, and total charges in the obese population.

Practical Applications

A. ***Evaluation***

For effective weight management intervention, a patient ideally would be assessed by a multidisciplinary team, including a physician, dietician, exercise physiologist, and a behavior therapist. Through the team approach, issues such as nutrition, physical activity, and change in eating behavior can be coordinated [4]. The evaluation should include a recent history, detailed dietary history, past history, and a family history.

1. **Current history**

   The history should include exercise habits and recent significant weight gains or losses. Potential precipitating factors for weight gain should be elicited such as surgery, fracture, initiation of a new medication, changes in social status, change in activity patterns, or depression many overweight individuals may not consider themselves to be obese which has significant implications on the approach for management, therefore, it is important to determine how individuals view their weight. Lastly, the impact of obesity on the individual needs to be identified, such as the inability to transfer oneself or perform urethral catheterization or a decline in the ability to walk.

2. **Dietary history**

   A detailed dietary history should be elicited including the frequency of meals and snacks and detailed examples of what constitutes a typical meal (breakfast, lunch, and dinner) or snack. Specific attention should be directed to the type and amount of beverages as well as the frequency and specifics of fast or convenience foods. Identification of the ability to shop for and prepare foods and knowledge of label reading should be included. Elucidation of the home environment in determining the amount of control one has in the choice of foods is also important.

3. **Past history**

   The past history should at a minimum include history of obesity including specifics of past attempts at weight loss, pattern of weight gain, eating disorders, thyroid disorders, diabetes mellitus, and cardiovascular disorders such as hypertension, coronary artery disease, and strokes.

4. **Family history**

   Important aspects of family history include obesity, thyroid disorders, diabetes mellitus, and cardiovascular disorders.

   Depending upon one's discipline, the next step in evaluation could include a physical exam, a functional evaluation, a psychosocial evaluation, laboratory studies, or radiologic studies.

5. **Physical examination**

   A physical examination should be comprehensive and begin with a general appraisal of body habitus with particular attention to distribution of body weight. The physical examination of individuals who are obese should pay particular attention to areas that may indicate secondary health conditions related to obesity such as blood pressure, heart and respiratory rates, and changes in neurological status.

a. ***Height*** should be measured for all individuals. For children and adolescents, height should be obtained serially and plotted on the appropriate National Center for Health Statistics (NCHS) growth chart. For those in wheelchairs who cannot stand or for those with significant contractures, heights can be approximated by measuring lengths of segments, for example, from heel to knee, knee to hip, and hip to crown of the head. Arm span may be used to approximate height in adults; however, it is likely not accurate for children and adolescents with disabilities.

b. ***Weight*** should be obtained for all individuals. For children and adolescents, weight should be obtained serially and plotted on the appropriate NCHS growth chart. Weight for those unable to stand unsupported or who use a wheelchair should be obtained using a wheelchair scale or a scale designed with handles for support.

c. ***BMI*** should be calculated using current height and weight measurements using one of the equations listed here, or a BMI table can be used and is readily available online (http://www.nhlbi.nih.gov/guidelines/obesity/BMI/bmicalc.htm).

   Formula for BMI calculator—English units

   BMI = (Weight in Pounds/[Height in inches × Height in inches]) × 703

   Formula for BMI calculator—metric units

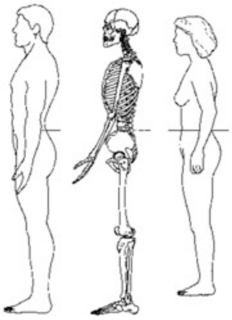
   BMI = (Weight in Kilograms/[Height in Meters × Height in Meters])

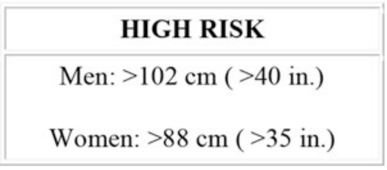
d. ***Alternative measures of body fat***

   There are other methods of estimating body fat and body fat distribution, such as measurements of skinfold thickness and waist circumference, calculation of waist-to-hip circumference ratios, and techniques such as DXA scans, ultrasound, computed tomography, and magnetic resonance imaging (MRI).

   – *Waist circumference*

   Although waist circumference and BMI are interrelated, waist circumference provides an independent prediction of risk over and above that of BMI. Waist circumference measurement is particularly useful in patients who are categorized as normal or overweight on the BMI scale. At BMIs ≥35, waist circumference has little added predictive power of disease risk beyond that of BMI. Measurements of waist circumference should only take place in individuals with BMIs <35. [nhlbi] (http://www.nhlbi.nih.gov/guidelines/obesity/e_txtbk/txgd/411.htm)





HIGH RISK
Men: >102 cm (>40 in.)
Women: >88 cm (>35 in.)

e. ***BMI and waist circumference used together*** are highly correlated with obesity and risk of other diseases and can be used to diagnose obesity.

Classification of overweight and obesity by BMI and waist circumference

	Obesity class	BMI (kg/m^2)	Disease risk	Disease risk with abdominal adiposity
				>35 Women
				>40 Male
Underweight		<18.5		Not applicable
Normal		18.5–24.9		Normal
Overweight		25.0–29.9	Increased	High
Obesity	I	30.0–34.9	High	Very high
	II	35.0–39.9	Very high	Very high
Extreme obesity	III	40	Extremely high	Extremely high

6. **Functional evaluation**

   An evaluation of the individual's functional abilities as it relates to obesity should be performed by an occupational therapist, a physical therapist, a physician, or a nurse, and ideally this should be a team effort. The functional evaluation should address activities of daily living and mobility including grooming, bathing, eating, food preparation, housework, bladder and bowel care, primary mode of mobility, and ability to transfer. An example of a functional disability related to obesity could include the inability to transfer from a wheelchair to bed or the inability to catheterize oneself. In addition, the ability to exercise should be assessed, which should encompass capability, access, and preference.

7. **Psychosocial Evaluation**

   This evaluation should include the history or presence of disorders such as depression, eating disorders, and substance abuse. The social history should include employment, recreational and avocational activities, and living situation, particularly how these may contribute to the development or management of obesity. The individual's living situation should be elucidated including the specifics of the other inhabitants and the type of dwelling such as number of floors. Details of who does grocery shopping and cooking should be determined.

8. **Laboratory and radiologic studies**

   A comprehensive metabolic and lipid panel in the fasting state should be performed with particular attention to fasting blood glucose and HDL and LDL cholesterol as well as excluding any renal or hepatic abnormalities.

9. **Determination of calorie needs**

   Resting energy expenditure (REE) provides important information about an individual's daily *caloric/energy needs*. The REE can be determined in a variety of ways. Energy needs should be based on resting metabolic rate, ideally using the REE measured by indirect calorimetry. Although there are some handheld portable devices that are reasonably accurate and readily available, the most accurate method of determining REE is to use a metabolic cart. If REE cannot be measured by indirect calorimetry, then the REE for overweight and obese individuals can be estimated using the Mifflin-St Jeor equation using actual weight. Equations for estimating REE have been developed for a few diagnostic categories, such as those with spinal cord injuries [5]. Comparing the REE to the individual's typical calorie/energy intake provides valuable insight into the imbalance that results in obesity.

   The Mifflin-St Jeor equations are

   Male: Basal Metabolic Rate (BMR) = (10 × weight in Kg) + (6.25 × height in cm) – (5 × age in years) + 5

   Female: BMR = (10 × weight in Kg) + (6.25 × height in cm) – (5 × age in years) – 161

B. ***Intervention***

1. **Goal setting**

The goals for individuals with obesity should be more than just numbers on a scale. The development of healthful behaviors for life requires behavior modification for overall fitness and health. Realistic goals should be identified with the individual as the leader. Motivational interviewing techniques should be used to encourage ideas for change. Goals may be as simple as prevention of weight gain in an individual who has been gaining weight for years. Improvements in eating, exercise, and other behaviors should also be viewed as successes. Health can be improved with as little as a 10% weight loss. An improved appearance is many times a motivator for weight loss but should be deemphasized in favor of goals that emphasize sustainable lifestyle and activity changes.

2. **Nutritional recommendations**

a. ***Calorie reduction***

An individualized reduced calorie diet is the basis of the dietary component of a comprehensive weigh management program. Reducing dietary fat and/or carbohydrates is a practical way to create a calorie deficit of 500–1000 kcal (kilocalories) below estimated needs and should result in a weight loss of 1–2 lb per week.

b. ***Portion control***

Portion control strategies should be emphasized for weight management. Using smaller plates, bowls, and glasses allows smaller portions to appear to be more food. Bulk food items should be portioned out into individual servings. Individuals should be encouraged to read nutrition facts labels to identify the calories contained in one serving and the number of servings in one container. Portion control strategies promote an awareness of consumption.

c. ***Food diaries/logs***

Write it down. By recording food intake, the individual begins to take responsibility for his or her food choices. Tracking food choices demonstrates what is really being consumed and may identify eating patterns or behavioral connections that cause overeating. Monitoring food consumption allows for adjustments for times of increased calorie intake, by eating less or exercising more. Keeping a food diary has been associated with increased long-term weight maintenance.

3. **Physical activity**

Regular physical activity is associated with a lower risk of death regardless of BMI; therefore, it is important that physical activity should always be included in any obesity treatment plan. The 2008 Federal Physical Activity Guidelines for Americans provided a comprehensive summary of the benefits of physical activity and stated that all adults should avoid inactivity and health benefits increase as physical activity increases. Recommendations included goals of at least 150 min/week of moderate-intensity aerobic physical activity for substantial health benefits and 300 min/week to meet weight control goals.

Individuals with disability have increased barriers to exercise. They may fatigue more easily, have significant mobility issues, need modifications to be able to participate in fitness activities, and have less access to many fitness facilities. Education regarding methods to increase participation in physical activity should be part of the rehabilitation process.

C. ***Outcomes***

Follow-up and reassessment is imperative. For weight-loss interventions to be successful, individuals need to be weighted or some other measure of adiposity must be obtained regularly. If food and activity logs are employed, then they must be evaluated by trained staff to reinforce successful behaviors and problem solve for problematic behaviors.

Success should be individualized with specific measurable and defined goals.

Weight or adiposity may be one goal but should not be the only measurement of success. Setting goals that include minutes of activity, new activities attempted, number of fruit and vegetable servings, or ounces of water consumed provide additional reinforcement when weight change may be lagging.

Tips

- Approach each individual as a whole person and avoid the words morbid and obese.
- Be realistic and meet individuals where they are at, one small change that is sustainable is better than a life makeover that fails. The focus is about helping them become successful, not defeated.
- Discuss an active lifestyle as an expectation not an exception.
- Discuss healthy eating as a process of choices, and focus on making informed choices not abstinence from favorite foods.
- Remember to discuss beverage calories consumed.
- Finally, remember that achievement of goals does not make someone good or bad. They have not failed you and you have not failed them; maybe you just need to attack the problem from a different direction.

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Suggested Reading

ChooseMyPlate.Gov http://www.choosemyplate.gov
Fruits and Vegies More Matters. http://www.fruitsandveggiesmorematters.org/
National Center on Health, Physical Activity and Disability www.nchpad.org

Burns

35

Kimberly Roaten

Topic

A **burn injury** is damage to the skin or other organic tissue primarily caused by heat or due to radiation, extreme cold, radioactivity, electricity, friction, or contact with chemicals. Serious burn injuries often require complicated medical treatment, a prolonged hospitalization, and extensive rehabilitation. The psychological sequelae of surviving a burn injury vary significantly and range from adjustment challenges to major mood and trauma-related disorders [1].

A. ***Key concepts in understanding burn injuries***

1. **Total body surface area (TBSA)**

   An assessment of the extent/size of injury to the skin as a result of injury or disease

   a. ***Rule of nines***: the most expedient method for estimation of the size of adult burns
      - i. Each leg = 18 % TBSA
      - ii. Each arm = 9 % TBSA
      - iii. Anterior and posterior trunk = 18 % TBSA each
      - iv. Head = 9 % TBSA

   b. ***Palm method***: the method for assessing small or patchy burns
      - i. The palm of the patient's hand, excluding the fingers, is approximately 0.5 % of the BSA, and the entire palmar surface, including fingers, is 1 %.

   c. ***Lund-Browder***: the most accurate method for assessing TBSA in both adults and children because it takes into account the relative percentage of BSA affected by growth

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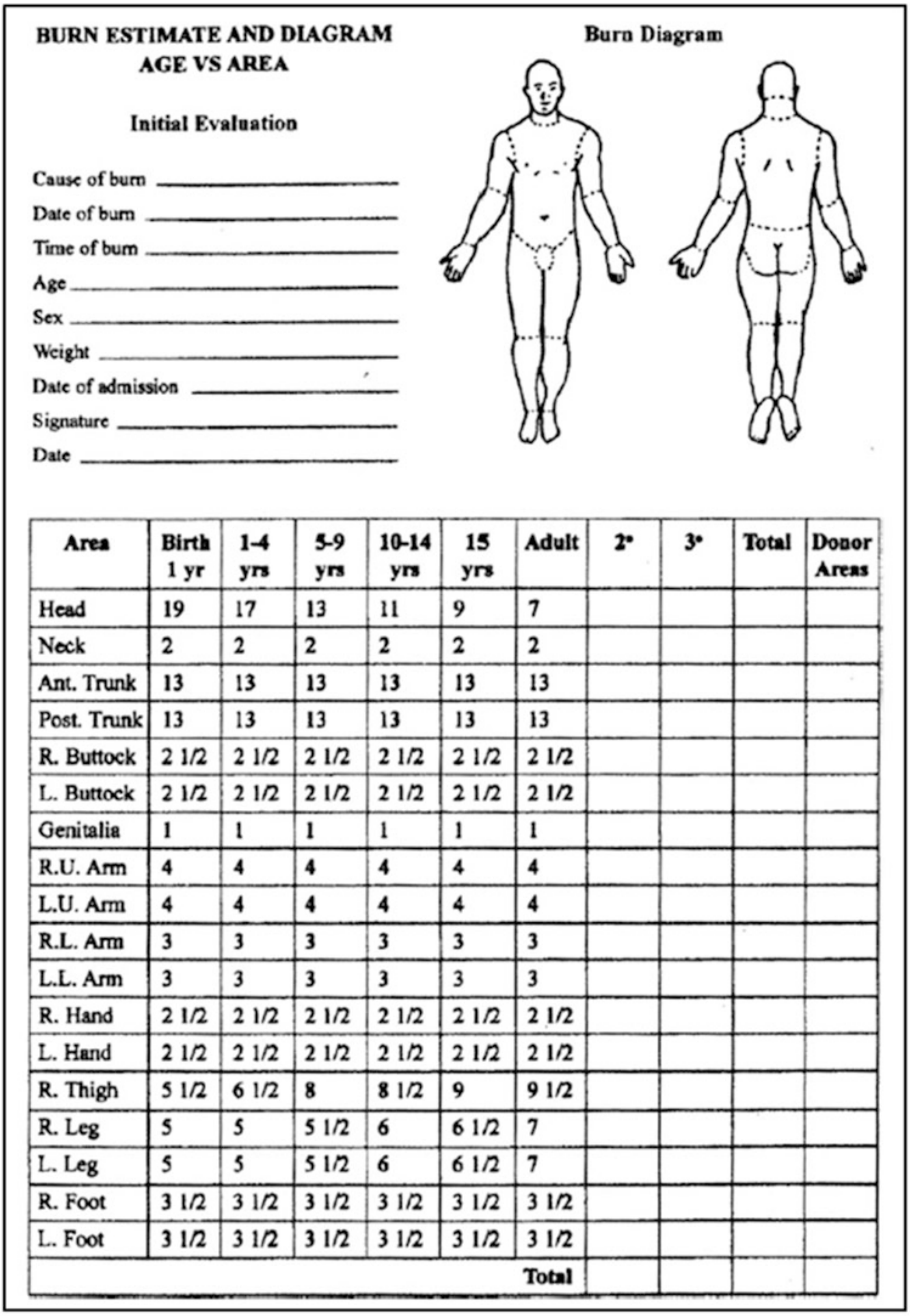
M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_35



BURN ESTIMATE AND DIAGRAM
AGE VS AREA

Initial Evaluation

Cause of burn ______________________
Date of burn ______________________
Time of burn ______________________
Age ______________________
Sex ______________________
Weight ______________________
Date of admission ______________________
Signature ______________________
Date ______________________

Burn Diagram

Area	Birth 1 yr	1-4 yrs	5-9 yrs	10-14 yrs	15 yrs	Adult	2°	3°	Total	Donor Areas
Head	19	17	13	11	9	7				
Neck	2	2	2	2	2	2				
Ant. Trunk	13	13	13	13	13	13				
Post. Trunk	13	13	13	13	13	13				
R. Buttock	2 1/2	2 1/2	2 1/2	2 1/2	2 1/2	2 1/2				
L. Buttock	2 1/2	2 1/2	2 1/2	2 1/2	2 1/2	2 1/2				
Genitalia	1	1	1	1	1	1				
R.U. Arm	4	4	4	4	4	4				
L.U. Arm	4	4	4	4	4	4				
R.L. Arm	3	3	3	3	3	3				
L.L. Arm	3	3	3	3	3	3				
R. Hand	2 1/2	2 1/2	2 1/2	2 1/2	2 1/2	2 1/2				
L. Hand	2 1/2	2 1/2	2 1/2	2 1/2	2 1/2	2 1/2				
R. Thigh	5 1/2	6 1/2	8	8 1/2	9	9 1/2				
R. Leg	5	5	5 1/2	6	6 1/2	7				
L. Leg	5	5	5 1/2	6	6 1/2	7				
R. Foot	3 1/2	3 1/2	3 1/2	3 1/2	3 1/2	3 1/2				
L. Foot	3 1/2	3 1/2	3 1/2	3 1/2	3 1/2	3 1/2				
						Total				

Lund-Browder Chart

2. **Classification of burn injury**

The declaration of a burn injury is a dynamic process, and histologic studies suggest that activity peaks at about 3 days and may not be fully evident for up to 3 weeks, making management and treatment planning challenging in the acute phase of burn recovery.

a. ***Superficial (first-degree burn)***: A minor burn that affects only the outer layer of the skin (epidermis). Causes redness and pain, but the symptoms usually resolve with basic first-aid measures. Sunburn is an example of a superficial burn.

b. ***Partial thickness (second-degree burn)***: A burn that affects both the epidermis and the dermis.

   i. *Superficial*: Typically associated with redness, pain, and a moist appearance. Blisters may develop and the pain can be severe in response to temperature and air. Scarring is less likely, but pigment changes are possible.

   ii. *Deep*: Typically associated with blisters, wet to waxy dry appearance, and absence of blanching with pressure. It may be excruciatingly painful. It can lead to significant scarring.

c. ***Full thickness (third-degree burn)***: A burn that extends to the fat layer beneath the dermis. The skin can look waxy, white, leathery, or dark.

d. ***Fourth-degree burn***: A burn that affects structures beyond the skin, such as muscle and bones. The skin may look blackened or charred.

3. **Severity of burn injury**

a. ***Major burn***: ≥25 % TBSA in adults, ≥20 % TBSA in children under 10 or adults over 40, ≥10 % TBSA full thickness, all high-voltage burns, all burns complicated by major trauma or inhalation injury

b. ***Moderate burn***: 15–25 % TBSA in adults with <10 % full thickness, 10–20 % TBSA partial-thickness burn in children <10 and adults >40 with <10 % full thickness

c. ***Mild burn***: ≤15 % TBSA or less in adults, ≤10 % TBSA or less in children/elderly

4. **Terminology**

- *Autograft*: a skin graft using the patient's own tissue
- *Allograft/homograft*: a graft using cadaver tissue for temporary wound coverage after excision of the wound, in preparation for final coverage
- *Background pain*: constant dull pain related to tissue damage
- *Breakthrough pain*: unpredictable surges of pain
- *Contracture*: inability to perform full range of motion of a joint as a result of multiple factors—limb positioning, duration of immobilization, and pathology of the muscle, soft tissue, and bones
- *Donor site*: area where the skin is harvested. Usually on anterior thighs
- *Eschar*: hardened remains of dead tissue are typically shed from healthy skin
- *Escharotomy*: surgical division and removal of nonviable eschar which allows for tissue expansion and healing
- *Full-thickness skin grafts*: donor skin including all layers. Harvested from redundant skin, usually in the groin. Only used for small areas of reconstruction—rare
- *Heterotopic ossification (HO)*: a relatively uncommon complication of burn injuries in which bone tissue forms outside of the skeleton (typically around the joints), leading to decreased range of motion and functional impairment
- *Meshed skin graft*: donor skin is harvested and perforated with a mesher before grafting in order to increase the area of wound that can be covered; the meshed pattern is permanent and less cosmetically desirable
- *Procedural pain*: pain related to dressing changes, wound care, debridement, and physical activity; typically high intensity and short duration

   - *Sheet graft*: donor skin is transferred to the burn site without meshing; better cosmetic and functional outcome, but only possible with smaller wounds and/or those on the face and hands
   - *Split-thickness skin grafts*: sheets of superficial and some deep layers of skin—epidermis and part of dermis
   - *Xenograft*: temporary wound coverage derived from porcine dermis; used to cover partial-thickness burns

Importance

- Incidence and prevalence [2]: Approximately 450,000 burn injuries are treated in US hospitals per year, 40,000 of which lead to an inpatient hospitalization. The majority of individuals admitted to a hospital with burn injuries are treated in a regionally accredited burn center. As medical knowledge has expanded, the survival rates following a burn have improved to ~96 %.
- The majority of individuals who sustain a burn injury are male (69 %) and Caucasian (59 %). Most burn injuries occur at home (72 %) and are caused by fire/flame (43 %) or scald (34 %). The average age of a burn survivor is 32 years old.
- Most burns are less than 10 % TBSA and the associated mortality rate is 0.6 %. The average length of a hospitalization for all burn injuries is 8 days, but varies significantly depending on TBSA burned. The average length of stay is roughly one hospital day per percent TBSA burned. Infection, pneumonia, and sepsis are the most common complication for those who require hospitalization after a burn injury.

Practical Applications

A. ***Early/acute phase***

   1. **Biological**

      Early excision and grafting of the wound is essential to achieving the best survival rates and functional outcomes possible after a burn injury. For patients with major burns, this often means repeated trips to the operating room during the acute phase of recovery.

      a. ***Delirium***: An acute and fluctuating change in cognition and attention that is a direct physiological consequence of another medical condition (e.g., opioids, infection, insomnia). Determining the cause of delirium is the first step in managing the symptoms.

         1. *Assessment*: The Confusion Assessment Method (CAM) is a brief, observation-based measure for assessing for altered mental status. The Intensive Care Delirium Screening Checklist (ICDSC) is an assessment completed by the patient's nurse over the course of a shift in order to capture the fluctuating symptoms of delirium and rate the severity.
         2. *Intervention*: An important first step in the management of delirium is educating the patient's providers and often his/her friends and family about the typical causes of an acute change in mental status. Mood lability in delirium is often confused with depression or stubbornness, and hallucinations can be frightening for both the patient and family/friends. The following behavioral interventions can be useful in the management of delirium:
            a. Reinforcement of an appropriate sleep-wake cycle: blinds open during the day, minimize nursing disturbances at night, increase time out of bed (as medically appropriate).
            b. Assistive devices: make sure the patient has his/her glasses, hearing aids, etc.
            c. Gentle reorientation: place a calendar and a clock in an easily viewable location in the patient's room.

   b. ***Pain*** [3]: Immediately after the burn injury, the pain is not proportional to the severity of the injury (e.g., the more superficial the burn, the more painful it is during the acute phase). Poorly controlled pain is related to the development of psychological complications later in the treatment course such as depression and posttraumatic stress disorder and is also correlated with increased rates of suicide attempts. Opioids are the most commonly used pharmacological analgesics.
      1. *Assessment*: Burn patients should be assessed for both procedural and non-procedural (background) pain levels. Numeric scales (i.e., rating pain on a scale of 0–10) are commonly used, and visual analog scales are helpful for pediatric burn patients.
      2. *Intervention*: Patients in the acute phase of burn recovery may benefit from assistance with communicating clearly and assertively about pain with their physicians. Distraction and relaxation techniques such as deep breathing and guided imagery can also be useful adjunct treatments. Patients' friends and families may be taught relaxation skills and provided with scripts in order to participate in the pain management regimen.

2. **Psychological**
   a. ***Rapport*****:** Establishing rapport with the patient during the initial phase of treatment lays the groundwork for longer-term intervention during a hospitalization. Patients in the acute phase respond most positively to reassurance, clear communication regarding treatment planning, and empathic listening. The primary focus is supportive intervention and normalization of the full range of emotional reactions.
   b. ***Grief*****:** Unfortunately some patients hospitalized with a burn injury will also be faced with the loss of a loved one or pet in the same event. Family members and/or friends may seek advice about the appropriate time to inform a patient about a death. Generally, the patient should be told as soon as he or she is cognitively able to understand the information being conveyed. It may be necessary to repeat the information on multiple occasions given the challenges associated with recall in the context of pain medication and other medical issues. Patients often benefit from opportunities to participate in memorial services whether it is via a recording, live video feed, or reading transcripts of a eulogy. Seeking support from the hospital chaplain may also be particularly useful.

3. **Social**
   a. ***Visiting hours***: While some patients may welcome visitors, the nature of a burn injury and the related treatment may mean that visitors are limited during the acute phase of treatment. Infection control is a priority, and patients with major burns are often in treatment or in the operating room, significantly limiting visitor access to a patient. Patients and their families may need reminders and assistance with establishing appropriate boundaries for visitors. Additionally, the course of recovery from a burn injury is often protracted, and it may be useful to encourage the patient and his or her family to schedule visitors so that the support remains steady throughout the long hospital course and during the transition home.
   b. ***Family support***: The family and friends of a burn survivor often need a great deal of support during the acute phase of the treatment and recovery process. It will be important to provide appropriate care for the family while balancing the boundaries of treating the patient. Issues of confidentiality and consent for treatment may arise during

the acute phase, and special care should be taken to clarify who is to be included in psychotherapy sessions and informed of treatment planning.

c. ***Chaplain*****:** The hospital chaplain is a valuable resource in providing the patient and his or her family with support following a burn injury. Ask about the patient's faith/spirituality early in the hospitalization in order to identify appropriate resources to bolster support.

B. ***Middle phase***

1. **Biological**

a. ***Pain*****:** Pain continues to be an issue for many burn survivors as they progress through the acute and rehabilitation phases of recovery. For those with major burn injuries, routine, even daily, wound care will continue throughout the hospitalization and often on an outpatient basis. During this phase of recovery mean open/unhealed TBSA is directly correlated with pain intensity. Poorly controlled pain will have a negative impact on the survivor's ability to effectively participate in rehabilitation activities, does little to reinforce the patient's confidence in the treatment team, and can lead to longer hospitalizations. As the tissue begins to regenerate, burn survivor often experiences uncomfortable tingling and itching sensations.

i. *Intervention*: A multidisciplinary approach is essential to maximize pain control during the middle phase of the recovery process. Progressive muscle relaxation and guided imagery are useful strategies for enhancing pain control when the burn survivor is cognitively able to utilize more complex strategies. Data suggest that hypnosis and music therapy protocols may also decrease survivor anxiety and perception of pain. Preliminary research, primarily in pediatric populations, suggests that virtual reality (VR) may also be an effective adjunct to pharmacological and other behavioral strategies for pain and anxiety management.

b. ***Infection***: Burn survivors are particularly vulnerable to infection because they have sustained damage to the skin, which is the primary barrier. Immunosuppression is also a consequence of major burn injuries and places the survivor at higher risk for contracting illnesses during and after hospitalization. Visitation may be limited due to concerns about infection, and major burn survivors are often placed on contact precautions, which require the use of protective coverings such as gloves and gowns. Patients may comment that the requirements for all visitors/providers to wear protective clothing make him or her feel "gross" or "contagious." It can be useful to provide the patient with basic education about the reasons for the precautions. The other potential complication related to infection for the burn patient is recurrence or exacerbation of delirium. Patients with recurrent infections may experience repeated episodes of altered mental status, and at times the change in cognition may be one of the first indicators of infection. Therefore, the presence of an acute change in cognition should be promptly brought to the attention of the treatment team and documented accordingly in the medical record over time.

c. ***Surgery***: One of the many challenges in effectively treating a burn survivor is working around the schedule and medical complications that arise from repeated trips to the operating room. Non-surgeon providers are much more likely to successfully treat patients if they are attentive to the operating room schedule. The day before a scheduled surgery or procedure requiring anesthesia is often an ideal time to assess and manage anticipatory anxiety.

  d. ***Nutrition***: Adequate nutrition is paramount for the recovery of a burn patient. Most major burn survivors will receive supplemental nutrition through enteral feeding mechanisms such as a nasogastric tube. The calorie requirements for wound healing after a burn injury are typically double those required for an adult of average height and weight.

2. **Psychological**
  a. ***Depression***: It is estimated that 5–26 % of burn survivors exhibit mild to moderate symptoms of depression during the acute hospitalization [4]. Depression has a negative relationship with physical function and long-term adjustment.
    i. *Assessment*: Both clinician-rated and self-report inventories may be used to screen for or fully assess depressive symptoms. The Patient Health Questionnaire-2 (PHQ-2) and Patient Health Questionnaire-9 (PHQ-9) are self-report tools for depression screening that are publically available and have been validated in primary care settings and for use with individuals who have physically disabling conditions. The Beck Depression Inventory-II (BDI-II) and the Hamilton Depression Rating Scale (HAM-D) are commonly used and well-validated measures of depressive symptoms. The Inventory of Depressive Symptomatology (IDS) and Quick Inventory of Depressive Symptomatology (QIDS) are also well-validated measures, free to users, available in clinician and self-report versions, and available in multiple languages.
    ii. *Treatment*: Research indicates that the presence of depressive symptoms after burn injury is not entirely related to the injury and its effects, and may best be explained as a function of pre-burn psychopathology and personality characteristics. Empirically validated treatment strategies for depression such as cognitive behavior therapy (CBT) and interpersonal therapy (IPT) are likely to be effective in the context of burn injury. Patients and their families should be educated about the signs and symptom of psychological distress and depression following a burn injury. Educational resources are available through the Burn Injury Model Systems (BIMS) Knowledge Translation Center [5].
  b. ***Acute stress disorder (ASD)/posttraumatic stress disorder (PTSD)***` [6]: The prevalence rate for ASD in burn survivors ranges from 11 to 32 %, and ASD is known to be a risk factor for later development of PTSD in survivors. Prevalence estimates of PTSD in burn survivors range from 9 to 45 % in the year post-injury. Severity of PTSD symptoms at 1 month after discharge are associated with poorer functioning and increased disability up to 2 years after release from the hospital. PTSD symptoms in burn survivors appear to persist and become chronic.
    i. *Assessment*: The Stanford Acute Stress Reaction Questionnaire (SASRQ) is a 30-item self-report measure that assesses the symptoms of ASD after a traumatic event. SASRQ scores are correlated with later PTSD symptomatology. The Davidson Trauma Scale (DTS) is a commonly used 17-item self-report tool to assess for the frequency and severity of PTSD symptoms. The PTSD Checklist Civilian version (PCL-C) was developed for use in general medical settings. It consists of 17 items but may be shortened to a 2- or 6-item screening version.
    ii. *Treatment*: Research suggests that CBT with exposure may be a useful strategy for early intervention and possible prevention of PTSD following a traumatic event.

   c. ***Adjustment disorder***: The diagnosis of an adjustment disorder is characterized by the development of clinically significant emotional or behavioral symptoms, which do not meet criteria for a mood or trauma-related disorder, following the experience of a stressor. To warrant the diagnosis of an adjustment disorder, the burn survivor must demonstrate distress that is out of proportion to that which is typically expected given the context of the event and any potential cultural factors [7].
      i. *Treatment*: Burn survivors with symptoms of an adjustment disorder often respond to supportive psychotherapy and psychoeducation regarding adaptive coping strategies. Burn survivors and their families may also benefit from basic education about the typical course of adjustment following a serious burn injury and the related treatment and prolonged hospitalization. Information regarding psychological distress and the adjustment process following a burn injury is available online through the BIMS.
   d. ***Substance/alcohol use***: Premorbid substance and alcohol use issues are common among burn survivors [8]. Early recognition of a pattern of problematic drinking or drug use is an important component of the burn survivor's recovery. Chronic alcohol and substance use places the survivor at increased of painful and/or dangerous withdrawal symptoms and may suggest a pattern of maladaptive coping skills that should be addressed early in the treatment.
      i. *Assessment*: The Alcohol Use Disorders Identification Test (AUDIT) is a ten-item tool developed to identify at-risk drinkers. The Drug Abuse Screen Test (DAST-10) is a ten-item yes/no self-report measure designed to screen for problematic substance use and can be administered in less than 10 min.
      ii. *Treatment*: Providers should be knowledgeable regarding early signs of withdrawal from commonly used substances and alcohol in order to alert the multidisciplinary team to potentially complicating factors. Motivational interviewing (MI) is a client-centered, semi-directive therapeutic modality that has been demonstrated to be effective in reducing both substance and alcohol use disorder symptoms [9]. Patients and their caregivers may benefit from receiving information about local 12-step programs prior to discharge in order to facilitate sobriety outside of the controlled environment of the hospital.
   e. ***Viewing injuries***: Burn survivors often have limited access to mirrors, particularly during the acute phase of their recovery and may not have viewed their wounds, scars, or graft sites. Anecdotally, burn survivors report appreciation for staff and mental health provider efforts to facilitate the process of viewing burn injuries for the first time, particularly facial burns. It may be useful to elicit the survivor's expectations regarding the appearance of the burns and the anticipated psychosocial impact of changes in physical appearance. When working as a provider in a multidisciplinary team, it is wise to communicate with other providers regarding the plans for initial viewing in order to avoid inadvertent and potentially traumatic glimpses of injuries (e.g., during work with occupational therapy or while being transported to a procedure).
3. **Social**
   a. ***Child life specialists***: Many large hospitals employ Certified Child Life Specialists (CCLSs) who are trained to help patients and their families cope with trauma, illness, and prolonged hospitalizations. CCLSs are skilled at

assisting young patients to manage the anxiety associated with interacting with medical professions, managing pain, and explaining procedures and treatment in developmentally appropriate terms. A hospital-based CCLS is also often able to work with children and siblings of burn survivors to facilitate the adjustment process and coordinate visitation efforts.

b. ***Peer visitation***: The Survivors Offering Assistance in Recovery (SOAR) [10] program through The Phoenix Society provides formal training for burn survivors and family volunteers to participate in peer support for hospitalized burn survivors. Burn survivors and their families report that the peer visitation process is often one of the most meaningful parts of the acute recovery process. Burn survivors report feeling understood and encouraged by those who have survived and thrived after sustaining similar injuries.

C. ***Reintegration phase***

1. **Biological**

   a. ***Sleep***: Burn patients report sleep disturbance even a year or more following the initial injury and hospitalization. Study estimates suggest that up to 50 % of burn survivors find it difficult to sleep without medication at 12 or more months post-injury. Research suggests a strong relationship between persistent pain, itching, and insomnia.

      i. *Treatment*: Provide the patient and his/her family with education regarding appropriate sleep-hygiene practices:

Good sleep-hygiene practices
Increase time out of bed and activity level, as medically appropriate
Minimize napping
Establish a sleep/wake schedule
Avoid any activity other than sleep and sex in bed
Open the blinds during the day
Avoid alcohol, caffeine, and nicotine within 4–6 h of bedtime

   b. ***Itching/pruritus***: Pruritus is exceedingly common after burn injury, affecting up to 87 % of patients 3 months post-injury and continuing to impact 67 % of survivors at 2 years [11].

      a. *Assessment*: The 5-D Itch Scale is a validated multidimensional measure of chronic pruritus that is sensitive to change in itch over time.

      b. *Treatment*: The majority of effective interventions for pruritus are pharmacological. However, behavioral strategies such as hypnosis and guided imagery that are useful for pain management may also be used to address post-burn itch.

2. **Psychological**

   a. ***Body image and social interaction***: Burn survivors describe experiencing a number of negative reactions in social situations following their injuries including staring, intrusive/unwelcome questions, avoidance, rude comments, startled reactions, and bullying.

      i. *Treatment*: A proactive approach is recommended to address potential concerns related to body image issues and social interactions. Social skills training may be a useful way to help burn survivors and their families prepare for reintegrating into social settings and spending time in public. Specifically, burn patients report that it is useful to predetermine how they will answer questions about their injuries. Role-playing is an effective strategy for exploring different situations and creating a "script" for interactions. Burn patients may be guided to develop a series of responses for different situations such using a simple explanation, distraction, humor, or reassurance.

   b. ***Sexuality***: Many major burn survivors and their partners report concerns about resuming sexual activity. Burn survivors may describe fear of pain and embarrassment regarding appearance as potential concerns. Partners may also report that they are fearful of harming the survivor and may struggle with shifting between the roles of caregiver and sexual partner.

  i. *Treatment*: It is recommended that concerns about sexual function and sexuality be explored early in the reintegration process. It may be useful to speak with the patient alone and with his or her partner to gather information about specific concerns. Coordinate sexuality education efforts with other members of the multidisciplinary burn care team, such as the occupational therapist, in order to address both the emotional and physical aspects of returning to sexual activity after a burn injury.

3. **Social**
   a. ***Burn support group***: Many large hospitals, particularly those with a verified burn center, offer regularly scheduled burn support groups. Support groups offer a sense of community for burn survivors and their friends and family. Many burn support groups are led by behavioral health providers, social workers, or nurses. Support groups may be primarily supportive, psychoeducational, or a combination of both.
   b. ***Pediatric burn camp***: Burn camps offer special opportunities for child and adolescent burn survivors to spend time away from home at a summer camp specially created to meet their physical and emotional needs. Burn camps are often available near large burn centers, last 5–7 days, and typically take place during the summer. Research suggests that attendance at pediatric burn camp promotes a sense of belonging and acceptance, enhanced self-esteem, and improved body image [12].
   c. ***The Phoenix Society***: The Phoenix Society [13] was founded in 1977 in an effort to establish a national system of support for those who have sustained burn injuries. It has many online resources for patients and their loved ones including printable information, videos, and links to available local resources. The Phoenix Society offers online weekly chat sessions and hosts The World Burn Congress annually: a meeting for burn survivors, friends, family, and health care providers.
   d. ***Return to work***: Ninety percent of burn survivors return to work within two years after injury [14]. Pre-injury level of functioning and burn severity play a role in return to work, and pre-injury employment is particularly influential. Physical factors such as pain and infection are likely to impact return to work early in the recovery process, and personality characteristics such as motivation and self-efficacy are important throughout the reintegration process. Burn survivors report that early attention to barriers to returning to work is beneficial. Vocational rehabilitation and assistance with workplace adaptations may be useful. It is also important to consider that some burn survivors will be returning to the site of their injury when they return to work. Exploration of anticipated fear and distress may ease the transition in such situations.
   e. ***Return to school***: Pediatric burn patients are typically able to return to school within 1–2 weeks post-discharge and seem to experience minimal negative impact on grades, particularly if a school reentry plan is implemented prior to matriculation [15]. School visits with support for the survivor and education for teachers and classmates will likely address questions and decrease stress. CCLSs,

nurses, social workers, or behavioral health providers may coordinate school reentry programs. Ongoing contact with burn providers will provide pediatric survivors and their families with support through this important transitional phase. The Phoenix Society offers online and print resources regarding school reentry.

Tips

- **Ask**. Be assertive about addressing typical burn-related adjustment concerns. Do not make assumptions about how the patient is feeling or what he or she understands about the recovery process following a burn injury.
- **Get to know the burn team**. The most successful health care teams for a patient with a burn injury work together to provide holistic care. Learn the roles and responsibilities of other team members in order to recognize opportunities for collaboration and interdisciplinary care.
- **Address pain early and aggressively**. Begin incorporating behavioral strategies for pain management early in the treatment process.
- **Learn about burn-specific community resources**. The burn survivor community is robust and an excellent source of information and support for survivors and their loved ones.
- **Monitor closely for delirium and trauma-related disorders**. Track changes in cognition over time, and screen frequently for trauma-related symptoms such as avoidance, hypervigilance, and nightmares.
- **Firmly reinforce sleep hygiene, particularly for major burn survivors who experience a prolonged hospital course**. Educate other members of the burn team (e.g., nurses, physical therapists, wound care technicians) about the importance of a sleep-wake schedule. Post signage to remind treatment team providers about specific schedule recommendations.
- **Monitor for team member burnout**. Caring for the burn survivor is a physically and emotionally demanding vocation. Encourage appropriate self-care and provide education about the signs of burnout.

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Respiratory and Pulmonary Disorders

36

Jacob A. Bentley

Topic

Rehabilitation approaches have become recognized as a key component to the effective management of **respiratory and pulmonary disorders**. Pulmonary rehabilitation (PR) represents a team-based approach that utilizes knowledge and expertise of multiple disciplines in order to assist individuals in adapting to chronic lung dysfunction of varying etiologies. Common respiratory and pulmonary disorders may be caused by spinal cord injury (SCI), neuromuscular disorders (e.g., amyotrophic lateral sclerosis, Duchenne muscular dystrophy), or genetic conditions such as cystic fibrosis. However, the most common diagnosis in this category is chronic obstructive pulmonary disease (COPD). This chapter will primarily focus on the clinical characteristics of COPD, general PR approaches, psychosocial aspects of COPD, and cognitive-behavioral interventions as applied to persons with respiratory failure. Though the following will focus on COPD in more detail, special considerations for other diagnoses with respiratory or pulmonary implications, namely, SCI and cystic fibrosis, will be briefly described.

A. ***Pulmonary rehabilitation and related conditions***

In 2006, a task force organized by the American Thoracic Society (ATS) and the European Respiratory Society (ERS) published a statement on pulmonary rehabilitation summarizing the multiple systemic effects of respiratory and pulmonary conditions and the growing evidence base for efficacious management approaches [1]. This statement was revised in 2013 with an increased focus on integrated care principles underlying PR [2]. These documents have conceptually defined PR and its components, which are summarized in Table 36.1. Additional information about specific cognitive-behavioral PR components will be discussed in greater detail in the Practical Application section below.

1. **Chronic obstructive pulmonary disease (COPD)**

   COPD is considered a preventable and treatable chronic condition characterized by progressive airflow limitation resulting from a response of the lung to harmful gases or particles. Causes include smoking, occupational hazard, and genetic predisposition. Assessment of COPD is based on spirometric testing in which a

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_36

Table 36.1 Therapeutic components of pulmonary rehabilitation programs

• *Exercise training*	Incorporates both upper and lower extremity modalities to assist with the development of endurance and strength. Typically follows a treatment plan for three sessions per week, with a minimum of 20 sessions provided
• *Oxygen therapy*	Can increase exercise tolerance and moderate cognitive outcomes. Long-term oxygen therapy (>15 h per day) is required when arterial oxygen saturation falls below 89 % and if individuals display evidence of pulmonary hypertension, peripheral edema, or other indicators of congestive heart failure. Assisting with community reintegration and quality of life, portable oxygen concentrators have become lighter and are able to be recharged as quickly as within 2 h when compared to earlier models
• *Chest physical therapy*	Consists of breathing exercises and retraining techniques. Chest PT techniques focus on maintaining positive airway pressure through exhalation while minimizing over-inhalation. In the case of COPD, strategies may include pursed-lip breathing, postural adjustments (e.g., head down and bending forward), slowed and paced breathing
• Body composition intervention	An important component due to the interaction between body morphology and respiratory function. This is observed in conditions leading to significant weight/muscle loss requiring caloric supplementation as well as obesity-related respiratory disorders (e.g., obstructive sleep apnea, pulmonary hypertension) necessitating nutritional intervention
• *Nutritional support*	A subcomponent of body composition intervention, nutritional support is essential in identifying underlying mechanisms of weight loss and supplementing/adapting diet in order to facilitate endurance, exercise capacity, and overall health status
• *Education and self-management skill development*	Targets the development of self-efficacy in persons participating in PR through enhancing knowledge of the medical condition, active participation in disease management, health behavior modification, and peer support/mentoring
• *Psychosocial interventions*	Are based on a thorough assessment of self-reported illness perception, health-related quality of life, resilience (e.g., adaptability; sense of being able to "bounce back" in response to illness), readiness for health behavior change, treatment adherence, symptoms of mood disturbance/anxiety, and neurocognitive functioning. Psychosocial interventions occur at the individual and family level. Treatment may take the form of individual cognitive-behavioral therapy and/or group sessions with educational and self-management elements
• *Cognitive-Behavioral Therapy (CBT)*	Enhances disease management through behavioral activation, development of adaptive health behavior change, modifying illness-related or sustaining thoughts, relaxation training, and management of comorbid or secondary psychiatric conditions such as depression, anxiety, and panic disorder. CBT in PR utilize the interventions listed above to assist with smoking cessation

person takes a maximum inhalation and exhales as forcefully and quickly as possible. This test provides measures of forced expiratory volume and forced vital capacity based on age, sex, and height norms (see below for more information). There are currently four stages according to spirometric testing, ranging from "mild" to "very severe" qualifications of disease progression.

2. **Neuromuscular disease**

   Neuromuscular conditions (e.g., amyotrophic lateral sclerosis) and spinal cord injury/disorder may lead to progressive respiratory muscle weakness. As a result, supportive ventilation may be required to assist with breathing. Interventions range with regard to level of invasiveness, with less invasive approaches available for people who maintain adequate bulbar muscle strength. Many individuals are able to gradually wean from ventilator support. However, this process can be challenging in the setting of recurrent respiratory muscle weakness or fatigue. Re-intubation and even tracheostomy for long-term support may be required if weaning is unsuccessful.

3. **Cystic fibrosis (CF)**

   An inherited autosomal recessive disorder, CF is characterized by production of viscous mucus that ultimately leads to susceptibility to lung infection. Viscous mucus results from degenerating neutrophils (e.g., infection-fighting white blood cells). CF can be classified as a severe combined obstructive-restrictive pulmonary disease. Life expectancy of children with CF has increased in recent years, bringing the importance of rehabilitative interventions and quality of life measures clearly into focus.

B. ***Terminology***

1. **Tidal volume**

    The volume of air inhaled or exhaled in a quiet breath, when extra effort is not applied.

2. **Functional residual capacity**

    The volume of air present in the lungs after a normal exhalation. There is no exertion by respiratory muscles, including the diaphragm.

3. **Vital capacity**

    The maximum volume of air a person can exhale from the lungs after a maximal inhalation.

4. **Total lung capacity**

    The total volume of air contained in the lungs after a maximal inhalation.

5. **Dyspnea (exertional)**

    Shortness of breath or labored breathing with physical activity symptomatic of an acute or chronic process. Examples of acute conditions include infection/inflammation of the respiratory tract, obstructed airway, traumatic injury, and anaphylactic swelling. In addition to those identified earlier, chronic disorders include pulmonary edema and congestive heart failure.

6. **Forced expiratory volume (FEV)**

    The most important measurement of lung function. FEV is a measure of how much air a person can exhale during a forced breath. It can be measured during the first (FEV1), second (FEV2), and/or third (FEV3) seconds of the forced breath. FEV1 is most frequently used.

7. **Forced vital capacity (FVC)**

    The total amount of air exhaled during the FEV test. The Tiffeneau-Pinelli index is a ratio of FEV1 and FVC. This index helps to inform diagnosis of lung disease. It represents the proportion of a person's vital capacity that they are able to exhale in the first second of exhalation.

8. **Peak cough flow rate**

    The maximal flow rate generated during a cough after a maximal inhalation. Under normal circumstances, peak cough flow rates are higher than peak exhalation rates.

9. **Diaphragmatic pacer**

    A surgically implanted device used to help people with severe weakness/paralysis of the diaphragm breathe when ventilator assistance is no longer an option. Some individuals with high cervical-level SCI will benefit from these devices. The device works through pacing of the diaphragm through stimulation of the phrenic nerve.

10. **Neuromuscular electrical stimulation**

    Used to enhance muscle performance and exercise tolerance in COPD by using electric impulses to elicit muscle contractions.

11. **Inspiratory muscle training**

    A series of controlled breathing exercises intended to strengthen respiratory muscles.

Importance

- **Incidence and prevalence:** COPD is the most common form of lung disease in the USA. The National Health Interview Survey estimated that 12.7 million adult Americans have received a diagnosis of COPD [3]. However, there is evidence that COPD is underdiagnosed and that up to 24 million exhibit evidence of impaired lung function. Cigarette smoking is the primary cause of COPD; it rarely occurs in people who do not smoke.

- SCI and neuromuscular disorders, such as ALS or Duchenne muscular dystrophy, account for the majority of restrictive pulmonary disease cases. There are approximately 270,000 individuals with SCI living in the USA. Respiratory compromise occurs in a subset of the 50 % of people with cervical-level SCI. People with injuries above C4 sustain chronic respiratory paralysis. Lower-level injuries at C6–C8 and the upper thoracic region are associated with loss of at least 60 % inspiratory muscle strength [4]. The incidence rate of respiratory complication following SCI ranges from 36 to 86 % in the literature. With regard to ALS, prevalence has been estimated at 3.9 per 100,000 in the USA [5]. ALS is more common among men, non-Hispanics, and people in the 60–69 years age range. Duchenne muscular dystrophy, another example of a neuromuscular condition with respiratory implications, has an estimated incidence of 21 per 100,000.
- An estimated 30,000 people in the USA have CF, with approximately 1000 new cases diagnosed each year [6]. The overall birth prevalence is 1 per 3700 in the USA. However, occurrence of CF is much higher among Caucasians of Northern European descent (e.g., estimated 1 per 2500 Caucasian births). CF occurs equally in male and female babies.

Practical Applications

A person's ability to participate in the PR interventions described above may be influenced by physiologic factors including ventilatory limitations, gas exchange limitations, cardiac limitations, lower limb muscle dysfunction, or respiratory muscle dysfunction [2]. Somatic symptoms such as fatigue and sleep disturbance can differentially influence involvement in a variety of social roles including that of rehabilitation participant.

Psychological and behavioral factors such as anxiety, depression, and motivation may also present barriers to therapeutic engagement. Prevalence of depression in COPD is consistent with those found in other advanced medical conditions and appears to vary based on a variety of factors including disease severity, stability, and whether a person has recently experienced an acute exacerbation [7]. It has been estimated that approximately 1/3 of those with COPD experience moderate to severe anxiety, and 41 % carry clinically significant symptoms of panic disorder [8]. Importantly, cognitive function has been recognized as a consideration for people with COPD. Patients with COPD have been found to have global cognitive inefficiencies with some studies showing focal findings in the domains of attention, memory, executive function, and motor planning [9]. Relationships between cognitive impairment and medical nonadherence have been found in patients with COPD [10], but a recent systematic review highlighted that much remains to be learned about the influence of cognitive impairment on daily functioning for these patients [11]. Additional data is needed in order to better understand the relative influence of psychological, behavioral, and cognitive factors on outcomes in PR.

Due to its capacity to support the development of adaptive health behaviors, therapeutic engagement, and mood management, cognitive-behavioral therapy is a core PR component. Table 36.2 displays examples of cognitive-behavioral and psychosocial interventions often applied in the context of PR.

Tips

- ***Assess cognition.*** Chronic respiratory and pulmonary disorders have been associated with cognitive impairment (e.g., attention, memory, executive function, and motor planning) due to long-term hypoxemia. Assessment of cognitive function should be routine in this population, and early evaluation is recommended in order to establish a baseline for future comparison given the chronic nature of many of these conditions.
- ***Assessment as intervention***. Assessment conducted in the care of individuals with respiratory and pulmonary disorder will be most impactful if approached in a way that serves as an individualized intervention based

Table 36.2 Examples of cognitive-behavioral and psychosocial interventions in PR

• *CBT for depression and anxiety management*	CBT protocols in PR often consist of a combination of education, relaxation training, decreasing avoidance behavior, increasing pleasurable activities, altering respiration-related thoughts, use of encouraging self-statements, improving problem-solving skills, and sleep hygiene. Randomized controlled trials have found CBT to be effective for the management of depressive and anxiety symptoms in COPD. CBT improves anxiety and depressive symptom severity above and beyond educational or exercise interventions alone [12]. Interventions incorporating multiple modalities including exercise, group therapy, and individual CBT appear most effective [13]
• *Relaxation therapy*	Breathing strategies underlie many relaxation interventions. There is evidence to support the use of pursed-lip breathing, positioning (forward leaning), and respiratory muscle training in COPD [14]. Diaphragmatic breathing, a common relaxation intervention, is *not* indicated in many PR populations. Careful patient selection, proper and repeated instruction and control of the techniques, and assessment of the effects are necessary. Progressive muscle relaxation and other relaxation training techniques may be helpful in reducing anxiety and depression symptoms in PR participants, though the additive therapeutic benefit is unclear [15]. Recent qualitative studies have suggested that interventions based on mindfulness meditation may hold promise as an intervention for those with COPD [16]; however, results from randomized controlled trials have been less promising [17]
• *Smoking cessation*	There is moderate evidence to suggest that smoking cessation is more effective when combining with intensive counseling and nicotine replacement therapy when compared to treatment as usual [18]. There is also moderate evidence that antidepressant medication contributes to higher abstinence rates when compared to placebo. One meta-analysis found smoking cessation care in combination with nicotine replacement therapy to have the largest effect as compared to other combined treatment modalities [19]
• *Self-management*	Self-management education is central to PR programs. There are four basic targets of self-management interventions: (a) knowledge of the condition and healthcare resources, (b) problem-solving ability or training, (c) skill acquisition (e.g., relaxation, assertiveness, pain management), and (d) self-monitoring (e.g., breathing strategies, exercise). These interventions are most effective when they incorporate peer mentoring, behavioral skill development, feedback on use of learned skills, and intervention for negative illness-related thoughts. These interventions are intended to be individualized and could be expanded to include a variety of disease management topics including sexuality or end of life concerns. Self-management interventions are intended to increase a person's self-efficacy and therefore adherence to medical recommendations
• *Group intervention*	Support group intervention can be useful for increasing available social supports for patients and providing an organizational structure for maintaining treatment gains following the completion of a bout of PR care. Peer mentoring, as part of a coordinated self-management program, is one mechanism for providing group intervention. Group-based integrated health interventions have shown promise for maintaining gains in physical and emotional function at 1 year following initial PR care [20]

on results specific to that person. These "mini-interventions" can come in many forms: educational, skill-focused, or caregiver training to name a few.

- ***Get creative.*** Intervention studies have identified several potentially beneficial complimentary therapies. Listening to relaxing music, tai chi, and singing classes have been found to enhance function and quality of life in a variety of domains.
- ***Use multiple modalities.*** The medical and psychosocial implications of chronic respiratory and pulmonary disease require a multimodal approach that incorporates the interventions outlined in this chapter within the context of an integrated PR program. Consultation and co-treatment are necessary.
- ***Caregiver support.*** There has been little empirical study into caregiver interventions within the context of PR. However, caregiver preparation and well-being has significant potential to influence individual outcomes. PR participants will benefit from direct inclusion of caregivers in educational and skill-based interventions.

- ***Peer to peer.*** Support and feedback from peers can influence patient outcomes when incorporated into self-management programs. Peer mentoring and consultation can enhance the quality of life and sense of social support of patients engaged in PR. These interventions also promote interactions with “insiders” who have a shared disease experience in addition to “outsider” interactions with healthcare providers or even caregivers.
- ***Go home.*** Though additional study is needed, there is evidence home-based PR programs offer a cost-effective model of care that can produce comparable results to hospital-based services [21]. Home-based care models appear well aligned with self-management approaches that promote patient knowledge of their health condition, skill development, and adaptive health behavior change. An integration of these approaches could enhance the financial sustainability of services while also increasing patient satisfaction and producing durable health outcomes.

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37

Mealtime Challenges

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Topic

Adequate nutrition is essential to maintain physical and emotional health, particularly when one is hospitalized and trying to heal from a sickness or injury. Mealtime challenges can be very frustrating for providers in medical rehabilitation settings. This chapter will highlight the importance of proper nutrition and discuss some common reasons for mealtime challenges, as well as tools to evaluate the problem, and evidence-based interventions along with how to monitor interventions. The objective of this chapter is to familiarize the reader with guidelines available to successfully assist the patient in maintaining their nutritional status while fostering quality mealtime experiences within the medical rehabilitation setting.

A. ***Terminology***
  1. **Agnosia** occurs when the person cannot recognize familiar items, particularly when sensory cuing is limited.
  2. **Albumin** the most abundant plasma protein, formed principally in the liver and constituting up to two thirds of the 6–8 % protein concentration in the plasma. Albumin is responsible for much of the colloidal osmotic pressure of the blood, and thus is a very important factor in regulating the exchange of water between the plasma and the interstitial compartment (space between the cells).
  3. **Apraxia** is the inability to conduct voluntary muscular activities because of neuromuscular damage (e.g., manipulate utensils or voluntary swallow).
  4. **Anorexia** loss of appetite for food, may be as a result of subjectively unpleasant food, surroundings, company, or emotional states such as anxiety, irritation, anger or fear, may also be a symptom of a physical disorder like cancer or emotional disturbance as in depression.
  5. **Dehydration** a dangerous lack of water in the body resulting from inadequate intake of fluids or excessive loss through sweating, vomiting, or diarrhea.
  6. **Dysphagia** any difficulty, discomfort, or pain when swallowing.
  7. **Malnutrition** a condition that occurs when your body does not get enough nutrients.
  8. **Minerals** inorganic substances which are obtained from foods in a well-balanced diet that are relevant to human nutrition.
  9. **Registered Dietitian** a health professional who has university qualifications consisting of a 4-year Bachelor Degree

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_37

in Nutrition and Dietetics or a 3-year Science Degree followed by a Master Degree in Nutrition and Dietetics, including a certain period of practical training in different hospital and community settings (in the USA, 1200 h of supervised practice are required in different areas).

10. **Sundowning Syndrome** Increased confusion or disorientation at dusk or through the night in persons with some form of dementia or delirium (see other chapters in this book on each topic).
11. **Vitamins** organic substances from foods that are necessary in the diet, in very small quantities, for normal growth and health.

Importance

Nutrition plays a particularly critical role in the progress of persons in the rehabilitation setting as all cells and systems of the body can be affected by malnutrition or under nutrition. Research shows poor nutrition prolongs length of stay in the hospital, increases the chance for infections, impairs wound healing [1], and affects immune efficiency [2]. The process of identification of malnutrition will be detailed further under **Practical Applications**.

A. ***Etiology of Malnutrition***

Causes are multifaceted: Consider physiological, psychological, cognitive, and environmental factors

1. **Physical Issues** decreased ability to self-feed due to:
    - Hemiplegia, paralysis, apraxia, tremors, movement disorder
    - Seating or positioning problems (e.g., poor balance)
    - Strength, endurance, sedation, pain
    - Vision impairment

    Alteration in digestive process:
    - Oral issues with teeth, dentures, mucosa, excess or lack of saliva
    - Dysphagia
    - GI issues
    - Olfactory impairment
    - Anorexia
2. **Psychological Issues** (one or combination of below)
    - Depression/anxiety
    - Substance abuse
    - Delirium
    - Undertreated mental illness
    - Paranoia
    - Eating disorder
3. **Cognitive and behavioral issues**
    - Decreased recognition of hunger or thirst
    - Decreased sense of smell and taste
    - Inability to recognize how to use utensils (agnosia)
    - Wandering
    - Sundowning
4. **Environmental or situational issues**
    - Eating in altered environment (e.g., wheelchair or bed)
    - Eating in an institutional setting; busy/noisy dining rooms
    - Tests/appointments/procedures interfering with mealtimes (NPO orders)
    - Poor lighting
    - Limited food choices
    - Too restrictive a diet
    - Poor food quality
    - Cultural dislike of food

Practical Applications

A. ***Identify those at risk for nutrition problems***

1. **Nutrition Screening**

    The process of identifying patients or clients who may have a nutrition problem and benefit from nutrition assessment and intervention by a registered dietitian (RD). Nutrition risk is assessed within the first 24 h of admission usually by nursing staff (Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requirement).

    ***Potential triggers to be addressed in the nutrition screen may include*:**
    - Unplanned weight loss
    - Inadequate intake
    - Chewing or swallowing problems

- GI problems, including nausea, vomiting, diarrhea, constipation
- Person is receiving central parenteral nutrition (CPN) or enteral nutrition (EN)
- High risk for or presence of pressure ulcer
- Loss of muscle mass or fluid shifts

Any problems identified in the screening process will generate a nutrition consult after which an RD (Registered Dietitian) would complete a full nutrition assessment.

2. **Nutrition Assessment**

Elements of assessment vary per facility but recommended components by AND (Academy of Nutrition and Dietetics) as outlined in Reference Manual for Standardized Language for Nutrition Care Process [3] contain the following:

Food and Nutrition Related History. Food and nutrient intake, medication and herbal supplement intake, knowledge and beliefs, food and supplies availability, physical activity, and nutrition quality of life

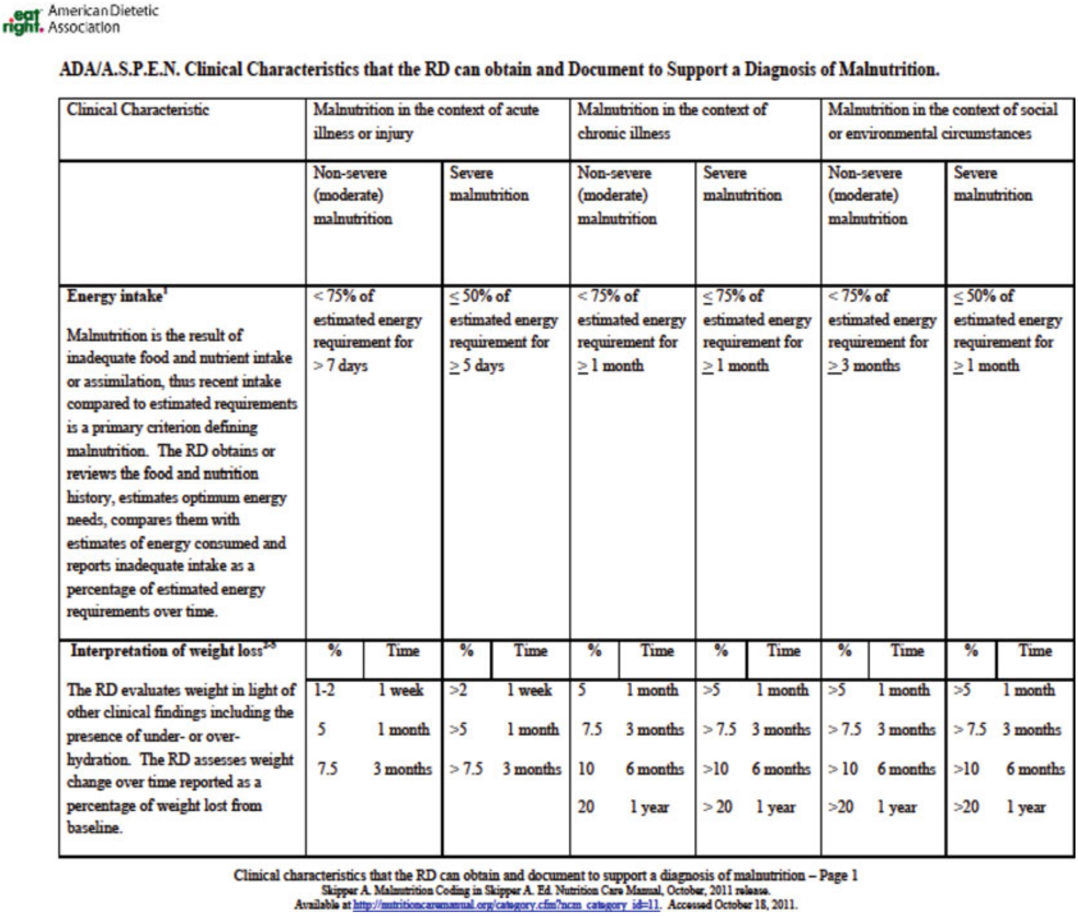
Biochemical data-/Medical tests and Procedures. Lab data, tests, such as gastric emptying or resting metabolic rate

Anthropometric Measurements. Height, weight, BMI (body mass index), and weight history

Nutrition-Focused Physical Findings. Physical appearance, muscle, or fat wasting, swallow function, appetite and affect

Client History. Personal, medical, health, family history, treatments and complementary/alternative medicine use, and social history

The Nutrition Assessment reveals nutrition related problems that the RD can positively affect or improve. One goal of the nutrition assessment is to identify malnourished patients. The guidelines for identification of malnutrition have recently been updated/developed by the American Society for Parenteral and Enteral Nutrition or A.S.P.E.N. in 2012 [4].



American Dietetic Association

ADA/A.S.P.E.N. Clinical Characteristics that the RD can obtain and Document to Support a Diagnosis of Malnutrition.

Clinical Characteristic	Malnutrition in the context of acute illness or injury				Malnutrition in the context of chronic illness				Malnutrition in the context of social or environmental circumstances			
	Non-severe (moderate) malnutrition		Severe malnutrition		Non-severe (moderate) malnutrition		Severe malnutrition		Non-severe (moderate) malnutrition		Severe malnutrition	
Energy intake[1] Malnutrition is the result of inadequate food and nutrient intake or assimilation, thus recent intake compared to estimated requirements is a primary criterion defining malnutrition. The RD obtains or reviews the food and nutrition history, estimates optimum energy needs, compares them with estimates of energy consumed and reports inadequate intake as a percentage of estimated energy requirements over time.	< 75% of estimated energy requirement for > 7 days		≤ 50% of estimated energy requirement for ≥ 5 days		< 75% of estimated energy requirement for ≥ 1 month		≤ 75% of estimated energy requirement for ≥ 1 month		< 75% of estimated energy requirement for ≥ 3 months		≤ 50% of estimated energy requirement for ≥ 1 month	
Interpretation of weight loss[2-5]	%	Time	%	Time	%	Time	%	Time	%	Time	%	Time
The RD evaluates weight in light of other clinical findings including the presence of under- or over-hydration. The RD assesses weight change over time reported as a percentage of weight lost from baseline.	1-2	1 week	>2	1 week	5	1 month	>5	1 month	>5	1 month	>5	1 month
	5	1 month	>5	1 month	7.5	3 months	> 7.5	3 months	> 7.5	3 months	> 7.5	3 months
	7.5	3 months	> 7.5	3 months	10	6 months	>10	6 months	> 10	6 months	>10	6 months
					20	1 year	> 20	1 year	>20	1 year	>20	1 year

Clinical characteristics that the RD can obtain and document to support a diagnosis of malnutrition – Page 1
Skipper A. Malnutrition Coding in Skipper A. Ed. Nutrition Care Manual, October, 2011 release.
Available at http://nutritioncaremanual.org/category.cfm?ncm_category_id=11. Accessed October 18, 2011.

These clinical characteristics take into account inadequate energy intake, severity of weight loss, evaluation of subcutaneous fat and muscle loss, fluid accumulation, and reduced hand grip. In these guidelines albumin is not used as an indicator for malnutrition diagnosis, as it is not a specific marker of nutrition status. Albumin levels decrease in response to stress, illness, injury, disease state, or fluid shifts.

There is evidence, though, to support albumin's use as a marker of severity of disease [5] and an independent predictor of poor outcomes of care [6].

B. ***Tools For Assessment***

1. **Handheld dynamometer**

   Used to test hand grip muscle strength; reduced hand grip strength is one of the criteria used to identify person with malnutrition as it relates to functional status

2. **Calorie count**

   Documentation of all portions/amounts of food and fluids consumed in 24 h. Nurses generally document amounts and types of foods while the RD calculates the calories, protein, and any other nutrients to assess adequacy of intake compared to actual needs.

3. **Percent of meal consumed**

   Nursing staff observe and document the percent of all meals and snacks consumed to assist in determination of adequacy of nutrition intake.

4. **Indirect Calorimetry**

   Machine that measures oxygen used to calculate resting metabolic rate. Resting metabolic rate is an indication of daily calorie needs.

5. **Calories/kg**

   When indirect calorimetry is not available, RDs will estimate calorie needs based on weight status, and use evidence-based calories per kilogram algorithms. Also, taken into account are age, disease and inflammatory state, wound healing needs, activity factors, and many other clinical standards. Generally, 20 cal/kg weight reduction, 25 cal/kg for sedentary, 30 cal/kg for weight maintenance, 35–40 cal/kg for anabolism.

6. **Mifflin St. Jeor calorie estimation formulas**

   Another way RD estimate caloric needs which is found to be the most accurate for obese patients.

7. **Males—Basal Metabolic Rate (BMR)** = (10 × weight in kg) + (6.25 × height in cm) − (5 × age in years) + 5
8. **Females—BMR** = (10 × weight in kg) + (6.25 × height cm) − (5 × age in years) − 161

A. ***Interventions***

The interventions used to improve the nutrition problem should be patient-centered and evidence-based. Some common nutrition problems in rehabilitation are explained below as well as appropriate interventions:

1. **Solutions for Generalized Problems with Inadequate Intake/Decreased appetite**
   - Liberalize diet
   - Offer favorite or culturally familiar foods
   - Offer between meal snacks
   - Encourage family and friends to visit at mealtimes and bring in favorite foods
   - Encourage social interaction in dining room setting, in a comfortable environment with soft background music
   - Offer supplemental foods—i.e., ice cream, custards, yogurts
   - Consider high calorie supplements like Ensure or Boost if the above interventions have failed
   - Consider mental health consult
   - Consider appetite stimulant
2. **Cognitive or Emotional Behaviors at mealtimes that may interfere with intake**

   Patients with dementia or delirium may exhibit behavioral problems which interfere with adequacy of nutrition intake. These are some strategies to assist in overcoming difficult situations.

   a. ***Wandering***
      - Toilet prior to mealtime as person may not be able to communicate that need
      - To alleviate nervous tension (and cause wandering) plan an activity prior to meals, like a walk, stretch, or

a physical, occupational or recreational therapy session.

b. ***Paranoia***
   - Patient may believe the food is poisoned so offering food/fluids in covered/sealed packages—for instance, dry cereals, milk in carton, sealed puddings, yogurts, custards, individual juices, wrapped breads, and sandwiches

c. ***Argumentative***
   - Avoid arguing, contradicting, or correcting
   - Avoid scolding or talking down to the person
   - Remain calm and speak in a soft and pleasant voice
   - Divert attention to another subject matter

d. ***Refusing food/spitting***
   - Check for ill-fitting dentures, mouth sores, thrush, consider if the person is constipated
   - Offer an alternate food, softer food, or high calorie supplement

e. ***Sundowning syndrome*** *(Increased confusion at dusk; disorientation through the night/restlessness)*
   - It is typical that person does not eat well at supper hour so may feed more calories during the day at breakfast and lunch
   - Offer snacks and high calorie beverages later at night
   - Limit caffeine later in the day

f. ***Lethargy***
   - Not safe to feed; try later when more alert/awake
   - Offer snacks; may need high calorie supplements when alert

g. ***Inattentiveness or lack of focus while eating***
   - Reduce distractions—avoid excessive noise, TV, calming background music is ok—keep very low volume
   - Relaxed, unrushed, well-lit dining area
   - Simplify mealtimes—present only 2–3 foods on table at one time
   - Avoid nonfood items on table within reach
   - Use contrasting colors for plates and placements to distinguish plate from table or food
   - May need verbal cues to direct eating; keep commands simple and direct "pick up fork," "take a bite," "chew," "swallow"
   - Keep positive comments/attitude at the table

3. **<u>Physiological problems</u>**

   a. ***Chewing and swallowing problems***
      - If it is a simple dental problem, alter texture of foods—softer diet
      - good oral hygiene; assess for thrush
      - dental consult
      - If dysphasia is present: consult Speech and Language Pathologist to evaluate patient tolerance of the proper texture of solids and liquid foods
      - Downgrade to dysphagia-type diet (standardized National dysphagia diets) [7].

National Dysphagia Diets: Levels of Solid Food Texture

Level 1—**Dysphagia Pureed** consists of pureed, homogenous, cohesive, and "pudding-like" foods. Excludes foods that may require a bolus formation, controlled manipulation, or mastication.

This diet is indicated for people with moderate to severe dysphagia, poor oral phase abilities, and reduced ability to protect airways.

Level 2—**Dysphagia Mechanically Altered** consists of moist, soft-textured foods that are easily formed into a bolus, meats are ground or minced

This diet is indicated for people with mild to moderate dysphagia, requires some chewing ability and some mixed textures tolerated.

Level 3—**Dysphagia Advanced** consists of foods near regular texture with moist, "bite-size" pieces. No hard, sticky, or crunchy foods allowed.

This diet is indicated for people with mild dysphagia, adequate dentition and mastication ability and expected that mixed textures tolerated.

Level 4—**Regular**—all food textures allowed

b. ***GI issues***

Nausea

- Try cold foods or at room temperature as they tend to have fewer odors
- Dry, starchy, or salty foods such as pretzels, saltines, and potatoes
- Avoid high fat or fried foods, high fiber foods, foods with strong odors
- Eat small frequent meals
- Consider antiemetic

Vomiting

- After vomiting stops, try 1 teaspoon ice chips every 10 min, increase to 1 tablespoon every 20 min
- Clear liquids—broth, apple juice or gelatin, popsicle
- After 8 h without vomiting, start solid foods
- One food at a time, small amounts
- Odorless foods low in fat and fiber: applesauce, banana, broth, baked chicken, crackers, toast, egg, juice, potato, rice, sherbet, yogurt

Diarrhea

- Limit foods with fiber, fat, lactose, and sugars
- Avoid caffeine
- Eat a small meal or snack every 3–4 h
- Avoid spicy foods
- Adequate fluids for replacement 8–10 cups per day
- Avoid foods with sugar alcohols xylitol, sorbitol, mannitol

Constipation

- High fiber foods—whole grains (whole wheat, oats, barley, rye, bran), beans or legumes, fresh fruits, and vegetables (with skins and peels)
- Increase fiber slowly over course of a few weeks
- Drink plenty of fluids—at least eight cups per day or more

4. **Physical barriers to self-feeding**

Physical limitations may impact a patient's ability to do self-care. For instance, post-stroke a person may no longer be able to use dominant hand or a person with high level spinal cord injury (SCI) may no longer have the ability to use upper extremities to feed themselves independently.

OT consult-therapist will evaluate the need for adaptive utensils, cups, and plates.

Offer finger foods/chopped or cut foods that do not require utensils

Place items within reach

Set up foods; open cartons, packages, condiments; prepare or cut up foods

Orient to plate if there is neglect on one side

Cueing as needed—verbal, mimic cueing

If a person has to be totally fed:

Toilet beforehand

Place in comfortable position; it is ideal to sit upright at 90° in chair or bed

Face the person; ideally sitting at eye-level

Allow person to choose the items they wish to eat, and to set the tempo of eating/bites

Do not mix solids and liquids in same bite

Engage in conversation or questions only between bites after clearing mouth

Never rush mealtime

Offer positive attitude/comments about the foods served

B. ***More Aggressive Interventions***

1. **Nutrition Support**

When interventions to promote adequate oral intake have been exhausted and a person still lacks appetite to consume foods or ability to swallow safely, a more aggressive method of support should be considered. Enteral nutrition or tube feeding is an option when the patient has a functioning gastrointestinal system.

Parenteral nutrition is used when a person cannot eat by mouth or by way of a feeding tube because the stomach or bowel may not be working properly. It is administered via IV catheter and is a complex form of nutrition support that has increased risks of infection and potential to induce metabolic and fluid abnormalities. The dietitian or Nutrition Support Team should be consulted when these advanced forms of nutrition are implemented.

C. ***Monitor and Evaluate***

The purpose of this step is to determine the amount of progress made and whether goals/expected outcomes are being met [8]. Dietitians use quantitative guidelines (as below) in order to accurately measure the outcomes. These outcomes may be organized into four categories (as outlined by AND in International Dietetics and Nutrition Terminology Reference Manual):

1. **Food and Nutrition Related History**
   Includes food and nutrition intake, medication and herbal supplement intake, knowledge, beliefs, attitudes, behavior, factors affecting access to food and nutrition related supplies, physical activity, or feeding ability; nutrition quality of life
2. **Anthropometric Measurement**
   Includes weight and BMI (body mass index)
3. **Biochemical Data**
   Including laboratory data and tests
4. **Nutrition-Focused Physical Findings**
   Includes findings from evaluation of body systems, muscle and subcutaneous fat wasting, oral health, swallow ability, appetite and affect

Examples of common monitors from each category:

Food and Nutrition Related History:

- Amount of meals consumed
- Percent of calories or protein consumed
- Feeding ability with adaptive utensils
- Knowledge of dietary guidelines

Biochemical Data:

- Glucose, electrolytes, cholesterol measured against normal ranges

Anthropometric Measurement:

- Weight (weekly) avoid weight loss/promote weight gain of body weight (measure daily to determine fluid retention or losses)
- BMI

Nutrition-Focused Physical Findings:

- Edema
- Subcutaneous fat or muscle repletion
- Handgrip measurement
- Bowel movements

As we monitor and reassess this measurable data, we will determine if the goals have been met and if the nutrition problem is corrected. If goals have not been met, new interventions should be implemented in order to resolve the nutrition problem with a positive outcome.

Tips

- **Nutrition screening and assessment are separate processes.**
- **Nutrition screening is identifying patients at risk usually done by nursing within the first 24 h of admission (Joint Commission Requirement).**
- **Nutrition assessment is a comprehensive process completed by the registered dietitian and includes food and nutrition history, client history, anthropometric data, biochemical data, and nutrition-focused physical findings.**
- **Albumin should not be used solely for purposes of identifying/diagnosing malnutrition; albumin is a marker of disease severity not nutrition state.**
- **When routine interventions have been exhausted to promote adequate oral intake, nutrition support, enteral, and/or parenteral should be considered.**

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Suggested Reading

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38

Decision-Making Capacity and Competency

Kristen L. Triebel, Lindsay M. Niccolai, and Daniel C. Marson

Topic

A. ***Decision-making capacity*** (hereafter, "capacity")

Refers to an individual's ability to make a range of decisions regarding his/her personal welfare and is a crucial aspect of individual autonomy. It has been defined as "a threshold requirement for persons to retain the power to make decisions for themselves" [1]. Capacity is an important element of the medical–legal doctrine of informed consent which requires that a valid consent be informed, voluntary, and **capable**—that is, the individual must have the cognitive and emotional ability to consent [2, 3].

Many different decisional capacities exist in our modern society. As discussed in greater detail later in the chapter, three capacities with particular relevance to clinical and rehabilitation settings are:

- **treatment consent capacity (TCC)**
- **research consent capacity (RCC)**
- **financial capacity (FC)**

TCC concerns an individual's capacity to make medical treatment decisions concerning his/her mental and physical health. RCC is a kindred capacity that concerns capacity to elect whether or not to participate in a research study. FC concerns an individual's ability to manage his/her finances and make related financial decisions.

Clinicians working in rehabilitation settings frequently encounter capacity issues in patients who have had a recent traumatic brain injury (TBI), stroke, or diagnosis of brain cancer. Such neurologically based disorders can cause substantial cognitive impairment and associated diminished capacity, particularly immediately following the neurological event. In these cases, clinicians must form judgments early on as to whether a patient has "capacity" and can make important decisions for herself, or whether a proxy decision-maker must be identified who can make decisions on behalf of the patient.

Patients in rehabilitation settings also often demonstrate cognitive and physical improvement and reacquisition of capacity during the course of recovery. For this reason, clinicians must continue to assess patient capacity over time and evaluate whether there has been sufficient recovery of decisional capacity such that the previously impaired patient can now resume personal decision-making on key matters such as medical treatment decisions,

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_38

management of finances, discharge decisions, or care of dependent children. There may be conflicts that arise between patients and their families regarding the extent of the patient's capacity recovery, and rehabilitation clinicians must be skilled in assessing these situations and facilitating communication and resolution between patients and their families. Furthermore, clinicians in the rehabilitation setting work in interdisciplinary or multidisciplinary teams. Thus, clinicians must be skilled in communicating and educating the rest of the treatment team about these issues. For all these reasons, capacity issues in rehabilitation settings present special challenges and responsibilities for clinicians.

While not an exhaustive list, the following summarizes key capacity-related assessment issues and related responsibilities of rehabilitation clinicians:

- **Assessment of a patient's decisional capacity soon after injury.** Many individuals with TBI and stroke will have impaired capacity immediately after a neurological injury. In some cases, a proxy decision-maker will be needed to make important decisions for the patient.
- **Monitoring and periodic reassessment of a patient's decisional capacity during the rehabilitation period.** Many patients who initially lack capacity will recover some or all of their decisional capacity during the course of their hospitalization and rehabilitation period, so capacity needs to be reassessed during recovery.
- **Ongoing attention to a patient's decisional capacity in connection to treatment and discharge planning.** Clinicians need to consider and address a patient's decisional capacity as part of clinical staff meetings, and in connection to clinical progress and discharge meetings with patients and their families. The status of a patient's decisional capacity can often be a critical aspect of treatment and discharge planning for the patient and particularly the family.

B. ***Key Concepts***

1. **Capacity** and **competency**
   a. These two terms are often used interchangeably, but are distinct concepts. ***Capacity*** refers to an individual's clinical status to make certain decisions and to perform certain acts as determined by a healthcare professional. Capacity decisions often bear upon but do not by themselves alter an individual's legal status to make decisions. ***Competency*** usually refers to an individual's legal status to make decisions, as determined by a legal professional such as an attorney and particularly a judge) [1, 4]. Put differently, a capacity evaluation involves a clinical assessment and judgment based on a patient's history, presentation, and test performance. A judge may consider such clinical capacity findings as part of his/her legal competency decision-making process, but will also consider other sources of authority in arriving at a decision, such as statutes, case law precedent, and principles of equity and justice [4]. Only a legal judgment of incompetence by a judge will alter an individual's legal status to make decisions. In this chapter, we will focus on clinical issues of capacity unless otherwise indicated.
2. **Proxy decision-makers**

   These are individuals who decide what healthcare actions are permissible for someone who temporarily or permanently has lost capacity [5]. A proxy decision-maker, such as a Legally Authorized Representative (LAR), will need to step in these cases and make decisions on behalf of the impaired individual [6]. Proxy decision-makers may also consent to research participation for impaired subjects [7].
3. **Treatment consent capacity (TCC)**

   Also known as medical decision-making capacity, TCC is a higher order functional ability that refers to a person's cognitive and emotional ability to make informed decisions related to medical treatment and care, including whether to accept or refuse a proposed treatment, or to choose among treatment alternatives [8, 9]. As noted above, in the United States TCC represents one element of the legal doctrine of informed consent, which requires that a consent to medical treatment be *informed*, *voluntary*, and *competent* [2, 3].

4. **Research consent capacity (RCC)**

   This capacity concerns an individual's cognitive and emotional ability to make a decision about whether or not to participate in a research study. Similar to TCC, RCC represents one element of the informed consent doctrine regarding research participation. In order for an individual to provide a valid informed consent to participate in research, the decision must also be *informed*, *voluntary*, and *competent* [6].

5. **Consent capacities or standards**

   Decisional capacities like TCC and RCC are traditionally assessed via four core consent abilities or standards [3, 10, 11]: *understanding, reasoning, appreciation*, and *choice*. In the context of treatment consent capacity, these consent abilities are presented in Table 38.1 in order of generally accepted clinical stringency. As reflected in Table 38.2, RCC comprises the same four consent abilities as TCC, but applied to the context of research participation [12].

6. **Financial capacity**

   This capacity refers to a person's ability to perform financial tasks and make financial decisions in a manner that meets a person's needs and that is consistent with the person's values and self/best-interest [11, 13]. Financial capacity involves a broad range of conceptual, procedural, and judgmental skills [14] ranging from simple skills such as counting coins/currency to more complex skills such as using a checkbook and register, paying bills, and making investment decisions [13, 14].

   - From a clinical standpoint, financial capacity comprises both performance abilities, and also judgment skills supporting financial decisions that promote and protect the individual's best interests. Financial capacity has been clinically conceptualized using a three-tier model that comprises [4, 14]:
     - specific financial abilities or *tasks*
     - broader *domains* of financial activities relevant to independent living
     - overall or *global* financial capacity

Table 38.1 Treatment consent abilities

Understanding	Capacity to understand the medical situation and treatment alternatives
Reasoning	Capacity to reason and provide rational reasons for and against different treatment choices
Appreciation	Capacity to appreciate the personal consequences associated with a particular treatment choice
Choice	Capacity simply to make a choice (yes or no) about a particular medical treatment

Table 38.2 Research consent abilities

Understanding	Capacity to understand the nature of the research study and research questions and procedures
Reasoning	Capacity to reason about and provide rational reasons for and against participation in a research study
Appreciation	Capacity to appreciate the personal risks and benefits associated with participation in a research study
Choice	Capacity simply to make a choice (yes or no) about participation in a research study

The model's financial tasks and domains are presented in Table 38.3.

In evaluating financial capacity, it is important to determine at the outset what have been the individual's premorbid levels of financial knowledge and experience. This will allow the clinician to make informed judgments as to how specific financial skills may have been affected by neurological and other injuries, and to ensure that lack of premorbid financial experience is not confused with the effects of injury [14].

Table 38.3 Clinical conceptual model of financial capacity

Domains	Tasks
Basic monetary skills	• Naming coins/currency
	• Understanding coin/ currency relationships
	• Counting coins/currency
Financial conceptual knowledge	• Defining financial concepts
	• Applying financial concepts
Cash transactions	• Grocery purchases
	• Calculating change/vending machine
	• Calculating a tip
Checkbook management	• Understanding a checkbook
	• Using a checkbook/register
Bank statement management	• Understanding a bank statement
	• Using a bank statement
Financial judgment	• Detecting mail fraud risk
	• Detecting telephone fraud risk
Bill payment	• Understanding bills
	• Prioritizing bills
	• Preparing bills for mailing
Knowledge of personal assets/ estate arrangements	• Knowing personal asset ownership and estate arrangements
Investment decision-making	• Understanding investment options, returns on investment choices, risks of investments

Importance

Although the topic of capacity has received a fair amount of attention in the psychiatric and dementia literature [4, 8, 10, 12, 15], a much smaller body of literature exists in the rehabilitation setting [16, 17]. As reflected below, the rehabilitation literature on capacity can be divided into conceptual and empirical studies.

A. ***Conceptual Literature/Findings***

This literature has focused primarily on issues of decision-making capacity in TBI patients, and has highlighted the following points:

- Cognitive and emotional sequelae of brain injury can directly impact an individual's decisional capacity [18].
- Acutely brain-injured patients in rehabilitation settings often face complex medical decisions such as shunting, orthopedic surgery, rehabilitation programming, and neuropsychiatric treatment [16, 19, 20].
- During rehabilitation and recovery, decisions will need to be made regarding the TBI patient's capacity to consent to medical treatments, to manage financial affairs, and to consent to research [21].
- The nature, recovery, and sequelae of brain injury poses different capacity issues for healthcare providers working in the rehabilitation setting [21, 22].
- Due to the high prevalence of cognitive impairment, the rehabilitation patient population is considered to be vulnerable, and special research safeguards need to be in place to ensure adequate protection of these individuals when consenting to research studies [22].

B. ***Empirical Literature/Findings***

Over the past 10 years, a small body of empirical capacity research has emerged examining issues of treatment consent capacity and financial capacity in patients with TBI. In addition, very recent studies have examined TCC and RCC in patients with brain cancer. Key findings from these empirical studies are presented below:

1. **Treatment Consent Capacity in TBI**

The level of initial capacity impairment and rate of recovery depends in part on the severity of the brain injury. Key findings from the studies examining TCC in TBI populations are summarized below.

a. ***Cross-Sectional Studies.*** Using the Capacity to Consent to Treatment Instrument (CCTI), cross-sectional studies have investigated TCC in individuals with acute TBI (1-month post-injury) across a range of injury severity [16, 19, 23] (see Section on Selected Capacity Assessment Instruments below for a description of the CCTI.).

Mild TBI

- Compared to healthy controls, patients with mild TBI performed worse on the *understanding* standard [23].

- Capacity impairment (defined as a score of 1.5 SD or below the control group's mean score on the consent standards) occurred in 10–30 % of persons with mild TBI [19].

Complicated Mild TBI

- Compared to controls, patients with complicated mild TBI performed worse on the *understanding* standard [23].
- No statistically significant differences between mild and complicated mild TBI groups although larger samples are needed to detect this difference.
- Capacity impairment occurred in 50 % of persons with complicated mild TBI [19].

Moderate to Severe TBI

- Compared to controls, patients with moderate to severe TBI group performed worse on the *appreciation*, *reasoning*, and *understanding* standards [16, 19, 23].
- 50–80 % of persons with moderate/severe TBI demonstrated TCC impairment [19].

b. ***Longitudinal Studies.*** Two studies have investigated recovery of TCC over a 6-month recovery period after TBI in a group of patients with a range of injury severity [16, 23]. Both studies used the CCTI to assess TCC.

Mild TBI

- At 6 months, the mild TBI group performed equivalently with controls and complicated mild TBI patients on all TCC standards [23].
- Relative to controls, at 6 months post-injury, 20 % of mild TBI patients had impaired performance on the CCTI.

Complicated Mild TBI

- At 6 months, the complicated mild TBI group performed equivalently with controls on all consent standards [23].
- A third of complicated mild TBI patients demonstrated TCC impairments at 6 months post-injury.

Moderate to Severe TBI

- At 6 months after TBI, the moderate to severe TBI group demonstrated significant improvements on all of the consent standards, but continued to demonstrate impairment on the *appreciation* and *understanding* standards compared to controls [23].
- About half of moderate to severe TBI patients demonstrate impairment on one of the CCTI standards at 6 months.

2. **<u>Neurocognitive Predictors of TCC in TBI</u>**

Neurocognitive predictors of TCC have been examined in patients with mild TBI (uncomplicated and complicated mild cases) and with moderate to severe TBI [17, 24].

Mild TBI

- Higher academic achievement as measured by the Wechsler Adult Intelligence Scale-3rd edition (WAIS-III) Arithmetic subtest [25] and the Wide Range Achievement Test-3rd edition (WRAT-3) Reading test [26] composite score predicted higher *appreciation* scores.
- Higher verbal memory predicted higher *reasoning* and *understanding* scores.

Moderate to Severe TBI

- Verbal fluency and academic achievement predicted *appreciation*.
- Academic achievement predicted *reasoning* and *understanding*. Verbal memory also predicted *understanding*.
- At 6-month follow-up, executive function, verbal processing speed, and working memory predicted performance on *understanding* (S5); working memory and short-term memory predicted *reasoning* (S4); and basic executive functioning predicted *appreciation* (S3) [17].

3. **<u>Financial Capacity in Moderate to Severe TBI</u>**

Studies have used the Financial Capacity Instrument (FCI) to investigate financial capacity in individuals with moderate to severe TBI at baseline and at 6-month follow-up [27, 28]. Key findings are presented below:

- Compared to controls, at 1-month post-injury, over half of individuals with moderate to severe TBI were impaired (defined as a score of 1.5 SD or below the control group's mean score on the FCI domain or total score) on FCI total score (sum of Domains 1–7) and on six FCI domains: bank statement management, bill payment, cash transactions, checkbook management, and financial concepts [27].
- At 6-month follow-up, there were significant improvements on two distinct FCI total scores (sum of Domains 1–7, and sum of Domains 1–7 and 9) and on four domains: basic monetary skills, cash transactions, bill payment, and investment decision-making. Despite these improvements, moderate to severe TBI patients continued to be impaired at 6 months on FCI domains measuring financial conceptual knowledge, checkbook management, bank statement management, financial judgment, and knowledge of assets/estate arrangements.
- At baseline, measures of working memory (Wechsler Adult Intelligence Scale-3rd edition (WAIS-III) Arithmetic) [25] and immediate verbal memory (Wechsler Memory Scale-Revised (WMS-R) Logical Memory I) [29] predicted impairment on the FCI total score [29].
- At 6 months, measures of executive function (Token Test) [30] and working memory (Wechsler Adult Intelligence Scale-3rd edition (WAIS-III) Arithmetic) [25] predicted impairment on the FCI total score [29].

4. **Consent Capacity in Brain Cancer**
    - Persons with brain cancer, specifically malignant gliomas (MG), have demonstrated impairment on TCC standards of *understanding* and *reasoning* [30]. Semantic verbal fluency, the ability to quickly name words that belong to a certain category, was a significant neuropsychological predictor of TCC impairment [30].
    - Persons with MG also have demonstrated impairments in RCC. Patients with MG have impairments on the abilities of *appreciation*, *reasoning*, and *understanding*. However, patients with MG perform equivalently to controls when simply *expressing a choice* [31]. Cognitive measures of verbal fluency (both phonemic/letter and semantic/word) predicted performance on the RCC consent standards of *understanding*, *reasoning*, and *appreciation*.

Practical Applications

A. ***Clinical Approach to Assessing Capacity.*** Suggested steps in a clinical capacity evaluation are outlined below.

- **Step 1:** Clarify the capacity referral question. What capacity or capacities are you as the rehabilitation clinician being asked to assess for this patient?
- **Step 2:** Identify the skills and functional abilities that are constituent to each of the capacities you are assessing. For example, in the case of TCC, these would be the consent abilities of *understanding, reasoning, appreciation*, and *choice*.
- **Step 3:** Collect clinical evidence relevant to the capacity at issue. Using clinical interview, capacity testing, and record review, collect and integrate evidence concerning cognition, mood and behavior, and everyday function relevant to the capacity and its functional requirements. Information reviewed can include current medical condition, past medical and psychiatric history, family history, social history, current medications, and substance abuse history [12]. It is also good practice

to speak with the patient's treatment team. Capacity assessment instruments may be used at this stage to collect direct performance information relevant to the capacity.

- **Step 4:** Analyze the clinical evidence in light of the capacity. Determine how congruent (or not congruent) the patient's actual decisional abilities are in relation to the requirements of the capacity being assessed.
- **Step 5:** Make a clinical capacity judgment. Based on the degree of congruence/non-congruence, decide whether or not the patient has capacity with respect to the issue at hand (e.g., TCC, RCC, or financial capacity). On occasion, a judgment of marginal capacity may best accord with the clinical circumstances.
- **Step 6:** Document your capacity judgment and associated clinical reasoning in a report or other written clinical document.

B. ***Selected Capacity Assessment Instruments***

As discussed above, capacity assessment instruments can be used by rehabilitation clinicians to help guide a clinician's judgment regarding a capacity issue [12]. Selected instruments are presented below by type of capacity:

1. **Treatment consent capacity**
    - ***MacArthur Competence Assessment Tool—Treatment (MacCAT-T)*** is a semi-structured interview that allows the evaluator to assess the patient's medical decisional capacity using open-ended questions tapping the four consent standards [15]. The MacCAT-T takes approximately 15–20 min to complete. A strength of the MacCAT-T is that it assesses a patient's decisional capacity with respect to their unique medical condition. A limitation of the MacCAT-T is that the lack of content standardization across patients and medical settings limits the ability scientifically to compare results across different disease entities.
    - ***Capacity to Consent to Treatment Instrument (CCTI)*** assesses TCC using standardized hypothetical clinical vignettes [32] that present a hypothetical medical problem and symptoms (e.g., cardiovascular disease) and two treatment options with associated risks and benefits. After presentation, individuals answer standard questions assessing the four core TCC standards and one experimental standard *reasonable choice* [S2]. A strength of the CCTI is its standardization across patient groups and disease entities, which facilitates scientific comparisons across different disease groups. A limitation of the CCTI is that the hypothetical vignettes are not specific to the patient's personal medical situation.
2. **Research consent capacity**

    MacArthur Competence Assessment Tool-Clinical Research (MacCAT-CR) is a semi-structured interview that assesses an individual's capacity to consent to a specific research study for which he/she is being asked to provide consent. Like the MacCAT-T, the MacCAT-CR employs the four consent standards and assesses a person's *understanding* of information about the research protocol's procedures, *reasoning* about participation, *appreciation* of the personal consequences of research participation, and the ability to *communicate a choice* to participate in the research [33]. A strength of the MacCAT-CR is its focus on the actual research protocol in question and the potential participant's research consent capacity. A potential limitation is a lack of content standardization across research settings/protocols and associated challenges establishing norms and conducting cross-research protocol comparisons.
3. **Financial capacity**

    The ***Financial Capacity Instrument (FCI)*** is a standardized psychometric instrument for assessing financial capacity in older adults and other neurocognitively impaired patients [4, 13, 34]. The FCI assesses 18 specific financial tasks, 9 financial domains, and has 3 distinct global scores. The FCI is based on the clinical conceptual model of financial capacity discussed earlier in this chapter. It takes approximately 60–90 min to administer the FCI depending on the cognitive ability of the patient. This research instrument is currently being developed for clinical use, but is not yet commercially available.

C. ***Assessment Considerations***
- Time of day
  - Choose the time of day when patient is most alert and when the patient's capacity is likely to be maximal.
- Sensory limitations
  - Ensure patients are wearing eyeglasses and/or hearing aids if needed.
  - If vision is impaired, use larger print materials and/or adjust the lighting in the room.
  - If hearing is impaired, reduce background noise or adjust your speaking style and pace.
- Fatigue
  - Provide sufficient time for rest and breaks.
  - As needed, break evaluation sessions into multiple, shorter sessions.
- Medical factors
  - Be knowledgeable about patients' medications. Patients' functioning may vary depending on medication use and time of day when they take their medications.
  - Be knowledgeable about patients' nutrition and hydration. Patients who have poor nutrition and hydration may not perform at their best.
- Sociocultural factors
  - Be knowledgeable about patients' cultural background. Select tests that are appropriate for a person's culture and socio-demographic status. Administer tests in the patients' primary language.
- Cognitive impairment
- Clinicians working in a rehabilitation setting should use strategies to support or maximize a patient's participation in the decision-making process. Interventions for specific types of cognitive impairment are listed in Table 38.4 [34, 35].

Table 38.4 Potential capacity interventions for rehabilitation settings

Cognitive impairments	Intervention strategies
Memory	• Provide summary notes and information sheets
	• Repeat, paraphrase, and summarize
Processing speed	• Conduct interview at a slower pace
	• Allow extra time to process information and respond
Attention	• Minimize environmental distractions
	• Do assessment when person is most alert
	• Discuss one topic at a time
	• Present only relevant information
	• Engage person through dialogue
Comprehension	• Break information down into smaller, more easily understood segments
	• Do not use medical "jargon"; use basic language
	• Use simple, direct questions
	• Ask patient to repeat back information and explain. If needed, provide corrected feedback
Reading	• Read written forms aloud
	• Provide illustrations if available

Tips

1. ***Capacity is not a global construct.*** Individuals may be impaired on one type of capacity (e.g., financial capacity), but not one another (e.g., treatment consent capacity). Therefore, clinicians should not automatically assume global capacity impairment, but rather discretely evaluate each type of presenting capacity issue unless global capacity loss is evident.
2. ***Diagnosis does not determine capacity status.*** A diagnosis of a neurological or psychiatric disorder is a relevant factor but does not by

itself determine capacity status [4, 36]. What does a diagnosis of complicated mild TBI tell a clinician about that individual's capacity to consent to medical treatment?

3. ***Presence of cognitive impairment does not determine capacity status.*** Degree of cognitive impairment is strongly related to impairment of decisional capacity [36], however, the presence of cognitive impairment by itself does not automatically mean impaired capacity. What does a neuropsychological finding of executive function in a case of complicated mild TBI tell a clinician about that individual's capacity to consent to medical treatment? Neurocognitive testing can illuminate cognitive impairments that may affect functional abilities constituent to a capacity, but cognitive testing alone is not sufficient for a capacity determination. As noted above, the clinician must perform a functional analysis of a person's skills and abilities relevant to performing a specific capacity in its context.
4. ***Presence of aphasia does not necessarily constitute impaired capacity.*** About a third of patients with stroke will experience aphasia. Indeed, some of these individuals will have cognitive impairments that limit their capacity to consent. However, some individuals with aphasia are capable of providing informed consent if modifications are made to the consent process [37]. Such modifications might include improving reading comprehension by using simplified terms and sentence structures, larger font sizes, and increased space between sections. There is currently no empirical support for the use of pictures or symbols to support understanding of text for individuals with aphasia [37].
5. ***Capacity is not a static entity.*** Capacity can improve, worsen, or fluctuate over time. Many decisionally impaired patients seen in a rehabilitation setting may demonstrate improvements in their decisional capacity over time. As discussed above, in such cases capacity needs to be periodically reevaluated during the recovery period. If capacity is impaired due to delirium, capacity should be reassessed after the patient's mental status clears.

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Enhancing Appropriate Use of Adaptive/Assistive Technology

39

Marcia J. Scherer

Topic

A. ***Terminology***

1. **Assistive technology devices (ATDs)**

   Products designed to enhance the functioning of individuals so that they can lead lives of enhanced independence and quality. ATDs can make the difference between being able to live at home as opposed to, for example, a skilled nursing facility. ATDs can be very simple mechanical devices or sophisticated and complex electrical or computerized ones [1].

2. **Assistive Technology Act of 2004**

   "Assistive technology device" was originally defined in the Technology Related Assistance for Individuals with Disabilities Act of 1988 (Pub. L. 100–407) [2]. This legislation was reauthorized as the Assistive Technology Act. The original Tech Act defined assistive technology device, and this definition has remained the same throughout its reauthorizations:

   "any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" [3].

3. "**Assistive technology service**"

   - Defined in the Act as, "any service that directly assists an individual with a disability in the selection, acquisition, or use, of an assistive technology device" [3].
   - ***The law gives the following examples of AT services:***

(A) the evaluation of the assistive technology needs of an individual with a disability, including a functional evaluation of the impact of the provision of appropriate assistive technology and appropriate services to the individual in the customary environment of the individual.

(B) a service consisting of purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices by individuals with disabilities.

(C) a service consisting of selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, replacing, or donating assistive technology devices.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_39

(D) coordination and use of necessary therapies, interventions, or services with assistive technology devices, such as therapies, interventions, or services associated with education and rehabilitation plans and programs.

(E) training or technical assistance for an individual with a disability or, where appropriate, the family members, guardians, advocates, or authorized representatives of such an individual.

(F) training or technical assistance for professionals (including individuals providing education and rehabilitation services and entities that manufacture or sell assistive technology devices), employers, providers of employment and training services, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of individuals with disabilities.

(G) a service consisting of expanding the availability of access to technology, including electronic and information technology, to individuals with disabilities.

Importance

An assistive technology device (ATD) is what the person uses. How they obtain and maintain it falls under the purview of assistive technology services. These federal definitions are important to know because, in many cases, the consideration of ATDs is mandated by law. If not mandated, their consideration is minimally supported by law regardless of the person's age or type of disability/chronic illness.

Practical Applications

A. ***Key aspects for*** matching individuals with disabilities and chronic illness with the most appropriate ATDs for their use are outlined below.

1. **Finding specific assistive technology devices**

   WWW.ABLEDATA.COM is a website funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to provide comprehensive information on available assistive technologies and other information of interest to persons with spinal cord injuries. It includes a searchable database of over 50,000 assistive technology products divided into 20 categories as follows:

Products

Clicking on a topic will link you to a list of the major categories within that topic, from which you can see the list of specific product types in that category. Just point and click.

- **Aids for Daily Living**
- Products to aid in activities of daily living.
- **Major Categories**: Bathing, Carrying, Child Care, Clothing, Dispenser Aids, Dressing, Drinking, Feeding, Grooming/Hygiene, Handle Padding, Health Care, Holding, Reaching, Time, Smoking, Toileting, Transfer.
- **Blind and Low Vision**
- Products for people with visual disabilities.
- **Major Categories**: Computers, Educational Aids, Health Care, Information Storage, Kitchen Aids, Labeling, Magnification, Office Equipment, Orientation and Mobility, Reading, Recreation, Sensors, Telephones, Time, Tools, Travel, Typing, Writing (Braille).
- **Communication**
- Products to help people with disabilities related to speech, writing, and other methods of communication.

- **Major Categories**: Alternative and Augmentative Communication, Headwands, Mouthsticks, Signal Systems, Telephones, Typing, Writing.
- **Computers**
- Products to allow people with disabilities to use desktop and laptop computers and other kinds of information technology.
- **Major Categories**: Software, Hardware, Computer Accessories.
- **Controls**
- Products that provide people with disabilities with the ability to start, stop, or adjust electric or electronic devices.
- **Major Categories**: Environmental Controls, Control Switches.
- **Deaf And Hard of Hearing**
- Products for people with hearing disabilities.
- **Major Categories**: Amplification, Driving, Hearing Aids, Recreational Electronics, Sign Language, Signal Switches, Speech Training, Telephones, Time.
- **Deaf Blind**
- Products for people who are both deaf and blind.
- **Education**
- Products to provide people with disabilities with access to educational materials and instruction in school and in other learning environments.
- **Major Categories**: Classroom, Instructional Materials.
- **Environmental Adaptations**
- Products that make the built environment more accessible.
- **Major Categories**: Indoor Environment, Furniture, Outdoor Environment, Vertical Accessibility, Houses, Polling Place Accessibility, Lighting, Signs.
- **Housekeeping**
- Products to assist in cooking, cleaning, and other household activities as well as adapted appliances.
- **Major Categories**: Food Preparation, Housekeeping General, Cleaning, Ironing, Laundry, Shopping.
- **Orthotics**
- Braces and other products to support or supplement joints or limbs.
- **Major categories**: Head and Neck, Lower Extremity, Torso, Upper Extremity.
- **Prosthetics**
- Products for amputees.
- **Major categories**: Lower Extremity, Upper Extremity.
- **Recreation**
- Products to assist people with disabilities with their leisure and athletic activities.
- **Major Categories**: Crafts, Electronics, Gardening, Music, Photography, Sewing, Sports, Toys.
- **Safety and Security**
- Products to protect health and home.
- **Major Categories**: Alarm and Security Systems, Child Proof Devices, Electric Cords, Lights, Locks.
- **Seating**
- Products that assist people to sit comfortably and safely.
- **Major Categories**: Seating Systems, Cushions, Therapeutic Seats.
- **Therapeutic Aids**
- Products that assist in treatment for health problems and therapy and training for certain disabilities.
- **Major Categories**: Ambulation Training, Biofeedback, Evaluation, Exercise, Fine and Gross Motor Skills, Perceptual Motor, Positioning, Pressure/Massage Modality Equipment, Respiratory Aids, Rolls, Sensory Integration, Stimulators, Therapy Furnishings, Thermal/Water Modality Equipment, Traction.
- **Transportation**
- Products to enable people with disabilities to drive or ride in cars, vans, trucks, and buses.

- **Major Categories**: Mass Transit Vehicles and Facilities, Vehicles, Vehicle Accessories.
- **Walking**
- Products to aid people with disabilities who are able to walk or stand with assistance.
- **Major Categories**: Canes, Crutches, Standing, Walkers.
- **Wheeled Mobility**
- Products and accessories that enable people with mobility disabilities to move freely indoors and outdoors.
- **Major Categories**: Wheelchairs (Manual, Sport, and Powered), Wheelchair Alternatives (Scooters), Wheelchair Accessories, Carts, Transporters, Stretchers.
- **Workplace**
- Products to aid people with disabilities at work.
- **Major Categories**: Agricultural Equipment, Office Equipment, Tools, Vocational Assessment, Vocational Training, Work Stations.

Source: AbleData website (www.AbleData.com), retrieved 7 May 2015 [4]

Once the relevant category is selected, then a hotlink will go to specific devices with further links to manufacturers for technical specifications, availability, cost, or ordering information.

2. **Funding**

   Under the Assistive Technology Act, each US state and territory receives money to fund an Assistive Technology Act Project (ATAP) to provide services to persons with disabilities for their entire life span, as well as to their families or guardians, service providers, and agencies and other entities that are involved in providing services. The list of ATAPs can be found at this website: http://www.ataporg.org/atap/

3. **Disciplines in Medical Rehabilitation and Interventions**

   Psychologists play key roles in helping individuals with disabilities or chronic illnesses cope with and adapt to living with functional loss. As key members of the inter- and transdisciplinary rehabilitation team, they are fundamental to identifying psychosocial benefits and barriers to ATD use. Other key members of the team include the following, along with the product categories they are particularly skilled in assessing:

Occupational Therapists: *Aids for daily living, Recreation, Computers, Controls, Workplace, Education, Housekeeping, Environmental Adaptations*

- **Physical Therapists**: *Walking, Wheeled Mobility, Seating, Transportation*
- **Prosthetists & Orthotists**: *Prosthetics, Orthotics*
- **Speech-Language Pathologists**: *Communication, Computers, Controls*
- **Audiologists**: *Deaf And Hard of Hearing, Deaf-blind*
- **Vision specialists**: *Blind and Low Vision, Deaf-blind, Computers, Controls,*
- **Vocational Rehabilitation Counselors**: *Workplace, Education, Safety and Security, Therapeutic Aids*
- **Special Educators**: *Education*
- **Engineers and Technologists**: (design, customize, modify all types of devices)
- **Nurses and physicians:** *Therapeutic Aids* (products requiring medical prescription, application and involvement)
- **Counselors and social workers** (assessment of individual preferences and priorities, supports for or barriers to use, funding)
- **Suppliers & Manufacturers:** (design, manufacture, and supply all types of ATD). Many belong to an organization called the Assistive Technology Industry Association (www.ATIA.org)

4. **Using the Matching Person and Technology Conceptual Model to Guide Practice (MPT)**

   The MPT Model (see Fig. 39.1) focuses on three primary rings representing levels of influences known to affect the appropriate match of person and AT device [5, 6]: Most fundamentally, is the ring regarding the user's **personal factors** or characteristics, then the ring of characteristics of the **environments of use**, and then the **features and characteristics** (attributes, qualities, properties) of the AT device itself. Knowing and integrating the details regarding the elements within the MPT Model rings or levels provides a comprehensive description of an individual's predisposition to and expectations of benefit from use of an AT device at baseline and realization of benefit from use at follow-up.

   a. ***The Person***

      Five examples of key areas to address are shown in the chart, but there are many others that could be added. Some key considerations regarding the characteristics and resources of the individual person include [7]:

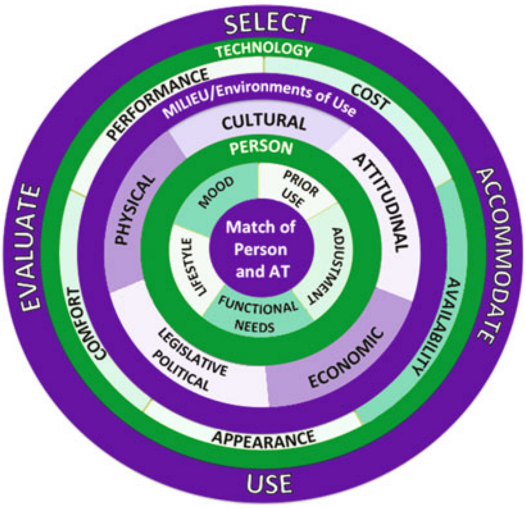

Fig. 39.1 The Matching Person and Technology Conceptual Model. *Source: Institute for Matching Person & Technology, Inc.*

      1. *Functional Needs*

         Can the person participate in desired life areas, such as ………? If not, what is getting in the way?

      2. *Adjustment and Motivation*

         Does the person perceive a discrepancy between the current and desired situation?

         Does the person view technology (or other support) use as a desirable means of achieving dreams and goals?

      3. *Prior exposure to and use of technologies (and other supports)*

         What is that person's receptivity or predisposition to the use of a technology?

         What is the person using or doing now in terms of technology? Why is that not sufficient?

      4. *Mood*

         What are the person's dreams and goals? What are the presenting, immediate, issues? Underlying ones?

         Is there a sad or anxious mood that might interfere with learning and using new technology?

         When faced with change, does the person generally approach it with a positive attitude, confidence and self-determination, or with confusion, helplessness, and/or dependence on others?

      5. *Lifestyle*

         How much will use of the support affect the timing and performance of typical routines and customary activities? How much does that matter to the person?

         What are the person's strengths, interests, and priorities?

   b. ***Milieu/Environment Factors Influencing Use***

      Moving outward from the center of the circle and beyond the characteristics of the person, considerations related to the characteristics and requirements of the environment(s)/

milieu of use and their impact on the individual become crucial. The word *milieu* is used because it connotes that our environment is not just a built one consisting of physical objects, but a place comprises people who have a variety of attitudes and values. Sample considerations regarding the characteristics and requirements of the milieu/environments include:

1. *Cultural*

   Will the family encourage and support use of technology? Sometimes caregivers and family members are primary users of these technologies. It's important to assess their perspectives as well as those of the persons.

   Will associates (co-workers, friends, etc.) encourage and support use?
2. *Attitudinal*

   Do caregivers and the family have expectations and are expectations of the person different from those of the individual? Professionals?

   Will using this device be distracting to other persons? For example, frequent beeping or loud clicking from keyboard entry.
3. *Physical*

   Are all of the necessary physical supports in place for this person to access and use the planned technology? Do room settings need to be reorganized? Is adequate space available in the room? Is the lighting sufficient? Will the person need to be near an electrical outlet?

   Will the person require extra table/desk space for a device?
4. *Legislative/Political*

   Are the people in settings where AT/CST will be used familiar with all of the relevant legislation related to technology use?

   Are additional supportive/advocacy resources in the community needed?
5. *Economic*

   Does funding exist to appropriately provide the device and ongoing support?

   Is a plan in place to upgrade or replace technologies that are no longer suitable?

   Have additional supports and assistance been considered and are they available and affordable if needed?

c. ***The Technology***

A technology must be adapted to the individual's needs, preferences, characteristics, and resources; individuals should not have to adapt to a technology's features.

1. *Availability*

   Can the ATD it be obtained in a timely fashion?

   Will it need adjustment or setup?
2. *Appearance*

   How compatible is the technology with desired social activities?

   Does the person feel self-conscious using it? Around family? With friends? At work or school? Out in the community?
3. *Comfort*

   Does using the technology cause fatigue, strain, or pain?

   Is the technology easy for the person to use, transport, setup?

   Does the individual have a sense of security with use?

   Is the person emotionally and socially comfortable with use?
4. *Performance*

   Does the technology require considerable setup, maintenance?

   For those with rapid developmental changes, how easily and quickly can upgrades be obtained?

   What is the impact of climate on this technology? How does it function in high humidity, heat, or cold?

   If the technology needs to be portable, is it?

How durable is it and can it withstand a lot of wear and tear in going from place to place?

How compatible is it with other technologies and supports being used or being considered for use?

Is the person already using a device or number of devices, and will it interface well?

Is training needed in order for the person to use this device and maximize benefit? How much training? Who will provide the training?

5. *Cost*

How much does it cost and who will pay for it?

What are the relative advantages to purchasing, leasing, or renting the technology?

Are there effective alternatives that cost less?

Is the cost reasonable in light of the expected gains?

Can it be serviced locally or must it be shipped elsewhere?

d. ***<u>Cycle of Selection, Use, Evaluation, and Accommodation</u>***

Both the first and last steps in achieving a good match of person and technology are to conduct a thorough assessment of person, milieu/environments, and proposed technology attributes and properties. After training and a trial period of use in actual situations and natural settings, feedback should be sought on how well the technology is performing for that person and how the person has realized benefit from use. This is utilizing an *evidence-based* approach to technology evaluation and *measuring outcomes* of the technology as an integrated component of treatment.

1. *Technology selection*
    a. What is the most empowering choice for this person?
    b. Have the options been prioritized and has it been documented why one product or feature is preferable to another?
2. *Use*
    a. Has the technology been assembled and set up correctly?
    b. Does the person have changing needs that need to be considered and are adjustments in the technology possible?
    c. Have there been changes in the settings and environments of use?
3. *Evaluation*
    a. Has trial use occurred in the applicable settings and environments?
    b. Is the technology being used as intended?
4. *Accommodations*

Does the technology require customization or other adaptations to better match the person's needs and goals?

A series of assessment forms exist to help standardize the process of information gathering in the above domains [7, 8], but are necessary for the psychologist only occasionally included in assistive technology selection. There is also a trilogy of books impact of various categories of ATDs on people's health and life quality. Each book uses real-life situations to examine how technologies are being used to provide assistance for getting around, seeing and hearing, doing everyday tasks and thinking, remembering, and learning [5, 7, 9]. These books contain more questions like those previously mentioned.

Tips

- ***Don't forget the value of strategies and personal assistance.*** As helpful as ATDs are, they often work even better in tandem with strategies and help from others designed with the individual's lifestyle, routine, and preferences in mind. Help from others can provide an essential social link.

- ***Sometimes you can just plant seeds.*** AT practitioners and health care professionals acknowledge that people develop and change over time. A consumer who is not ready for technology use now may be ready in a few months. Professionals should raise the topic of ATD use again, when it appears the consumer may be more receptive to considering alternative approaches.

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Suggested Reading

AbleData: Website lists almost 40,000 different AT devices as well as other AT resources. www.AbleData.com

Assistive Technology Industry Association (ATIA): Website lists varied practical and educational resources. www.ATIA.org

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA): Website lists varied practical, legislative and educational resources. www.resna.org

40 Group Psychotherapy

David R. Topor and Kysa Christie

Topic

Group psychotherapy is a form of psychotherapy where a group of clients are treated together. Group psychotherapy has a number of distinct features that differ from individual psychotherapy. There are many types and variations of groups and group formats. Groups may be psycho-educational, self-help, skills based, relationship oriented, or supportive. Groups may consist of people diagnosed with a shared medical or mental health diagnosis or be open to people with any condition. Types of group psychotherapy include those that focus on psycho-education, families, cognitive and behavioral psychotherapy, and psychodynamic psychotherapy. Groups may have a leader, or co-leaders, and may be run from a number of different theoretical orientations including cognitive behavioral, interpersonal, or psychodynamic.

One of the main features of group psychotherapy is the experience of interacting with other people with a shared experience. Group therapists are able to integrate discussion of these interactions as part of the therapeutic intervention. Specifically, group therapists help group members identify and process the thoughts and emotions these interactions elicit.

A. ***Eleven primary factors that define the group therapy experience*** [1]
   1. **Installation of hope**

      Hope that the treatment will be effective is crucial to any successful psychotherapy. Providers should focus on the client's belief and confidence in the efficacy of the group throughout the course of the group. Further, group members are able to observe the improvement and hope of other group members, which can be regularly discussed as part of the group. Therapists must also believe in themselves and in the efficacy of their work and discuss this with the group. Self-help groups especially rely on the installation of hope.
   2. **Universality**

      Group psychotherapy helps clients appreciate that they are "not alone" in their experiences. For example, clients realize that other people have similar disabilities, emotions, and thoughts that they do. This realization helps to diminish stigma and shame and increase self-disclosure.
   3. **Imparting information**

      Groups serve to educate group members about their illnesses, medical conditions,

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_40

and symptoms, and convey information on effective treatment and coping strategies. Didactic instruction allows group members to learn factual information about their illnesses, to correct misconceptions about their conditions and treatments, and to understand treatment options and recommendations. Group members are able to provide advice to each other about symptom management and treatment, based on their own lived experiences.

4. **Altruism**

   Both giving and receiving help in therapy groups can increase a client's self-esteem and belief in their ability to help others. Clients with medical conditions may view themselves as burdens to others, and their ability to help other group members may shift this mind-set.

5. **The corrective recapitulations of the primary family group**

   Many people have difficulties in their relationships with family members. Group members may interact with each other and with the group leader(s) in a manner that reflects how they interact with family members. These resemblances allow group members to explore their interpersonal and family relationships and, as part of group therapy, learn new ways to interact with others.

6. **Development of socializing techniques**

   Group members can gain understanding and insight into their social skills and interpersonal relationships through direct and indirect ways in group psychotherapy. Group members can learn and practice specific social skills (i.e., being assertive) through instruction and/or experiential activities such as role-plays. Group members receive feedback on the manner in which they interact with others and learn more about how their communications are perceived by others.

7. **Imitative behavior**

   Group members may model their own behaviors based on their observations of the actions of the group leader(s) and of the other group members. This may allow group members to engage in patterns of behavior they see as effective.

8. **Interpersonal learning**

   Group members gain insight into the importance of their interpersonal relationships, learn new ways to handle emotional experiences, and learn new patterns of interacting with others. Group members may experience new emotions as a result of these interpersonal experiences and can process these emotions in the group. Further, group members can identify and discuss thought distortions they have when interacting with others. Finally, group members can identify and change maladaptive patterns in their interactions with others.

9. **Group cohesiveness**

   Group members are able to accept each other's experiences and emotions and form supportive and meaningful relationships with one another. Members may feel accepted and understood as a result. An increased sense of cohesion will likely lead to increased self-disclosure and stability of the group.

10. **Catharsis**

    Catharsis occurs when group members are able to freely express their emotional reactions in a safe and supportive environment. Members may be able to share personal details, without shame or guilt.

11. **Existential factors**

    Group members learn to make sense and to give meaning to their existence. They also learn to recognize that at times life is unfair and that each individual ultimately is responsible for their actions.

Importance

Group psychotherapy is frequently used in medical care and rehabilitation. Psychotherapy groups can address concerns that are specific to a particular illness or disability, as well as common concerns across medical conditions. Benefits include emotional support to clients and members of their family, psycho-education about medical conditions, learning coping skills particularly relevant to an illness or disability, as well as building motivation to sustain long-term changes in lifestyle and coping [2, 3].

Practical Applications

A. ***<u>Group topics: what to talk about</u>***

1. **<u>Shared experiences across illnesses in medical settings</u>** [3]
   - Understanding diagnosis and prognosis
   - Coping with treatment, medications, and side effects
   - Adjusting to lifestyle changes and new levels of functioning
   - Coping with changes in mood and energy
   - Navigating relationships with family, friends, coworkers, medical personnel
   - Existential issues: changes in identity, self-image, and priorities
   - Living with uncertainty
2. **<u>Unique experiences with a particular illness or injury</u>** [3]
   - ***Amputation***: pain, grief, changes in body- and self-image
   - ***Arthritis***: pain, loss of motoric functioning
   - ***Burn injuries***: body image, pain, and sleep problems
   - ***Cancer***: treatment side effects, fear of recurrence, fatigue, and body image
   - ***Chronic fatigue syndrome and fibromyalgia***: lack of medical and social support, lack of concrete diagnosis, and variable course of illness
   - ***Coronary artery disease***: stress, personality characteristics that may predispose, angina, loss of independence for a time, and the need to improve lifestyle behaviors
   - ***Multiple sclerosis***: progressive but unpredictable course of illness, fatigue, and motor and cognitive changes
   - ***Spinal cord injury***: stigma, the lack of accessibility, increased dependence on others, and pain
   - ***Stroke***: motor, speech and cognitive changes, and physical vulnerability
   - ***Traumatic brain injury***: invisible disability and cognitive and emotion regulation changes
3. **<u>Family support</u>**

   Finally, in addition to client-focused groups, family members can also benefit from groups as a source of support, education, and a way to develop new coping skills, as illness affects the entire family unit. Groups for family members may focus on caregiver stress and self-care, how to cope with distress about loved ones, and ways to strengthen communication strategies.

B. ***<u>Setting up a group: planning and participation</u>***

There are a number of considerations when using group psychotherapy as an intervention:

- **Appropriate physical space** must be identified, particularly a space with accommodations for clients with disabilities related to their medical condition.
- **Selection of group members** must be considered. That is, is a certain diagnosis required for group membership? What is the cognitive ability and insight needed for group membership?
- **Open or closed**. Groups may be open to new members on an on-going bases (open groups) or may be limited to people who join in the first week or two (closed groups).
- **Time limited**, with a predetermined number of sessions or **open ended**, with no specified end date.
- The **ideal number** of participants per group is about eight, although this can vary depending on the type and nature of the group.
- The **duration and frequency** of the group need to be specified before the group begins.

- **Assessments** that will be conducted as part of the group need to be identified. These might include assessments of change in symptoms or satisfaction with the group therapy.
- Will there be **one group therapist or co-therapists?** Either can be beneficial, and each approach has strengths and limitations. If there will be co-therapists, scheduling additional time to plan for the group, and process how the group is running, will be necessary.
- **Strategies to deal with difficult behaviors** in group should be thought of, and planned for, prior to the group. That is, what resources are available if a client becomes unsafe in group, if a client dominates the group discussion, and if a client does not actively participate during the group?

Tips

- Educate team members on the benefits of group psychotherapy. Ensure that all members of the interdisciplinary team are familiar with the benefits of group psychotherapy, the format of the groups being run, and the way to refer clients. Informational materials about the group may be helpful.
- Some clients may experience anxiety about participating in group psychotherapy. When discussing potential group membership with clients, identify that anxiety is a normal response when considering joining a group and normalize the experience.
- Reinforce a therapeutic, trusting milieu atmosphere in the group. Discuss ground rules of the group, including respectful behavior, consequences of tardiness or nonattendance, safety protocols, and expectations of confidentiality, at the beginning of the group. Discuss these expectations throughout the group, and explore if a group member does not abide by these expectations in a therapeutic manner, as needed.

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Part III

Assessment and Practical Intervention

Dementia

41

William Stiers and Jessica Strong

Topic

A. ***Definition of Dementia***

Dementia is a persistent or progressive neurologic syndrome that negatively affects cognitive functioning and leads to difficulties performing daily tasks involving self-care, household management, and social and community activities. Dementia involves problems with at least two cognitive functions and the inability to perform some daily tasks. Dementia is a condition lasting more than 6 months, not present since birth, and not caused by delirium, physical illness, mental illness, substance abuse, or medication effects.

So-called reversible dementias are not actually dementias, but rather are transient or modifiable factors affecting cognitive functioning. These include such things as:

- Meningitis or encephalitis
- Metabolic imbalances (thyroid, pituitary, adrenal, blood sugar, electrolytes)
- Organ failure (hepatic or renal encephalopathy)
- Medication effects
- Vitamin deficiency
- Cerebral vasculitis

Although these are usually reversible, some permanent changes may occur.

B. ***Types of Dementia***

The most common types of dementias are [1]:

Alzheimer's: 35 %
Vascular-Alzheimer's (mixed): 15 %
Vascular (pure): 10–20 %
Dementia with Lewy bodies: 15 %
Argyrophilic grain disease: 5–10 %
Frontal-temporal: 5 %
Parkinson's: 3–5 %

Other types of dementia have less than a 1 % prevalence rate.

Idiopathic dementias can be classified by the type of clinical presentation:

- Conditions that present with initial cognitive symptoms but not motor symptoms (the cortical dementias, such as Alzheimer's)
- Conditions that present with initial motor symptoms but not cognitive symptoms (the subcortical dementias, such as Parkinson's)
- Conditions that present with initial cognitive <u>and</u> motor symptoms (the Parkinson's plus dementias, such as dementia with Lewy bodies)

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_41

Idiopathic dementias can also be classified by type of protein error. For example:

- Alzheimer's disease is a *tauopathy* involving β-amyloid peptide-containing plaques and intraneuronal neurofibrillary tangles composed of hyperphosphorylated microtubule-associated protein tau.
- Parkinson's disease is a *synucleinopathy* involving the presence of Lewy bodies that are intraneuronal proteinaceous cytoplasmic inclusions with α-synuclein as a major protein component.
- Huntington's disease is a *polyglutamine disease* resulting from an expansion of the CAG codon that encodes glutamine, resulting in an accumulation of a mutant protein in large intranuclear inclusions.

Table 41.1 shows the common cognitive, neurologic, and psychiatric symptoms associated with these types of idiopathic degenerative dementias.

However, recent work suggests that the tauopathies and synucleinopathies have many similarities. For example, many patients with Alzheimer's disease (a tauopathy) have numerous Lewy bodies (composed of synuclein). In addition many patients with progressive supranuclear palsy and cortical-basilar degeneration (both tauopathies) exhibit extrapyramidal dysfunction as is seen in synucleinopathy-related Parkinson's disease. Patients with frontal-temporal dementia, which is a tauopathy, have also been shown to have synuclein-immunoreactive lesions [2]. In addition, although Alzheimer's disease is categorized in this schema as a tauopathy, recent findings show that this disease also involves independent Aβ amyloid deposits [3].

In addition to the idiopathic degenerative dementias described above, there are some additional genetic disorders that result in dementia, and these are listed below but will not be discussed in further detail here:

- Trinucleotide repeat disorders:
  - Fragile X syndrome
  - Fragile XE MR syndrome
  - Friedreich's ataxia
  - Myotonic dystrophy
  - Spinocerebellar ataxia types 8 and 12
- Polyglutamine diseases:
  - Spinocerebellar ataxia types 1, 2, 6, 7, 17
  - Machado-Joseph disease
  - Dentatorubral-pallidoluysian atrophy
  - Spinal and bulbar muscular atrophy, X-linked 1

There are also a number of other conditions that can lead to dementia, and these are listed below but will not be discussed in further detail here:

- Vascular dementia and vascular cognitive impairment:
  - Cerebral autosomal-dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL)
  - Multi-infarct dementia
  - Subcortical vascular dementia (white matter disease)
- Other diseases:
  - Transmissible spongiform encephalopathies (TSEs—prion diseases):
    - Creutzfeldt-Jakob disease (CJD)
    - Inherited genetic mutations
      - Fatal familial insomnia:
      - Gerstmann-Straussler-Scheinker disease
  - Autoimmune:
    - Multiple sclerosis
    - Systemic lupus erythematosus
    - Cerebral vasculitis
  - Wilson's disease (excessive copper buildup)
  - Brain tumor
  - Hydrocephalus:
    - "Normal pressure" hydrocephalus
    - Obstructive hydrocephalus
  - Metabolic disorders:
    - Mitochondrial disorders (over 50 subtypes)
    - Leukodystrophies (9 subtypes)
    - Lysosomal storage diseases (over 50 subtypes)
- Brain injury:
  - Trauma:
    - Traumatic brain injury

Table 41.1 Cognitive, neurologic, and psychiatric symptoms of idiopathic degenerative dementias classified by clinical presentation [3]

Dementia (brain area) (usual age of onset)	Protein error	Cognitive symptoms	Neurologic symptoms	Psychiatric symptoms
Cortical dementias (early onset cognitive not motor)				
Alzheimer's disease (temporal-parietal cortex) (>65 years)	Tauopathy	• Significant memory deficits: first episodic and recent memory, without benefit from cuing. Later remote memory deficits • Language: starts with word-finding difficulties, later impaired comprehension, and empty speech • Visual-spatial impairment with spatial confusion • Apraxia in the moderate stage • Difficulties with organization	• Motor symptoms only in later stages: extrapyramidal or Parkinsonian rigidity	• Apathy and depression in early stage • Delusions and agitation in middle stage with disinhibition
Frontal-temporal dementia (Pick's disease—frontal-temporal cortex) (50–60 years) • Frontal subtype (behavioral variant) • Temporal subtype (primary progressive aphasia) ○ Semantic dementia ○ Progressive nonfluent aphasia ○ Logopenic variant	Tauopathy	All • Memory is relatively preserved Frontal subtype • Executive and behavioral dysfunction Temporal subtype *Semantic dementia* • Receptive language problems, with poor comprehension and loss of word meaning • Fluent speech that is empty of content • May also have impaired naming • Preserved repetition • Prosopagnosia *Progressive nonfluent aphasia* • Expressive language problems, nonfluent • Impaired naming, phonemic paraphasias, agraphia • Impaired repetition • Preserved comprehension *Logopenic variant* • Paucity of output • Impaired naming • Impaired repetition • Slowed speech • Preserved word meaning and grammar • Phonological alexia (selective deficit in pseudo-word reading)	All • Can have Parkinsonism later in course of disease • Can have incontinence	All • Apathy • Loss of insight • Compulsive-like behavior, perseveration Frontal subtype • Early prominent social or interpersonal misconduct • Disinhibition Temporal subtype • Apathy, disinhibition *Semantic dementia* • Loss of empathy

(continued)

Table 41.1 (continued)

Dementia (brain area) (usual age of onset)	Protein error	Cognitive symptoms	Neurologic symptoms	Psychiatric symptoms
Posterior cortical atrophy (occipital cortex) (50–65 years)	Tauopathy	• Impaired visual-spatial processing • Visual agnosia and prosopagnosia • Impaired spatial navigation • Impaired praxis • Impaired reading and calculation • Possible transcortical sensory aphasia aphasia • Impaired ability to visually id entify and/or locate objects.	• Motor symptoms only in later stages: extrapyramidal or Parkinsonian rigidity	• Anxiety as a prominent symptom • Apathy and depression • Visual hallucinations and agitation in middle stage
Argyrophilic Grain disease (cingulate [limbic] cortex) (80–85 years)	Tauopathy	• Memory loss • Executive dysfunction • ADL and IADL dysfunction in excess of overall cognitive dysfunction	• Limbic system dysfunction	• Agitation, irritability • Depression • Delusions
Subcortical dementias (early onset motor not cognitive)				
Parkinson's disease (>65 years)	Synucleinopathy	• Dementia in 20–40 % with later stages of disease	• Parkinsonism: asymmetric tremor, bradykinesia, axial rigidity, gait abnormalities with small stride length, postural instability	• Hallucinations, delusions in 40 % in later stages (primary or related to treatment with dopaminergic agents)
		• Executive dysfunction	• Autonomic dysfunction, dysphagia later in course	• Depression in 40 %
		• Visuospatial deficits • Fluctuation of attention • Impaired memory recall aided by cues	• REM sleep behavior disorder	
Huntington's disease (35–45 years)	Polyglutamine disease	Cognitive problems may co-occur with motor and emotional symptoms (not entirely consistent with cortical/subcortical distinction)	• Involuntary jerking or writhing movements (chorea)	Emotional symptoms may co-occur with cognitive and motor symptoms (not entirely consistent with cortical/subcortical distinction)
		• Difficulties with executive functioning, word finding, and memory	• Muscle problems, such as rigidity or muscle contracture (dystonia)	• Depression
			• Slow or abnormal eye movements	• Irritability
			• Impaired gait, posture and balance • Dysarthria and dysphagia	• Obsessive-compulsive symptoms

(continued)

Table 41.1 (continued)

Dementia (brain area) (usual age of onset)	Protein error	Cognitive symptoms	Neurologic symptoms	Psychiatric symptoms
Parkinson's plus dementias (early onset cognitive and motor)				
Dementia with Lewy bodies (>65 years)	Synucleinopathy	• Fluctuating cognition, especially fluctuations in attention and alertness	• 70 % have Parkinsonism, including axial rigidity, bradykinesia, postural instability, gait abnormalities	• Psychiatric features in early stage
		• Transient disturbances of consciousness in 50–70 % may be mistaken for transient ischemic attacks	• Tremors less common than PD	• Especially visual hallucinations (usually colorful, often people and animals)—rarely happen early in other dementias
		• Deficits in executive function, memory, attention, and language	• Autonomic dysfunction with falls and syncope in up to one third	• Psychosis similar to Parkinson's disease with dementia but more common
			• REM sleep behavior disorder	• Also other hallucinations, delusions • 40 % have depression; similar to Parkinson's disease with dementia but more than in Alzheimer's disease
Multiple system atrophy (45–55 years)	Synucleinopathy	All	• Parkinsonism with axial rigidity, bradykinesia, postural instability, gait abnormalities	All
• Olivopontocerebellar atrophy (OPCA)		• Dementia uncommon	• Autonomic symptoms—urinary incontinence, postural hypotension, impotence, and syncope	• May have depression

(continued)

Table 41.1 (continued)

Dementia (brain area) (usual age of onset)	Protein error	Cognitive symptoms	Neurologic symptoms	Psychiatric symptoms
• Striatonigral degeneration (SND)		• Mild frontal-subcortical system dysfunction involving attention and executive deficits	• Ataxia	
• Shy-Drager syndrome (SDS)			• REM sleep behavior disorder	
			OPCA • Greater ataxia and less prominent Parkinsonism and autonomic dysfunction	
			SND • Prominent Parkinsonism and autonomic failure	
			SDS • Ataxia, Parkinsonism, and autonomic dysfunction	
Cortical-basilar degeneration (55–65 years)	Tauopathy	• Executive dysfunction	• Parkinsonism with bradykinesia, postural instability, gait abnormalities	• Depression common
		• Aphasia in over 50 %	• Asymmetric akinetic-rigid syndrome	• Anxiety, irritability, disinhibition
			• Asymmetric apraxia	
			• Alien limb phenomenon	
Progressive supranuclear palsy (45–75 years)	Tauopathy	• Subcortical pattern	• Parkinsonism with axial rigidity, bradykinesia, postural instability, gait abnormalities	• Early personality changes
		• Severe dementia is rare	• Vertical gaze palsy	• Pseudo-bulbar dysfunction (e.g., emotional incontinence)
		• May have prominent executive dysfunction	• Dystonia of facial muscles	• Irritability, apathy, disinhibition
			• Speech dysfunction	• Personality change frequent and early

(continued)

Table 41.1 (continued)

Dementia (brain area) (usual age of onset)	Protein error	Cognitive symptoms	Neurologic symptoms	Psychiatric symptoms
Parkinsonism dementia—amyotrophic lateral sclerosis complex (30–70 years)	Tauopathy	• Executive dysfunction • Bradyphrenia	• Axial rigidity, bradykinesia, without tremor • Muscle weakness of extremities, face, tongue • Impaired fine-motor coordination • Falls • Dysarthria and dysphagia • Spasticity and hyperreflexia	• Abulia-apathy • Hallucinations
Familial frontal-temporal dementia—amyotrophic lateral sclerosis complex (30–70 years)	Two subtypes: • TDP-43 proteinopathy • Protein C9orf72 error *These two subtypes are not well understood or differentiated*	Usually frontal/behavioral variant of FTD • Memory is relatively preserved • Prominent executive and behavioral dysfunction • May also have some language disturbance	• Axial rigidity, bradykinesia, without tremor • Muscle weakness of extremities, face, tongue • Impaired fine-motor coordination • Falls • Dysarthria and dysphagia • Spasticity and hyperreflexia • Pseudo-bulbar palsy (emotional behaviors without subjective emotional experience)	Usually frontal/behavioral variant of FTD • Apathy • Loss of insight • Compulsive-like behavior, perseveration • Social or interpersonal misconduct • Disinhibition

Adapted from Hickey C, Chisholm T, Passmore M, O'Brien J, Johnston J. Differentiating the dementias: revisiting synucleinopathies and tauopathies. Curr Alzheimer Res. 2008;5:52–60

    - Chronic traumatic encephalopathy
    - Epidural (extradural) hematoma
    - Subdural hematoma
  - Subarachnoid hemorrhage
  - Paraneoplastic syndromes
  - Hypoxia
  - Poisoning (heavy metals, organophosphates, many others)
  - Wernicke's encephalopathy related to B12 (thiamine) deficiency (in the USA, often related to chronic alcoholism; can also be related to dietary insufficiencies)
  - Korsakoff syndrome (persistent changes from Wernicke's encephalopathy)
- Infectious diseases:
  - Viral:
    - HIV
  - Bacterial:
    - Syphilis
  - Fungal

C. ***Diagnostic Nosology for Dementia***

1. **ICD-9**

   The International Classification of Diseases, Version 9 (ICD-9) [4] has multiple codes for dementia across multiple chapters, including infectious diseases, mental disorders, neurologic disorders, circulatory disorders, and general symptoms. However, the ICD-9 does not categorize dementias into subtypes based either on clinical presentation or protein error, provides no guidance into diagnostic criteria, and does not specify severity.

2. **DSM-5**

   The Diagnostic and Statistical Manual of Mental Disorders Version 5 (DSM-5) [5] has a chapter titled "Neurocognitive Disorders" that distinguishes mild neurocognitive disorder vs. major neurocognitive disorder.

   A mild neurocognitive disorder is defined as:

   - Evidence of modest cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual motor, or social cognition) based on:
     - ○ Concern of the individual, a knowledgeable informant, or the clinician that there has been a mild decline in cognitive function
     - ○ A modest impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment
   - The cognitive deficits do not interfere with independence in everyday activities (i.e., complex instrumental activities of daily living such as paying bills or managing medications are preserved, but greater effort, compensatory strategies, or accommodation may be required)

   A major neurocognitive disorder is defined as:

   - Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual motor, or social cognition) based on:
     - ○ Concerns of the individual, a knowledgeable informant, or the clinician that there has been a significant decline in cognitive function
     - ○ A substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment
   - The cognitive deficits interfere with independence in everyday activities (i.e., at a minimum, requiring assistance with complex instrumental activities of daily living such as paying bills or managing medications)

   Major and mild neurocognitive disorders are specified as with or without behavioral disturbance. Major neurocognitive disorders are also specified as mild, moderate, or severe.

   In both cases:

   - The cognitive deficits do not occur exclusively in the context of a delirium.
   - The cognitive deficits are not primarily attributable to another mental disorder (e.g., major depressive disorder, schizophrenia).

   DSM-5 lists ten of the most common subtypes of dementia and provides diagnostic criteria for them:

   - Alzheimer's disease
   - Frontotemporal lobar degeneration
   - Lewy body disease
   - Vascular disease
   - Traumatic brain injury
   - Substance/medication use
   - HIV infection
   - Prion disease
   - Parkinson's disease
   - Huntington's disease

D. ***Classification of Dementia Severity***

Morris [6] defined the Clinical Dementia Rating system:

- Stage 1: CDR-0—no impairment

  No significant memory problems, fully oriented, normal judgment and problem solving, normal community and vocational functioning, well-maintained home life and hobbies, fully capable of self-care
- Stage 2: CDR-0.5—questionable impairment

  Minor memory lapses, slight difficulty with time relationships, slight difficulty with problem solving and financial management, slight difficulties at work or with social activities, slight difficulties with home life and hobbies, fully capable of self-care
- Stage 3: CDR-1—mild impairment

  Moderate memory loss for recent events which interferes with daily activities, moderate difficulties in problem solving and managing financial affairs, unable to function independently at work and with community activities, cannot complete more difficult home tasks and hobbies, needs prompting for self-care
- Stage 4: CDR-2—moderate impairment

  Severe memory loss for recent events, disoriented to time and place, unable to solve problems and manage financial affairs, not able to function independently outside the home but can maintain appropriate behavior, can only do simple tasks at home, requires assistance with personal care
- Stage 5: CDR-3—severe impairment

  Severe memory loss for recent and remote events, disoriented to time and place, unable to solve simple problems, cannot maintain appropriate behavior, cannot do any tasks at home, is totally dependent for self-care, and often incontinent

Importance

A. ***Prevalence***

The prevalence of dementia is higher in women than in men and nearly doubles with every 5-year increase in age: 1 % in the group age 65–69 years, 3 % in the group age 70–74, 8 % in the group age 75–79, 12 % in the group age 80–84, 20 % in the group age 85–89, and 28 % at age 90 years and older [7]. An estimated 4.2 million adults in the United States and more than 135 million worldwide had dementia in 2010, based on a meta-analysis of epidemiologic studies. The economic impact of dementia, including unpaid care provided by families, is estimated at $159 billion to $215 billion per year in the United States and more than $600 billion worldwide [8].

Dementia incidence increases significantly at ages above 75, so the expected growth in the worldwide elderly population in the decades ahead (from about 600 million now to 1.5 billion in 2050) may lead to a tripling of dementia cases by 2050, assuming no new interventions to stop or slow the trajectory of cognitive decline. In addition, conditions such as obesity, hypertension, and diabetes, all of which are suspected to contribute to higher risks of dementia, have been increasing [8].

Rates of dementia in inpatient rehabilitation settings have been estimated to be around 22–25 % [9–12]. Dementia in rehabilitation inpatients is associated with approximately a threefold increase in negative outcomes, including increased length of stay (OR 2.74, 95 % CI 1.65–3.83, $P<0.001$) [11], increased walking dependence at discharge and at follow-up (OR 3.45, 95 % CI 2.39–4.97, $P<0.01$) [10], and increased institutionalization (OR 3.3, 95 % CI 2.1–5.3, $P<0.01$) [10].

B. ***Distribution***

Prevalence rates vary widely across world regions and across the United States, even after adjusting for age and sex differences. In the world, the highest prevalence rates are found in Western Europe, Australia, and North America, while lowest rates are found in Africa. Intermediate rates are found in Asia and South America [13]. In the USA, the highest prevalence rates are found in the South and Southeast (Texas, Arkansas, Mississippi, Alabama, Georgia, South Carolina), while the lowest rates are found in states in the North and West [14].

Practical Applications

A. ***Assessment***

It is important to accurately differentiate the presence of dementia vs. other factors which may affect cognitive functioning, including acute changes related to stroke, dehydration, protein or vitamin malnutrition, metabolic imbalances (thyroid, pituitary, adrenal, blood sugar, electrolytes), organ failure (hepatic or renal encephalopathy), medication effects, sleep disturbance, and other causes of delirium. It is often difficult in an inpatient rehabilitation setting to differentiate acute vs. chronic impairments, and history is the key to accurate diagnoses [15–17]. Idiopathic degenerative dementias have a characteristic time course of symptoms that are distinct from more acute or transient symptoms.

Key historical information for accurate diagnosis of dementia includes:

- The onset and course of changes in cognitive functioning
- Past neurological history including prior head injuries or other central nervous system insults (e.g., strokes, tumors, infections)
- History of alcohol and drug use
- Family history of dementia

Key current information for accurate diagnosis of dementia includes:

- Current psychiatric symptoms and significant life stressors
- Current prescription and over-the-counter medication use
- Current alcohol and drug use
- Consultation with medical staff regarding alternative diagnoses

These data are most accurately interpreted in the context of history of:

- Preexisting disabilities
- Educational and cultural background
- General medical and psychiatric history

In inpatient rehabilitation settings, cognitive screening measures are usually more appropriate than lengthy comprehensive neuropsychological assessments because of limits in patient tolerance, limits in time availability, potential confounding effects from medical conditions, and changes in patients over time. Cognitive screening tests include:

- Repeatable Battery for the Assessment of Neuropsychological Status [http://www.pearsonclinical.com/psychology/products/100000726/repeatable-battery-for-the-assessment-of-neuropsychological-status-update-rbans-update.html] which has alternate forms for test-retest
- Montreal Cognitive Assessment [http://www.mocatest.org] which has versions in over 50 different languages
- Cognitive Assessment Toolkit from the Alzheimer's Association [http://www.alz.org/documents_custom/the%20cognitive%20assessment%20toolkit%20copy_v1.pdf] which includes both a cognitive screening test as well as an 8-item informant interview with sensitivity of >0.84 and specificity of >0.80 for detection of dementia
- The Modified Mini-Mental State Examination, the Cognitive Abilities Screening Instrument, the Mini-Mental State Examination, the Short and Sweet Screening Instrument, the Short Test of Mental Status, and Addenbrooke's Cognitive Examination-Revised, which have been shown to have good sensitivity and specificity for all dementia types in unselected populations and which elicit information about key cognitive abilities which can then be compared with neuropsychological profiles in different types of dementia [18]
- Saint Louis University Mental Status Exam [http://aging.slu.edu/index.php?page=saint-louis-university-mental-status-slums-exam]
- Mattis Dementia Rating Scale-2 [http://www4.parinc.com/Products/Product.aspx?ProductID=DRS-2] which is especially useful for low-functioning patients

Alternatively, clinicians may choose an abbreviated neuropsychological battery using other independent measures of cognitive functioning examining:

- Attention (e.g., digit span and spatial span)
- Language processing (e.g., Boston Diagnostic Aphasia Exam, short form, assessing receptive language, expressive language, and repetition)
- Visual-spatial processing (e.g., clock drawing and figure copy)
- Memory (e.g., the Hopkins Verbal Learning Test and the Brief Visual Memory Test-Revised)
- Reasoning/problem solving (e.g., Cognitive Estimations Test, "what would you do if" scenarios)

B. ***Intervention***

Direct interventions with the patient can focus on:

- Promoting adequate hydration and nutrition. It is important to have regular times for meals and to limit snacks in between meals so as to allow sufficient time to become hungry. Regular times for fluid intake are also important, but sugared drinks and juices should be limited so as not to interfere with appetite. Eating is facilitated by social interaction, and so patients may eat better with company than they will alone.
- Providing frequent orientation to time using calendars and clocks and opening shades to allow direct perception of the time of day.
- Correcting sensory deficits (e.g., use of hearing and visual aids).
- Maintaining appropriate sleep cycles. Melatonin is a hormone that is essential for sleep. Melatonin signals both time of day (a "clock" function) and time of year (a "calendar" function) to all tissues of the body [19]. The optic chiasm sends input to the suprachiasmatic nucleus of the hypothalamus, which in response to environmental light/dark cycles regulates melatonin secretion by the pineal gland. Therefore, it is important to have maximum light exposure during the day and maximum darkness at night. Televisions, computers, and other self-luminous displays (tablets and phones) inhibit melatonin production at night and significantly disrupt sleep [20]. Noise at night should also be minimized. In some situations, ear plugs and visual masks at night may be helpful for sleep. In addition, regular times and routines for going to bed and awakening are important, as well as maintaining activity to avoid unregulated naps during the day. A scheduled nap of 20 min can provide some benefit; a scheduled nap of 90 min allows for one full sleep cycle. Naps beyond 90 min are likely to interfere with nighttime sleeping.
- Use of medication. The Food and Drug Administration has approved some pharmacological treatments for dementia. These include cholinesterase inhibitors (donepezil, galantamine, rivastigmine, tacrine) and a neuropeptide-modifying agent (memantine). A literature review [21] showed that all these medications were associated with statistically significant but not clinically meaningful improvements in cognitive functioning. In addition, there is no clear evidence that these medications are associated with delayed progression of cognitive deficits [http://archive.ahrq.gov/clinic/epcsums/demphsum2.htm]. They were also associated with side effects of diarrhea, nausea, and vomiting (Tacrine was found to have minimal beneficial effects and serious side effects including liver damage.) Additional pharmacological interventions for behavior management include antipsychotic medications; however, these increase the risk for significant negative outcomes (decreased cognitive functioning, decreased participation, tardive dyskinesia, malignant hypertension, increased risk for stroke, and heart attack). All sedating medications (such as antipsychotic and antianxiety agents) also inhibit recovery from brain damage, such as stroke.
- Balancing an individual's level of and desire for independence with concerns for

safety. It is important to maintain as much independence and participation in valued activities as possible. For many activities, there are modified or alternative options to explore if the medical team and individual can be flexible. For example, they may be able to participate in familiar activities such as cooking or household upkeep, but may need to participate as a helper under the direction of a family member. They may be able to make choices about activities, but in the context of an established daily schedule.

- Maintaining quality of life. For individuals who are less able to express their needs (moderate or severe stage of dementia), quality of life remains important. Care should include managing comorbid medical conditions (e.g., pain management) and efforts to maintain emotional and psychosocial quality of life. Efforts should be made to help the individual be involved in the community or enjoyable activities to the extent they desire and are able.

C. ***Consultation***

The symptoms that most distress caregivers are (measured on a 0 = "not at all" to 5 = "extremely" Likert scale) [22]:

- Delusions (M = 2.6, SD = 1.2)
- Agitation (M = 2.6, SD = 1.2)
- Irritability (M = 2.6, SD = 1.0)
- Anxiety (M = 2.4, SD = 1.0)
- Apathy (M = 2.4, SD = 1.1)
- Disinhibition (M = 2.3, SD = 1.3)
- Depression (M = 2.3, SD = 1.1)
- Sleep disturbance (M = 2.2, SD = 1.3)
- Aberrant motor behavior (M = 2.0, SD = 1.0)
- Hallucinations (M = 1.86, SD = 1.3)
- Decreased appetite (M = 1.8, SD = 1.2)
- Elation (M = 1.5, SD = 1.3)

It may be important to help caregivers develop and implement interventions for the following types of behaviors:

- Delusions—Common delusions include people stealing (due to misplacing or losing items related to memory loss or disorientation) or thinking that the caregiver is a stranger or an imposter. Interventions may include buying multiple copies of important items (e.g., glasses) or using a remote locator to track important items so that the individual can find them easily. Additionally, a caregiver could introduce him/herself regularly to help decrease confusion regarding roles.
- Hallucinations—Not all individuals find hallucinations distressing (e.g., conversing with a deceased loved one could provide comfort). Caregivers can carefully assess how disturbing hallucinations are and the extent to which they are related to sensory loss or deprivation. There may be place for intervention by correcting sensory losses (adjusting hearing aids or glasses prescriptions) as well as ensuring an appropriate level of sensory stimulation. For example, an individual who experiences seeing strangers in the yard may benefit from placing a curtain over the window where this most frequently occurs.
- Agitation or irritability—Caregivers can ensure that all needs are met (e.g., toileting, nutrition) and schedule times for each of these basic need to be addressed. An ABC (antecedent, behavior, consequence) analysis may help caregivers understand aspects of the behavior or the environment that contribute to agitation or irritability. Identifying temporal or geographic patterns in the behavior (e.g., in the gym, just before lunch, when the television is loud or the television program is fearful) may help identify how to treat it (e.g., remove individual to a quieter location during busy times, have a snack mid-morning). In addition, individuals with dementia may respond to reinforcement that is unintentionally given for disruptive behaviors (e.g., screaming or vocal disturbances leads to attention). Caregivers can practice reinforcing positive behaviors and ignoring agitated or irritable behaviors.
- Anxiety or depression—Behavioral activation is an effective tool to increase positive mood and reduce symptoms of depression. Caregivers could schedule positive activities

for the care recipient, for example, going to the salon, working in the garden, going for a walk, or listening to favorite music. Anxiety in individuals with dementia may stem from confusion or misunderstanding of the environment. Regular routine and structure that includes relaxing activities (e.g., hand massages, calming music, aromatherapy) may help reduce ongoing anxiety.

- Disinhibition—Similar to agitated/aggressive behaviors, an ABC analysis may reveal other ways to approach this behavior. Reinforcing appropriate behaviors may help decrease disinhibited behaviors. Caregiver education around disinhibition may also help the caregiver respond to the behavior differently. In response to disinhibited and impulsive behavior, rather than say, “That is inappropriate,” it may be better to say “Please do this” (keep a respectful distance, speak in a calm voice, wait for the food to be served, use the bathroom for personal needs).

Caregivers of individuals with dementia can suffer from grief, depression, and social isolation due to the physical and emotional demands placed on them. There are many local and national caregiver resources available, including caregiver respite programs, caregiver support groups, and caregiver education programs. Caregiver education regarding how dementia affects behavior is important in reducing caregivers’ distress at problematic behaviors—coming to understand that problematic behavior is a function of the disease rather than meanness or willful intransigence helps caregivers not to “take it personally” and maintain a problem-solving approach. In addition, caregiver satisfaction with life depends on continued involvement in valued activities, so caregivers should also be educated on the importance of maintaining these activities and of resources to help them do so.

Particularly in early stages of dementia, an individual can still be involved in planning their future care. Ensuring that an advanced directive or medical proxy document is in place, as well as any wishes for level of care as the disease progresses (e.g., nursing-home level of care sooner or staying at home as long as possible) can be expressed. Financial planning for the level of future care may be helpful as well.

Tips

- Sometimes in medical settings adults are diagnosed with dementia without a careful history having been taken. It is essential to get an accurate history from knowledgeable informants about the time course of the cognitive and motor difficulties and their order of appearance in order to reach an accurate diagnosis.
- Individuals with dementia function better in familiar environments and with usual routines, and the extent of their deficits may not be obvious at home. When they are admitted to the hospital, with its unfamiliar environment and routines, their deficits may become more obvious. Families sometimes misperceive that the condition has worsened, when in fact it has just been more clearly revealed.
- The majority of individuals who have dementia can continue to have a positive quality of life, even as the disease progresses. Even if an individual is confused or forgetful, they can still enjoy participating in activities that they have always enjoyed. It is important to allow adult independence, while also balancing safety risks.
- The person with dementia may benefit from becoming involved in activities during unstructured times, ranging from more simple tasks such as matching and folding socks or sorting nuts and bolts to looking at magazines or more complex tasks such as working on puzzles.
- Medications are often given for behavioral disturbance in lieu of staff time, although the latter is more effective and humane. To the extent possible, direct interaction to assist with orientation and help structure behavior in

positive ways is useful. Family members can also be recruited to provide companionship and structured activities.

- Psychologists working with dementia must become familiar with and able to competently perform basic motor examinations for Parkinsonian symptoms. There are a number of videos available showing Parkinsonian symptoms, including:

  https://www.youtube.com/watch?v=sJqKvajUC3k

  https://www.youtube.com/watch?v=kXMydlXQYpY

  https://www.youtube.com/watch?v=Be2Enu65ZE8

  https://www.youtube.com/watch?v=j86omOwx0Hk

  Psychologists wishing to increase their competency in examination for Parkinsonian symptoms may seek consultation from a physician familiar with these conditions.

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Depression and Anxiety Assessment

42

Nicole Schechter and Jacob A. Bentley

Topic

Generally speaking, psychological assessment may include many measures of human behavior, including a clinical interview with the patient, behavioral observations, data from the medical record, information from family members or loved ones, and data from norm-referenced tests. More specifically, depression and anxiety assessment refers to an evaluation process that uses a combination of standardized and nonstandardized measures to identify the presence, severity, and impact of symptoms of anxiety and depression. In order to understand the assessment of depression and anxiety, it is first imperative to have a general understanding of depression and anxiety symptoms.

A. ***Depression***

Depression, or major depressive episode, describes a period of low mood or decreased interest or pleasure in daily activities lasting at least 2 weeks, which represents a significant change from an individual's baseline mood and causes impairment in functioning in the social, occupational, and/or educational areas of life. In a rehabilitation setting, clinical depression can often be confused with adjustment difficulties or emotional distress related to adapting to a new illness, injury, and/or a new environment. Although there are additional differences in symptomatology, adjustment difficulties, as compared to major depressive disorder, are characterized by intermittent, nonpersistent periods of distress.

Specific symptoms of depression:

- Depressed mood or irritability lasting most of the day, nearly every day by patient report or observation of others
- Decreased interest or pleasure in most activities, most days
- 5 % weight change or notable change in appetite
- Change in sleep (hypersomnia, insomnia)
- Change in activity (psychomotor agitation or retardation)
- Fatigue or loss of energy
- Feelings of guilt or worthlessness
- Reduced concentration or indecisiveness
- Suicidal ideation

Definitions:

Hypersomnia: sleeping for excessive periods of time

Insomnia: prolonged inability to obtain sleep

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_42

Psychomotor agitation: observable increase in rate of often unintentional movements or thoughts

Psychomotor retardation: observable slowing down of movements, thoughts, and emotional reactions

Suicidal ideation: thoughts of killing oneself, sometimes accompanied by a plan of action or action itself

B. ***Anxiety***

Anxiety describes a future-oriented mood state associated with preparation for possible, negative events [1] that represents a significant change from an individual's baseline mood and causes impairment in functioning in the social, occupational, and/or educational areas of life. Anxiety also describes an acute feeling of apprehension or fear from the anticipation of a threatening or catastrophic event [2]. According to the American Psychological Association, anxiety is an emotion characterized by feelings of tension, worried thoughts, and physical changes. In a rehabilitation setting, some patients have long-standing challenges with anxiety and some have acute onset of anxiety due to an increase in stress and difficulties with adjustment. Acute anxiety in a rehabilitation setting is often related to anticipation of pain, anticipation of falling, anticipation of difficulties with discharge planning or environment and difficulty with sleep onset, and anticipation of new medical procedures or equipment.

Symptoms of anxiety:

- Excessive uneasiness, worry, and anticipation of negative events
- Recurring intrusive thoughts, often causing impairment in concentration
- Agitation and/or irritability
- Restlessness
- Muscle tension, increased heart rate, and sweating
- Sleep disturbance, often difficulty with sleep onset

Post-traumatic stress disorder (PTSD) is considered by the Diagnostic Statistical Manual—Fifth Edition (DSM-5) to fall within the category of trauma and stress-related disorders [3], whereas it was previously considered a type of anxiety disorder. This new description of the disorder also includes specifiers for involvement of dissociative symptoms (depersonalization or derealization) or delayed expression (full criteria not met until >6 months from event). Of note, PTSD cannot be diagnosed until 1 month after the traumatic event, so depending on the length of acute care hospital stay and length of inpatient rehabilitation facility stay, patients may meet criteria for acute stress disorder instead. Acute stress disorder describes the same symptom constellation occurring within 1 month of the trauma. Some rehabilitation patients with PTSD or acute stress disorder may experience poor sleep quality, discomfort with physical procedures, and decreased ability to participate in therapies in a busy rehabilitation gym. The diagnosis of PTSD will allow the rehabilitation team to adapt the patient's treatment environment to maximize recovery potential. Diagnostic criteria for PTSD are summarized below.

Symptoms of PTSD:

- Experience of a traumatic event, which now includes:
  - Direct exposure
  - Witnessing in person
  - Indirect learning of an intimate person's exposure to trauma (if death, must be accidental or violent)
  - Repeated or extreme indirect exposure to aversive events
- Symptoms of intrusion (i.e., nightmares, intrusive memories, physiological reactivity)
- Symptoms of avoidance (effortful avoidance of trauma-related stimuli)
- Negative alterations in cognition and mood (i.e., persistent negative beliefs about self or world, inability to remember details of the event, persistent distorted blame)
- Alterations in arousal and reactivity (i.e., hypervigilance, self-destructive behavior, sleep disturbance)
- Duration of >1 month
- Significant impairment in functioning
- Disturbance not due to substance abuse or another medical condition

Importance

Most individuals who face a condition requiring rehabilitation services will experience feelings of sadness, worry, nervousness, or fear to some degree. Though some individuals may experience these emotions intermittently or at a low level, others may experience them with such persistence and severity that their ability to function in day-to-day tasks is compromised. Depression, or major depressive disorder, and anxiety are two of the most prevalent mental health conditions experienced by individuals engaged in rehabilitation. Research suggests that patients who experience depression and anxiety have increased difficulties engaging in rehabilitation services, show less functional recovery over time, and have increased risk for secondary medical conditions and health problems [4].

A. ***Prevalence Rates***

Depression is one of the most commonly reported psychological conditions in rehabilitation populations. Though prevalence rates of depression are variable depending on the specific medical condition, 11–80 % of individuals engaged in rehabilitation report depression:

- Amputation: 33 % of persons after amputation [5]
- Stroke: 50–80 % of persons after stroke [6]
- Spinal cord injury (SCI): 11–30 % [7]
- Multiple sclerosis (MS): 50 % lifetime [8]

Anxiety prevalence in the rehabilitation population occurs at approximately the same rate as in the general population. For some patients with clinical conditions such as mild traumatic brain injury (TBI), amputation, and SCI, acute stress reactions and eventually PTSD are experienced:

- Stroke: 25 %
- Mild traumatic brain injury (TBI): 25 %
- SCI: 25 %
- MS: 30 % lifetime [9]

PTSD prevalence in the rehabilitation population appears to be somewhat higher than in the general population; however, specific rates of PTSD are variable depending on the specific medical condition. Regarding amputation, upper limb amputations are significantly more associated with PTSD than lower limb amputations, as upper limb amputations are more commonly traumatic in cause [10]. Due to impaired availability of traumatic memories secondary to disrupted consciousness in moderate and severe traumatic brain injury, there is some controversy over whether or not PTSD can develop in this subset of individuals. As well, there is significant overlap between symptoms of PTSD and symptoms of other anxiety and mood disorders experienced by rehabilitation populations, which makes the diagnosis of PTSD more complicated in this population:

- SCI: 7–17 % [11, 12]
- Amputation: 18 %
- Mild TBI: 3–27 % [13]

B. ***Relevance to Health Outcomes***

Depression symptoms and other health factors affected by depression often contribute to slowed rehabilitation progress:

- Pain experience can be exacerbated in patients with depression. That is, pain severity and frequency increases, often requiring higher doses of pain medications for effective management. This can cause drowsiness and reduced ability to engage in rehabilitation therapies, or if the pain is not well managed, the pain itself makes it difficult for the patient to tolerate therapies.
- Disturbed concentration makes it difficult for a patient to attend to rehabilitation tasks and reduces the likelihood for carryover from therapy session-to-session.
- Sleep disturbance can cause reduced energy and a decline in cognitive efficiency, contributing to difficulties following through with rehabilitation tasks, including exercises and other health behaviors.
- Irritability and/or low frustration tolerance can negatively impact a patient's relationships with therapists, medical providers, and loved ones. Withdrawal from social interactions may influence health behaviors such as adherence to an exercise program (if done in a group setting), substance use/abuse, attendance at medical appointments, and perceived sense of support.

Research shows that for certain clinical conditions, depression can have specific effects:

- Stroke: increased mortality, increased suicide rate, limited functional recovery, "increased use of medical services after discharge, and compromised social reintegration and quality of life" [6]
- Cardiac disease: increased rates of mortality, increased frequency of hospital readmissions, and increased frequency of emergency room visits [14, 15]
- Cancer: increased rates of mortality, receipt of non-definitive treatment, increased pain experience, and decreased perceived quality of life [16–18]
- SCI: longer hospital stays resulting in less functional independence and mobility [19], increased pressure sores, UTIs, increased use of paid attendants, and incurred increased overall medical costs

Practical Applications

Importantly, clinical depression and anxiety must be distinguished from feelings of sadness or grief and feelings of nervousness or worry, respectfully. Adjustment disorders with anxiety, with depressed mood, or with mixed anxiety and depressed mood are very common and are often situation appropriate for individuals in a rehabilitation setting. The differentiation between an adjustment disorder and a clinical depression or clinical anxiety is an important goal of assessment, as this will guide intervention implementation. The assessment of depression and anxiety involves the collection of information from multiple sources, using several different types of measurement. This process is dependent on the individual patient and his or her psychosocial circumstances and phase of rehabilitation. Assessment may include:

A. ***Clinical interview***

A clinical interview is defined as an interaction during which a provider observes, questions, and interacts with a patient in order to collect information to aid in making a diagnosis. In a rehabilitation setting, clinical interviews are conducted by every provider upon first meeting the patient. The use of open-ended questions during the clinical interview enables discussion of the patient's experience more so than close-ended forms of questioning. Important information for assessment of depression and anxiety includes:

1. **Premorbid mental health history**
    - ○ "What has been your experience with mental health challenges or treatment in the past?"
    - ○ "Have you ever had difficulties with depression or anxiety in the past?"
    - ○ "Have you ever been diagnosed with a mental health difficulty?"
    - ○ "Have you ever sought professional treatment for a mental health difficulty? Ever seen a psychologist? Psychotherapist? Psychiatrist?"
2. **Current feelings of sadness and nervousness**
    - ○ "How have you been feeling emotionally over the last few days?"
    - ○ (If reporting feelings of sadness or worry—ask about persistence) "When you have these feelings, how long do they last?"
3. **Current sleep and appetite (change from baseline?)**
    - ○ "How have you been sleeping in the last few days?"
    - ○ "How has your appetite been over the last few days?"
4. **Family mental health history**
    - ○ "How have mental health problems impacted your family members, if at all?"
5. **Substance use/abuse history**
    - ○ "Tell me about your use of alcohol (drugs, etc.) [in the past/currently]."
    - ○ "Before coming to the hospital, how often were you having a drink containing alcohol or using a drug in a way other than prescribed?"
    - ○ "How would you know if you were drinking/using too much?"

6. **Coping tools/strategies**
    - ○ "What helps you get through hard times?"
    - ○ "Tell me about the hardest challenge you've overcome in your past. What helped you overcome this challenge?"
    - ○ "What do you do to relax?"

B. ***Behavioral observations***

Behavioral observations are another way to glean information about a patient's current anxiety and depression. Behavioral observations can be made by any and all providers who interact with the patient. They are informative when collected by one provider during a time-limited interaction and can be even more valuable when collected by multiple observers at varying times. That is, behaviors that are observed consistently among observers and across times, or behaviors that are observed only by certain providers and/or at specific times, give important information about a person's interpersonal functioning, factors that will enhance or inhibit motivation, and, most importantly for this concern, their mental health functioning. Broad aspects of behavior to which a provider should attend include:

- Grooming—dress and hygiene
- Pain behaviors—shifting position, grimacing, sighing, labored breathing, facial expressions, and verbal expressions
- Thought process—ability to follow conversation and time for responses
- Thought content—hallucinations, delusions, paranoia, reactivity, catastrophizing, and perseveration
- Speech—rate, rhythm, and volume
- Orientation—alertness and awareness of surroundings and context
- Establishment of rapport—pace and guardedness
- Affect—defined as observable emotional expression, often seen in facial expressions, tearfulness, and body position
- Psychomotor—pace of movements and pace of thinking

C. ***Behavioral observations specific to depression and anxiety***

Specific behavioral observations that may indicate a patient is experiencing anxiety or depression are outlined below. Importantly, behavioral observations are specific to each individual and those outlined below are simply a guide:

- Grooming—Due to decreased energy and low motivation, patients with depression may have increased difficulty initiating and managing hygiene and grooming behaviors. Patients engaged in rehabilitation services may be physically limited and require assistance with grooming tasks, so it is important that providers differentiate between a patient's reduced desire to initiate in grooming tasks, which may be reflective of depression, and reduced ability or energy due to physical limitations.
- Thought process—Patients with anxiety or depression often have increased difficulty following conversation. Those with anxiety may be circumstantial in their thinking and require increased structure to stay organized. Patients with depression, due to a decline in the ability to concentrate, may take longer to respond to questions or have trouble following along.
- Thought content—Individuals with anxiety may be perseverative on a particular topic, especially future-based worries or present concerns. They may be increasingly reactive to changes in schedules, therapists, medications, and procedures. Individuals with anxiety or depression may have catastrophic thinking. Those with depression may be highly negative in their thought content and have difficulty discussing positive experiences, thoughts, or events.
- Speech—Individuals with anxiety may speak at an increased rate or with volume of speech that is outside normal limits (either decreased or increased). Individuals with depression may speak with decreased volume.
- Establishment of rapport—Slow establishment of rapport and/or hesitancy to interact or share information are behaviors attributable to a number of factors, only two of which are anxiety or depression.
- Affect—Patients with depression may show restricted or flat range or blunted

intensity of emotionality. They may show reduced or inappropriate eye contact during interactions. Patients with anxiety may show an increased range or intensity of emotionality.

- Psychomotor—Individuals with depression may show psychomotor slowing or agitation.

D. ***Standardized measures of depression and anxiety***

Standardized measures are a vital component of the assessment of anxiety and depression. When using tests that are standardized, clinicians are able to compare a patient's score to scores of a large group of individuals on which the test was normed. In many cases, tests of psychological variables are normed on a large sample of individuals from the general population. At times, tests of psychological variables are normed on a sample of individuals from a psychiatric population or, in this particular case, a specific clinical population, such as individuals with spinal cord injury or individuals with stroke. Nearly all of the measures used to assess depression and anxiety are based on patient self-report. Patients' responses are compared to responses from a group of individuals with a particular medical condition or the general population. This comparison provides information regarding the individual's experience of depression and anxiety.

There is some overlap between symptoms of depression and anxiety and symptoms of physical conditions or medical problems. Therefore, when assessing patients in a rehabilitation setting, clinicians must avoid overinterpreting results of tests that have not been normed on rehabilitation populations in particular. Table 42.1 lists a number of measures of depression and anxiety that are appropriate to use with rehabilitation populations.

This section has described the multiple components of depression and anxiety assessment. The chart below is intended for use as a guide or decision tree for non-psychologist providers working in a rehabilitation setting.

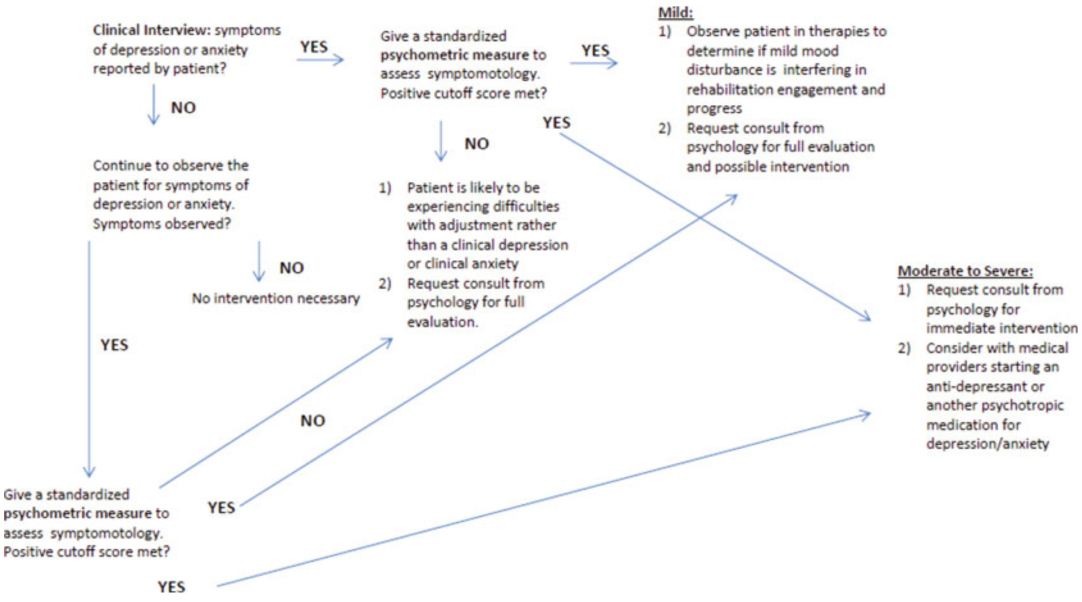

Table 42.1 Standardized measures of anxiety and depression

Test name	Anxiety or depression	Required training	Length of time	Reliability and validity	Population	Reference
Beck Depression Inventory (BDI-II)	Depression	None	<5 min	Reliability $\alpha=0.81$–0.92 Validity $r=0.56$–0.83	Adults	[20]
Center for Epidemiological Studies Depression Scale (CES-D)	Depression	Reading an article and manual	6–30 min	Reliability $\alpha=0.64$–0.91 Validity $r=0.55$–0.82	Adults	[21]
Geriatric Depression Scale (GDS)	Depression	None	6–30 min	Reliability $\alpha=0.75$–0.99 Validity $r=0.69$–0.96	Geriatrics	[22]
Hospital Anxiety and Depression Scale (HADS)	Depression and anxiety	None	<5 min	Reliability $\alpha=0.70$–0.90 Validity $r=0.44$–0.73	Adults	[23]
Patient Health Questionnaire (PHQ-4) for anxiety and depression	Depression and anxiety	None	<5 min	Reliability $\alpha=0.62$–0.82 Validity $r=0.52$–0.79	Adults	[24]
Patient Health Questionnaire (PHQ-9)	Depression	None	<5 min	Reliability $\alpha=0.79$–0.90 Validity $r=0.52$–0.79	Adults	[25]
Beck Anxiety Inventory (BAI)	Anxiety	None	<5 min	Reliability $\alpha=0.73$–0.94 Validity $r=0.51$–0.73	Adults	[26]
Generalized anxiety disorder—seven item (GAD-7)	Anxiety	None	<5 min	Reliability $\alpha=0.73$–0.94 Validity $r=0.51$–0.73	Adults	[27]
PTSD checklist (PCL)	PTSD	None	6–10 min	Reliability $\alpha=0.85$–0.94 Validity $r\geq 0.75$	Adults	[28]
Primary care PTSD screen	PTSD	None	<5 min	Reliability $\alpha=0.82$–0.85 Validity $r=0.89$	Adults	[29]

Tips

- Individuals who are in a rehabilitation setting are likely to experience feelings of sadness, nervousness, or grief. This is within normal limits, considering many of them have recently experienced something that is new, scary, concerning, or life changing. These kinds of emotional adjustment challenges must be differentiated from a clinical anxiety or depression, as this will impact what kinds of interventions are utilized.

- A diagnosis of anxiety or depression should not come from one mode of assessment alone. Utilize multiple measures (interview, behavioral observations, standardized tests) to determine whether or not an individual is experiencing significant anxiety or depression.
- When assessing individuals in a rehabilitation setting, it is imperative that the patient is assessed in a variety of environments (PT, OT room, during a medical procedure) and by a variety of individuals. Someone who is tearful during one session of PT but has a positive mood through the rest of the day is likely not to be depressed but may be mislabeled as such if observed at only one time point.
- Be careful in choosing psychometrics. Many tests that are used to assess for anxiety and/or depression in the general population or a psychiatric population will have skewed results in a rehabilitation setting. This occurs because many patients will report somatic symptoms of anxiety or depression that are likely to be more related to physical problems or somatic symptoms related to physical or environmental difficulties (i.e., an individual may meet the criteria for a sleep disturbance, but rather than this symptom being a result of depression, it is a result of a hospital environment in which their sleep is interrupted throughout the night to take labs).

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Cognitive Screening

43

Terrie Price and Bruce Caplan

Topic

Cognitive screening aims to obtain a broad—yet admittedly shallow—understanding of an individual's higher cortical functioning. This type of limited evaluation may be necessary due to such factors as the individual's health, physical needs, pain, fatigue, sensory impairment, interruptions and environmental distractions, and time constraints, all of which can affect the reliability and validity of results.

Importance

A. ***Intensive Care and Other Acute Hospital Units***
Many screenings occur in intensive care and other acute hospital units for patients being evaluated for rehabilitation potential. The findings of cognitive screening may highlight neurocognitive domains of deficit that warrant further examination and suggest potentially effective interventions based on areas identified as relatively intact. However, as Larner [1] states, "Cognitive screening instruments are not equivalent to a neuropsychological assessment administered by a clinical neuropsychologist, which remains the gold standard for cognitive assessment" (p. 5). This is not to demean the value of screening, a common practice of clinicians throughout health care. Nonetheless, given the brevity of screenings, the likelihood of false positives and false negatives must be kept in mind. More detailed, reliable, and informative testing will likely need to be deferred until the patient's transfer to the rehabilitation unit, by which time the impact on test performance of at least some of the above-noted factors ought to have declined.

B. ***Rehabilitation Settings***
In requested, the majority of diseases and injuries treated (e.g., traumatic brain injury, stroke, brain tumor, multiple sclerosis) have cognitive consequences. However, many conditions not previously thought to be accompanied by cognitive decline (even peripheral vascular disease) have also been shown to affect higher cortical functions [2, 3]. Thus, cognitive screening may be frequently requested.

C. ***Reasons for Cognitive Screening***
For most individuals, because a diagnosis will have been established by the time of transfer to rehabilitation, staff may have

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_43

certain expectations about the individual's cognitive functioning based on what is known about the "neuropsychological signature" of the condition(s). However, referrals for cognitive screening occasionally involve a request for assistance with differential diagnosis, such as confusion in a senior adult that could reflect age-related cognitive changes, evolving dementia, sleep disturbance, novelty of the hospital environment, or medication side effects.

D. ***Decision-Making Capacity***

Assessment of decision-making capacity is not addressed in this chapter as this is an issue which cannot be adequately addressed by brief cognitive testing. While a cognitive screening instrument might be a component of such an evaluation, it is not sufficient; thus, the evaluator should be knowledgeable about their state requirements and ethical guidelines.

Practical Applications

A. ***Test Content and Selection***

Although some [4] have suggested using single measures, most cognitive screening tests assess multiple domains including orientation, simple attention (e.g., digit repetition), short-term memory, spatial construction (drawing a clock face or geometric design), and verbal comprehension and expression. Some instruments also include tasks requiring delayed memory (an area of particular importance in rehabilitation where therapeutic success relies substantially on the patient's capacity to learn and recall)[1] and executive functions. Although not usually construed as a "cognitive" area, formal assessment of emotional status is typically presumed to be the psychologist's responsibility, although valuable observations can be obtained from other staff members. While speech therapists and/or occupational therapists may have initiated screening of certain cognitive abilities (e.g., expressive language, visual-perceptual skills), requests are often directed to a neuropsychologist or rehabilitation psychologist for assessment of memory, problem-solving, and executive abilities to provide broader and deeper understanding of the case at hand.

In selecting an instrument, consideration should be given to patient limitations (e.g., hemiparesis; visual field cut, aphasia) that might impede task completion or, at a minimum, introduce "noise" because of factors irrelevant to the skills or functions the test purports to assess.[2] In recognition of these possible extraneous influences, some judicious use of nonstandard techniques based on the notion of "reasonable accommodation" may be indicated (see [6, 7]); in such instances, the examiner should justify and describe the modifications and note the risk in using conventional normative data bases for comparison and interpretation.

The choice of instruments should take into account the measure's positive and negative predictive power, reliability, validity, sensitivity and specificity. Lezak et al. (2012, p. 127) describe the latter factors as follows: "The sensitivity of a test is the proportion of people with the target disorder who have a positive result" (i.e., the probability of correctly identifying a true instance of the specific disorder). "Specificity is the proportion of people without the target disorder whose test scores fall within the normal range; this proportion is useful for confirming a disorder" (i.e., the probability of correctly identifying a "true negative"). Positive predictive power is the likelihood that an examinee who earns a "positive" score (in this scenario, one who falls in the "impaired" range) truly has

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[1] Note, however, that learning and retaining verbal material such as story content or word lists differs from the "procedural learning" required in physical and occupational therapies.

[2] However, some studies have shown little intermanual difference in performance of such tasks as the Trail Making Test, suggesting that useful data may be obtained from persons with hemiplegia who use their unaffected (even if nondominant) hand (e.g., [5]).

the condition in question, while negative predictive power reflects the probability that an individual who scores in the "unimpaired" range does not have the condition.

B. ***Utility of findings***

The obtained test data are typically interpreted with reference to available applicable normative data bases (except as noted above)—in light of factors that can affect test performance (e.g., age, educational/vocational history, preexisting health conditions, alcohol and substance use, depression)—and estimated premorbid level, against which current findings are compared to gauge degree of change. Comparisons are also made with findings of other pertinent specialties (e.g., speech therapy, occupational therapy) to determine consistency or variability of performance.

Cognitive screening may provide insight into the cortical basis of behaviors interfering with rehabilitation. Consider, for example, a middle-aged individual who exhibits aggressive behavior following repair of a ruptured cerebral aneurysm. Belligerence, emotional lability, and other erratic behaviors can be incongruent or exaggerated responses to a benign situation. Understanding the neural origin of emotional disinhibition and anger can prove critical in developing management strategies. Cognitive screening may uncover an immediate memory deficit that, coupled with impaired reasoning, leads the individual to misconstrue therapists' instructions, fostering frustration and behavioral outbursts. The rehabilitation psychologist can help staff appreciate that the individual's emotional response derives from their injured brain's (mis)interpretation and inability to modulate their behavior. Such insight helps prevent unjustified negative labeling of patients as "difficult" or "hateful" [8, 9].

The characteristics of several common cognitive screening instruments are displayed in Tables 43.1 and 43.2. Interested readers should consult Larner [1] and Lezak et al. [10], Chaps 9 and 18, for detailed treatments of these and other screening measures.

While most of the above tests offer adequate reliability and validity, the majority are affected by education in that adults with less education tend to score lower than better-educated same-age peers, increasing the potential of false positive findings and warranting caution in interpretation. Education history has a greater impact on language-based tasks.

Tips

A. ***Before screening***

First, clarify the referral question(s). While the referral may originate from a physician (or be automatic in some settings), interview of the medical rehabilitation team members and nursing staff can help to clarify and specify the question(s), concerns and desired information. Through record review, identify patient variables pertinent to test selection (e.g., diagnosis, age, education, sensory difficulties, cultural background and language, medical/psychiatric history, vocational status, frustration tolerance). Determine what, if any, cognitive tests have been given by other team members.

B. ***Conducting the screening***

If possible, identify a quiet location or, if the patient cannot be moved, inform staff that you will need a short period of uninterrupted time with the door closed. This will help to elicit the individual's best performance.

Introduce yourself to the patient and family (if the latter are present) and explain your role. Describe the purpose of assessment and how the information will be used. Discuss confidentiality and the limits on same. Ask for and obtain consent from the patient, if possible, or from a qualified surrogate, if circumstances warrant. Interview the patient to confirm/refute demographic, medical, and neurobehavioral information obtained from chart review. Determine their understanding of and interpretation of the impact of their injury or illness. Gauge the patient's endurance, motivation, and insight.

Table 43.1 General brief screening batteries

Test	Montreal cognitive assessment (MoCA) [11]	Mini mental status exam (MMSE) [12] Modified MMSE (3MSE) [13]	Repeatable battery for assessment of neuropsychological status (RBANS) [14]	Dementia rating scale 2 (DRS2) [15]	Cognistat assessment system (formerly called Neurobehavioral cognitive status examination) [16]	Brief cognitive status exam of WMSIV (BCSE) [17]	Neuropsychological assessment battery (NAB) screening module [18]
Response	Verbal, writing, drawing	Verbal, writing, drawing	Verbal, writing, drawing	Verbal, drawing, hand movements	Verbal, drawing, writing	Verbal, drawing	Verbal, hand movement, drawing
Assessment target	MCI, CVA, Alzheimer's, vascular dementia, substance abuse	MCI, dementia, stroke	Brain injury, concussion, dementia, stroke, substance abuse	Dementia	MCI, dementia, stroke	Screens significant cognitive impairment	Adults-severely impaired to intact
Time to administer	10 min	8–20 min	25–30 min	20–30 min	10–30 min	5–10 min	45 min
Cognitive domains	VC, Mem, Attn, VF, Abst, Nm, Or, CD	Orientation, Attn, Nm, VC, Calc, Rep	Attn, Mem, Lang, VC, VF, perseveration	Attn, Lang, Mem, VC, Abst	Attn, Lang, Mem, VC, Abst	Orientation, VC, speed, mental control, CD, Nm, Ri, VF	Attention, language, memory, spatial, executive
Cut-off score	>26/30 = nml	=/>26/30 3MSE >75	By age	By age	Uses a "screen and metric" format with cut-offs for each area	Ave, low ave, borderline, low, very low	Standard scores and %ile
Age range	>50	18–85 3MSE + 65	20–89	≥55	Adol-96	16–90	18–97
Sensitivity/ specificity	83–92 % Improved: <23	76–84 % 18–23 (mild imprmt)	Strong for MCI, cognitive screen	<123 Total score—83 % Alz and Vasc Dem	Ave, mild, mod, severe levels	Borderline and higher not likely to have cognitive impairments	0.95/44-/75 for mod-severe
Considerations	Multiple English language versions; French version. Correlates with certain neuropsychological tests	Age, education, and cultural effects	Individual subtest scores available by age (see [10], p. 759); parallel forms	Mayo older adult norms, age and education effects	Stand alone domain scores available		

Abst abstraction, *Attn* attention, *Calc* calculation, *CD* clock drawing, *MCI* mild cognitive impairment, *Mem* memory, *Nm* naming, *Or* orientation, *Rep* repetition, *Ri* response inhibition, *VC* visual construction, *VF* verbal fluency

Table 43.2 Orientation assessment

Test	Galveston orientation and amnesia test (GOAT) [19]	Orientation Log (O-Log) [20]	Cognitive Log (Cog-Log) [21]	Confusion assessment method for the ICU (CAM-ICU) [22]
Response style	Verbal	Verbal	Verbal, hand movement	Yes/no
Assessment target	TBI	TBI, CVA, anoxia	TBI, CVA, anoxia	Adults
Time to administer	5 min	10 items 5 min	10 items 7–10 min	2 min
Cut-off score	≥75/100 (nml)	>24/30	≥25	>0 = altered mental status
Considerations	Strong association with injury severity Can modify for aphasia % vented patients	Cues allowed. Useful for serial assessment. Correlates with certain neuropsychological tests	Use with O-Log of >15. Useful for serial assessment. Correlates with certain neuropsychological tests	Assessment of delirium in ICU setting

The essential cognitive domains to be addressed are listed above. During testing, be cognizant of signs of distractibility, fatigue, pain, or failure to comprehend task instructions. End with praise for the individual's effort.

C. ***After screening***

Enter the findings in the chart using terms likely to be familiar to team members, and attend team meetings to clarify findings and implications and answer questions.. Note your impression of the reliability and validity of the results. Offer suggestions for treatment strategies. Meet with the patient and family to discuss the results and possible implications with due attention to limitations.

D. ***Caveats and Encouragements***

1. **Don't over-reach with your data**—acknowledge the inferential and interpretive limitations of screening results. Screenings likely involve individuals with acute conditions that can diminish performance. Furthermore, test performances are multiply determined, and low scores can reflect many factors, some of which may be transient. Nonetheless, a set of scores that comports with established neuropsychological patterns may permit stronger inferences, therefore…
2. **Look for coherence in the data**—i.e., internal consistency and congruence with what is known about the cognitive consequences of the medical condition and functional status. Inconsistencies may result from attentional fluctuation (which could itself be caused by fatigue or pain) or variable effort, among other factors. Unexpected results need to be explained.
3. **Identify both weaknesses AND preserved functions.** The former may guide therapists in targeting impaired skills while the latter may suggest relatively intact abilities that can be capitalized upon.
4. **Recommendations should be clearly stated, feasible and functionally relevant** so as to: (a) foster understanding of the individual's functional status and coping skills, (b) promote the individual's ability to profit from rehabilitation, and (c) be understood by those who will use the data.
5. **Recognize that your results reflect a certain point in time** and that recommendations may well require revision as changes occur in the individual's condition.
6. **Help the treating team grasp how the person's cognitive status affects their behavior** as well as their interpretation of the illness/injury/disease and understanding of treatment goals.

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Pain

44

Philip Ullrich

Topic

Pain is a complex, treatment-resistant condition with negative impact on functioning and well-being. Unfortunately, pain is also common enough to be an expected complaint among most populations treated by rehabilitation psychologists.

A. ***What is Pain?***

Pain is a biopsychosocial phenomenon. It involves the nerve signals triggered by injury (nociception) that travel from the point of injury to the brain, as well as the subjective suffering brought on by pain, and the pain behaviors that influence the social environment [1]. A broad biopsychosocial model of pain recognizes the complex, bidirectional interactions among physical, psychological, and social factors that cause and maintain the pain experience [2]. Specifically, pain has origins in biological nociceptive and hypothalamic–pituitary–adrenal axis activity, with immediate perceptual and emotional reactions that are influenced by cognitive processes [3]. Pain-related cognitions can then provoke emotional and behavioral reactions that aggravate pain, distress, and disability [3].

B. ***Important Definitions***

1. **Acute pain versus chronic pain**

   Acute pain arises from current damage to the body. Chronic pain is typically defined simply by duration, i.e., pain present for more than 3 months. Chronic pain is considered to be the product of repeated episodes of acute pain, and is likely to have bidirectional relationships with psychosocial factors.

2. **Musculoskeletal versus neuropathic pain**

   Musculoskeletal pain is due to damage to tissue or bone. In contrast, neuropathic pain is due to nervous system damage or disease.

Importance

A. ***Pain is Common***

Many individuals seen by rehabilitation psychologists will experience clinically significant pain throughout their lives. About 58 % of persons with traumatic brain injury (TBI) report pain concerns, with the prevalence rates being higher among those with mild (75 %) versus moderate or severe (32 %) TBI [4]. Among patients with TBI plus additional disabling injuries (e.g., burns, amputation, spinal cord injury (SCI)) the prevalence

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_44

of significant pain may be over 80 % [5]. Headache pain is, of course, experienced after TBI but most patients with these conditions report multiple pain problems, especially shoulder pain [6]. Pain problems can worsen over time among persons with TBI [6]. Over 75 % of patients with SCI report some pain, with severe, disabling pain conditions occurring in about one-third of persons with SCI [7]. Musculoskeletal pain is the most common variety of pain after SCI, but neuropathic pain tends to be the most severe [8, 9]. Longitudinal studies show that pain conditions after SCI are likely to assume a chronic course [9–11] with a chance of worsening over time in spite of active treatments [12, 13]. Similarly, Over 60 % of patients with MS experience pain and pain conditions have been shown to endure or worsen over time as the disease progresses [14, 15]. Pain is one of the most common complications to follow stroke [16, 17].

B. ***Pain Negatively Impacts Function***

Pain problems aggravate and amplify the functional difficulties experienced by patients with disabling conditions, from the time of inpatient rehabilitation to long after an acute injury. Pain has been shown to reduce the frequency of rehabilitation therapies [18] and is the most frequently cited factor complicating rehabilitation treatments; more than fatigue, spasticity, or other medical complications [19]. Pain interferes with daily activities and work roles among numerous populations with physical impairments [16, 20–22]. Among survivors of burn injury, 66–75 % report pain interference with work and other functional activities years after initial injury [23].

C. ***Pain is Associated with High Levels of Psychological Distress***

Robust positive associations between pain, psychological distress, and functional disability are very well-documented in many medical populations [24–26]. Studies in rehabilitation settings have found pain and depression to co-occur among 19–27 % of patients [12, 27, 28]. In some studies, co-occurrence rates are elevated such that patients experiencing co-occurring pain and psychological distress outnumber those with individual syndromes [5, 27, 29, 30]. Pain and distress levels tend to be more severe and enduring when conditions co-occur [12, 25]. Also, co-occurring conditions are more resistant to treatment and have additive negative effects on functioning [25].

Practical Applications

A. ***Pain Assessment***

Basic principles:

- Pain assessment should progress sequentially from basic screening, to assessment of biopsychosocial aspects of pain, to more detailed analysis, as determined by the practice environment and the apparent importance of the pain problem [31].
- Most people with physical disability have numerous pain problems; three or more on average [32, 33]. If numerous pain problems exist then the worst three pain problems should be assessed.
- Use consistent, standardized assessment. Consider time of measurement, measurement approach, and use of medication when conducting and interpreting pain assessments.
- How you assess pain helps establish your patients' pain "point-of-view", an important foundation of any treatment.

1. **Pain screening: Intensity and interference**

Pain presence and intensity should be screened with the 0–10 Numerical Rating Scale (NRS): "On a scale from zero to ten where zero means no pain and 10 means the worst possible pain, what is your current pain level?" Pain levels are classified as follows: mild (1–3), moderate (4–7), and severe (8–10). Pain levels of 4 or greater are generally considered to indicate need for additional assessment and likely treatment [34, 35]. Wording of the NRS can be altered to cover pain averaged over a time period, e.g., "the past week", and to understand "least" and "worst" pains over a specified time period. A "Faces" pain scale provides pain intensity measurement equivalent to NRS among persons with cognitive impairment [36].

Pain interference should also be screened with a NRS: "On a scale from zero to ten where zero means did not interfere and 10 means completely interfered, how much has pain interfered with activities in the past week?"

2. **Detailed assessment**

When clinically significant pain is detected through screening then subsequent pain assessment should include a pain interview, a multidimensional pain measure, and measures of psychological distress. In addition to quantifying the pain experience, these assessments help clarify the environmental, cognitive, emotional, and behavioral variables that can be targeted for treatment [37]. Environment assessment should help understand the reinforcers and punishers of pain and wellness behaviors. For example, functional analysis can identify the antecedents and consequences of pain, e.g., social responses, avoidance, de-activation. Behaviors such as guarding, resting, asking for assistance, and task persistence are important to assess. In terms of cognitive variables, beliefs about pain and self-efficacy for pain self-management should be assessed. Cognitive reactions and coping strategies should also be understood, for example, focusing on or ignoring pain, rumination, catastrophizing, and acceptance.

(a) *Pain interview*

A detailed pain interview is vital for understanding the patient's pain experience and pain-related features of the environment. The interview should address pain features such as location, distribution, descriptive qualities, temporal trends, and duration. Circumstances of pain onset should also be understood: when does pain occur and under what conditions? What makes pain worse or better? For example, movement, heat, cold, pressure, stress, social factors, and/or mood?

(b) *Multidimensional pain measures*

A multidimensional pain measure should be used to quantify psychosocial aspects of the pain experience. The following readily-available pain measures have good empirical records of reliability and validity in numerous populations, while also being brief and easy to use:

- The Short Form McGill Pain Questionnaire [38] is a 17-item measure involving descriptive pain words that patients rate in terms of severity. The measure yields sensory, affective, and total scales of pain intensity and interference.
- The West Haven-Yale Multidimensional Pain Inventory (WHYMPI/MPI) [39] is a 52-item scale that yields the following scales: intensity, interference, negative affect, control, social support, social responses, and activities. The MPI has also been adapted for patients with SCI [40].
- The Brief Pain Inventory (BPI) [41] is a 36-item measure that yields pain intensity and pain interference scales. The measure also provides information on location of pain, pain medications and amount of pain. The BPI includes a diagram that is used to mark areas of pain on the body.
- The Pain Outcomes Questionnaire-VA (POQ-VA) [42] is a set of pain measures designed to be used at various stages of pain treatment: intake (45 items), post-treatment (28 items), and follow-up (36 items). The POQ-VA was developed specifically to be a comprehensive pain outcomes measure assessing all pain-related domains of functioning identified by the Rehabilitation Accreditation Commission [43]. Its scales include pain intensity, pain interference, negative affect, activity level, pain-related fear, vocational functioning, patient satisfaction, and healthcare utilization.

(c) *Measures of psychological distress*

Diagnostic assessment should also identify psychological conditions. Depression and anxiety are the most important distress constructs to be measured as part of pain assessment. Some multidimensional pain measures include assessments of negative affect, i.e., the WHYMPI and the POQ-VA. If those measures are not used, a number of brief and psychometrically sound options are available. The Patient Health Questionnaire 9 [44] is a 9-item depression measure based on the nine diagnostic criteria for major depressive disorder. Other commonly used distress measures include the Center for Epidemiological Studies Depression scale [45], the Beck Depression Inventory [46] the Beck Anxiety Inventory [47], the State-Trait Anxiety Inventory [48] and the Tampa Scale of Kinesiophobia [44].

(d) *Additional assessments*

With more complex or chronic pain conditions it may be helpful to assess pain coping strategies with a measure such as the Chronic Pain Coping Inventory [49] or the Coping Strategies Questionnaire [50]. An in-depth appraisal of personality and psychopathology could be gained with measures such as the Schedule for Nonadaptive and Adaptive Personality [51] or the Minnesota Multiphasic Personality Inventory 2 (MMPI-2) [52]. Guides for using the MMPI in the context of chronic pain treatment are available [53, 54].

3. **Cognitive dysfunction and pain assessment**

The presence of cognitive impairment makes it challenging to obtain valid and reliable pain assessments, especially when verbal abilities are diminished. Behavioral disturbances due to pain may be indistinguishable from those due to other discomforts or dissatisfactions. If general discomfort behaviors are the only available data then psychologists should approach the problem empirically, i.e., generate hypotheses regarding discomfort sources, target those sources with interventions, and observe results. Persons with Mini-Mental State Examination scores of 15 or greater can usually provide valid and reliable pain ratings [55]. Multiple approaches to pain assessment should be used help the psychologist develop a clearer picture of the pain problem. For example, multiple and more specific pain descriptors should be used, e.g., aching, hurt, soreness, tightness. The polarity of pain questions should be varied, e.g., "are you feeling comfortable?" Faces scales, with adequate verbal queuing and explanation, provide pain measurements equivalent to NRS or VRS [36].

B. ***Pain Treatment***

Psychological treatments for pain should be administered in the context of close communication and coordination between disciplines that represents effective, evidence-based interdisciplinary care [3]. Psychological treatments are a critical aspect of interdisciplinary pain care, and should be delivered as a primary treatment for all pain concerns, not merely as a secondary approach. Meta-analyses of randomized, controlled clinical trials shows that the effects of psychological treatment on pain are comparable in magnitude to pharmacologic interventions [56]. Psychological treatments for pain should be tailored for individual patients based upon results of rigorous psychological assessment. Psychological assessment should identify the environmental, cognitive, emotional, and behavioral aspects of pain that require the most attention in treatment [37].

1. **Psychoeducation**

Pain psychoeducation should cover the biopsychosocial model. It should be explained that pain conditions often persist and are difficult to treat; complete resolution of pain may be elusive. However, patients should understand that psychological treatment can reliably reduce pain severity and help alleviate pain-related problems such as poor sleep, fatigue, and mood. Psychoeducation should make it clear that psychological treatment will focus primarily on improving functioning.

2. **Motivation**
   Patients may expect pain treatment to consist entirely of medical interventions such as medications and surgery; these expectations may be a barrier to engaging patients in psychological treatments for pain. Therefore, psychological pain treatments may be more effective if rendered within a motivational model of pain self-management [57]. According to this model, engagement in pain self-management behaviors and other aspects of psychological treatment depends upon the patient's readiness to change. In turn, readiness to change is contingent upon the patient's beliefs about the importance of psychological treatment, and beliefs about one's ability to successfully engage in psychological treatment for pain. Motivational interviewing techniques should be used to influence patients' beliefs about pain treatment and their role in it. Motivational interviewing should also be used throughout treatment to decrease and eliminate pain-related problem behaviors and increase healthy behaviors and functioning.
3. **Operant behavioral therapy**
   The premise of operant behavioral therapy for pain is that the social environment influences the display of pain behaviors through operant conditioning (reinforcement) [58]. The aim of operant behavioral therapy is to modify how the social environment responds to pain behaviors in order to promote activity and functioning. In this treatment approach, behavioral analysis is first used to identify social factors that precede, accompany, and follow pain behaviors. Thereafter, the aim is to manage the reinforcement and punishment contingencies in a way that increases functioning and wellness behaviors. For example, remove environmental contingencies that reinforce pain behaviors such as guarding or inactivity, and establish contingencies that reinforce activity. Specifically, it is often important to make rest and medication use time-contingent, versus contingent upon pain, distress, or fatigue levels.

   Operant behavioral therapy is most appropriate when overt pain behaviors are present, along with meaningful reinforcing and punishing factors. This approach is also most effective when control over the patient's social environment is possible. For example, in inpatient settings where staff can be enlisted to reinforce wellness behaviors and implement other aspects of the treatment, or when family members can be earnestly engaged in the approach.
4. **Cognitive-behavioral therapy**
   Cognitive-behavioral therapy (CBT) is based on the idea that maladaptive patterns of thought and behavior influence pain experiences and functioning [59]. The aim of this approach is to promote adaptive patterns of thought, emotions, and behavior in order to improve functioning. CBT uses specific techniques such as relaxation training, behavioral activation, problem-solving, and cognitive re-structuring. Cognitive restructuring techniques are used to target common maladaptive cognitive patterns identified during assessments, such as catastrophizing, or avoidance, and to encourage more adaptive cognitive coping strategies such as acceptance of pain and a focus on normalizing function. Patients are trained to identify thoughts and beliefs about pain and functioning and to evaluate those cognitions as to whether they are helpful, accurate, and based on evidence. Thereafter, maladaptive thought patterns can be challenged, stopped, and replaced with more adaptive thoughts.
5. **Hypnosis**
   Over 30 randomized clinical trials have demonstrated the efficacy of hypnosis in treating acute and chronic pain [60, 61]. Hypnotic interventions have immediate and long-term benefits for pain conditions. The premise behind hypnosis is that people can be trained to enter states of relaxation and cognitive focus wherein perceptions, sensations, thoughts, and behavior are influenced by the suggestions of the hypnotist. Ultimately the patient is able to use hypnosis on their own as an active coping strategy. Hypnosis has benefits not just for pain itself but for pain-related problems with sleep, mood, and fatigue. Manualized hypnotic interventions including scripts for hypnotic inductions can be used effectively.

C. ***Cognitive dysfunction and psychological pain treatment***
Effective pain self-management relies heavily on efficient memory and executive function, areas of cognitive functioning that are often impaired in rehabilitation populations. Psychologists can adapt treatment approaches to minimize the impact of cognitive dysfunction. For example, psychoeducation, treatment summaries and plans, and homework assignments can be provided in writing. Treatment plans can involve caregivers and family members, and may require more close work with interdisciplinary team members. Persons with cognitive dysfunction may benefit from highly structured and routinized homework and coping strategies plans.

Tips

A. ***Become Proficient in Pain Psychology***
Develop your skills and tools to participate fully in pain care. Promote and maintain your role in pain assessment and treatment. Advocate for a role on pain treatment teams and clinics. Speak up and otherwise participate when pain issues are present. Without earnest advocacy and vigilant maintenance of psychologists' roles in pain care there is a tendency for treatment providers, teams, and patients to retreat to models of care that are more familiar, simpler, and less effective, i.e., biomedical models.

B. ***Pain Assessment is More Than Data Collection***
Your earliest pain assessment efforts are the first stages of pain treatment. Pain assessment is an opportunity to show your patient understanding and caring, and to communicate adaptive ways of thinking about pain. Specifically, assessments of pain intensity, interference, mood, and other variables should lead to interpretive discussions that highlight the complex, biopsychosocial nature of pain and thereby frame psychological treatment targets. Implicit in the process of pain assessment are the notions that their experiences are understood scientifically and that treatments are effective. Careful pain assessment should be leveraged towards reducing the confusion and frustration that surrounds the pain experience, and increasing their optimism towards treatment.

C. ***Understand Medical Care***
Develop a good understanding of the medical pain treatments that your patients are likely to use. This will establish your credibility with patients and other providers and will help inform the treatments that you deliver.

D. ***Pain May Not be the Focus of Your Pain Treatment***
Many patients are skeptical of psychological treatments so it can be helpful to focus instead on pain-related concerns such as sleep, fatigue, mood, and activity levels. In fact, chronic pain patients who are maladaptively invested in their "sick roles" may benefit from focus in treatment away from pain intensity and towards adaptive functional activities.

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Suggested Reading

Department of Veterans Affairs, Veterans Health Administration, Pain Management Website. http://www.va.gov/PAINMANAGEMENT/Clinical_Resources.asp. Includes clinical resources such as measurement tools, clinical practice guidelines, pain assessment and treatment guides.

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Psychotherapy: Individual

45

Michele J. Rusin

Topic

“Psychotherapy is the informed and intentional application of clinical methods and interpersonal stances derived from established psychological principles for the purpose of assisting people to modify their behaviors, cognitions, emotions, and/or other personal characteristics in directions that the participants deem desirable” [1].

In psychotherapy, the psychologist embeds scientifically based interventions in the relationship with the patient. While on the surface psychotherapy may look like a conversation or even a casual visit, the psychologist is continually evaluating the interaction and crafting responses to facilitate desired gains. While interventions may be focused primarily on one domain (e.g., the patient’s thoughts), positive changes in that arena often produce improvements in other areas (e.g., behaviors). A person’s world-view is altered through psychotherapy. An intra-personal change can affect a macro-level shift, which impacts behavior, thoughts, emotions, and relationships, although only one area may be intentionally targeted.

Persons who are not familiar with psychotherapy may hold negative biases based upon societal stigma, portrayals in the media, or even religious teachings. They might think that psychotherapy is for “crazy” people, that the interventions are nothing more than a friendly visit, that people should not need help making decisions about their lives, or that psychology is antithetical to religious beliefs. Some might assume that they will be required to describe childhood events while venting emotions. Some might expect the therapist to be passive and the process to be lengthy. If there are indications that a patient or family member or significant other hold such negative opinions about psychotherapy, these beliefs are best addressed early on.

Patients involved in inpatient medical rehabilitation typically consent at admission to treatments considered necessary for their individualized rehabilitation program. However, given that patients may have little understanding of the role of psychology in rehabilitation, it may be helpful, when the psychologist first meets the patient, to introduce oneself as a “rehabilitation psychologist,” thus putting the service into the “medical” category rather than “mental health”. The more the psychologist is able to put the patient at ease and use everyday language—even better, use the client’s language—during interactions, the less anxious the patient is likely to be about participating in psychotherapy. However, if a competent patient outright declines psychological services, that refusal should be honored.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_45

As with any potent intervention, there are potential iatrogenic effects of involving a psychologist in a patient's care. Common negative reactions include the patient mistrusting the physician, concluding that "my doctor thinks everything is in my head," "I must be worse than I think," or "my doctor thinks I am a weak person". It is helpful for the physician, psychologist, and indeed the entire rehabilitation team to proactively address these concerns by normalizing the work of the psychologist in rehabilitation, and to address the patient's specific questions. Identifying and addressing these questions can be a therapeutic intervention if it results in increased trust. It also demonstrates respect for the patient's autonomy.

Only part of the psychologist's psychotherapeutic work will occur in one-on-one meetings with the patient. The psychologist will also consult with the rehabilitation team. Knowing the patient's personality style, psychosocial situation, and values/priorities can help the psychologist inform the team about ways to interact with the patient to elicit the best participation, maintain hope and motivation, and ultimately achieve the best outcome.

A. ***Terminology***

1. **Depression**

   Depression is a clinical disorder characterized by changes in mood, behavior, sleep, appetite, self-esteem, and/or desire to live that persists over at least a 2 week period. In assessing medical patients, consideration should be given to the overlap between medical symptoms and those of depression.

2. **Anxiety**

   Anxiety disorders are those in which there is excessive fear or worry, accompanied by physiological arousal and behavioral changes. Many disorders, (e.g., panic disorder, obsessive-compulsive disorder, generalized anxiety disorder) are classed in the category. Studies of anxiety in medical populations and community studies often look at the number and intensity of symptoms, but do not classify the disorder more specifically. There is significant overlap in anxiety and depression.

Importance

A. ***Whole Person Care in Medical Rehabilitation***

Quality of life is a key outcome in rehabilitation. The World Health Organization defines quality of life as: "the individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment" [2]. Psychological factors appear multiple times in this definition. The person's interpretation of what has occurred and what this means for life going forward will have a powerful impact on quality of life. Managing the psychological needs of persons going through rehabilitation is a key part of whole person rehabilitation.

When a person experiences a disabling event, his/her position in society will shift in both subtle and obvious ways [3]. Patients are rarely prepared for these changes, which are part of the social psychology of disability. Rehabilitation psychologists can help patients make sense of these changes and work to develop strategies to manage them. Patients may need to be informed that they have legal rights and access to benefits, with some patients needing help accessing such benefits. Piecing together the social fabric and resource network are key aspects of adjustment leading to higher quality of life.

B. ***Prevalence in Medical Populations***

Persons in medical rehabilitation settings are at significantly greater risk of depression and anxiety than persons in the general population. While at any one time, 7 % of US adults report depression [4], rates are at least four times higher among individuals who have experienced stroke (30 %) [5], spinal cord injury (22 %) [6], or amputation (35 %) [7]. Persons who had experienced traumatic brain injuries on average 2–8 years previously were noted to have very high rates of depression (42–61 %) [8, 9].

In the United States 18 % of the general population report anxiety [10], We know less about anxiety among rehabilitation patients; it is not as frequently studied. However, one study showed that 28 % of stroke patients had an anxiety disorder [11] within the 3 years following the event.

C. ***Psychological Health Affects Rehabilitation Outcomes***

1. **Depression**

Depression is a major risk factor for poor health outcomes. Depression is associated with greater risk of death both in the general population as well as in those known to have chronic illnesses such as stroke, cardiovascular disease, cancer, and diabetes [12, 13]. Those who have undergone organ transplantation [14] who suffer from depression are at greater risk of mortality. While most studies focus on those with "clinical" depression, persons with mild- to moderate- depression may also be at risk for excess mortality [15].

Persons with depression also have poorer rehabilitation outcomes. For example following a stroke, those with depression have poorer cognitive recoveries, they do not engage as much socially, and they do not achieve the same level of gains following rehabilitation interventions. In addition, they are at higher risk of having another stroke [16–22].

2. **Anxiety**

There is more to learn about the impact of anxiety on health outcomes. Anxiety is a risk factor for earlier death among women, but not for men, in community (i.e., non-medical) settings [23]. There may be an increased mortality risk in persons with co-occurring anxiety and coronary artery disease [24]. In those with cardiac illness, anxiety puts people at risk for poorer medical outcomes after a myocardial infarction; mortality rates (from any cause, including cardiac disease) are also higher [25]. In contrast, anxiety is not associated with increased mortality risk or morbidity among persons recovering from organ transplants [14], and there were no meta-analyses showing an impact of anxiety on medical outcomes in stroke or cancer. At this point, it appears that the identification and treatment of anxiety is important for persons having cardiac disease. Anxiety may not be a negative prognostic factor for health outcomes in other chronic diseases.

It is not clear what impact anxiety has on rehabilitation outcomes in general. Specific fears, such as fear of falling, affect activity level [26] and will likely impact functional independence and community activity.

Practical Applications

A. ***Illuminating Signs of Emotional Distress***

- Refusing therapies or making excuses to avoid treatment sessions
- Underperforming in therapies
- Dependent or helpless behaviors that are out of character
- High number of requests to staff
- Self-criticism
- Repugnance at looking at or caring for affected body part
- Unusual display of affected body part
- Irritability, frequent anger, verbalizations of dissatisfaction
- Hopelessness
- Trouble sleeping or excessive sleep
- Verbalizations of preference to be dead

B. ***Assessment***

- There are many effective screening tests for depression and anxiety: some frequently used ones are listed below. This list includes those suitable for use with adults; adolescent and child versions have been developed for many of these instruments. All of the instruments listed have been translated into multiple languages. While the quality of the translation has usually been verified, the translated instrument is not always validated against a clinical interview. Nonetheless, diagnoses are not made from test results alone in clinical practice; these instruments will help identify persons for whom additional follow-up is advised. In most cases, the "cut-score" that is listed is one that has either been recommended by the test developers, or is a point suggesting a "moderate" level of symptoms.

- In medical settings, assessments frequently must be adapted to deal with cognitive or other limitations of the patients. Therefore, it is acceptable to use geriatric questionnaires with younger adults if the test format makes questions easier to understand.
- All of the instruments have face-validity and are self-report measures, but lack validity indicators. They are therefore subject to possible response bias.
- Many instruments, including those in the public domain, have been adapted for electronic administration, scoring, and documentation. A search will likely yield apps or other aids, as well.

Depression assessment

Instrument	Critical score (range)	Number of items/comments	Source
PHQ-2 [27]	≥3 (0–6)	2: For rapid screening	Public domain phqscreeners.com/select-screener
PHQ-9 [28]	≥10 (0–27)	9: To identify likely depression, track symptoms over time	Public domain phqscreeners.com/select-screener
BDI-II: Beck depression inventory-II [29]	≥20 (0–63)	21: Multiple choice format may be confusing for those with cognitive impairments	Copyrighted pearsonclinical.com
GDS: Geriatric depression scale, short form [30]	≥5 (0–15)	15: Yes/no format	Public domain healthcare.uiowa.edu/igec/tools/depression/GDS.pdf web.stanford.edu/~yesavage/GDS.html
Pictographic rating scales	N/A	1: Gross indication of mood for persons having communication barriers	Examiner generated: smiling face on one end, sad face on the other

Anxiety assessment

Instrument	Critical score (range)	Number of items/comments	Source
GAD-7 [31]	≥10 (0–21)	7	Public domain phqscreeners.com/select-screener
BAI (Beck anxiety inventory) [32]	≥19 (0–63)	21: Some symptom overlap with medical conditions	Copyrighted pearsonclinical.com
State-trait anxiety inventory [33]	S-Anxiety ≥39: young, middle aged ≥54: older adults (20–80)	40: (20 T-Trait, 20 S-State) rated on 4 point scale	Copyrighted mindgarden.com
GAI: Geriatric anxiety inventory [34]	N/A (0–20)	20: Symptom assessment	License required http://gai.net.au/
Pictographic rating scales	N/A	1: Gross indication of anxiety for persons having communication barriers	Examiner generated: smiling face on one end, worried face on the other

C. ***Interventions***

The Schachter-Singer model of emotions [35] suggests a strategy for treating emotional disorders. According to the model each emotion has two ingredients: physiological arousal and an interpretation. According to this model, a person's emotional experience can be influenced by changes in level of arousal or the person's understanding of the arousal.

Learning to reduce the level of physiological arousal is a basic emotional management skill. Fortunately, these techniques are very easy to teach and implement, and extremely effective. If the first option does not work, reassure the patient that not every technique works for everyone, and there are many more options to try. Remind the patient that this skill, like any, will improve with practice.

Reducing arousal	
Breathing	
1. Deep breathing	Ask the patient to take a deep breath and hold it for a few seconds, until they feel a bit of discomfort and want to exhale. Repeat three to five times. Although this exercise usually leads to increased relaxation, it does not always! Ask the person what they experienced. If they do not report feeling more relaxed, accept that answer, and say "Let's try something different"
2. Exhaling slowly	Request the patient to take regular sized breaths, and exhale through the mouth, with lips pursed (as if blowing through a soda straw, or playing a flute). Breathe at a regular rate. Inquire into the patient's experience.
Muscle relaxation	
1. Progressive muscle relaxation	The classic form of progressive muscle relaxation involves tensing a muscle group, holding the tension for a few seconds, and then relaxing. This should be done twice before moving on to the next muscle group. Generally, it works to suggest muscle groups that make common sense to people (lower leg, thigh, abdomen, chest, hand, forearm, biceps, shoulders, neck, jaw, forehead). Have the person tense one leg/arm at a time, and then move on to the limb on the other side of the body. If a person has an injury in one part of the body, skip that section because tensing that area might increase the pain. People with reduced sensation or movement (such as hemiplegia) might find this distressing because it may inadvertently draw attention to the impairment.
2. Imaginal body relaxation	A good posture for this exercise is lying on one's back, or sitting comfortably in a chair or couch that provides good support, with eyes closed. If a person is more comfortable with eyes open, one suggestion is that they look at an area on the ceiling or wall. Ask the person to focus on different parts of their body, starting from their feet, eventually moving upward toward the head (one side foot, shin, thigh, other side foot, shin, thigh, hips, lower back, middle back, upper back, shoulders, one side hand, lower arm, upper arm, other side hand, lower arm, upper arm, neck, jaw, forehead). Ask "I wonder if your toes could become a little more relaxed? I wonder if the muscles in your leg could become a little bit looser?" Note that you are not telling the person to relax the muscles; you are merely making a suggestion. There is no failure here!
3. Relaxing memories	In using images, a person is benefitting from memories of pleasant times to help in difficult present circumstances. The more sensory memories that are evoked, the more effective the relaxation. Before suggesting an image, inquire about some of the pleasant relaxing places the person has been. Inquire about any fears. Use this information to guide the choice of images. Notice that the suggestions are stated in ways that allow the patient a breadth of choice, i.e., "I wonder if", "perhaps", rather than "See yourself" "you will"; the former wording reduces reactance. Here are several suggestions that many find pleasant:

Reducing arousal	
3. Relaxing memories	Floating on water. I wonder if you would like imagining that you are lying on a float in a swimming pool, or perhaps in a gentle, calm sea. Can you remember what it feels like to have the gentle waves moving the float easily? I wonder if you can remember what it feels like to have your muscles go looser as they sink into the float. Perhaps you can even imagine what it is like to have the float pushing up against your body, with the float supporting your body. The more relaxed your body, the more your body sinks into the float. I wonder if you can remember the pleasant tiredness you feel when the warmth of the sun soaks into your skin. Perhaps, you can remember the sounds of sea gulls calling, or perhaps children playing in the distance. I wonder if you can recall the scent of the salty sea air, the smell of suntan lotion. I wonder if you can bring back the memory of how your mind was clear and at ease, just enjoying the warmth, the comfort, the ease of the day.
	Floating on a cloud. I wonder if you can imagine yourself lying on a soft, puffy cloud. I wonder how much the warm soft moisture of the cloud allows your muscles to loosen and lengthen. The more your muscles let go, the more your body makes contact with the warm, soft, soothing texture of the cloud. If you like, you can just enjoy this experience of resting in a warm, soft cocoon, where nothing need bother or disturb you as you continue to enjoy this soft, calm, quiet place.
	Mountain stream. I wonder if you can bring to mind memories of resting beside a fresh mountain stream, the sunlight glinting on the water, the stream bubbling across and down the rocks. Perhaps as you breathe comfortably you will notice the scent of pine from the evergreens. Maybe you can recall the dusky smell of the earth with moist pine needles and wet leaves mixed in. I wonder if you can notice the way the earth feels as you run your hand through it: the moist earth on your fingertips and under your fingernails as you run your fingers through it, gathering up a clump of soil and crushed leaves. Perhaps you can recall how cool the water feels as you dip your hand into it, washing the soil from your fingers. Perhaps you would enjoy lying down on a soft bed of pine needles, listening to the stream, enjoying the scents of pine and soil, hearing the soft whisper of the breeze high in the treetops, feeling the cool gentle breeze brushing against your skin.

Identifying and looking critically at our thoughts is a learned technique. Albert Ellis and Aaron Beck were pioneers in developing clinical applications from research showing that emotions are more strongly influenced by the meaning attributed to an event, than by the event itself. They pointed out that when we are distressed, our thoughts are often unrealistic to some degree, and are often distorted in ways that add to emotional distress [36, 37]. These ideas helped form what is now called cognitive behavioral therapy (CBT). CBT is aimed at helping people identify the emotions and thoughts that are triggered by a certain event and, to see how the thoughts are distorted, leading toward another realistic, believable, plausible thought that fits the circumstances. When this process is completed, the level of emotional intensity quickly decreases.

Amending cognitions	A procedure that can be helpful in identifying and amending thoughts that are associated with emotional upset is as follows:
	1. Name the upsetting event
	2. Identify the emotions you were feeling and rate their intensity
	3. What thoughts ran through your mind?
	4. Identify the type of cognitive distortions in these thoughts
	5. Teasing out the distortion, name a believable, realistic thought that could fit this situation
	6. Rate the intensity of your emotions again [38]
Behavioral activation	Activity in itself is often helpful in combatting depression in that it creates opportunities for the person who is depressed to feel efficacy and power against the depression, and to have opportunities for positive social feedback. Any activity, regardless of a measurable outcome, generally improves mood for a time.

Goal setting	Goal setting helps combat hopelessness. In conjunction with the patient, identify a desirable outcome. Agree on a goal that is a small step towards that outcome. After completing that step, move to the next one. The initiation of activities and experiencing success are important in maintaining motivation and building confidence.
Physical activity/ exercise	Physical activity and exercise decreases depressive symptoms [39], and to a lesser degree, anxiety symptoms [40]. Exercise plans will include consideration of the person's medical condition and the circumstances that would be most reinforcing, and therefore, most likely to be maintained.

Tips

- Put energy into establishing rapport; it is the most important factor in psychotherapeutic outcomes. Learn enough about the patient that they become a person in your eyes. Envision them in street clothes instead of a hospital gown. Look at pre-injury photos. Inquire about their work, their family, their use of free time.
- What is important to the person? What activities, if they could resume them, would really make a difference in how much they enjoy life?
- Look for what's working in the patient's life, talk about it, and build on that.
- What are their resources and how can they help in the recovery process?
- Ask about difficult situations the person has faced already in life. What helped them get through those times?
- Do not break down denial, unless it is interfering with rehabilitation efforts. Denial is there for a reason and will decrease as a person feels strong enough to deal with the challenges.
- In inpatient settings, nursing staff, ward clerks, cleaning staff, and others who are working in the background are often useful resources in finding out more about the patient and patient's family.
- Use stories and analogies that are relevant to the person's life.
- Support the patient's hope for recovery. When patients say, "I want to be the same person again", support them by saying "We'll work hard to get as far as you can." At some later point, inquire into their fears about how they would be affected if they had residual changes.
- Most people can tolerate difficulties if they know they are time-limited. Help the patient think in terms of what they must do for the next year, month, minute, and so forth.
- Wisdom Gained from Experience
- Patients surprise us with unexpected levels of success, much more often than we expect.
- We all have strengths of which we are unaware.

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Family Adaptation and Intervention

46

Sara Palmer

Topic

The family is often the primary unit of social support for individuals with a disability or chronic illness. Family members provide a wide variety of supports, including emotional, practical, and financial. They act as advocates or spokespersons for the patient during hospitalization, and many provide care for the patient after discharge. Importantly, family members are also affected by the disability, and this can be particularly challenging during inpatient rehabilitation. The onset of a disability or an exacerbation of illness in their loved one is a major disruption or crisis for some families. Families need to cope with strong, sometimes difficult emotional reactions within themselves that can interfere with their optimal functioning; at the same time, families are expected to take in a great amount of complex information about their loved one's medical condition, make plans for post-discharge care, and begin to learn and assume new caregiving duties. Families need support—as well as education, resources and sometimes psychotherapy—to help them manage these emotional, intellectual and practical demands. Providing targeted interventions during inpatient rehabilitation can help families learn ways to manage their emotional responses, support the patient more effectively, anticipate future problems, and restructure their roles and priorities. Giving the family information on community resources and peer supports will help them continue the process of adaptation after discharge.

A. ***Terminology***

1. **“Caregiver”—or not?**

    The special role of “family caregiver” is recognized and valued by society. However, not all family members are caregivers, and some that do provide care do not identify with the “caregiver” label. Instead they view caregiving as a natural part of their role as a spouse or child, an expression of caring about or helping the person they love—not an “extra” or “extraordinary” role. Families who prefer to keep caregiving tasks separate from their relationship with the patient may employ professional caregivers, especially for personal hygiene and help with activities of daily living (ADLs). It is helpful to ask family members how they define their roles, use the terminology they prefer, and respect individual choices about caregiving.

2. **“Burden”**

    Much of the literature on family caregivers refers to the “burden” of caring for

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_46

a person with a disability. The term "burden" has been criticized for its implication that disability is a non-normative event with a uniformly negative impact on families [1]. Acceptable alternatives are "*appraisal*," which refers to the family member's own evaluation of their caregiving experience, and "*responsibility*," which suggests that caring for a person with a disability is a normative part of family relationships (parents, for example, are responsible for their children, not "burdened" by them; spouses are committed to caring for each other "in sickness and health"). In fact, many family members experience benefits from caregiving and positive effects of having a relationship with a person with a disability.

Importance

A. ***Families Affect Outcomes***

The quality and quantity of family relationships significantly affects an individual's psychosocial adaptation to disability, as well as the medical and rehabilitation outcomes. In particular, the family's communication, problem-solving skills, affective involvement and capacity for empathy are linked with better patient outcomes. Family support is associated with improved ADL function, increased treatment adherence, reduced rate of hospital readmission and nursing home care, and greater participation in life activities. In contrast, lack of support has been linked with higher rates of depression and greater severity of symptoms. Emotional support appears to be most helpful. Instrumental (practical) support is often necessary, but excessive instrumental support (doing more for the patient than is needed) can lead to increased dependence and depression in the patient.

B. ***Families Need Support***

So while the patient's needs are given priority during acute rehabilitation, involvement of family members is essential. To fully engage the family, rehabilitation staff must recognize the family's paradoxical double roles as care providers partnering with the rehabilitation team, and as "co-patients," at least from a psychological standpoint. Family members face predictable challenges and stresses of disability along with the patient. Their initial emotional reactions may include anxiety, sadness, anger, helplessness, frustration and guilt. They may feel distressed and overloaded as they try to cope with their feelings, take on the additional tasks their loved one can no longer do, learn about medical needs, and negotiate complex medical and social systems. Interventions for families during inpatient rehabilitation can help them feel better and be more effective in supporting the patient.

In addition to support for the family as a whole, addressing the special needs of the patient's designated family caregiver is critical. The impact of caregiving on family members is no small problem: about 65 million people in the US provide care for a family member with a disability or illness in any given year [2]. Long-term family caregivers, especially spouses, are more likely to experience severe fatigue, role stress, social isolation, depression, and health problems over the long haul [3]. Interventions for family caregivers during inpatient rehabilitation aimed at managing emotional responses, anticipating changes in roles and responsibilities, and utilizing community resources and supports have potential to prevent some of these common problems.

C. ***Professional Practice Guidelines***

The APA Division of Rehabilitation Psychology emphasizes that clinical services for people with disabilities are provided "within the network of an individual's environment," which "necessarily includes the provision of training, educational and support services to families and primary caregivers" [4]. Similarly, APA practice guidelines recognize "that families of individuals with disabilities have strengths and challenges" and urge psychologists and treatment teams to "include families in assessments and interventions to help manage stress, develop resiliency, enhance quality of family life, and resolve feelings about disability." The guidelines recommend family systems and resiliency models as broad bases for working with families, as well as practical interventions such as helping families find information and resources and teaching them self-advocacy skills [5].

Practical Applications

A. ***Preliminary Considerations:***

1. **Think Family Systems**

   Family systems theory emphasizes the interactions between family members and views individual behavior in the context of family relationships. Change in one individual affects other family members, and changes in those family members affect the individual in a circular fashion [6]. Disability affects the entire family and the family's patterns of interaction determine whether or not it can adapt effectively. A family systems perspective increases awareness of family dynamics and helps target interventions to the family as a whole.

2. **Use an Inclusive Definition of Family**

   "Traditional" two-parent families are in the minority today. Gay and lesbian partners (or spouses), non-married heterosexual partners, step-relatives, foster children or parents, close friends, or other extended family that function as the patient's primary family unit should be included in family interventions. It's important to let the patient define the family circle.

3. **Be Sensitive to Cultural Diversity**

   The relative importance of independence and interdependence, positive or negative appraisals of family caregiving, and expectations for adult children to care for elderly parents are examples of values that vary across cultures (and individual families). For example, African–American families are more likely to choose in-home caregiving, and less likely to acknowledge stress or ask for help, whereas Caucasian families tend to view caring for a person with a disability as a disruptive situation, and are more inclined to use respite or nursing home care. Chinese–Americans, whose culture reveres the elderly, may worry about bringing shame to their family or dishonoring their parent if they are unable to handle caregiving tasks. It's important to respect the family's cultural and individual values and preferences. When families have sufficient resources and support to be successful, they may derive considerable pride and self-esteem from being a caregiver [7].

4. **Legal and Ethical Considerations**

   (a) People with disabilities, especially children, the elderly and those with cognitive limitations, are vulnerable to abuse and neglect. Know your state's laws and protocols for mandatory reporting of abuse.

   (b) Adult patients have a right to confidentiality. Patient permission is necessary prior to conversing with family members about the patient; patients can choose not to involve family, even if it is in the patient's best interest to do so.

   (c) The family's role in making decisions for patients who lack decision-making capacity is affected by legal and ethical issues (e.g., confidentiality, health care proxy, hospital ethics committees). Difficult decisions can trigger stress and conflict for families, for example, siblings' disagreements about nursing home placement for a parent. In some cases, the psychologist can help resolve these disagreements; in rare cases outside mediation or guardianship may be needed. Including the patient and the family in shared decision-making discussions is recommended, even when the patient is a child or cognitively impaired adult. Whether or not the patient is present, psychologists can facilitate family discussions that consider the patient's values and preferences.

B. ***Assessments***

1. **Ability to Cope**

   Assess the family's ability to cope with the acute emotional impact of hospitalization and disability. Are family members depressed or overwhelmed? What supports or interventions does the family need to manage immediate stresses?

2. **Resources**

   Determine whether the family has sufficient emotional, social and practical resources to support and/or help take care of the patient after discharge. Do they have a workable and feasible plan for providing care at home? Can they be entrusted with a vulnerable patient? What supports, resources or information do they need to succeed? Is there an alternative care plan that would be better? Although these areas overlap, it is helpful to assess the impact of disability on the family's emotional life and relationships irrespective of "caregiving." Some examples of relationship issues are changes in sexual and emotional intimacy between spouses or disruption of progress towards psychosocial independence of a teenager with a newly acquired disability. The impact of caregiving has to do with the additional work involved in meeting the patient's needs and is dependent on external resources available to the family.

3. **Preparedness**

   If a family member will be the patient's primary caregiver, do they fully understand the patient's needs? Do they need more education about the medical condition and skills to properly care for the patient? What types of support or respite are available to help the family member care for the patient while maintaining the family member's own health and well being?

4. **Types of Assessments**

   Family assessments in the rehabilitation hospital are usually informal, based on behavioral observations of the family during visits, training sessions with rehabilitation staff, and family conferences. When time allows, a brief structured interview with the primary family member(s) can provide valuable additional information. Key points to include are: the family constellation; the quality of the patient's closest family relationships; other major stressors on the family; the family's overall function, especially in the areas of communication, affection/emotional support and problem solving; who will live with the patient after discharge; the family's resources (financial, social/community support, educational, spiritual); and the family's attitudes or belief systems about disability.

   Note: While religious faith is a source of strength for many families, some belief systems can lead to self-blame, excessive guilt feelings, or unrealistic expectations for recovery. Rehabilitation team members must work within the family's religious or moral framework as much as possible, while presenting alternative interpretations and attitudes in a non-threatening and respectful manner.

5. **Instruments**

   Several measurements of family function, such as the Family Assessment Device [8] are available, but most have limited applicability in the rehabilitation setting, are too time consuming, or are not generally covered by insurance. The family may view paper-and-pencil assessments as intrusive or unhelpful, compared to an interview, which also serves as an opportunity for them to be heard and supported.

C. ***Interventions***

The broad goals of family intervention are to assist the family in the processes of coping, adaptation and restructuring roles and relationships, so that they can meet the needs of all members, including the family system and the patient. Interventions for families in medical rehabilitation include a continuum of: empathic listening and support, education about their loved one's disability and recovery timeline, provision of resources for education, peer support and practical help, brief couple or family therapy, sexual counseling, and referral to mental health providers for outpatient intervention.

1. **The Basic Package: Support, Education and Resources**

   All families can benefit from the most basic level of intervention: empathic support; education about the patient's disability and expected course of recovery; and resources for information, peer support and practical help. These services can be delivered in one-on-one sessions or team meetings with the family, or by telephone conferences. Some hospitals may have video conference or Skype capability for individual or group meetings with family members. Some critical goals of the "basic package" are to normalize the family's emotional experience, help them anticipate their future needs and provide access to resources.

2. **Family Conferences**

   Many rehabilitation teams schedule at least one family conference per patient admission, to report on the patient's current status and plan for care after discharge. The family conference is an ideal time for psychologists to support and advocate for the family, in addition to educating them about the patient's status and needs. The psychologist can facilitate communication between the family and the team by translating medical information into language the family can understand and inviting them to ask questions; and by promoting consideration of the family's needs, values and preferences when making discharge plans.

3. **Therapeutic Leave of Absence**

   In some rehabilitation hospitals, patients take an overnight "therapeutic leave of absence" or LOA with spouse, family or friend, either in an apartment-like space within the hospital, or (rarely) at home. The LOA is designed as a trial run of self-care and/or family caregiving routines to help identify and address potential problems before the patient goes home. Psychologists can assign LOA "homework" to couples and families—to practice particular communication skills, express affection or physical intimacy, apply problem solving techniques, self-manage anxiety, and so forth. Results of the LOA can guide further psychological intervention during inpatient rehabilitation, or determine the types of referrals or resources the family needs for the future.

4. **Brief Couple or Family Therapy**

   Brief couple or family therapy is recommended when the family's emotional distress interferes with their ability to function in their daily lives or their ability to support the patient in the rehabilitation process Interventions should focus on: managing intense emotions; altering cognitions, beliefs and attitudes regarding disability; exploring role changes; improving communication; and increasing support from the extended family and social network.

5. **Group Interventions**

   Some hospitals host family support groups or psycho-educational groups for caregivers that teach problem-solving and self-management skills. These are usually geared to outpatients, but families may benefit from participation during inpatient rehabilitation. Support groups for families of patients with particular conditions (such as stroke) can be an efficient vehicle for delivering the "basic package" discussed above.

6. **Sexual Counseling**

   Some acquired disabilities can affect sexual function directly (such as spinal cord injury), or have a psychological impact on a couple's sexual intimacy (such as stroke), due to fear of another medical event, or changes in cognitive abilities, body image, or marital roles. Intervention to address couples' sexual concerns while they are in inpatient rehabilitation can alleviate fears and dispel myths, potentially preventing chronic problems in intimacy. The PLISSIT model, a continuum of Permission, Limited Information, Specific Suggestions and Intensive Therapy [9], is a useful guide for intervention. Patients and partners often have questions about sex that would not be asked without Permission. Raising the issue and inviting couples to discuss concerns is useful. Giving them the "green light" to continue their sexual relationship is particularly helpful. Providing Limited Information (general and disability-specific sexual education) will further empower couples. If more specific or intensive intervention is necessary, referral to an outpatient couples or sex therapist may be necessary.

7. **Referring a Family Member to Mental Health Services**

   The time constraints of inpatient rehabilitation preclude intensive treatment of individual family members. Referral to an outpatient psychiatrist or psychologist is recommended when a family member is depressed, manic, or psychotic; is actively abusing alcohol or drugs, or is otherwise mentally impaired. If the patient must depend on help from a family member after discharge, it may be necessary to ensure that an alternative person is available.

8. **Referring the Whole Family to Outpatient Therapy**

   Families should be referred for outpatient family and/or individual therapy if: they have been unable to benefit from brief interventions during inpatient rehabilitation; or have a history of physical, sexual or emotional abuse, or chronic mental illness or substance abuse. A vulnerable patient should not be discharged to an abusive or neglectful home. Home health social work services can help ensure patient and family safety after discharge, and encourage their use of mental health services.

9. **When the Person with a Disability has Significant Cognitive Impairment**

   An adult patient with a physical disability with no, or very minor, cognitive involvement, can be psychologically independent and a full partner in relationships with a spouse or other family members. The patient can make independent decisions and plans with the family's input, if desired. Resources, supports and counseling if needed, can help the patient participate actively in reciprocal relationships within the family and beyond. However, when an adult patient develops impairments in executive function, memory or attention that interfere with understanding their needs, participating in problem-solving, organizing their activities, or making sound decisions, the ability to be an equal partner in relationships is a challenge. This situation is particularly difficult for spouse or partners who need to provide care and make decisions for the patient—either temporarily or permanently—without the expectation of reciprocity that normally characterizes couple relationships. The caregiver spouse may need guidance in transitioning to a more active, "parent-like" role as the primary decision maker, initiator and organizer of the patient's life, and help to find alternative sources of support or care for themselves. Adult children may have difficulty recognizing the extent of their parent's impairments, or feel guilty or fearful about making decisions on the parent's behalf. While the patient should be informed and included as much as possible, validation and support for the family member(s) who must be responsible for the patient is very helpful.

10. **Expectations and Outcomes**

    Short lengths of stay and competing demands on family members' time during inpatient rehabilitation make it difficult to assess intervention outcomes in a systematic way, but understanding what generally helps families and caregivers after inpatient rehabilitation is a useful guide for intervention. Research shows that family interventions combining education and individualized counseling are beneficial to participants and family interventions are most likely to have a positive impact on emotional functioning, physical health and ability to provide care for the patient. Family caregivers who have more support from extended family and friends are less vulnerable to depression and burnout. Family members who take "time-out" to attend to their own medical, social and emotional needs are less depressed and better able to support their loved one with a disability. Utilizing community supports after discharge (peer and caregiver support groups, respite care, mental health services, religious and community groups, social service agencies, and so forth) can be very helpful to families. The importance of providing families with information about and referral to these resources should not be underestimated.

11. **Include Family After Discharge**

Rehabilitation providers can facilitate better outcomes over the long term by inviting spouses or family members to accompany the patient for follow-up visits, doing a quick reassessment of their needs at that time, and making further referrals or recommendations. Short of that, the patient's positive adaptation to disability and consistently good social function is a reasonable proxy for family adaptation.

Tips

A. ***Couples***

Disability or illness affects both members of a couple. A patient and his spouse or partner may be interviewed separately to gather information, however, including both spouses as much as possible in education about the impact of the disability and discussions of discharge plans and support resources is preferred. Spouses want to—and should—be recognized by rehabilitation providers for the essential role they play in the patient's life. It's useful to emphasize that disability is a shared problem they can work on together. Addressing issues relating to affection and sexually intimacy validates the couple's special relationship as more than a caregiving/care-receiving contract.

B. ***Teenagers***

Keep the family focused on the pre-disability trajectory as much as possible. Parents commonly step in to provide care when a teenager or single young adult has an acquired disability or exacerbation of a chronic condition. Parents may become fearful and excessively protective, and the young person may retreat from natural development and movement toward psychological independence. Helping families access services to support the patient's independence is a valuable intervention. These include disability services provided at most schools and colleges, vocational rehabilitation services, personal care assistants, and independent living services. It's also helpful to encourage the young person to invite friends and peers to visit during the rehabilitation stay and to solicit assistance, if necessary, in resuming the teen's social life after discharge.

C. ***Elderly***

Guide families to err on the side of too much, rather than too little care—this can prevent extra moves, disruptions and crises in the future. Family members tend to underestimate the care needs of their frail or cognitively impaired geriatric parent or spouse. It is helpful to ask families to consider what the loved one needs right now, and to anticipate what will be needed when they age or the condition worsens. This might mean planning for regular help (such as adult day care) to support the family caregiver or choosing a higher level of care by professionals (such as an assisted living facility versus a part-time aide in the patient's home).

D. ***Children***

Parents' attitudes are crucial in determining how disability affects their child and the child's role in the family system. Encourage parents to expect competency, facilitate worldly experiences and allow the child to take some reasonable risks. This will permit the child to be more self-sufficient and the family less stressed.

The onset of a new disability in a child is very disruptive for many parents. Connecting parents with experienced peers is critical for coping with changes and finding resources. Many disease-specific advocacy groups (such as Spina Bifida Association or United Cerebral Palsy) have peer support groups for parents. Siblings of kids with disabilities can benefit from inclusion in education about the disability and the opportunity to ask questions and contribute their opinions on decisions affecting the family. Few formal supports exist for siblings of kids with disabilities, with the exception of Sib Shops, available at some hospitals and clinics around the country [10].

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Coping Effectiveness Training

47

Paul Kennedy and Alice Kilvert

Topic

Acquired physical disabilities often result in numerous life changes that require individual adaptation and adjustment. There is no set pattern of reaction. Most people have very normal emotional responses to their illness or injury. Some people may get depressed because of the losses they experience, some people may feel anxious because of fears and doubts about the future and some people may get angry and feel a strong sense of injustice. The resulting life changes which are required may represent potential sources of stress. When so many changes are needed this can seem overwhelming, so it is essential that the individual develops effective coping strategies to address and break down global stressors into smaller, more manageable components.

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Importance

Depression and anxiety can interfere with rehabilitation progression; increased levels of depression have been found to be associated with more secondary complications, longer period of hospitalisation and higher use of speciality care services [1–3].

For example, the prevalence of prevalence of depression is thought to be between 20 and 30 % of individuals with a Spinal Cord Injury (SCI) [4], and when measured over time has shown high levels of stability across various samples [5–7]. This is not dissimilar for other groups with chronic health conditions [8]. Prevalence of anxiety is thought to be between 23 and 35 % of the SCI population [9].

It is fundamental to understand how individuals cope effectively when faced with an illness or injury and identify the factors that lead to effective adjustment. This will enable better support for the one-third of individuals who do report elevated levels of anxiety and depression [10]. Resilience is one such psychological construct which has been identified as helping to contribute towards successful coping [11].

In light of these findings, it is critical that depression and anxiety are sufficiently dealt with in a timely and efficient manner to reduce negative interference with progress within rehabilitation. Equipping individuals with more effective coping

M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_47

strategies through psychoeducational interventions has been associated with improved functional independence and decreased risk of secondary complications such as reduced frequency of pressure ulcers for individuals with SCI [12, 13].

A. ***Key Definitions***
   1. **Coping**

      A process whereby the person with the illness or injury sustains an integrated view of the self while constructing a new reality that is both helpful and credible.
   2. **Appraisals**

      A process whereby the individual with the illness or injury constructs a personal evaluation of a stressful situation. It is essentially a primary review of the situation that perceives threats or challenges. It is the process by which individuals first analyse the stress of the situation and then evaluate its relevance and importance for themselves. This primes the individual for reviewing resources and options.

Practical Applications

Coping Effectiveness Training (CET) has been found to reduce levels of depression and anxiety, improve self-efficacy and reduce negative self-perceptions seen in those coping with chronic physical disability [7]. CET has been found to significantly reduce stress, anxiety and burnout within a group-based intervention for men living with HIV [14, 15]. In a further evaluation by Duchnick and colleagues [16], CET was compared against supportive group therapy. Those who completed CET were found to need a fewer number of sessions than those who just received the supportive group therapy. CET has been designed to both increase people's capacity to cope, and to increase their belief in their ability to manage this situation [17].

A. ***Aims of CET Are***
   1. To improve strategies for assessing stress.
   2. To help break down stressful situations into manageable sections.
   3. To teach a range of coping strategies that can be used to tackle stress across different situations.

The intervention consists of seven sessions, running for approximately 60–75 min twice a week. Each session builds on the discussion of the last. In this chapter, an overview of each session is given, detailing the relevant teaching and exercises which should be covered. To support learning, it is suggested that individuals participate in the exercises that are given. These tasks are often short reflective exercises, which are beneficial as they allow individuals to start to apply what they have learned to their own situations.

B. ***Session 1: Introduction to Stress and Coping***

The first session provides a general overview of the training and what to expect. In particular the following topics are covered:

- Stress
- Appraisals
- Types of Coping

It is important to emphasise that key terms will be explored in more depth, with each session adding to the previous, so as time goes on everything will become progressively more clear!

1. **Stress**

   Stress is a normal response to demanding situations that occur every day. It is a normal reaction to an injury or health condition, and to the subsequent changes caused by an injury or health condition. People usually respond well to the pressures and demands of everyday life through using flexible adaption and mobilising effective ways of coping with pressure, such as taking breaks from tasks, relaxing, watching TV or seeing friends. However, problems may arise when demands are excessive or prolonged. In these situations, excesses of stress may exceed usual ways of managing and coping, and individuals will become 'stressed'. Conversely too few demands, or a lack of stress, can lead to under-arousal and boredom. The optimum amount of stress is when we perceive a situation as being demanding but within our capabilities; situations then become a challenge, a way of improving our sense of competence, and successfully managing these challenges leads to greater self-respect and self-worth.

When there is an optimum amount of stress, task performance is high. However, when there is too little or too much stress, task performance is low. Because stress is an interaction between situational demands and individual capabilities, a key point is that the same situation may provide a challenge for some people, while being stressful for others.

Stress reactions occur when stress is excessive or overwhelming. Such uncontrolled tension can reduce an individual's ability to enjoy life and place them at risk for depression and anxiety, as well as physical disorders. Common stress reactions include:

- Low mood—Muscular tension
- Negative thinking—General fatigue
- Poor sleep—Abnormalities in heart function

2. **Appraisals**

Following the onset of a disability people face challenges that they have not previously experienced. Stress results if the demands of these new situations are perceived to be greater than the resources individuals feel they have available to deal with them. Thus, stress can be caused by both internal and external factors.

External factors are the demanding situations or events. These may include anatomical changes, physical pain or how the illness or injury impacts on the family.

Internal factors are the thoughts and interpretations that the individual makes about the external factors. Different people react in different ways to the same situation because they make individual interpretations, according to past experience of the situation, and consequently apply different meanings to it.

The Cognitive Model is based on the theory that an individual's emotions and behaviour are largely determined by the way in which he/she structures the world. It is the interaction between internal and external factors that determine how we perceive and subsequently cope with stressful situations. The Cognitive Model proposes that by thinking about the ways in which one deals with stress, the individual is able to improve the strategies necessary for effective coping. It is not what happens to you in life that is important, it is what you think about it.

The impact of events is influenced by two factors.

- *Appraisal*: This is the individual's personal evaluation of a situation. It is the process by which individuals first analyse the demands of the situation and evaluate its relevance and importance for themselves.
- *Coping*: This is a review of the resources that individuals have and their belief in their own ability to manage the situation. The individual then makes a decision about what is to be done about the perceived threat or challenge. These processes are how people attempt to manage the situation.

3. **Types of Coping**

There are a number of core elements in an individual's coping response when faced with a stressful situation. Broadly this can be broken into *problem-focused coping* and *emotion-focused coping*.

- *Problem-focused coping* is when an individual tries to change the stressful situation itself.
- *Emotion-focused coping* is when an individual tries to change the way they react to the stressful situation.

Following a disability, an individual may face a number of different situations that require specific coping responses. It is therefore important not only for the individual to appraise the situation, but also to use an appropriate or ‘adaptive’ coping strategy.

- *Adaptive coping*: This results from a realistic appraisal of the stressful situation combined with an appropriate choice of coping strategies. This will result in the effective management of stress and an increase in the likelihood of gaining control.
- *Maladaptive coping*: This results from an unrealistic appraisal of the situation, or an inappropriate choice of coping strategies. This in turn results in increasingly poorly managed stress and an increase in stress-related symptoms. As they remain in the stressful situation, the individual can do nothing to restore the imbalance, leading to further weakening of their coping resources and exacerbation of the stress reaction.

Suggested Homework Task:

Over the next few days please think about and note down:

- Personal signs of stress
- The way it interferes with your life
- Situations that particularly trigger stress

C. ***Session 2: Appraisal, Coping and Stress***

In the second session the following topics are examined.

- Appraisals Strategies and Effective Coping
- Breaking Down Stress
- Problems Resistant to Change

1. **Appraisal Strategies and Effective Coping**

Physical disability causes a number of critical life changes and difficulties, and as such it is very important for individuals to be able to effectively identify those things that cause them to feel stressed so as to best cope with their new situation. Often the first signs of stress are emotional reactions. These emotions are a normal reaction to a difficult situation. Improving an individual’s appraisal strategies will help them to form a better understanding of the situation and equip them to be able to select the most appropriate coping strategies. Without this, the individual may generate and engage in maladaptive coping which can exacerbate the stress reaction.

Effective coping depends on clearly defining the problem that the individual needs to cope with: *How are the consequences of a disability important to the individual?* The answer is different things for different people.

2. **Breaking Down Stress—Who, What, Where, and When**

When individuals experience a complex stressor, it may, as a whole, feel too big and overwhelming to deal with at once, making an individual feel incapable of dealing with it and not knowing where to start. Coping involves breaking down a situation that is causing stress into smaller and more manageable parts. This is useful in helping to choose an effective coping strategy. CET attempts to address these issues through asking the following questions:

WHO is involved?	‘*Staff on ward. Particularly Nurse ……’*
WHEN did they last occur	‘W*hen I need some help, staff always claim that they are too busy. They seem to make time for everyone else. I feel they’re all ignoring me’.*
WHEN did they last occur? or **WHEN** are they likely to occur again?	*On the ward mostly, when I need help with something’.*
WHERE are these situations likely?	*This morning when I needed help washing, and at dinner time when I wanted some assistance’.*
	‘It is most likely to happen in the mornings and at meal times’.

The more detailed the description of the stressful situation, the easier it will be to establish the goals of coping and the more likely it is that the most appropriate strategy will be chosen. Coping works to both help the individual to manage or alter the problems causing distress, and to help him/her deal with the emotional responses to the problem.

Acknowledgement of emotional responses is fundamental. Emotional responses can be broken down into three broad categories:

- Loss or harm (usually situations that have already occurred)
- Possible threat (things that have yet to occur)
- Challenge (opportunity for growth, a chance to develop strategies and master them)

It is important for the individual to recognize exactly what aspects of the problem can be changed. There are times when an individual may think; *'nothing can be changed'*. In certain cases, it may be possible to change the situation by challenging this type of thinking. It can be useful to ask the following questions:

- What are the external aspects of the specific situation that can be changed?
- What elements of this problem are amenable to change?
- Is it possible to change your behaviour or your actions

3. **Problems Resistant to Change**

There are many occasions when it really is not possible to change external aspects of the problem. In these situations losses may need to be accepted. However, the goal of coping still remains—to manage the demands in a better way and to reduce distress. These situations may require an initial acceptance of things which cannot be changed, and also require an attempt at reducing distress by changing an individual's emotional reactions to the situation. This can be done by changing the approach, attitudes and thoughts and involves issues of acceptance. Thus, the emphasis is switched from problem-focused coping to emotion-focused coping. In these situations, individuals may not be able to change the problem itself, but they may learn to reduce distress by changing their feelings towards it.

Adaptive coping requires making an accurate appraisal of the stressor and then matching an appropriate coping strategy to the appraisal. If the matching is not good, coping will be ineffective. It is therefore important to know in which situations it is better to use emotion-focused vs. Problem-focused coping, as this enables the individual to be adaptive when faced with stressful situations.

Problem-focusing coping is used with the elements of the problem that can be changed. This may include practical problem solving, adaptive coping, making decisions, rehearsing solutions and developing social and communication strategies. In situations where change is not possible, emotion-focused coping should be used. This may include relaxation, changing thinking style about the problem, re-evaluating the significance of issues, changing the meaning of something and use of humour.

D. ***Session 3: Problem Solving***

In the third session, the following topics are examined.

- **Problem Solving**

Having appraised the stressful situation and established which aspects of the problem are changeable, the individual is now in a position to change these aspects. Problem solving is a logical, systematic procedure for developing practical ways of changing those aspects of a problem that can be changed. It comprises six steps, each of which should be addressed in sequence.

Step 1: Identify the problem

The aim is to obtain a detailed and specific description of the problem. The appraisal skills learnt in Session 2 provide a framework for this, using the 'who, what, where and when' questions. Using strategies such as self-monitoring of anxiety levels may help to identify more specific problems by illustrating the who, what, where and when.

Step 2: What are the consequences of the problem?

It is very important to identify the consequences for you of the problem and new needs that have resulted from the identified problem. This helps to further specify the problem and helps in identifying where efforts need to be focused.

Step 3: Generate possible solutions

A wide range of possibilities should be considered here. All the possible solutions should be identified and new ways of solving both old and new problems considered. Every possible solution should be considered, no matter how ridiculous it may seem.

Step 4: Choose the best solutions

In choosing solutions, it is necessary for the individual to assess his/her resources for change. Assets and strengths might include adaptive coping in the past, personal support from family or friends, and new skills to deal with problems. The advantages and disadvantages of each solution should be considered, as well as what skills and resources are available to the individual so as to help choose the most appropriate solution.

Step 5: Determine to implement the solution

The individual will need to apply the solution to the problem. Using the 'who, what, where and when' questions can provide a framework for implementation. The individual should be committed to applying the solution and following it through to completion. Even if a solution seems unlikely to work, without testing it there is no solid evidence that this is the case. Careful planning about the implementation of the solution maximises the individual's chance of success.

Step 6: Evaluate the success of the solution

Without evaluation, there is no way of knowing how effective a solution is. Finding that a solution does not work is as valuable as finding one that does, since it illustrates to the individual what not to do in the same situation. Success cannot be guaranteed all the time, but planning the implementation of a solution in a systematic manner will lead to the optimum outcomes available to the individual.

Scenario: Your family keeps saying 'Work harder in physical therapy (PT) and you'll get better':

Step 1: Identify the problem

'My family thinks I am not trying hard enough in my rehab. They think that I could achieve a lot more if I put more effort into it'.

Step 2: What are the consequences of the problem?

'I feel low, threatened and picked upon. It makes me less inclined to try as maybe they will think this no matter how much I do'.

Step 3: Generate possible solutions

'I could be mad and tell my family that they have no idea what it is like, and tell them to leave mealone. I could get sad and quit trying. I could be submissive and agree. Or I could be assertive'.

Step 4: Choose the best solution

'If I'm mad I could start disagreements with my family, or worse lose their support. If I'm submissive I could lose the motivation to continue with rehab. But If I'm assertive, I can maintain my self- respect and my family will learn something'.

Step 5: Determine to implement the solution

'I will explain to my family that I am currently working hard in PT, and that working harder won't always necessary lead to better results. If needed, I will ask my PT to support me in having this conversation. I will involve my family more by telling them what smaller goals I am currently working towards. I will act in control of the situation and will be polite without being submissive'.

Step 6: Evaluate your success

'My family really appreciated being given further information about my progress to date in PT. They explained that they didn't really understand the nature of rehabilitation, and weren't aware of the goals I was currently working towards. Afterwards, I felt a lot more in control, and more determined to reach my goals in rehabilitation, with the knowledge that I had my family as a support mechanism in doing so. I think we all realise that getting better means different things. My family now knows it's about getting stronger, becoming more independent in my transfer skills and being more able to look after myself'.

Suggested Homework Task:

- Identify different situations and problems that lead to you feeling stressed.
- Identify the changeable and unchangeable aspects of these situations.
- For each situation, identify a couple of different coping strategies that you could use and what the merits and consequences of each would be.

E. ***Session 4: Active Coping***

The fourth session will explore:

- Emotions
- Negative Thoughts
- Activity Planning

1. **Emotions**

Understandable Emotions. Most people have a very normal emotional response to a disability. They may feel depressed because of the losses they have experienced, anxious because of their fears and doubts about the future or they may feel angry and experience a sense of injustice.

Unhelpful Emotions. Some of these emotions and the severity of them may be new. They may remind the person of previous vulnerabilities in times of stress. They may also lead to or deepen problems such as sleep disturbance, loss of appetite, reduced motivation and increased passivity, apathy and withdrawal, and feelings of sadness, anxiety and anger. These emotions are generated and maintained by thoughts and negative assumptions.

2. **Negative thoughts**

When individuals feel depressed, they often have negative thoughts about themselves or the world in general. A negative spiral develops in which negative thoughts lead to increased feelings of depression, which further increase negative thoughts. The spiral leads to further loss of interest in activity. If the individual thinks that life is over after an injury then he/she will not be motivated to do anything. The less he/she does, the more it seems to be confirmed that he/she has little to do in life. People often focus on the emotions and not the negative thoughts. Emotions tend to result from, and are maintained by, thoughts and negative assumptions.

The negative cycle described above need to be changed in order to reduce negative thinking. The most productive method of changing these cycles is for the individual to change the way he/she thinks.

3. **Active Planning**

In addition to changing emotions and thoughts, it is also important to change behaviours.

Pleasant activities. When feeling low or under stress, people may have a tendency to be less motivated to do things, especially things they enjoy. Participating in enjoyable activities can improve mood and is therefore a powerful tool for combating depression. There are three broad types of pleasant activities:

- Pleasant social activities.
- Competency activities (activities in which a goal is achieved).
- Activities that are incompatible with emotional distress.

Activity scheduling. It is important to develop a plan for increasing the number of pleasant activities. This can be especially difficult when feeling down. Therefore, it is important to plan and introduce pleasant activities into daily schedules. A simple yet effective initial method of scheduling pleasant activities is to generate a list of pleasant activities which can be accomplished. A small selection of this list should then be chosen to achieve within the next week. It is important that a time and place be decided upon for each activity.

Relaxation training. Difficult situations cannot always be changed. Relaxation is a useful way of dealing with emotional reactions to difficult situations and has also been shown to help individuals to better cope with adversity. It is a skill which needs to be practised regularly to become effective. There are various different ways to relax, for example recordings providing instruction on physical and mental relaxation, listening to music, reading a book, doing exercise or watching TV. Participating in relaxation activities can allow the individual to take a break from and develop a new perspective.

Suggested Homework Task:

Choose three pleasant and/or relaxing activities that you would like to do over the next week.

- Decide what day, time and place you are going to do them (plan in advance).
- Be prepared to discuss these in the next session.

F. ***Session 5: Changing Negative Thinking***

The fifth session will explore:

- Negative thoughts and assumptions, and how to challenge them.

Thoughts are very powerful in influencing mood and behaviour. Specific thoughts are generated by assumptions, attitudes and beliefs. Together they influence emotional reactions and in many ways have a stronger effect on mood than the reality of the event itself.

Negative assumptions and expectations are irrational beliefs about one's self or the world around us, and are common amongst all people, irrespective of their circumstances. These may include; '*I should not make mistakes*', or, '*I can't help myself'*, or, '*It is better to avoid challenges than to risk failure*'.

These beliefs and expectations generate negative automatic thoughts that influence emotional reactions to events and can have a stronger effect on the individual than the reality of the situation itself. By confronting these thoughts, the individual is able to feel in control and to manage, even if some efforts end in failure. Examples of negative thoughts include *'I can't cope with this'*, '*I will never enjoy going out again'*, '*People will react badly to me if I go out'* or '*I am being a nuisance'*. Negative thoughts can make an individual feel depressed, anxious or demoralised. This, in turn, influences behaviour and action, which in turn confirms the negative belief or assumption.

Recognising negative thoughts and thinking errors is difficult. People tend to be more aware of their emotions than their thoughts. Negative thoughts are difficult to identify because they are automatic. Individuals need try to be aware of what their negative thoughts are, and to understand the beliefs that these negative thoughts arise from.

It is important to challenge negative thoughts. The key to challenging negative thoughts is to find out whether they are true and real, or just faulty views. One way of doing this is to test negative thoughts by asking:

- What is the evidence for and against these thoughts?
- What are the other alternatives (what else might be true)?

In challenging negative thoughts, it can be useful to realise that thoughts are not always accurate and that they can be a consequence of thinking errors.

Suggested Homework Task:

- Identify times when you had negative thoughts. Write down how you were feeling at the time, and see if you can challenge them (what is the evidence for and against these thoughts; what else might be true instead).

G. ***Session 6: Maladaptive/Adaptive Coping***

This session reviews the major themes which have been covered in the training up to this point. It is helpful in consolidating learning so far, as well as giving individuals the opportunity to share which coping strategies they found effective and ineffective.

It is helpful to revisit the following topics and see how they apply to different individuals within a group setting. This can be a helpful way in which individuals can expand their knowledge on coping.

- Stress, appraisal and coping
- Adaptive and maladaptive coping
- Review of effective coping strategies
- Individual coping strategies
- Reappraisal: dealing with change
- Maladaptive coping strategies

Within this session it can be useful to get group members to share what they find helpful and unhelpful. It is useful to remind individuals of the dynamic nature of coping, and how it is very much an individual process which is dependent on choice and circumstance. It can be helpful to identify a situation where a maladaptive coping strategy was used and consider more helpful alternatives that would be better at reducing stress.

Suggested Homework Task:

- Think about the kind of coping strategies you generally use. Are these helpful or unhelpful in reducing the problem and stress?
- Think of one helpful strategy to continue using and to increase, and one unhelpful strategy to reduce.

H. ***Session 7: Social Support***

The final session will consider:

- Social Communication and maintaining social support

Having a disability may have an impact on how one interacts with others socially. Learning how to now deal with people without a disability is important so as to minimise distress, maintain social support, assert needs and aid communication (both verbally and non-verbally). The most common ways of managing situations are through using aggressive, submissive or assertive behaviours.

Aggression. When people behave aggressively, it gives the message that others matter less than they do. Behaviours include being prepared to harm others, and being frequently rude, abusive or sarcastic. Aggressive behaviour may help individuals get what they want in the short term; however, persistent aggressive behaviour can result in hostile reactions from others, social exclusion and reprisals.

Submission . When people make submissive responses they give the message that they do not matter or that other people's needs are more important than their own needs. Being submissive usually requires the repression of feelings, and although it may avoid conflict, the price is being perceived as unimportant.

Assertion. Someone who is being assertive communicates self-respect and a wish to have their own needs met while according equal status to others. Being assertive requires the ability to express how you feel and what you want, as well as acknowledge that your own rights are as important as anybody else's rights. Assertiveness is an important skill that may take time to develop effectively.

Social support can be very helpful when managing and adjusting to an acquired disability. There are different types of social support that serve different functions. Different people will be better at providing different kinds of support. Assessment of the type of difficulty experienced can help determine the most beneficial type of support.

Social support is an exhaustible resource. Like any other resource, if it is not cared for properly it will become less useful or disappear. Maintaining social support can be achieved through rewarding the people who provide support by acknowledging their help and providing feedback about what was helpful and what was less helpful.

In summary, this chapter has highlighted the importance of coping and explored strategies that can be used to manage the challenges of living with an acquired disability. Some of these components, such as problem solving, challenging negative thinking and activity scheduling, can be used when working on a one-to-one basis or in group format.

Tips

A. ***Ground rules***

It is very important in the first session to set the ground rules for discussion, emphasise confidentiality and the need to give everyone the chance to contribute to the discussion. It is also important to engage in rapport building exercises with attendees, such as sharing how they had their injury in pairs.

B. ***Resilience***

It will be useful to harness the coping and resilience experiences of members of the group. Many will have good quality coping strategies that can be shared. Experiences of effectively managing bladder accidents, dealing with physical obstacles and getting support.

C. ***Hope***

It is important to get the balance right between hope and expectation. The **hope is that if something can be done about the illness or injury we should do it,** but the expectation is to get on with life as it is now.

D. ***Never Challenge Denial Directly***

It is never helpful to challenge unrealistic beliefs about ever walking again or finding a cure, better to say, "I don't know about the future, but if you were not able to walk, what would be your personal challenges and how might you go about coping".

E. ***Many of these strategies can be implemented on either an individual basis or in groups***

CET has previously been used within a small group format (six to nine people); although it is thought that it could also work on an individual one-to-one basis.

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Treatment Adherence

48

Nancy Hansen Merbitz

Topic

A. ***Terminology***

- Many topics of concern in rehabilitation research and practice involve adherence, although they are often described by terms such as "participation," "engagement," etc. [1]. Patient adherence is vital to patient health and progress during and after inpatient rehabilitation.
- "Adherence" is preferable to "compliance," a term that is still encountered in medical literature.
  - "Adherence" keeps the focus on the patient as an active collaborator, agreeing to try the recommendations, rather than on the healthcare provider as someone to be obeyed.
  - A central tenet of rehabilitation is that patients should be active partners with healthcare professionals in their own care, thus the concept of "adherence" provides the best fit for rehabilitative efforts.

B. ***What is Adherence?***

- The World Health Organization defines adherence as "the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes corresponds with agreed recommendations from a health care provider" [2].
- Fundamentally, to adhere means to behave in certain ways, and the ultimate aim of adherence promotion is behavior change.
- For patients with substantial impairments and/or complex medical needs, adherence may include acceptance of and cooperation with personal care and procedures, such as catheterization, bowel care, blood draws, imaging, etc.
- At its most basic, adherence in early phases of rehabilitation for some conditions (e.g., high tetraplegia) may mean allowing personal care to be performed by others.
- Adherence is a complex and dynamic phenomenon, particularly within a rehabilitation setting. There is considerable variation in adherence from patient to patient, and in a given patient's adherence over time and different contexts. It should not be regarded as present or absent, since adherence and its promotion involve a sequence of patient–provider decisions and actions [3, 4].

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_48

- Adherence involves awareness and some level of comprehension.
    - Prior to understanding the rationale for recommended behaviors and procedures, the patient may simply acknowledge the provider as trustworthy and give permission, explicit or tacit.
    - The behavior of patients with confusion and/or acute stress reactions should be addressed via modification of antecedents, that is, identify and reduce external stressors and focus on basic levels of support and rapport. Avoid labeling patients as generally 'nonadherent'; some individuals at some time(s) may lack the wherewithal to comprehend and cooperate.
- Among patients during inpatient rehabilitation, adherence (at minimum) may include:
    - Attending therapies
    - Taking medications that are given
    - Following safety plans (e.g., what they may or may not do in their rooms without calling for assistance)
    - Following preventive recommendations (e.g., position changes to prevent pressure ulcers)
    - Following the particular regimen for nutritional intake
    - Tolerating/not interfering with procedures and equipment (blood draws, tubes, intermittent catheterization, turning at night, etc.)

C. ***<u>What Affects Adherence?</u>***

- Given the reported prevalence of nonadherence among patients receiving treatment across multiple medical conditions, some amount of nonadherence to treatment recommendations should be considered normal.
- The determinants of adherence may be conceptualized in terms of:
    - Personal (psychosocial) factors
    - Condition and treatment regimen factors
    - Environmental factors (such as residential environment, availability of safe places to exercise, and availability of sources to purchase healthy food)
- A perusal of psychosocial factors identified in the health psychology literature easily shows their relevance for rehabilitation patients [5]:
    - *Personal Beliefs*: Personal health beliefs, often drawn from family and cultural history, strongly influence health-related behaviors. These include beliefs about the condition, what treatments are effective, and the perceived expertise and authority of the person who recommends them.
    - *Personality Traits and Characteristics*: Tendencies including conscientiousness and neuroticism, as well as perceptions of self-efficacy appear to significantly affect the degree, style, and adequacy of disease management among adults with chronic disease.
    - *Family, Community, and Social Contexts*: Adherence can be impacted by how the family handles different aspects of disease management (e.g., food preparation and medication taking), the emotional tone of family interactions (e.g., hostility and detachment), and the degree of family organization.
    - *Stress and Depression*: Situational stressors can disrupt disease management behavior because of competing demands for attention and energy. Also, there are direct physiological consequences of stressors on pulmonary functioning, cardiovascular functioning, and glycemic control. If clinical depression is present, this has interactive effects on behavior and health that are well documented [6].
- The scope and intensity of treatment demands in medical rehabilitation increases the likelihood of some nonadherence. Many factors known to increase nonadherence are in effect during inpatient rehabilitation, including:
    - The necessity of long-term, persisting adherence.
    - Complexity of the treatment regimen.

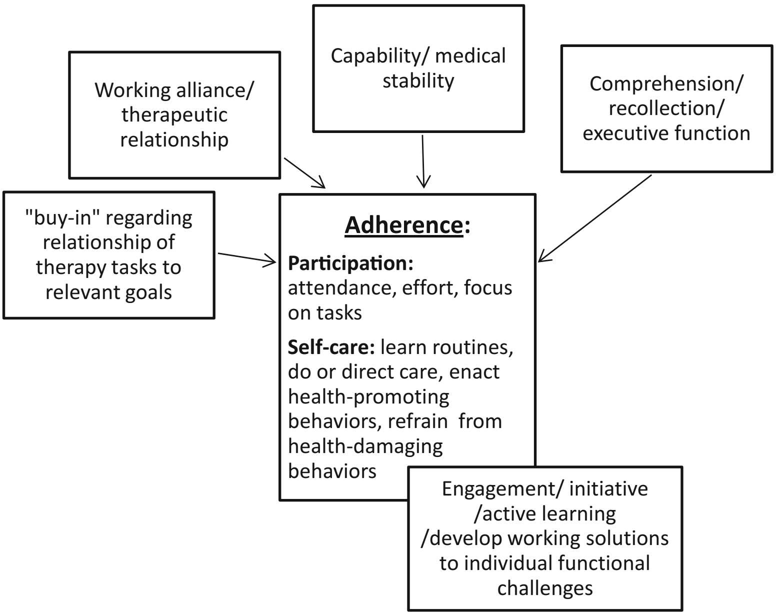

Fig. 48.1 Some components of adherence during inpatient rehabilitation. Engagement entails moving toward a more informed and negotiated adherence; the patient prepares to manage his/her health and circumstances with initiative, reasoning, and creativity. Moving forward from a base of adherence, the patient begins to actively engage in his/her own rehabilitation and life management

  - ○ Doubt about the expected benefits and efficacy of treatment, particularly when the benefits relate to prevention of complications and not cure of the condition itself.
  - ○ Requirement of change in habits and routines.
  - ○ Disruption to usual supports and coping strategies.
  - ○ Threats to identity.
- In addition, rehabilitation patients often face challenges to basic and advanced intellectual capacities (ranging from impaired arousal to executive function) that are necessary for:
  - ○ Awareness of deficits and safety awareness
  - ○ Comprehension and recall of complex material
  - ○ Cognitive and behavioral flexibility
  - ○ Problem-solving
- These challenges to intellectual capacities can arise from:
  - ○ Recent traumatic experience with critical illness/injury and critical care (e.g., acute respiratory distress, mechanical ventilation, sepsis, and delirium)
  - ○ Injuries and/or hypoxic episodes with known or occult brain insult
  - ○ Metabolic derangement(s)
  - ○ Medications and interactions
  - ○ Nutritional deficiencies
  - ○ Sleep deprivation
- Additionally, recent traumatic experiences and losses—with accompanying depressed mood and/or anxiety, can impede the formation of a trusting bond with the treatment team.
- Over time and with varying success for each patient and for each behavioral domain, patient adherence is achieved and may include real buy-in, with full engagement and participation from the patient (see Fig. 48.1)
  - ○ The achievement of patient adherence and engagement typically requires treatment accommodation (individualization of the therapeutic regimen according to patient needs, goals, and preferences) [3].
  - ○ A working alliance with treatment providers strongly enhances adherence.
- Identifying and addressing *systemic* environmental barriers to adherence and engagement, for example, by clustering nighttime cares to promote sleep, can reduce the need for *patient-specific* accommodations, such as having to shorten and simplify rehabilitative sessions for a tired, distracted, and irritable patient who is sleep deprived (see Table 48.1).

Table 48.1 Adherence and engagement in rehabilitation: Barriers and strategies.

Indicators of basic Adherence	Barriers	Facilitators	Indicators of full Engagement
Overall rehabilitation			
Overall good cooperation and attendance: • Therapy sessions and nursing cares are not declined due to mood or interpersonal conflict	Ubiquitous and generally relevant barriers include: • Traumatic stress in the aftermath of injury/ critical illness/ critical care • Sleep deprivation • Pain • Infections • Metabolic or endocrine derangements • Anemia • Cognitive impairment/ slowing • Adjustment reaction • Information overload • Difficulty accepting information • Insufficient rapport with team	Systemic Strategies: • Reduce sleep interruptions, cluster cares • Implement evidence-based pain-management protocols • Implement protocols for monitoring patients' behavior (e.g. cognition, learning, cooperation, mood, participation) • Maintain or achieve sufficient staffing (including Social Work and Psychology) to be able to address difficult adjustment and changes in patients' behavior • Dedicate sufficient resources for team communication to share data and success strategies • All team members: learn basic strategies of rapport-building, listening and teaching (e.g., motivational interviewing) Patient Specific Strategies: • Share data across team; identify problems of this patient • Identify and address barriers, e.g., poor sleep, medication side effects, dehydration, malnutrition, infection, pain medications, family problems, interpersonal conflict with staff member(s), discontinuity in routines across staff	Overall participation: • In goal setting, learning, doing, directing
Personal Care-related activities			
• Accepts personal care without resistance • Learns to do personal care to the extent allowed by impairments • Learns to direct care, and allows appropriate family involvement with personal care	• Privacy concerns • Pain with care routines • Scheduling pressures and time constraints • Differing care routines by different providers • Patient unaware of rationale for the care routines • Patient unable to tolerate short-term discomfort for prevention of complications	Systemic Strategies: • Pay scrupulous attention to basic privacy, e.g., use of curtains, low voice when discussing personal care • Place dedicated time in all patients' therapy schedules for personal care • Follow good practice, e.g., talk with patient about procedures/next steps during provision of care • Reduce discontinuity of staff/patient assignments (including nurses and therapists) Patient Specific Strategies: • Learn this patient's personal care routines, e.g., washing up on commode vs. in bed • Elicit and discuss patient concerns • Explain rationale for routines and procedures; provide encouragement and reinforcement for progress	• Patient requests personal care instruction and opportunity to practice • Participates to the extent possible • Directs routines knowledgeably • Selects family members to assist and helps instruct them

Follows safety precautions regarding: • Infection control • Transfers or ambulation in room • Dietary restrictions • Skin care and pressure ulcer prevention	• Safety precautions and rationale not communicated with team, patient, and family • Patient does not believe or comprehend, due to low health literacy or cognitive barriers • Patient is impulsive • Patient's cognitive deficits are not apparent, or fluctuate; team does not realize need for extra monitoring • Patient is discouraged about the future, e.g., prefers to eat now even with risks • Family not in agreement with precautions	Systemic Strategies: • Establish procedures to communicate information across personnel and shifts regarding patients' safety precautions and observations of patients' behavior/judgment; update safety plan as needed • Enable regular interaction of team members with patients and family via adequate staffing levels and individualized schedules • Encourage families to attend therapies, observe and learn cares • Address barriers to cognitive function (see above) Patient Specific Strategies: • Rehab Psychology / Neuropsychology identifies barriers to understanding and following safety precautions • RN and team develop safety plans, and all team members contribute observations; share plan and rationale with patient and family • Identify and maximize patient's learning capabilities through targeted delivery of information, with repetition/ encouragement provided by multiple team members • Learn patient's preferences, implement enjoyable alternatives for the restricted activities	Patient follows and prompts others to follow precautions: • "Should I wait to eat until they check my blood sugar?" • "I've had my limit of ice chips this hour." • "Can you please recline my wheelchair?" Patient notes acceptable alternatives: • "The pureed carrots are better when they're shaped like carrots" • "The community trip in my wheelchair went fine"
Attendance and performance in therapies			
• Attends therapy sessions • Performs requested tasks as able • Remembers tasks from previous session	Therapy sessions are missed: • Patient is tired or ill • Conflict between nursing care and therapy sessions • "I don't care anymore" Limited participation: • Patient is tired or ill • Patient doesn't recall strategies from previous sessions • Patient in isolation • Patient too anxious to try tasks with less assistance • "I don't need to learn this because…"	Systemic Strategies: • Have daily 'huddles' to discuss high priority issues e.g., tracking patient therapy hours per day/week • Learn about medical factors that can affect energy, cognition, mood • Ensure continuity of staff assignment to learn patients' preferences, note changes in behavior, hear patients' and families' concerns • Promote sleep (see above); ensure staffing levels are sufficient for well-organized nighttime care routines Patient Specific Strategies: • Elicit patient's preferences and goals, share information regarding progress, listen to concerns regarding prognosis • Sufficient numbers of psychologists to provide supportive psychotherapy, help patients process information, review preferences and opinions, and articulate goals to discuss with other team members. As time and role permits, Social Work may do much of the same, with focus on discharge options and barriers • Team members and patient determine how goals, progress, and home resources may enable discharge to home within specific time • Examine modifiable medical barriers, e.g., medication side effects, anemia, malnutrition, sub-syndromal delirium, sleep apnea	• Applies previously learned skills to new tasks • Trusts therapist's judgment regarding when help is or isn't needed • Requests info on progress; asks to do more, but also learns pacing • Discusses relevance of therapy activities for reaching goals • Understands rationale for intermediate goals; accepts activities that may not seem relevant for ultimate goals

(continued)

Table 48.1 (continued)

Indicators of basic Adherence	Barriers	Facilitators	Indicators of full Engagement
Behaviors related to health-promotion			
Follows recommended health behaviors during rehab stay: • No use of tobacco or alcohol • Eats 3 meals daily • Limits sugar /carbs • Up and active every day • Takes medications • Talks with physician and other providers about any questions	• Active withdrawal from tobacco, ETOH, other substances. • Patient may adhere while hospitalized but return to use • Medications may alter taste and decrease appetite, or increase appetite (e.g., atypical antipsychotics) • Stress exacerbates 'comfort eating' • Discontinuity of physician, nurse and therapist assignments hinders relationship-building (crucial to behavior change and maintenance), and hinders delivery of consistent messages about health behaviors • Outpatient services may be limited / not covered by insurance or charity care (especially psychology) • Limited resources after discharge (for housing, personal care, medical and psychological/ social support) can severely constrain adherence and engagement	Systemic Strategies: • Train providers in listening skills and motivational interviewing • Prepare and deliver accessible educational materials, written at no more than a 7^{th} grade level to match average U.S. reading level (also facilitates comprehension for anyone under stress) • Enact continuity of provider assignments to the greatest extent possible • Note the metabolic effects of atypical antipsychotics when considering off-label uses (e.g., insomnia) • Advocate for adequate staffing levels of team professionals (including but not limited to Psychology, Social Work and discharge planners) • Urge your facility to utilize tele-health / tele-mental health to the limit of current policies (stay abreast of these as they evolve) Patient Specific Strategies: • Gather and share information about patient-specific barriers to health management, e.g., history of substance abuse, depression / anxiety, family conflict, low health literacy, financial strains • Plan for outpatient services and referrals as guided by this information • Identify and address barriers to services and community resources	• After discharge, patient follows specific recommendations for ETOH use (no use; moderate use) • Patient with history of ETOH / other substance abuse seeks assistance as needed to achieve or maintain sobriety • Patient with history of smoking does not resume; seeks assistance as needed to achieve or maintain cessation • Follows regular routine of healthy meals and exercise, modified as needed by disability • Able to resist pressures from family/friends to resume former negative health habits

Note: "Environment" is broadly defined, including the social/interpersonal as well as medical, rehabilitative and procedural: everything that is external to the patient, and in which he/she is embedded. For some period of time, the patient lives in that world, and it is up to the rehab team to shape it for optimal results. A patient-specific strategy related to the built environment could include arranging (or assigning) the room so that a patient with severe left neglect is approached from the right as providers enter the room (to encourage orientation and interaction). Providers constitute the interpersonal environment much or most of the time

Importance

- Individuals with chronic, disabling conditions are at risk for a number of health and mental health complications. It has been estimated that up to 95 % of the variation in chronic disease outcomes results from patient lifestyle and disease management behaviors [5].
- Research about adherence generally shows that across a wide variety of settings and in regard to various treatment recommendations, roughly half of all medical patients, in the United States and world-wide, do not adhere fully to physicians' advice [2].
  - ○ Consistent adherence among patients with chronic conditions is low, and drops substantially after the first 6 months of therapy.
  - ○ Nonadherence, and physicians' lack of accurate information regarding their patients' nonadherence, lead to incorrect diagnoses and poorly informed treatment decisions.
  - ○ The consequences of suboptimal adherence are known to contribute to increased morbidity and mortality, and lowered quality of life.
  - ○ Open communication between patient and provider allows for recommendations to be adjusted, based on patient needs and preferences as well as treatment response.
- The success of rehabilitation rests on the ongoing, effortful involvement of the patient. It is clear that many secondary complications may be prevented or delayed according to the quality and intensity of patients' rehabilitation and their adherence to the recommendations and strategies conveyed during rehabilitation.
  - ○ The risk factors for five major secondary conditions (chronic pain, respiratory complications, urinary tract infections, pressure ulcers, and depression) after spinal cord injury include nonadherence to complex preventive guidelines, with pressure ulcers likely having the strongest linkage to behavior [7].
  - ○ Stroke patients are typically encouraged to make major behavioral changes related to risk factors for a subsequent stroke, in the context of some degree of decrement in cognitive functioning in many patients.
  - ○ Patients with TBI are at risk for subsequent TBIs and are counseled on risk-taking behaviors, in the context of some degree of decrement in cognitive functioning.
  - ○ Patients with limb loss typically have a number of comprehensive behavioral risk factors to address, such as managing diabetes and/or hypertension, and are challenged in their ability to follow the typical recommendation for regular physical exercise.
- Results of a very large meta-analysis of research on patient adherence and the outcomes of treatment [8] pointed to the following:
  - ○ On average, >25 % more patients experienced a good outcome by adhering than by not adhering, suggesting that the behavioral phenomenon of adherence may be as important to outcomes as many well-established medical interventions.
  - ○ Good outcomes after adherence may promote subsequent adherence.
  - ○ Notably, adherence is no guarantee of better outcomes, which also rest on the efficacy of recommendations and treatments.

Practical Applications

A. ***Goals and Implementation***

- The aims of adherence promotion among individuals with disability include:
  - ○ *Primary Prevention*: prevent other conditions not yet present, for example, depression, heart disease, and diabetes after onset of mobility impairment).
  - ○ *Secondary Prevention*: prevent conditions at high risk after the disabling condition, for example, pressure ulcers after SCI, falls and fractures after limb loss,
  - ○ *Tertiary Prevention*: manage symptoms of the disabling condition, for example, neurogenic bowel and bladder, autonomic dysreflexia, memory loss, and impulsivity, to reduce their negative impact

  on quality of life and reduce risk of further injury or premature death
- The targets of adherence for patients in rehabilitation are their behaviors, such as cooperation, attendance, effort, and utilization of information and skills. True engagement is the ultimate goal, so that patients are more likely to persist with health- and function-maintaining behaviors after discharge [8, 9, 10].
- The working alliance has been found to predict adherence in TBI rehabilitation [11] and many other diagnoses. The components of a working alliance include:
  - Agreement between client and therapist on goals, and patient perceptions of the relevance of the activities to their needs.
  - Their agreement on how to achieve these goals (common work on tasks).
  - The development of a personal bond between client and therapist.
- Rehabilitation providers, such as OTs and PTs, can learn and apply strategies of motivation and behavior change to obtain concrete, measurable, and clinically significant results, such as greater walking speed and endurance, as well as higher patient ratings of alliance with their therapists [9], by:
  - Increasing time spent eliciting and addressing patient goals
  - Increasing rehabilitation intensity (focus on efficient time use)
  - Providing frequent feedback to patients on their effort and progress
- While no clear evidence supports any one theory as a basis for adherence interventions, there is evidence for a combination of interventions in a team approach [12, 13]. This is, of course, highly relevant for the team-based interventions of rehabilitation. Effective interventions often include:
  - Identification of adherence-relevant barriers and resources
  - Provision of consistent prompts and reminders
  - Instruction and practice opportunities to enhance specific skills, problem-solving, and self-efficacy
  - Encouragement and enablement of self-monitoring
- Comprehensive interventions, combining cognitive, behavioral, and affective components, have proven more effective than single-focus ones [13].
  - Affective components involve the provider–patient relationship and focus on issues such as empathy, attentiveness, care, concern, or support.
  - The addition of affective components to behavioral and/or educational approaches appears to enhance the effectiveness of the interventions.
  - The relationship between the patient and the healthcare provider (physician, nurse, or other health practitioner) must be a partnership that draws on the abilities of each.
  - Effective treatment relationships are characterized by an atmosphere in which alternative therapeutic means are explored, the regimen is negotiated, adherence is discussed, and follow-up is planned.
  - Meta-analysis of individual and family psychological interventions has shown that behavioral and multicomponent approaches also promote adherence in pediatric populations [14].
  - Ideally there is a shared “blame-free” perspective, normalizing nonadherent behaviors and providing aids to adherence.
  - Communication in healthcare is strongly related to better outcomes, and training providers to communicate well enhances their patients’ adherence. This includes relationship building and collaborative goal setting [15].

B. ***Data and Measurement***

- Continuous rather than dichotomous measures provide greater power to detect differences in adherence and outcomes [8]. Whenever possible:
  - Use measures to track adherence and outcomes that are continuous.
  - Use more than one measure of adherence, including self-reports.

- Regarding data to track adherence, consider the following options:
    - Minutes of therapy and number of missed sessions
    - Number of reps of an activity in PT or OT
    - Patient self-tracking of selected activities
    - Frequency of pressure lift-offs during encounters with various team members
    - Patient statements indicating acceptance of rationale (e.g., for NPO restrictions)
    - Frequency of impulsive behaviors, for example, violating safety recommendations such as not locking wheelchair, standing without asking for help, requesting food when NPO
- For more global assessment, consider standardized rehabilitation-specific measures such as the Pittsburgh Participation Scale, the Rehabilitation Therapy Engagement Scale, and the Hopkins Rehabilitation Engagement Rating Scale [16].
- Social problem-solving abilities are implicated in the development of secondary complications, for example, pressure ulcers [17]. Persons with ineffective problem-solving abilities might benefit from psychological services including assessment of knowledge and skills, with counseling for education and practice as needed.
- Data gathering and data sharing can be incorporated into processes of relationship building, goal setting, and the promotion of adherence [18]. Adherence is observed in the learning, acceptance, and use of compensatory strategies, and patients need data in one form or another to do this.
    - The methods of Collaborative Therapeutic Neuropsychological Assessment [19] promote acceptance of deficit-related information and patients' understanding of the need for compensatory strategies.

Tips

- Help your team view their own behavior as a modifiable feature of the patient's environment.
- Help your team avoid making the Fundamental Attribution Error [20]:
    - "My own less-than-optimal behavior is due to external or temporary factors, but my patient's less-than-optimal behavior is due to his internal and enduring traits;
        - he doesn't really have a good work ethic,
        - he's unmotivated, and has a difficult personality."
- Consider that patients' objections and nonadherent behavior may indicate:
    - A need for more dialog
    - More demonstration
    - Modification of communication strategies
    - Modification of the rehab/care plan
- Since individual, familial, and cultural factors play a large role in adherence, which plays a central role in rehabilitation outcomes (including safe and timely discharge), do not shortchange psychosocial factors in team discussion during staff meetings.
- Remember that patients in rehabilitation are probably not at their best (whatever their baseline), in terms of cognitive, psychological, and interpersonal functioning. Make it your goal to provide the optimal learning and healing environment for this patient at this time.
- Learning proceeds by reinforcement. Be a reinforcer.

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Managing Challenging Behavior in an Inpatient Setting

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Thomas R. Kerkhoff and Lester Butt

Topic

Challenging behavior, considered in the context of the psychosocial milieu of an inpatient rehabilitation program, can be any behavioral pattern that disrupts the provision of rehabilitation services and/or compromises safety. Operationally defining challenging behavior requires that the reader adopt a wide-ranging perspective regarding behavioral difficulties in the rehabilitation process. Behavioral expression of neurological insult resulting in either agitation or lethargy, emotional distress in response to disability demonstrated via maladaptive behavior, chronic behavioral patterns reflecting psychological intolerance of disability, or lack of a socially acceptable behavioral repertoire can result in challenging behavior when an individual is admitted to a highly structured, performance-based treatment program.

The social expectations of compliance with operational rules and performance demands are a given in any health care treatment program. Indeed, the current health care environment of limited access to rehabilitation services and limited lengths of inpatient stay based upon diagnostic actuarial algorithms do not account for challenging behaviors that impede the treatment delivery process. These result in increased pressure upon the rehabilitation team to actively engage the patient in the rehabilitation process on a consistent basis or risk discharge before program goals have been met—independent of the cause of program difficulties. While medical complications and comorbid health conditions are accommodated in terms of specialist consultations and transfers to acute care for treatment and length of stay extensions, behavioral 'complications' are not imaged on the health care system's radar screens. Nevertheless, they need to be integrated into a truly holistic health care model.

Importance

The clinical issue of the treatment team effectively and constructively responding to challenging behavior in the context of a comprehensive inpatient rehabilitation program is a daily concern, especially in programs serving individuals with significant acquired physical and/or cognitive impairments. While treatment team members are acutely aware of individuals who are noncompliant, nonparticipative, assaultive, or demonstrate inappropriate social behavior, the varied programmatic impacts of maladaptive behaviors

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_49

are typically not gathered in a comprehensive manner. More importantly, these data are not systematically included in any widely used program outcome measures routinely employed in the field of rehabilitation. Thus, the incidence of challenging behavior, the extent of its negative effects upon treatment program participation and the broader rehabilitation process are not reflected in national outcome data repositories—which prototypically provide the impetus for self-corrective processes of formal program evaluation, ongoing quality improvement, and policy development. Further, development of effective behavior management interventions remains ensconced at the level of the treatment team, perhaps presented in case study poster sessions at conferences, but rarely subjected to rigorous evaluative multicenter research. The potential consequences of program noncompliance or nonparticipation are acquired secondary complications, reduced quality of life, and compromised staff job satisfaction. Addressing these challenges directly and constructively can help to ameliorate these issues.

In addition to the important role that challenging behaviors play in disrupting rehabilitation and compromising the safety of individuals with disabilities and their care providers is the risk to patient and family relational stability. The observation of maladaptive behaviors by family members can engender self-doubt regarding their ability to successfully manage caregiving in the immediate situation, and often for an ill-defined span of time into the future. Observing a son or daughter in the midst of an agitated, combative episode attempt to injure staff members trying to assist them, or observing a spouse's neglect to cooperate in preventing formation of a decubitus ulcer serve to remind the family of the fundamental behavioral changes that have occurred and the complex caregiving responsibilities they face. These behavioral changes can threaten the foundations of the family caregiving system that allows the patients to return safely to the community. These behaviors can reflect altered personal identity, essentially rendering them 'familiar strangers' to the persons integral to their care and support.

Rehabilitation programs rely on patient populations of compliant, task-focused, hard-working, emotionally balanced, and socially engaged individuals, who efficiently navigate the goal-setting process and demonstrate consistent functional performance gains in activities of daily living and mobility. Functional benefits that accrue to these individuals stem from the efficient treatment delivery system that has evolved in the field of rehabilitation across the past half-century.

Fortunately, this optimal patient description fits the majority of individuals who successfully complete rehabilitation programs. It is those patients who are behaviorally challenging that place an inordinate burden upon the limited resources available to rehabilitation programs, consequently reducing the pool of those available resources and the efficiency of service provision. This burden is primarily defined in terms of staffing levels and patient contact (increased frequency and duration) and can include assignment of therapeutic behavioral attendants across multiple shifts; assigning multiple staff members to an individual to assist with transfers and personal care; providing personal support and education to family members struggling with caregiving skills acquisition and emotional adjustment; scheduling 'make-up' treatment sessions when scheduled sessions are missed because of noncompliance—often requiring overtime or volunteered staff time to accomplish; and additional staff meetings focused upon developing and refining behavior management strategies. With modest staffing models currently populating the rehabilitation landscape, these resource demands quickly stress already strapped salary and resource budgets.

Thus, challenging behaviors that result in suboptimal rehabilitation program engagement can take a significant toll on individual patients, their social support systems, and on the health care system. The practical goals of this chapter are to assist the reader in identifying factors that can trigger challenging behaviors and to offer intervention strategies to ameliorate the effects of maladaptive behavior in the rehabilitation setting.

Practical Applications

This section commences with descriptions of various categories of behavioral challenges from the perspective of underlying factors. However, this summary by no means subsumes all possible variations of challenging behavior experienced in the context of rehabilitation treatment. The reader is encouraged to investigate the etiological influences that underlie the individual's expression of behavioral challenges. This investigation is recommended prior to crafting an intervention to modify maladaptive behavior, as strategic approaches will vary considerably across categories and people predicated upon etiology and patient history. It is critical for the clinician to understand that behavioral challenges are treated as separate from clinical presentation of signs/symptoms of specific health conditions. The pivotal concept central to behavioral challenges is that either consistent rehabilitation program participation or patient, family, and/or staff safety are at risk.

A. ***<u>Cognitive Impairment</u>***

   Individuals sustaining neurological insult related to injury or illness can experience a variety of behavioral sequelae stemming from neural network disruption [1]. In overview, if facilitative neural circuits are affected, the patient can become lethargic, responding minimally to the physical and social environmental stimulation, with generalized slowing of cognitive processing. In cases of inhibitory neural circuit disruption, the patient can become agitated, impulsive, combative, or assaultive (also with negative effects upon cognitive processing—for example, inattention, impaired new learning and recall, and impaired complex reasoning). More localized injury and illness effects can result in discrete cognitive processing impairments that can impede attention and concentration, acquisition and retention of new information, motor function, sensation and perception, language utilization, and complex reasoning. All of the above factors slow the process of generalizing beneficial rehabilitation treatment effects from the health care setting to home environments, and typically require some level of physical assist and/or supervision from caregivers.

1. **<u>Intervention Strategies: Generalized Cognitive Impairment</u>**

   a. *Agitation/impulsivity*

      Patient, family, and staff safety is the most pressing need to be addressed by the treatment team. Providing the patient with a predictable, minimally changing daily routine and staffing pattern throughout this early period of neurological recovery is paramount. Minimizing sensory/perceptual overstimulation is accomplished by reducing environmental stimulus intensity—for example, lowering ambient lighting, eliminating use of electronic broadcast and communication devices, providing one-on-one staff care and treatment in a noise-abated area (with a back-up staff person available to prevent safety compromise), use of adaptive equipment (e.g., a Vail bed to reduce fall risk and provide restricted perceptual degrees of freedom, thereby reducing confusion) and ensuring adequate sleep–wake cycle restoration via medication management. Tracking the accuracy of acquisition and carryover of relevant information across treatment sessions and days is a priority, as these data are indicative of cognitive recovery. Use of psychotropic medications for behavioral control is considered a form of restraint, requiring close monitoring and discontinuation at the earliest possible opportunity. Such pharmaceutical agents, intended to provide control over potentially harmful behavior, should be carefully evaluated for side effects negatively affecting cognitive processing, with continued use dependent upon preservation of adaptive cognitive function [2].

   b. *Lethargy*

      The treatment team's focus will shift to providing a stimulating social and physical environment at appropriate times during the sleep–wake cycle, in an attempt to incrementally boost activity level. Again, offering the patient a predictable daily activity schedule and treatment team staffing will assist with acquisition of cognitive orientation. Discussing with family or significant others the patient's premorbid likes and dislikes can assist with creating positive stimulation strategies that reinforce cognitive activation.

c. *Tracking Observational Data*

Daily cognitive processing accuracy and carryover of new information will alert the team to changes in neurological status. While use of stimulant medication is not typically considered a restraint, careful monitoring for signs of seizure activity, overactivation, or other cognitive function compromise is paramount for patient safety [2].

2. **Intervention Strategies: Localized Cognitive Impairment**

Intervention strategies for localized cognitive impairment will be highly variable, given the complexity of brain network interactions. Some examples of challenging behaviors may include abrupt onset of suspiciousness and/or paranoid thinking with nondominant hemisphere lesions; confabulatory thinking with anterior communicating artery lesions; perceptual neglect syndromes with visual sensory pathway lesions (typically unilateral); and emotional dyscontrol with basal ganglion or dominant temporal lobe lesions affecting limbic circuitry. The variety and quality of such challenging behaviors must be considered as unique patient-specific events, requiring generation of intervention strategies consonant with the individual patient's clinical behavioral presentation. Again, we emphasize that clinical behavioral presentation of signs/symptoms of neurological conditions or syndromes does not necessarily warrant the label of behavioral challenge, unless program participation and/or patient, family, and staff safety are compromised.

B. ***Emotional Adjustment: Absence of mental health history***

Individuals struggling to cope with new onset functional loss in the face of injury or illness can express this emotional adjustment process in multiple ways, varying from no appreciable change from emotional baseline to clinically significant signs/symptoms of emotional distress—perhaps significant enough to meet diagnostic criteria for mental health disorders [3]. Emotional resilience [4] in the face of significant changes in function will often influence the likelihood of emergence of challenging behaviors. Obviously, the severity of emotional reactions to disability will influence the probability of challenging behaviors occurring in the rehabilitation setting.

Factors affecting behavioral expression of emotional reactions can include previous experience of significant health compromise (positive or negative); family system integrity and presence of adaptive or maladaptive social support networks; presence of peer mentorship opportunities for relationship experience with an individual or individuals with disability; and the culture of physical and psychological healing within the rehabilitative setting. Additionally, demographics including gender, age, education, socioeconomic status, and vocational status may also affect emotional resilience [5, 6].

Any interventions in the rehabilitation setting must be based upon a trusting relationship among the patient, family members, and the health care professional (as a representative of the rehabilitation program). Trust-building is a process that must begin with the first contact. This can be fostered by open, honest, caring interactions that communicate interest in the patient and family in the context of their unique attributes and needs. Trust in an ongoing positive working relationship is realized and reinforced when the patient and family members understand the treatment rationale and experience consistent team behavior management plan implementation across all shifts coupled with consistent staffing (including requisite staff respites if behavior is highly challenging).

For the sake of simplifying the presentation of intervention strategies, behavioral challenges will be divided based on emotional drivers: anxiety-fear/apprehension; depression/sadness; and anger/frustration.

1. **Anxiety-Fear/Apprehension**

   Individuals who resist program participation are often fearful of becoming active after orthopedic and soft-tissue injuries, spinal cord compromise (neurological injury), or postsurgical sequelae, in which pain and/or sensory motor activity are the early somatic indices of disability. Movement, even passive movement, resulting in pain can trigger an overly cautious response in the patient to remain immobilized to avoid perceived harm. This protective somatic reaction, amplified by fear and coupled with reduced ability or inability to voluntarily activate varied muscle groups, and further complicated by possible sensory alteration from affected body parts can induce rehabilitation program nonparticipation. Thus, such self-protective reactions can be considered an understandable fear response, amplified by pain, and often coupled with ruminative anxiety regarding recovery probabilities and potential unrealistic catastrophic ideation.

   a. *Reduce Physiological Reactivity*

      Coupled with effective acute pain management, addressing the underlying emotional overactivation is often the first step in reducing the physiological effects of anxiety. Presenting the patient with instruction in protective body mechanics and relaxation techniques, and ensuring adequate practice—both within and outside treatment sessions—will assist with calming the somatic system.

      The ideational component of anxiety can be addressed by providing realistic and balanced information surrounding their health-related expectations. Self-assessment tools can be utilized by the patient to track progress toward recovery of functional abilities. In addition, exploration of automatic thoughts that give rise to false assumptions with consequent physiological and psychological reactivity need to be appreciated.

      Since progress in rehabilitation treatment is measured in small incremental steps, orienting the patient to this method of self-assessment will assist with realistic self-appraisal, as well as mirroring the evaluative style of the treatment team members. It is likely that this process will require time for both the physiological and informational results to become evident to the patient. Therefore, daily selective social recognition by each member of the treatment team in response to the patient demonstrating effective task focus and engagement in the activation process is recommended, even if the adaptive behaviors are initially infrequently or minimally demonstrated.

   b. *Medication for Anxiety/Pain*

      Use of anxiolytic medication (see the chapter on Practical Psychopharmacology for a more detailed discussion) to augment pain control and treat physiological symptoms or anxiety can be an adjunctive treatment to behavioral intervention. In cases of neuropathic pain, medications (e.g., gabapentin or pregabalin) can provide added anxiolytic relief. However, the most commonly used anxiolytic agents (benzodiazepine family) have abuse potential and interact negatively with narcotic analgesics—for example, risk of respiratory depression [2]. Nonetheless, for adjunctive treatment of clinically significant acute anxiety that impedes rehabilitation program engagement, a short carefully monitored course of benzodiazepines can be useful. Once the acute anxiety reaction subsides, this medication can be tapered across 1–4 weeks to reduce risk of dependence. Concurrent use of SSRIs (selective serotonin re-uptake inhibitors) can be started along with the benzodiazepine medication because of their several-week treatment effect delay. Assuming that the latter medication proves effective, it can then be continued after the completed benzodiazepine taper and discontinuance.

2. **Depression/Sadness**

These reactions are another variant of emotional responses to functional loss. Feelings of hopelessness, inability to meet physical performance expectations, occasional suicidal ideation (in the absence of intent/plan/means), perceived social stigma, and feeling overwhelmed by the prospect of returning to the community with functional limitations are common emotional reactions that can trigger behavioral challenges to participation and safety.

Cognitive Behavior Therapy and Motivational Interviewing are evidence-based interventions that have strong bases of support in the research literature, but require competency-based training on the part of the health care provider to administer. While psychological services are typically available to the patient and team, other team members gaining facility with general supportive strategies helps to promote efficient initial responses to patient distress. Rehabilitation team members can facilitate emotional adjustment in individuals with depressive or sadness reactions by engaging in the following intervention strategies.

a. *Behavioral Activation*

Depression and sadness are often characterized by inactivity, a pessimistic view of the current health condition, tearful lability, perceived reduction in quality of life, and the belief that being active may actually be harmful in the context of recovery from illness or injury. The first step is trying to supportively alter this maladaptive belief system in the context of the rehabilitation process. Activating the patient, initially via small steps, begins the resolution of the negative emotional reactions and exploration of false assumptions that may underlie inactivity. With the gradual increase in the level of tolerated activity, misconceptions about performance limitations may diminish, thereby building cautious optimism upon initial functional gains. Offering initially conservative predictions about the patient's performance achievements, in line with the constraints of the person's health condition, sets an expectation of a typical or normalized recovery process in light of previous rehabilitation experiences working with patients under similar conditions.

Again, the critical precondition for this approach is a trusting relationship with the patient. Taking the first steps toward activation requires the patient's substantial trust in the health care provider to possess the necessary expertise and to proffer protection against further injury. Once the initial activation occurs, selective reinforcement of patient initiative and actual performance results helps orient the patient to program priorities. Ultimately, the patient and staff sharing responsibility for the direction and management of treatment activities helps to generalize adaptive behavioral responses. Brief nontreatment-contingent supportive social contacts with the patient outside treatment sessions can further reinforce the adaptive nature of social engagement and the expectation of further functional gains as treatment progresses.

b. *Medication for Depression*

Use of antidepressant pharmacologic agents, coupled with cognitive-behavioral psychotherapy is strongly supported in the literature (e.g., Keller, McCullough, Klein, et al. [7]). Low-dose activating agents (SSRIs and SNRIs—selective norepinephrine uptake inhibitors) appear to be effective in ameliorating depressive signs and symptoms [2]. They can be especially effective with moderating aggression and irritability and have fewer side effects than antipsychotic medications. However, when activating agents are not sufficient for controlling irritability and agitation, particularly when paranoia or psychosis are present, low-dose atypical antipsychotics can provide relief. Other agents for treatment of aggression and agitation, like anticonvulsants and beta-blockers are reviewed in the chapter on Practical Psychopharmacology in this handbook.

3. **Anger/Frustration**

Intervening with individuals who express clinically significant anger/frustration to the point that challenging behavior occurs requires prioritizing time for thorough evaluation of baseline emotional response to distressing life situations.

a. Interview/History

During history taking, look for a pattern of outwardly directed emotion—including projective blame, threats of retribution, claims of malpractice, etc.—indicative of externalizing causation for disability. Family and other support system constituents can often provide historical information that qualifies the patient's angry reactions to life challenges observed at admission to a rehabilitation program.

It is important that the patient understands the reciprocal networked system of communication extant in rehabilitation programs. When family and other individuals from his/her support system become involved in the rehabilitation process, patient informed consent to such open communication is required for ethical practice. Most individuals will opt for truthful communication of priority information, even if the content is negative. However, failure to obtain patient consent for information sharing with family or the team will constrain the rehabilitation team process, with predictable negative consequences on program quality. At the same time, patient confidentiality regarding personal information must be defined and respected unless there is substantial risk of harm to the patient or others. The patient's understanding of the limits of confidentiality is a critical initial step in relationship building. It is incumbent upon the clinician to exercise discernment regarding issues that warrant communication in confidence.

b. *Previous Abusive Behavior*

During interviews, specifically ask for incidents in the past where compensatory skills allowed the patient to constructively channel potential frustration and aggression into more adaptive expressive modes. A key consideration at the time of initial evaluation is a history of abusive behavior (verbal and/or physical). This factor can provide valuable safety-related information for the team to be factored into the treatment planning process.

The treatment team is encouraged to define themselves and the rehabilitation process as a means of reversing the recent trend of functional loss from illness or injury toward a pattern of functional gain—attempting to conceptualize the rehab team as allies in the path toward functional and psychological gains. The treatment team cannot realistically address perceived wrongs perpetrated upon the patient, but can redirect all supportive and treatment efforts toward regaining or compensating for functional losses.

The concept that the process of achieving functional gains requires a partnership between the patient and team members brings the concept of adaptive working relationship into sharp focus for the patient. The rehabilitative model is a collaborative construction of a shared vision. Accompanying this working relationship is a set of behavioral limitations—social rules—that cannot be violated without risking the therapeutic partnership. For example, emphasizing a mutually respectful working relationship allows effective, emotionally unfettered communication and increases the likelihood of adaptive goal attainment. It is critical that team leadership be prepared to enforce these behavioral limits when necessary in a consistent and equitable manner. Inviting questions regarding the rationale underpinning each facet of the individualized, planned patient treatment program is critical to avoiding misconceptions about team intent. Assuring the patient that all treatment plan decisions will he made collaboratively in concert with him/her and their treatment team is also emphasized. Finally, communicate that any evaluative findings—positive or negative—will be openly shared with the patient to ensure adequately informed and collaborative decision making—the spirit of the rehabilitation process.

C. ***<u>Emotional Adjustment: Presence of mental health history</u>***

In the experience of the authors, it appears almost counter-intuitive that patients who are admitted to rehabilitation programs with histories of a variety of mental health problems often respond well to the predictable operational structure of the rehabilitation process. Several potential factors can contribute to the positive reactions of these individuals to rehabilitation.

1. **<u>Maintain Prior Treatment</u>**

First, it is strongly recommended that any predisability efficacious medication regimen is maintained. At times, pharmaceutical treatment may require adjustment in response to new life stresses linked to the disabling condition. Bearing that in mind, access to psychiatric consultation services is a necessity.

2. **<u>Provide Education/Reassurance/Orientation/Concrete Tasks</u>**

Second, the initial contact by team members with the patient should provide supportive information about rehabilitative and behavioral expectations, reassurance of assistance and support in all treatment activities, and detailed descriptions of the predictable nature of the daily treatment schedule. Attempt to communicate with the patient in nontechnical language, avoid health care jargon, and assess patient comprehension of shared information. When medically feasible, accompanying the patient on a tour of the rehabilitation facility will assist with adapting to a new set of daily living parameters and the novel physical environment in which activities will occur. Orienting the patient to tasks and activities, as well as new treating staff members, will begin the familiarization process. Repetitive structure and event predictability instill a sense of comfort in individuals whose lives have been in chronic emotional turmoil.

Finally, focusing upon concrete, measurable functional tasks, as is typical of the rehabilitation process, provides the patient with frequent and conceptually accessible information about how they are functioning. Importantly, admission to an inpatient rehabilitation facility is not a psychiatric admission, focused upon modifying emotional disturbances. Rather, a rehabilitation admission serves as an experiential event occurring in a sector of the health care system that emphasizes and reinforces adaptive everyday living. Acceptance and normalization of functional challenges and altered self/body image by the treatment team often circumvent social stigma that accrues to individuals with mental health conditions. In a very real sense, the intensity of the clinical presentation of mental health problems negatively affecting these individuals' community living contexts is often minimized during rehabilitation admissions by virtue of the treatment team's 'can do' problem-solving approach to the challenges of daily living in the face of disability.

3. **<u>Caregiver Issues</u>**

This predictable and highly structured approach to enhancing everyday living in individuals with prior mental health histories can also translate into reducing caregiver burden. Asking family and/or significant other caregivers to frequently attend treatment sessions will provide them with nuanced caregiving strategies to augment those already employed in the home. Additionally, the caregivers' sharing of successful caregiving strategies employed prior to rehabilitation admission can assist the treatment team in providing services to the patient in a manner that is consistent with effective baseline function, making good use of task familiarity.

D. ***Program Noncompliance***

When patients and/or family members are not compliant with rehabilitation program expectations, the clinician must investigate the contributing factors. A multiplicity of such factors may apply in any given situation. Several examples follow.

1. **Misunderstanding**

   The first involves misunderstanding the purpose for the admission and/or the performance expectations of the rehabilitation process—this could relate to lack of pertinent information communicated prior to admission, mismatched functional goals, or unvoiced patient and family doubts about ability to tolerate performance demands. In such cases, a review of the educational components of the preadmission process is in order, especially as that initial patient contact seeks to both educate and reassure the patient and family about the value, realistic goals, and expectations of rehabilitation.

2. **Relationship Management**

   Patient–health care provider relationship management is a relevant consideration. A reciprocal working relationship is key to facilitating program participation and optimizing effort during treatment. Modeling reciprocity by treatment team members can be achieved through 'give and take' during the initial interview. Sensitive listening to patient and family needs and preferences, balanced with clear communication regarding the program engagement expectations is a first step toward trust-building, the foundation for a productive rehabilitation admission.

3. **Staff Relationships**

   Patient and family familiarity with all levels of facility staff with whom they interact is important. Patient and family members may develop 'special relationships' with selected staff by virtue of the variety of social skills and personality characteristics that they will encounter, and the variability of patient and family social preferences. This social process is a normal part of congregate living, as long as this selective affiliation does not result in staff-splitting or social manipulation of staff or peers that interferes with program engagement. Should the latter occur, flexibility in staff assignments is a priority, with a goal of adaptive matching of patient and staff characteristics. A protective stance is recommended regarding patients who find themselves immersed in conflictual relationships with fellow patients or staff. Additionally, in-service instruction for the staff regarding these kinds of complex relationship issues will assist the rehabilitation facility staff in deflecting development of maladaptive relationships when first detected, and in crafting acceptable solutions without alienating the patients or family members.

4. **Flexibility**

   Treatment regimen flexibility is a fourth example. The tradition of accommodating individual differences is a hallmark of the rehabilitation process. Patients will sometimes respond with noncompliant behavior when treatment plans are mismatched to their needs. Each individualized treatment plan attempts to account for differential patient performance capabilities, in order to properly address performance issues linked to health conditions, including endurance, strength, treatment modality tolerance, etc. The process of individualizing treatment requires thorough knowledge of underlying health conditions, comorbidities, baseline activity level, intervening psychosocial variables, etc. Additionally, the current structure of the US health care system dictates limitations on length of stay by diagnosis (further complicated by complexities of the health insurance cost reimbursement authorization process), all of which can influence how aggressively the treatment team approaches particular patients. Just as it is patently absurd to expect severely health-compromised patients to perform above their measured capacities, it is likewise an injustice to the patient with minimally disability to remain in the rehabilitation facility beyond the timeframe of program goal achievement in order to adhere to externally prescribed lengths of stay.

This illustration supports the validity of levels of care characterizing the rehabilitation continuum (acute hospital intervention, acute inpatient rehabilitation, subacute rehabilitation, and home health care/outpatient treatment) designed to meet the varying health needs most representative of the general population. Securing optimal program compliance demands matching patient needs/preferences and performance abilities to program intervention type, intensity, and duration.

5. **Sociocultural factors**

For the fifth example we consider sociocultural factors. These are myriad in expression, but can be exemplified in beliefs grounded in ethnic, spiritual, and family traditions. The fundamental requisite in this regard is staff and organizational sensitivity to such behaviorally influential factors. Importantly, sociocultural influences represent the community context to which the patient and family will return at discharge from rehabilitation. Treatment relevance for patients and families is often evaluated against this contextual backdrop. To the extent that rehabilitation treatment is relevant to sociocultural belief systems and traditional practices, generalization of treatment gains to the community will be facilitated.

Instances of program noncompliance linked to sociocultural factors can be adaptively addressed with the cooperation of family members or other representatives of the patient's cultural niche. When enlisting community resource input, thorough explanation of the rehabilitation process, goals to be achieved and methods for goal achievement must be communicated in understandable language. Conversely, the rehabilitation team must be open to incorporating sociocultural accommodations into the treatment process as possible to increase personal relevance for the patient and family.

6. **Organizational factors**

The final example is found within the health care organization itself. Depending upon the nature of organizational philosophy and culture, program compliance can be affected by staff members' (functioning as organization representatives) rigid and unswerving implementation of policy and procedure. In organizations heavily focused upon revenue production [8], time and cost efficient staff performance is the critically important revenue generator. This business approach requires the assumption that patients are consistently compliant with all treatment evaluations and interventions, moving smoothly through the treatment process. Patient noncompliance for any of the above reasons cannot be tolerated for any length of time, as staff productivity will be negatively affected. Pressure to perform can be applied to the patient in the form of an unfortunate ‘ultimatum’ from the team—“perform or discharge.” Such a situation harms both the organization and the rehabilitation process as a result of an unnecessary and avoidable contentious working relationship with the patient/family.

While it is rarely the case that organizational policies and procedures are worded or intended to be draconian in nature, how those organizational rules and regulations are interpreted and implemented by the staff is vitally important. In order to decrease the incidence of misinterpretation, health care organizations have instituted mandatory in-service programs and as-needed staff meetings to clarify policies and procedures—however, these events are often reactive to a patient or family incident. In some instances, revisions of these documents are undertaken when misinterpretations frequently occur. It is the goal of every health care organization for procedural changes to occur before the risk management or legal systems become involved, thereby avoiding or ameliorating patient and family distress. Organizational management, in parallel with the treatment team, must set an example for high-quality care, strong professionalism, and personal relevance for each person served, as well as the community at large.

Tips

A. ***Pick Your Battles***

Given shorter lengths of stay and specific regulatory requirements for program participation, pick your battles carefully. Behavioral challenges that present as signs/symptoms of early neurologic recovery (agitation or lethargy) will typically resolve across several weeks of an acute inpatient rehabilitation admission as a function of the natural healing course. Directing and monitoring the challenging behavior to emphasize patient, family, and staff safety is the program priority. On the other hand, maladaptive behavior reflecting chronic psychological problems (noncompliance, socially inappropriate behavior, and self-defeating behavior) will not likely be amenable to significant behavioral modification during a typical short length of stay admission. Simply securing the patient’s minimally acceptable threshold of cooperation with treatment requirements under the rationale of personal benefit is recommended. Finally, appropriate referral to community-based resources is then advisable.

B. ***Delayed Hydrocephalus and Seizures***

When dealing with neurological insult, fundamental considerations as recovery unfolds are the possibilities of delayed hydrocephalus and/or seizures [9]. In the former instance, the patient will most often demonstrate a functional decline in basic motor, balance, and coordination function, typically involving postural trunk control. Should such signs occur, immediate acute emergent evaluation and possible transfer to an acute medical setting is recommended. Regarding seizures, the team should be observant for any type of seizure activity—varying from absence episodes through grand mal types. While it is standard of care to offer prophylactic antiseizure medication to such patients for several months post event, dosage is dependent upon presence or absence of early seizure activity. Management of such medications can occur in the rehabilitation facility, with neurological consultation or acute hospital transfer typically required for uncontrolled seizure activity.

C. ***Measure Functional Change in Small Increments***

The patient’s metric for recovery is most often return to preillness/injury level of function.

Any divergence from that goal, realistic or not, in the context of the disabling condition can be interpreted as catastrophic failure. Assisting the patient in adopting the rehabilitation professionals' perspective of measuring functional change in small increments will provide an adaptive alternative metric for increasing self-appraisal accuracy. Proactive provision of frequent functional achievement updates via informational feedback is an important part of daily interaction with patients, some of whom are reluctant to query in this regard. In addition, denial can provide an adaptive function by emotionally insulating patients from being overwhelmed by their health circumstance. As a result, the patient can hopefully integrate information in a personally constructive manner across time, with focused team support.

A role for the rehabilitation professional is the fostering of realistic hope wherein accurate appreciation of typical recovery curves and time lines are considered. The message is to work collaboratively with the rehabilitation team toward maximal recovery of physical and psychological functioning. The guarantee is not a specific outcome; in contrast, the emphasis is upon utilization of collective expertise, time, and staff energy toward attainment of optimal rehabilitative gains.

D. ***Cultural Variability in the Expression of Emotionality***

Cultural variability in the expression of emotionality is noted in rehabilitation patient populations. In instances where strong and sustained vocal expression of emotional distress occurs, a novel strategy is suggested. Based upon the premise that yelling, screaming, or crying out in a congregate treatment environment like a rehabilitation gym will cause distress in other patients, ask the emotionally vocal patient to 'scream on the inside.' Patients engaged in this habitual emotional expressive style typically do not want to cause distress in their peers. This behavioral approach has the adaptive effect of acknowledging the patient's need and habit of vocalizing emotional distress and provides a socially acceptable manner in which the emotional expression can occur. Several successful case examples in the experience of the first author have demonstrated the usefulness of this approach. However, if this strategy proves impractical for the patient, it is recommended that a more isolated venue in which to treat the individual is secured; thereby allowing the more 'customary' mode of affective expression, while minimizing collateral peer distress.

E. ***Behavior Management Guidelines***

Behavior management guidelines are tools that the clinician can provide the rehabilitation team to organize and facilitate management of challenging behavior. This tool has two components: contextual information regarding the individual patient and family (if pertinent to clinical management) that presents relevant historical, evaluative clinical, and observational data in brief tabular summary form to the treatment team, and specific behavioral management strategies that build upon the data presented.

Offer alternative strategies if possible and encourage ongoing interaction among team members to modify the strategic alternatives until adaptive behaviors (program engagement and patient safety) are reliably observed. Serial modified iterations of these guidelines can be generated in response to newly observed undesirable behavioral manifestations. These guidelines are documented, along with evaluative statements regarding the patient's program compliance and safety, in the patient health record for easy team access. In this regard, if behavioral management guidelines are implemented, it is imperative that all staff across shifts appreciate the recommended behavioral parameters and are capable of instituting and maintaining this paradigm. In-service training may be necessary in order to support behavioral management guideline implementation in a consistent manner.

F. ***Suspension of Psychiatric Symptoms During Early Recovery from Brain Injury/Illness***

When dealing with individuals with acquired brain dysfunction and a premorbid history of significant mental health problems, it is not unusual to see a suspension of psychiatric symptoms during early recovery from brain injury/illness. It is important to prepare family members, who may initially perceive the brain injury/illness as a 'good thing,' to expect return of behavior indicative of the pre-existing mental health problems as recovery progresses.

G. ***Team Approach***

As can be seen in the above examples, understanding and successfully intervening to minimize challenging behavior in the rehabilitation setting requires a team approach. No single team member can achieve the complex strategic goals required for successful behavior management without a coordinated effort from the entire rehabilitation team. Indeed, it is in the resolution of behavioral challenges that the true reciprocal and collaborative nature of the interdisciplinary treatment team is expressed and realized.

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Vocational Participation

50

Lisa Ottomanelli

Topic

A. ***Definition***

Vocational rehabilitation (VR) is a rehabilitation process that helps to begin work, prevents loss of work, or facilitates return to work through interdisciplinary interventions [1]. In medical rehabilitation, services provided by a variety of health care providers both indirectly and directly enhance the ability of a person with a medical condition and/or disability to participate in the workforce. An effective VR program requires medical, psychological, and occupational services that are directed toward maximizing functions needed to begin, maintain, or restore employment. Services may be provided by the existing interdisciplinary team as part of the overall comprehensive rehabilitation program or by referral to and collaboration with a separate vocational agency or provider.

B. ***Terminology***

1. **Vocational Rehabilitation**

This broad term encompasses a variety of services aimed at helping a person with a disability become employed, maintain employment, or reenter the workforce after injury or illness; often used as a general reference to state or Federal VR programs [2]. (For a discussion of state VR services, see "Vocational Rehabilitation" by Fraser and Johnson in *Handbook of Rehabilitation Psychology*, 2nd edition, 2010.)

2. **Supported Employment**

A generic term that refers to programs or funding streams within the Rehabilitation Services Administration (RSA) of the U.S. Department of Education (DOE) for persons with disability. Widely used in community settings to refer to ongoing job support services provided to persons with disabilities.

3. **Individual Placement and Support (IPS) Supported Employment**

A standardized model of employment practices integrated with clinical care to help persons with disabilities find or maintain competitive employment in the community. Also referred to as *evidenced-based supported employment* (EBSE); research demonstrates its effectiveness for persons

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_50

with mental illness [3] and spinal cord injury [4]; EBSE also has clinical applications among other populations such as persons with cognitive impairments.

4. **Customized Employment**

   A flexible strategy designed to meet the needs of both employer and job candidate with a disability. This model strives to match the business needs of the employer with the strengths and interests of the job candidate. May include specific task assignments, job carving, and job sharing.

Importance

A. ***Employment Outcomes.***

Effective VR services are critical to improving employment outcomes. During rehabilitation, establishing a goal of restoring employment provides a focus for the rehabilitation itself. This goal also motivates persons with a disability to learn and become proficient at new and effortful care routines that maximize physical function and maintain health so that they can participate in work and community life again. Ideally, vocational interventions are provided early and often throughout the health care continuum. Work needs to be discussed as both therapy and as a health care goal, and information needs to be provided on the benefits of employment and on vocational resources or interventions that support employment following disability.

B. ***Community Integration.***

Effective VR services are important in promoting community integration. Employment is a central aspect of activity and participation according to WHO's International Classification of Functioning, Disability and Health (ICF) and is a primary route to community integration and social inclusion following disability [5]. Following injury, return to work has both direct and indirect associations with improvements in quality of life, psychological adjustment, health, and well-being [6–10]. Employment can represent an avenue to ameliorate and possibly prevent depressive symptoms [11]. Hence, restoration of employment is often considered the hallmark of effective rehabilitation. Yet, in 2012, only approximately 32.7 % of working-age (18–64) people with disabilities were employed compared with 73.6 % of people without disabilities [12].

Practical Applications

A. ***When is Vocational Intervention Appropriate?***

Address vocational issues at the beginning of rehabilitation for every person of working age or emerging adult irrespective of the severity of the physical impairment or disability. Include a plan for beginning or returning to employment, and/or education and training as a pathway to employment, in the initial rehabilitation plan. Setting work as a goal creates a positive expectation that not only leads to good employment outcomes but also sets the stage for rehabilitation to lead to a hopeful and meaningful future.

B. ***Who is Responsible?***

1. **Vocational Rehabilitation Counselor (VRC)**

   Ideally, a qualified VRC is included in the interdisciplinary rehabilitation team and will have primary responsibility for organizing the team's efforts around employment. A VRC is usually a master's prepared professional who is a Certified Rehabilitation Counselor (CRC). If there is no dedicated VRC on the rehabilitation team, designate another team member with interest and willingness to serve as a vocational champion to ensure employment is addressed. A designated person on the team (such as a clinical care coordinator, social worker, or occupational therapist) increases the likelihood that the team will identify, assess, and address vocational issues throughout rehabilitation.

2. **Community Vocational Provider**

   Another approach is to build a collaborative relationship with a community vocational provider, such as a state VR counselor, who is invited to regularly attend interdisciplinary team meetings.

3. **Vocational Team**

   Whether a VRC or other professional has primary responsibility for championing employment, addressing the complex physical, psychological, and social barriers to return to work following injury or illness requires a broad range of health care team members, such as physician, nurse, psychologist, social worker, occupational therapist, assistive technology specialist, and recreation therapist. An effective vocational team is one where there is a dedicated lead person (VRC or another discipline) and all the other team members apply their expertise in helping to reach an employment goal.

C. *What Key Data Should Be Given Focus?*

The focus for developing a vocational plan is the interests, desires, needs, strengths, and capabilities of the person in rehabilitation. A thorough work history is essential, with particular attention to what type of work is best suited to the person, what jobs were liked the most, and what working environments were considered most exciting and led to success. If previous work was not enjoyed, it is helpful to explore the person's "dream job" irrespective of physical capacity or educational qualifications. Assess whether return to a previous employer is an option and if it is desired, as this increases the likelihood of employment postinjury. If a previous occupation can no longer be performed due to physical impairments, related positions in the same field can be considered, for example, a firefighter could become an emergency dispatcher. In addition to medical history, other key factors affecting employment options are legal history, substance use history, family or social supports, and transportation or access to the community (see Sample Vocational Assessment Interview in Appendix.)

D. *How Are Vocational Data Obtained and Incorporated into the Rehabilitation Assessment Process?*

A comprehensive vocational assessment can be obtained by the VRC or the designated clinician. Key features of this assessment can be incorporated into other routine initial assessments such as history and physical, psychological interview, or social history. As team members perform their initial respective assessments, each should inquire directly about employment goals to plan treatment accordingly. Assessment is an ongoing process as the person moves through rehabilitation: Basic employment questions are introduced on initial consult or intake and, as rehabilitation progresses, additional data are added to develop and elucidate goals.

E. *How Would These Data Be Interpreted or Evaluated?*

Rather than focusing on what the person can no longer do, the emphasis should be on what the person wants to do and how the person's strengths and supports can be leveraged to reenter the workforce with assistance of the rehabilitation team. A person-centered treatment focus is critical. The person's passions and interests need to be the primary factor in identifying and working toward a vocational goal. The assessments capture essential data that initiate and inform the process of job exploration and goal setting.

F. *What Interventions Would Be Indicated and How Would These Interventions Be Applied?*

1. **Assessment of Vocational Needs**

   Vocational assessment begins early in rehabilitation and is an ongoing, shared decision-making process among the individual served, the VRS or designated vocational champion, and the clinical team. The assessment guides the development of the vocational plan.

   - *Assessing vocational goals* is a naturally occurring part of comprehensive assessment at admission to rehabilitation.
   - *Formal vocational testing and inventories are not necessary*. As part of the discussion about work, they can be offered by those who are proficient in using them to help inform and direct the development of the initial vocational plan. However, they are not help-

ful simply as screening instruments or when used as routine assessment apart from guided discussion of work goals.

- *Neuropsychological assessment or cognitive testing is indicated for those persons with traumatic brain injury and/or cognitive impairments.* Cognitive testing can be helpful in matching a person with appropriate job environments and providing recommendations for compensatory strategies and devices to maximize job functioning and performance over time.

2. **Development of a Vocational Treatment Plan**

   The vocational treatment plan should be incorporated into the overall medical rehabilitation plan.

   - *State the employment goal:* Include specifics regarding preferences such as type of employment, setting, desired duties, and hours per week.
   - *Create timeframes:* Each employment objective should include a timeframe for accomplishment.
   - *List barriers and which team member is responsible for each:*
     - ☐ Medical (maximizing physical health, managing new care routines), psychological (mood and cognition, adjustment, confidence), or social (transportation, housing, benefits counseling, social support systems).
     - ☐ Rehabilitation in general focuses on maximizing overall function and independence. When vocational rehabilitation is included, specific interventions focus on maximizing the ability of the individual to participate in the work environment with regards to health maintenance, social skills, mobility, and effective use of accommodations and supports.
   - *List supports and how they will be provided, including adaptive equipment, accommodations, assistive technology:*
     - ☐ After careful assessment of the job environment and functions with respect to the individual's physical capabilities, the team can problem solve and create effective solutions for everyday use on the job. In general, accommodations may be considered with respect to desk or workspace height and access, bathroom accessibility, and computer and phone use. In many cases, low technology and no-cost or low-cost accommodations are sufficient, such as a universal handcuff to hold common objects and type, or a flexible schedule to allow for bladder management issues or frequent rest breaks. In some case, special equipment or technology such as voice-activated computer software or standing wheelchairs are indicated.
     - ☐ Determine whether the health care team will provide these supports or whether community referrals and funding streams such as state VR assistance are needed.
   - *List any natural supports available:* Assist the person in identifying current social support networks and gaps where new supports need to be developed. Give consideration to family and caregiver issues. Identify other employees in the company who might provide assistance if needed.
   - *Identify additional training or education necessary for employment:* Obtaining further education by itself does not fulfill a vocational goal; timing and linkage with a target job need thoughtful delineation.

3. **Benefits Counseling**

   If fear of losing current or future disability benefits is a concern, refer the person to a qualified benefits counselor for information about their current income and benefits, how future earned income could impact their finances, and eligibility for work incentive programs (see VR Resources section).

4. **<u>Peer Mentors</u>**

   Enlist the help of peers who are employed to provide support, facilitate networking, and instill hope for a return to working life. If there is a formal peer mentoring program in the rehabilitation center with recurring meetings, consider making employment a meeting topic and recruit peer volunteers who are employed to participate. If not, create informal opportunities for discussion with working persons with disabilities in the community who are willing to be contacted about their employment.

5. **<u>Follow-Up Support</u>**

   At follow-up visits and any routine health visits, the vocational treatment plan should be revisited and revised as necessary.

   - *During the job search*: Assess whether objectives and timeframes are on target. Consult with other providers and team members as necessary to ensure appropriate services and supports are being provided.
   - *After employment*: Assess the effect of employment on goals, lifestyle, overall health, and well-being. Does the job fit in terms of the type of work desired? How many hours are worked? Does the schedule need adjustment? Are supports and accommodations appropriate? Is any additional vocational follow-up support indicated such as job coaching?

6. **<u>Vocational Rehabilitation Resources</u>**

   - *State VR offices*: Assists persons with disabilities interested in employment. Local offices listed at http://askjan.org/cgi-win/typequery.exe?902.
   - *Department of Labor One Stop or Career Center*: Offers resources for job searches, employment preparation, and workforce reentry. www.careeronestop.org
   - *Association for People Supporting Employment First (APSE)*: National organization that advocates for integrated employment opportunities for those with disabilities. www.apse.org
   - *Job Accommodation Network (JAN):* Provides guidance on workplace accommodations, the Americans with Disabilities Act (ADA), and disability employment issues www.askjan.org.
   - *Work Incentives Planning and Assistance (WIPA) Projects:* Community-based organizations that help Social Security beneficiaries with disabilities make informed choices about work and plan for successful transition to financial independence. WIPA counselors analyze a person's income and work history to advise them about how future employment would impact them financially. Locate a WIPA counselor in your area and find information on Ticket to Work and other supports at https://www.choosework ttw.net/findhelp/.
   - *The Red Book:* This summary guide for Social Security on employment supports for persons with disabilities provides information about work incentives and benefits programs. https://www.socialsecurity.gov/redbook/
   - *<u>Department of Veterans Affairs (VA)</u>*
     - ☐ Chapter 31—Vocational Rehabilitation and Employment (VR&E), Veterans Benefits Administration (VBA): For eligible Veterans with a service-connected disability. Provides evaluation, counseling and vocational case management, postsecondary education support, job training, and assistance finding a job. For information, go to: www.benefits.va.gov
     - ☐ Compensated Work Therapy (CWT) Program, Veterans Health Administration (VHA). For Veterans enrolled in VA health care who are referred by their health care providers. Provides both evidence-based supported employment and traditional vocational rehabilitation

(transitional work experience, situational work assessment). http://www.va.gov/health/cwt/

G. ***What Is the Expected Outcome?***

Competitive employment is the optimal outcome. Competitive employment is a job in the community that is available to any qualified person (not a set-aside job for a person with disability) in an integrated work setting (not a sheltered workshop) and pays minimum wage or higher.

H. ***What Is Expected from Interventions?***

1. **Referrals**

   If referrals to community providers and other medical services are used, expect them to appropriately evaluate and provide services for which the person is eligible in a timely fashion. If a referral is made to a large and potentially overburdened system, then the referring provider may need to take an advocacy role to increase services (the squeaky wheel approach often works).

2. **Job Placement and Follow-Along Support**

   State-of-the-art vocational rehabilitation, regardless of the model used, includes job placement and on-the-job support interventions. These are the two specific vocational services that are consistently linked with successful competitive employment and that are most likely to lead to finding and maintaining employment with a disability.

3. **Prevocational Preparation vs. Rapid Job Search**

   Conventional wisdom is that a person with a significant disability (e.g., traumatic brain injury, spinal cord injury) often needs time in prevocational activities such as independent living and/or "work hardening" programs focused on job readiness issues. While these programs may have some time-limited value, often they indefinitely delay services geared toward finding real jobs in the community and thereby run the risk that a person may become demoralized and lose motivation. If a person spends too much time in these programs without progressing, there should be a reevaluation of vocational needs and referral to a program that focuses on finding an actual job.

4. **Integrated Vocational Services**

   The best employment outcomes can be expected when vocational services are integrated with ongoing medical rehabilitation clinical care. Simultaneously addressing vocational needs in a coordinated fashion with medical rehabilitation is more effective than ad hoc referrals to vocational rehabilitation at the conclusion of medical rehabilitation. If there is a disconnect between vocational services and medical rehabilitation, providers are encouraged to strengthen connections by building effective working relationships with vocational experts and including them in the treatment team while the person is in rehabilitation.

Tips

A. ***Use PLISST***

This model was originally developed to help providers of different disciplines and backgrounds address sexual health care issues among persons with chronic illness and disability. For those with less familiarity, training, and experience in vocational rehabilitation, adapting the PLISSIT model for discussions about employment may prove useful [13]. This model can provide a framework for introducing the topic of returning to work by giving:

- *Permission* to talk about employment as a valid concern
- *Limited Information* on employment and disability
- *Specific Suggestions* on how to return to work
- *Intensive Therapy* referrals for more specialized services such as supported employment programs.

B. ***Consider Vocational Issues as Part of Your Usual Role as the Rehabilitation Psychologist***

- **Consensus Builder and Advocate**: Communicate and validate the goal of employment.
- **Team Leader and Visionary**: Motivate and orient the team to embrace employment as a goal.
- **Problem Solver and Negotiator**: Identify and resolve barriers to employment and facilitate services to support employment as needed.
- **Skill Builder**: Use psychological interventions to support employment, such as cognitive testing, sleep and pain management, therapy for negative mood states, problem solving or social skill building, and team development.

C. ***Treating Depression with Work as Therapy***

Work is a central aspect of identity and creates opportunities for belonging, self-efficacy, and accomplishment. As such, work represents an activity that may prevent or reduce depressive symptoms associated with illness or injury. Consider including employment as part of assisting overall adjustment and adaptation to disability. A person who presents with significant depression may have additional barriers to work, but work itself can become part of a behavioral activation plan to address depressive symptoms.

D. ***Remember You Are Qualified to Address Vocational Issues***

You do not have to have a background in vocational counseling to impact vocational outcomes. Asking about employment, connecting the person with services both on the team and outside the team, and monitoring the effectiveness of these interventions can have a powerful impact on whether a person pursues and realizes employment following disability.

E. ***Create Positive Expectations***

Creating a positive expectation for a future that includes working with a disability is foundational to building success in this area. Both research and personal narratives suggest that early communication from health care providers that they expected a return to work was critical in the person's decision to pursue this path and realize future employment.

Appendix

Sample Vocational Assessment Interview

Personal Information

- Tell me about yourself.
- What do you consider your strengths, skills, abilities, and passions?
- How would a friend describe you?

Employment

- What do you want to do for a job?
- What is your dream job?
- Why does that appeal to you?
- Talk about your career aspirations for the next 5 years.
- Describe your health history and your functional strengths and challenges.
- What is your educational background? List school degree(s), certification(s), dates, subjects, likes, dislikes, professional and personal connections made (for potential network contacts).
- What is your work history? List dates of employment, title, employer, tasks, likes, dislikes, professional and personal connections made (for potential network contacts), terms of job discontinuation.

Daily Life, Routines, and Community Involvement

- Describe your family and current living arrangements, including immediate and extended household members, primary family relationships, type of domicile, and configuration of living space.
- Describe access to community transportation.
- What can you tell me about your personal mobility?

- How do you spend your free time?
- What are your favorite activities and why do you like them?
- Describe a typical day.

Substance Use Information

- What is your current use of alcohol or drugs? Describe amount and frequency.
- Do you have any history of alcohol or drug problems? If so, how did it affect your employment? In what ways? Does substance use currently interfere with your life? What things should we consider in terms of current substance use now and looking for a job?

Justice System Involvement

- Have you ever been arrested?
- If so, have you ever been convicted of a crime? Inquire about dates, state, and type (misdemeanor vs felony; robbery, assault, sexual).
- Do you have any legal charges pending?
- Has legal involvement affected employment for you in the past?
- What needs to be considered in terms of your legal status now and looking for a job?

Supports

- How do you see your medical status impacting the way that you use your strengths?
- What anxieties/fears do you have about working?
- How do you typically handle it when you need help in accomplishing something?
- What do you generally do to help yourself feel calm and confident?
- What ideas do you have now for supports you might need for successful employment?

Networks

- We want to develop a network of people who might lead to future employment. Think of all the people you know in the community (e.g., family, friends, hair stylist/barber, coffee shop owner, grocery store manager).
- What places in the community do you go regularly? Do the business owners/organizers know you? (e.g., gym, church, Rotary Club, Boy Scouts, recreation centers, billiards hall, fabric store, gun range).

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Nonvocational Participation

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Eunice Kwon

Topic

Individuals with disabilities construct their identities through interaction with the environment. Through socialization experiences, whether positive (i.e., self-empowerment) or negative (i.e., empowerment deficit), individuals with disabilities develop perceptions regarding competencies and a sense of identity, as well as their social position. Providing ample opportunities to participate in activities that promote mastery, self-efficacy, and internal locus of control while supporting the individual in establishing new hobbies and developing healthy relationships may enhance their recovery process.

A. ***Participation***

Participation is an interaction between the person and the environment as a member of society. Social memberships can range from being a worker, student, friend, spouse, parent, or citizen. Impairments or limitations in resuming social roles after injury may result in participation restrictions that can significantly impact perceived quality of life [1, 2]. Participation can be viewed as objective based on social standards (i.e., employability) regardless of the individuals' perceived participation restriction (society-perceived participation or handicap). Participation can also be viewed as subjective based on the individuals' perception regarding involvement in daily activities and social roles (person-perceived participation or handicap). Participation can be comprised of daily activities (i.e., getting in and out of bed, preparing a meal, taking a shower), activities at varying frequencies (i.e., taking part in social activities, getting around in local stores), activities related to survival (i.e., sleep, nutrition, hygiene), or activities that are performed according to the individual's choices (i.e., interpersonal relations, work) [3].

B. ***Empowerment***

Empowerment is a process whereby individuals from a disadvantaged group acquire mastery skills and become proactive agents in their own lives. Specifically, rather than being passive recipients and relying on the assistance of others, individuals are encouraged to initiate action on their own behalf [4]. One of the effective approaches to promoting empowerment is through physical fitness activity (i.e., recreational therapy and adaptive sports).

C. ***Quality of Life***

Quality of life (QoL) is defined as "individual's perception of their position in life in

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_51

the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." QoL can be viewed in regards to the subjective perception of aspirations and achievements (subjective QoL); observable characteristics such as education, health status, income, etc. (objective QoL); or functional status, participation in social and daily activities as a result of health status (health-related QoL) [2, 5].

Importance

As individuals adjust and cope with their situations while creating a new identity, it is important to consider aspects of physical self (perceptions regarding physical competencies) and social self (social competencies) as critical components in their rehabilitation treatment [5]. Research has demonstrated that interacting with others through social participation is positively associated with subjective well-being and contributes to life satisfaction. Furthermore, self-perceived view of physical and social capabilities may also increase positive feelings about their lives, thus allowing them to become more sociable [6].

A. ***Physical capabilities***

Previous research has elucidated that one of the potential ways to enhance self-perception and longevity for individuals with physical disability is through participation in physical activities (i.e., sports, recreational activity) [7]. Being restricted to watching television through nonsocial/home-based rehabilitation was associated with lower level of satisfaction with life. Opportunities to participate in activities that will enhance physical self through developing physical skills and competencies may increase resilience and lead to more fulfilling and meaningful lives.

B. ***Subjective well-being***

Individuals adjusting to life-changing injuries may initially experience four common responses [8]:

1. Cognitive disorganization (i.e., confusion, disturbance of identity, sense of disrupted future, search for meaning)
2. Dysphoria (i.e., distressing emotions, yearning, loneliness)
3. Health deficits (i.e., physical consequences of grief)
4. Disrupted social and occupational functioning

This reorganization of self presents a great challenge for individuals and being able to discuss these adjustment difficulties with therapists may help to validate their distress without resorting to simple reassurance. As previous research has demonstrated, improvements in subjective well-being have significant impact on increasing the likelihood of social engagement.

C. ***Social capabilities***

Consistent with interactionist framework (people are viewed as capable of interpreting and assigning meanings to various social stimuli), increase in social contact opportunities aids in development of social skills. Participation in social setting enhances the development of goal-setting ability and cooperation skills as well as their ability to respond to challenges and engage in problem-solving behaviors [4]. Furthermore, social participation and community integration through implementation of recreational programs can greatly increase social competencies.

Practical Applications

Reintegration into the community after injury may be ameliorated through aspects of recreational therapy. Working with a recreational therapist through adaptive sports, leisure activities, or animal-assisted therapy may all augment development of a new social identity after injury.

A. ***Adaptive Sports and Recreational Therapy***

Adaptive sports and recreational therapy can help to improve or maintain physical, cognitive, social, emotional, and spiritual functioning of individuals with disability by facilitating participation in life. Some of the activities include archery, bowling, cycling, fishing, golf, rock climbing, table tennis, and yoga.

B. ***Animal-Assisted Therapy***

Animal-assisted therapy, "the use of animals (i.e., dogs, horses) in therapeutic situations that involve disabled persons," through animal contact has been shown to have significant health benefits. Evidence suggests that it can positively influence physiological states (i.e., increase oxytocin levels, decrease cortisol levels), emotional status (i.e., improvements in feelings of self-worth), and increase treatment adherence [9]. Hippotherapy (i.e., horseback riding) is a most common form of animal-assisted therapy and has been shown to be effective in treating individuals with movement disorders enhance balancing exercises [10].

C. ***Aquatic Therapy***

Aquatic therapy can be useful for pain management; relaxation: reducing edema; increasing circulation and cardiovascular capacity; reducing weight; and increasing flexibility, strength, and endurance [11].

- ○ Ai Chi: based on elements of Qi Gong and Tai Chi and uses diaphragmatic breathing and active progressive resistance training in water to relax and strengthen the body
- ○ Bad Ragaz Ring Method: therapist-assisted exercise performed while the patient lies horizontal in water where the therapist guides the patient through specific patterns of movement to increase strength
- ○ Watsu: based on the idea of stretching the "body's meridians (pathways of energy)" through rotational movements to increase flexibility

D. ***Creative Arts Therapy***

Creative arts therapy utilizes the creative processes through various art modalities (i.e., dance, music) and helps to promote wellness, alleviates pain and stress, fosters healthy expression and understanding of emotion, enhances cognitive abilities and learning of new skills, and provides opportunities for social interaction and connection.

- ○ Art: creative process allows for artistic self-expression and may help individuals to solve conflicts, manage behavior, improve self-esteem, develop self-awareness and insight, manage stress, and develop interpersonal skills.
- ○ Dance/Movement: movement can promote assessment and healing by helping the patient to identify, access, and develop internal resources.
- ○ Music: may help to provide distraction from anxiety and pain by directing the listener to relaxing or comforting music. Similar benefits can be achieved by actively engaging in music-making sessions, such as drumming, singing, or group keyboard lessons.

E. ***Horticultural Therapy***

Horticultural therapy is an active process which occurs in the context of preplanned activities involving plants and gardening. Nurturing and cultivating plants is considered a therapeutic process which helps to create personal meaning, spiritual healing, and a sense of being in touch with nature. It can be utilized as a recreational activity where the focus is on social interaction (i.e., Social Horticulture) as well as a vocational activity where the focus is on providing training to help individuals entering horticulture industry (i.e., Vocational Horticulture). Existing literature suggests that horticultural therapy can provide physiological benefits (i.e., help strengthen muscles, improve coordination, balance), cognitive benefits (i.e., improve memory, initiation, language), as well as social benefits (i.e., improve skills in following directions, working independently, and problem solving) [12, 13].

F. ***Assessment Measures***

The following measures have often been utilized in rehabilitation settings for gathering information to assess level of participation perceived by the individuals themselves as well as by healthcare providers. These measures can also be used as outcome measures to assess treatment efficacy.

1. **Craig Handicap Assessment and Reporting Technique (CHART)** [14]
    - ○ Most commonly used questionnaire in the field of SCI
    - ○ Assesses the degree of disadvantage in five out of six handicap dimensions listed below of people living in the community:
        - ■ Physical independence
        - ■ Mobility
        - ■ Occupation
        - ■ Social integration
        - ■ Economic self-sufficiency
        - ■ Cognitive domain was added in 1995
    - ○ Collects information on degree to which patients are able to fulfill the roles typically expected from individuals without disabilities
    - ○ Scores range from 0 to 100: maximum attainable score is equivalent to individuals without disabilities
2. **Assessment of Life Habits (LIFE-H)** [15]
    - ○ Assesses performance of regular activities (eating meals, communicating with others, moving around, etc.) and social roles (holding a job, studying, practicing leisure activities, etc.) that ensure a person's survival and well-being in society throughout the individual's lifetime
    - ○ 77 items measuring self-perceived level of difficulty and the assistance required to perform a series of life activities
    - ○ Total score as well as scores in 12 dimensions covering the field of participation are computed
3. **Impact on Participation and Autonomy Questionnaire (IPAQ)** [16]
    - ○ Assess the severity of restrictions and needs related to participation and autonomy (person-perceived participation)
    - ○ Two different features:
        - ■ 31 items on perceived participation
        - ■ Experience of problems in eight dimensions of participation
    - ○ Scores in five domains are computed:
        - ■ Social relations
        - ■ Autonomy in self-care
        - ■ Mobility and leisure
        - ■ Family role
        - ■ Work and educational opportunities
    - ○ Developed for use as a profile for disease severity assessment, needs assessment, and outcome assessment
4. **Participation Objective—Participation Subjective Scale (POPS)** [1]
    - ○ 26 item self-report assessment developed to prioritize preferences and goals of individuals with TBI
    - ○ Areas of participation are organized into five subscales:
        - ■ Domestic life
        - ■ Interpersonal interactions and relationships
        - ■ Major life areas
        - ■ Transportation
        - ■ Community, recreational, and civic life
        - ■ Measures two areas of participation:
        - ■ Objective participation:

          Frequency or duration of engagement

          Quantifies participation as proportion of responsibility, number of hours, or frequency of participation
        - ■ Subjective participation:

          Importance of activity and satisfaction with level of engagement

          Quantifies the importance of the activity to the individual and the desire for change in the level of participation
5. **Community Integration Questionnaire (CIQ)** [17]
    - ○ 15-item questionnaire measuring three aspects of community integration:
        - ■ Home integration (HI)

          Ability to manage personal finances independently

          Perform common activities of daily living (housework, cooking, grocery shopping)

          Sum of items 1–5
        - ■ Social integration (SI)

          Leisure activity participation

Frequency of visiting friends
Sum of items 6–11

    - ■ Productivity (PA)
      Extent to which individuals participate in employment, educational programs, and volunteer activities
      Produced by a formula involving items 12–15
  - ○ Yields scores for each of the three subscales as well as an overall score
  - ○ 15 questions are provided with multiple choice with two-to-five response alternatives

Tips

- Exploration of previous involvement in the community as well as hobbies and/or preferred physical activities may serve to guide direction of available recreational therapy options to increase social participation.
- Consistent meetings with treatment providers to discuss physical barriers, external barriers (i.e., transportation, architectural, policy), as well as mental health concerns due to social stigma may be essential in monitoring level of subjective participation as well as quality of life/life satisfaction. Providing resources to increase social support may help to reduce feelings of disempowerment.
- Collection of collateral information regarding individual's adjustment from family members as well as gathering feedback from other providers is an important aspect of rehabilitation treatments.

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Part IV

Consultation and Advocacy

Models of Consultation

52

Robert L. Karol and Laura Sturm

Topic

Consultation refers to clinical work in which the psychologist receives a request to advise attending physicians and staff on a case-by-case basis or to provide treatment for such cases. More traditional roles for a psychologist are those of a practitioner working independently in an office setting or a clinician working as an integrated team member. A consulting psychologist draws from both of these practice patterns, but in a modified manner: providing assessment and treatment for a case, like an independent practitioner, and providing advice on a case like a (temporary) team member.

Importance

Consultation is a growing role. In medical settings, consultation may come to represent a greater percentage, if not the majority, of a psychologist's time. However, psychologists wishing to adopt the consultant role must reflect on their training and specific issues that will impact on their satisfaction with the role.

A. ***Training***

Psychologists considering consultation work must think about whether they are trained for the consultant role. Consultation receives relatively little focus in many training programs, perhaps because it is a recent growth area. Hence, psychologists may be unaware of the unique skills and knowledge necessary for this work, and thus may struggle in the consulting role. Yet, as one of the American Psychological Association's competency benchmarks for professional psychologists [1], it is important for psychologists to prepare for the role of consultant. In addition, consultation skills are a listed competency for the American Board of Rehabilitation Psychology [2]. The consultant role can be rewarding, intellectually stimulating, and exciting; however, the opportunity to thrive is best fulfilled with knowledge about its challenges. This chapter

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_52

provides topics for reflection before initiating consultation work.

B. ***Specific Issues***

1. **Personal Comfort with the Role**

   The psychologist must have the constitution for consulting work. The consultant is typically engaged when other professionals lack knowledge or are stymied. The consultant is looked upon as the person to relieve the burden of uncertainty or the frustration of ineffectualness. The consultant must be enamored of this role and intrigued by the responsibility that it engenders: Consultant is not a role for the timid. Do not be misled into believing that the consultant role is easy, with a false sense of lowered responsibility. In truth, the performance pressure on the consultant may be greater than in other roles.

2. **Setting**

   There exists great diversity across organizations. There may be type-of-setting (large medical hospital vs. smaller rehabilitation hospital), location (rural vs. urban), or organization-specific variables to consider. Smaller facilities might require a consultant to consult with many different types of people whereas a larger facility might require specialization. At a rural facility, physicians might be more used to handling things on their own, with less use of consultants than in urban settings, because consultants might be historically less available in rural locales. A specific organization might favor employed consultants rather than independent ones, or vice-versa. In a consultative role, one's effectiveness will be mediated by considerations related to the exact setting. Psychologists must always learn how to work most efficaciously within their setting, but a consultant must be particularly aware of setting-specific considerations because one is operating without the reassuring routine of individual office work or the safety net of the team.

3. **Culture**

   Each organization has a distinct culture; however, organizations that seemingly occupy the same provider niche (e.g., large hospital) may have very different cultures. Sometimes, an organization's culture can be quite divergent from one's expectations for such a niche. Culture includes how teams function in the organization, terminology used, hierarchies, degree of formality, and other approaches to daily work. Consider whether the organization is family-like, entrepreneurial, bureaucratic, or productivity-oriented. Is there collaboration between clinicians and administrators? Are team relationships supportive, formal, task oriented, or adaptable [3]? It may be tempting for a consultant to disregard organizational culture, particularly if not on site full-time. Doing so will make the consultant appear to be an outsider which will negatively impact the consultant's effectiveness.

Practical Applications

A. ***Issues Related to Referrals***

1. **Nature of Referrals**

   Referrals usually arise when treatment providers encounter one of two scenarios: (1) they lack knowledge about a particular clinical issue and require the expertise of a consultant to provide information, or (2) they have tried interventions that have either insufficiently succeeded, failed altogether, or made the situation worse. An example of the first scenario might be when a team is aware of emotional distress but cannot determine if the symptoms are indicative of depression or other diagnoses. Another example might be when they seek help to determine if a person is suicidal, and they seek advanced knowledge about how to conceptualize their observations. An example of the second scenario might be when an intervention for anxiety is tried, but fails to provide enough relief or even makes the person more anxious. The team is looking for a consultant to provide intervention strategies or to directly intervene. It is important for a consultant to appreciate what is being sought by the referral source. If one only provides information when intervention is sought, the consultant's services will appear inadequate. Alternatively, if an opinion is sought but the consultant proceeds to intervene, the consultant risks overstepping and offending the team or physician.

2. **Constituent Needs**

   There are two primary consumers of a consultant's services: the physician and the treatment team. The team may be either a well constituted group such as in a rehabilitation transdisciplinary team [4] or a more typical acute-care medical multidisciplinary or interdisciplinary team. The explicit need of consumers is for clinical assistance in assessment or treatment. However, it behooves the consultant to also attend to the implicit variables influencing the referral. Consultant services are often sought when providers are frustrated or even desperate, although sometimes providers merely want to hand the issue to someone else. The consultant should understand the motives of the constituencies. Providers may be looking for confirmation of decisions made so far, reassurance regarding ability to handle a situation, resolution of differences between team members, etc. The astute consultant will be attuned to the emotional functioning of the providers seeking consultation and the team dynamics. Moreover, team culture and functioning may be contributing to the psychological issues of the patient.

3. **Referral Timeline**

   It is better to be consulted earlier than later. Too often, a consultant does not receive a referral until the situation has become significantly problematic [5]. This is unfortunate: it always better to be able to intervene early and avoid having to address concerns that should never have arisen. Once the situation has deteriorated the consultant is being asked to do recovery: prevention is easier. However, the consultant must train referral sources not to wait. Some referral sources prefer to handle things on their own until forced to concede by inadequate or negative outcomes that their efforts were insufficient; some are unable to appreciate the signs of a pending problem until it is too late to easily solve the problem; some referral sources are concerned about the perceived cost of a consultant to the facility or the patient—they usually fail to factor in the indirect cost of longer length of stay, worse clinical outcome, dissatisfied patient or family ratings of themselves and their facility, lawsuits, etc. One poor outcome or unhappy patient/family can easily outweigh the direct cost of using the consultant a little too soon or slightly too often.

   The consultant should educate referral sources and administrators about the calculus of early referral to head off issues versus waiting, with a concomitant possibility of an unrecoverable disaster. A true example may help the consultant make this argument: A surgical clinic that failed to use presurgical psychological consultant screenings on everyone—it just did so when the surgeon was concerned—experienced an unhappy postsurgical patient, who the psychological consultant had not seen, coming to the clinic with a gun to kill the surgeon. Once the person was apprehended, the clinic decided to have a mandatory psychological consultation on every patient before deciding whether to operate.

   The problem with not using a specialized psychological consultant consistently is that the more generalist physician must make a case by case decision as to whether to refer, and may miss psychological concerns [6]. The physician who is not an expert in psychological history and functioning is likely to have insufficient time to determine the presence of psychological conditions, inadequate understanding of the nature of psychological conditions, or simply does not know or is hesitant to use the appropriate questions or methods of inquiry (consider sexuality, physical/emotional/sexual/financial abuse and criminal histories). Often, physicians are surprised at the information the psychological consultant uncovers.

The consultant should be cognizant that the team may spend considerably more time observing issues pertinent to the psychological consultant than the physician. In many cases, the team can encourage a reluctant physician to make a referral. Often, the team is the consultant's best ally in facilitating referrals. Hence, establishing a close working relationship with the team is important. The team can also provide important assistance with case conceptualization and treatment implementation, and with providing updates that the consultant might miss by not always being in attendance.

4. **Referral Request Structure**

Some consultants prefer orders for consultation to be explicit as to the nature of the service being requested. For example, an order might read: "Consult Dr. X to determine presence of depression." This is a clear order that specifies the issue at hand and the limits placed on the consultant. In contrast, other consultants prefer orders that are more open-ended: "Consult Dr. X—concerned about emotional status (depression? other?): Please evaluate, advise, and treat." In part, this reflects the desires of the physician and the consultant and familiarity of each with the other. Writing the second order requires far greater trust by both parties. It is important for the consultant to know the type of order the consultant prefers and to educate referral sources on this point [6].

A related issue is how to present referrals to the person being seen. When referrals are routine, it is easier for a physician to relate to the person that psychological consultations are part of the clinical pathway or that the physician's practice pattern includes psychological consultation. The explanation of clinical pathways or practice patterns permits the consultant to begin the consultation with the person utilizing the explanation that such consultations are the standard of care and the person is not being singled out. However, if the consultant works in a system in which referrals are only made on selected people, particularly if referrals are made only once there are suspected psychological issues, then the physician may be averse to explaining the referral at all to the person due to physician discomfort or fear of angering the person. The consultant needs to be prepared in such situations for the person to perhaps be unaware that the physician has requested the consultation. The consultant must be ready for objections from the person along the lines of "It is not all in my head" or "I am not crazy" [5]. Being prepared to discuss the person's medical condition from a mind-body, stress-body, etc. perspective is critical to begin the consultation. The actual application of this strategy will vary across health conditions. The consultant must engage the person and achieve a consensual framework, but it behooves consultants not to be apologetic about their involvement: physicians generate consultation requests because of symptom concerns and psychologists should acknowledge such symptom concerns. Patients, as consumers, should be made aware of the consultant's role.

B. ***Clinical Considerations***

1. **Psychological Issues**

While it is beyond the scope of this chapter to address psychological issues in general, the psychological consultant should at least be cognizant of the need to address certain reoccurring reasons for referrals. These include issues of depression, anxiety, anger, nonparticipation or nonadherence, behavioral dyscontrol, sexuality, cognitive dysfunction, pain, decision-making capacity, desire to leave against medical advice, personality functioning, family functioning, and surgical/procedure preparation. The wise consultant will develop an armamentarium of intervention strategies for these issues.

It also incumbent upon the consultant to sometimes direct interventions at the treatment team, rather than focusing on changing the person being treated. Sometimes, the person is having healthy reactions to problems with the care provided and the team is the root cause of the psychological reactions.

2. **Knowledge of the Medical Condition**

Knowledge of health conditions is essential [6]. Psychological knowledge without accompanying appreciation of pertinent medical illnesses, diseases, or injuries can be detrimental: it is too easy to give advice contrary to the likely course of care. One cannot help assess and treat issues of patient responses to health conditions without knowledge about the true nature of the conditions and the courses of recovery or decline. If one consultants on spinal cord injury cases, one must know about the neuroanatomy of the spine, surgical interventions and medical advances, metabolic changes following injury, effects at different levels of injury, disability issues related to spinal cord injury, course of treatment, prognosis, posthospital care, etc. If one consults on brain injury cases, one must know about the behavioral neuroanatomy of the brain, surgical procedures, metabolic management, medication effects and brain injury, manifestations of nonadherence versus initiation versus depression, etc. If one consults on lower back surgery for chronic pain cases following work injuries, one must know about lower back ortho- and neuroanatomy, the types of surgical or neurostimulator options, recovery courses post surgery, factors such as smoking that affect recovery, the workers compensation system, etc. Regardless of the condition, it is recommended that the consultant read medical texts and take medically oriented classes or seminars. For surgical cases, it is valuable to get permission to observe surgeries in the surgical suite at the operating table. For cases that involve other medical procedures, it is similarly invaluable to watch them being performed. Consultants should ask questions and get information from the referring physician and team to help them increase their understanding of the conditions being treated as applicable to each case.

C. ***Relationships***

1. **Roles**

Psychologists tend to gravitate toward process models involving teams in which there is a synthesis of information across providers and shared decision making. Intervention is often a shared endeavor. A consultant by nature is not an integral team member. One large challenge therefore is to determine if the consultant will remain outside of the team or become an adjunct member of the team. A good indication of the position the consultant takes in this regard is whether the consultant attends rounds. If not, then the consultant remains outside of the team and chooses to function somewhat more independently. For example, if an internist consults a cardiologist on a particular case, the cardiologist is unlikely to attend the internist's unit staff rounds. The cardiologist remains a consultant outside the team. The consulting psychologist in this role must decide the comfort level the psychologist has with this role. In contrast, the psychologist could become a temporary adjunct team member attending rounds periodically. Either model is satisfactory depending upon clinical needs, time demands, and role expectations. The only caveat is to make a conscious decision about the role being adopted and why. Note that attendance at a physician's team rounds usually necessitates permission: do not just show up.

2. **Physician Relations**

   Consultants earn their keep by solving problems—clinical, family, administrative, staff, etc. Physicians worry about how cases are proceeding, their responsibilities and decisions, family satisfaction and interference, administrative pressures, etc. Typically they do not reveal this to the clinical team, but do so with other physicians. The consultant can earn trust when the consultant appreciates these physician pressures and concerns. When physicians know that the consultant thinks as would physician colleagues in this regard, in addition to having unique clinical knowledge, the physicians will come to confidently rely on the consultant. They learn that the consultant will solve problems and share or take responsibility.

   A consultant is invaluable to physicians when the physicians know that if they follow the advice of a consultant and it does not go well, even so far as to result in ombudsman office complaints or malpractice lawsuits, the consultant can independently defend to such external parties their advice based upon clinical expertise and the research literature. Physicians will rely less on advice if they believe that the consultant will indicate that they were following physician orders as to what evaluation or treatment they provided; such consultants are failing to take responsibility.

D. ***Communication***

1. **Methods of Communication**

   It is essential that there be good lines of communication between the physician and the consultant. Chart entries are the usual formal means of communication. However, that avenue of communication is often either intermittent or disjointed. Conversations through the chart have been likened to email back and forth—there is a lack of true dialog without real-time comparison of ideas and joint problem solving. In addition, written chart communications do not include the emotional and nonverbal aspects of communication that can influence decision making. Underlying concerns that are hard to communicate in a referral order are missed by the consultant and the subtleties of recommendations from the consultant to the physician are not apparent. Personal discussions are key. It is recommended that the psychological consultant establish trusting relationships with physician referral sources to facilitate dialog. The consultant and physician should make available to each other pagers and cell phone contact information and agree that their use really is desired by the other. The doctoral consultant should arrange for access to the doctors' lounge and dining room so as to maximize informal communication and bonding. Perhaps no other method of contact will prove more fruitful than this access. However, the consultant should balance time there with the general lounges and dining rooms so as to similarly bond with the team and other front-line staff.

2. **Making Recommendations**

   Psychologists are trained to consider nuances in situations and to appreciate diverse opinions while seeking middle ground. Psychological reports are often dense with discourse examining the underpinnings of recommendations. In fact, many reports offer pages of findings and data, but a very brief section on recommendations and courses of action. However, much of medicine is action oriented. The referral source wants to know what to do. While the reasoning behind the consultant's advice should be included in a findings section of the consult report, the crucial communication is the recommendations [6]. These should be comprehensive but succinct.

   In many medical arenas in which the consultant might function, the physician must make a go/no-go decision. Do I do surgery or not? Should I prescribe an opiate medication or not? Do I admit someone or not? Admittedly, there are shades of gray: surgery could be offered, but delayed to see how factors develop; an alternative, less addictive medication could be tried; ambulatory treatment could be started instead of hospitalization to see how that helps. Still, those remain yes–no choices: not surgery now; not opiates now; not hospitalization now. In this universe, the consultant can help the physician explore the pros and cons of these decisions, but is most helpful when also advising from a psychological perspective what choice is recommended.

One example can serve to demonstrate this and provide a model. When a psychologist consultant was advising a team of neurosurgeons and orthopedic surgeons as to whether to proceed with surgery from a psychological/psychosocial perspective, the surgeons wanted go/no-go recommendations. The reasoning behind the recommendation had to available, understandable, and defensible. However, because they trusted the consultant, what they needed most was the recommendation. Figure 52.1 shows a four-point ordinal scale of recommendations that meet the criteria for being concise and easily absorbed by nonpsychologists [7]. The system quickly communicates a go/no-go type answer. A good candidate for an intervention is one for whom there are little psychological/psychosocial red flags (i.e., go); a fair candidate has some issues, but the consultant can address these and mitigate their effects (i.e., go); an uncertain candidate has enough issues, or the ones that exist are significant enough, that the consultant has doubts about the likelihood that these they can be successfully addressed—the variables are probably going to hinder outcome (i.e., go with caution); a poor candidate is someone with issues that the consultant deems will certainly be problematic, the consultant will likely not be able to resolve these, and the outcome of care intervention are predicted to be unsatisfactory (i.e., no go).

The recommendations reflect the anticipated degree to which psychological variables will hinder successful outcome and the ability of the psychological consultant to mitigate those effects. Good and fair candidates are hard "go" recommendations; uncertain candidates are a soft "go" recommendation with a warning; poor candidates are a "no go" recommendation. (Adapted from [7]).

This model of recommendations can be adapted for many situations. Of course, there are recommendations for which this model does not apply: the person is not depressed, but is worried about being away from work, so the team should facilitate communication with the employer; the person is not unmotivated, but is having initiation problems so offer assistance at the start of an activity to initiate performance. Still, awareness of the model in

Fig. 52.1 Psychological/psychosocial evaluation recommendations

Good Candidate:	Handle care in standard fashion Proceed with intervention/procedure
Fair Candidate:	Handle care with attention to specific needs Proceed with intervention/procedure
Uncertain Candidate:	Care likely to present care management problems Proceed with caution
Poor Candidate:	Care presents clear problems Recommend defer planned intervention/procedure

Fig. 52.1 can help the consultant communicate when pithiness is advantageous.

It is recommended that consultants be willing to "own" their recommendations. It is easy to do an evaluation, report the recommendations to the team and physician, and move on. However, many physicians—though not all, so it is prudent to discuss this with each physician—are thankful when the consultant will share in communicating the recommendations to the person. Too often, the physician is left to tell the person, at the advice of the consultant, that an intervention is not going to be offered, or certain psychological factors must be addressed as part of the care plan, without the consultant present to take responsibility for the advice. Consultants gain physician respect when they are willing to take the heat stemming from their advice.

E. ***Practice Management***

1. **Hospital Privileges**

It is important that the consultant establish clinical hospital privileges [8, 9]. One must know what services one is allowed to perform in the hospital. These vary immensely between hospitals. Ideally, the consultant can (1) evaluate and treat primary psychological conditions, (2) evaluate and treat psychological contributions to the medical condition (e.g., cognitive, behavioral, emotional, and social), (3) evaluate—including neuropsychological evaluations, if the consultant is qualified—and treat the primary medical condition in selected circumstances (e.g., pain and brain injury), and (4) finally, write orders. The hospital privilege of writing orders varies tremendously across settings. In some settings, psychologists cannot write orders; in other settings they can, in specific circumstances, write certain orders for physical therapy, occupational therapy, speech language pathology, recreational therapy, social work, chaplaincy, nursing, etc. The psychologist seeking privileges must be certain that the psychologist has the requisite competencies to request specific privileges.

The consultant should be cognizant that if one is not employed by the organization in which one is practicing, forms such as releases of information, consent to treat, etc. should be obtained, since the hospital forms signed at admission may not cover a consultant. Having hospital privileges does not obviate this step, nor does receiving referrals. Both consultant and hospital-employed psychologists should read hospital admission paperwork and insure that it is adequate for psychological evaluations and treatments.

2. **Reimbursement**

Consultants who are self-employed and are seeing people with the intent to bill insurers should be aware that generally only direct clinical services are reimbursable, with the exception of neuropsychological assessment. The consultant must carefully monitor their time and reimbursements because referral sources often have needs that take considerable time, and adequate clinical care usually requires ancillary indirect time such as reading charts, meeting with team members, meeting with collateral sources, making phone calls, writing treatment plans, charting, and attending rounds that affects billing productivity. Unfortunately, sometimes unreimbursable, indirect clinical time spent advising the team is more therapeutic for the patient than the direct clinical service. The consultant nevertheless must be attentive to time management. If one has a consulting contract, the consultant should seek to have indirect clinical time paid for in the contract. For some consultants, contracted administrative responsibilities (e.g., committee work and program directorship) might financially offset unreimbursed time. This is a point for negotiation.

If one is not directly billing, but has productivity standards instead, as may occur for salaried employees in an internal consultant model, the same issues apply unless indirect clinical time is considered productive time in the accounting system. It behooves the consultant who wants to be perceived as efficient to have the accounting system consider both direct clinical and indirect clinical time as counting toward productivity. Alternatively, at least tracking indirect clinical time will permit the consultant to document participation in care apart from official productivity statistics.

3. **<u>Crisis Management</u>**

   The consultant needs to clearly specify responsibilities for crisis management. Ideally the locus of responsibility as a consultant lies with attending physicians or their designees. Nevertheless, for some crises the team might naturally contact the psychological consultant first. The consultant must establish whether this is acceptable. It is neither appropriate nor inappropriate to have first-call responsibilities, but it must reflect the expectations and accepted responsibilities of the consultant and the expectations of the attending physicians. This may prove easier or harder to implement when a hospitalist model is in place: in-house hospitalists onsite are likely to be called first, relieving the consultant of first-call responsibilities, or because the hospitalists rotate, the team may call the more consistent consultant who does not rotate. Plus, hospitalists just coming on service may not know what arrangements have been made so that errors are made during a psychological crisis as to who the team should call. The wise consultant will establish practice patterns in regard to crises in advance with all players; if the consultant accepts first-call responsibility, the consultant must insure availability and back-up.

Tips

1. Be clear whether the consultant is being asked for opinion, intervention, or both.
2. Attend to the motivations of the referral source. Be sensitive to the emotional functioning of the team.
3. Encourage routine referrals or, at minimum, early referrals before crises develop.
4. Educate referral sources about the preferred referral structure.
5. Be educated about the underlying medical conditions of the people about whom referrals are received. Be prepared to address common reasons for referrals.
6. Understand the pressures under which physicians perform and be ready to operate with the same level of responsibility. Help relieve the pressures.
7. Utilize personal avenues of communication to supplement chart entries. If a doctoral practitioner, gain access to doctors' lounges and dining rooms.
8. Make succinct recommendations. Figure 52.1 provides an example of this.
9. Seek broad privileges that permit evaluation and treatment of psychological and health conditions.
10. Be vigilant about indirect clinical time.
11. Have agreed upon expectations about who provides first-call crisis management.

Acknowledgment Grateful acknowledgment is due Dr. Robert Sevenich and Dr. Marie Volbrecht for their thoughts regarding consultation. However, the authors are responsible for the perspectives in this chapter.

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Interdisciplinary Teams

53

Michael Dunn

Topic

Since most of us in rehabilitation work in interdisciplinary teams, we all have an idea of what they are. Good team functioning like love is a many splendored thing and like love is hard to define. However, we do know when we feel it. This chapter will discuss a variety of suggestions for individual staff members in a team to help strengthen and maintain their team and describe group activities that they can support and encourage. It will also discuss several ways of more formally training the staff as a whole in group functioning.

Nancarrow et al. [1] in a recent study have discussed the concept of interdisciplinary team working and after an exhausting literature review and a large qualitative study of interdisciplinary primary care teams concluded that characteristics of effective teams included positive leadership and management attributes; communication strategies and structures; personal rewards, training, and development; appropriate resources and procedures; appropriate skill mix; supportive team climate; individual characteristics that support interdisciplinary team work; clarity of vision; quality and outcomes of care; and respecting and understanding roles.

In addition, Lemeiux-Charles [2], Strasser [3], and Butt and Caplan [4] have discussed the various kinds of teams and their functions, processes, and development, but for purposes of this chapter, we will assume that the practical suggestions given here will apply to most teams.

Importance

It's easy to assert that interdisciplinary teams are important in rehabilitation units because most rehabilitation units have them in some degree of functionality. Perhaps more importantly, accrediting agencies like the Joint Commission on Accreditation of Healthcare Organizations and the Commission on the Accreditation of Rehabilitation Facilities as well as administrative agencies such as the Department of Veterans Affairs require them. However, there are more compelling reasons why the team concept has been embraced by the rehabilitation community.

"Rehabilitation, by virtue of the complexity of the disability, the variety of disciplines involved, and the relatively long-term interaction of staff with patients, makes a persuasive argument for the necessity of a team approach" [5]. Research supporting team effectiveness bears out this necessity Nancarrow et al. [1], Lemeiux-Charles and McGuire [2], Cashman et al. [6], Strasser

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_53

et al. [7]. Strasser et al. [7], for example, using a cluster randomized trial of 31 rehabilitation units, showed that stroke patients treated by staff who participated in a team training program were more likely to make functional gains than those treated by staff receiving information only. Lemieux-Charles and McGuire's review of the literature on team effectiveness concludes that "the type and diversity of clinical expertise involved in team decision making largely accounts for improvements in patient care and organizational effectiveness. Collaboration, conflict resolution, participation, and cohesion are most likely to influence staff satisfaction and perceived team effectiveness" [2].

Additionally, many medical, nursing, rehabilitation therapy, and behavioral approaches won't work unless most of the staff cooperates. It's easy for one staff member to feel that they have a "special" relationship with patients and try to sabotage any intervention, but with consistent messages from the rest of the staff, such sabotage will not be as effective. Furthermore, surveys of 287 rehabilitation staff in five different facilities about which types of situations are most discomforting and difficult to manage found that the most troublesome situations involved other staff [8]. Additional surveys on 269 rehabilitation staff in three additional facilities confirm this finding.

Even though it has been shown that there are no consistent stages of adjustment to disability, there is some qualitative evidence that the process of rehabilitation does have different stages [9]. Such a theory of stages of rehabilitation implies (and has been demonstrated in one center) that different approaches are more helpful at different stages and that different staff may be more liked and/or appreciated at different stages. For example, Nelson [9] found that in the acute phase, patients report needing nurturing, touch, and support, while just before discharge, a tough love approach emphasizing independence is more effective. Different staff may be better suited by discipline and personality to provide these services.

Socializing new employees and students is another important team function. Orienting new folks offers the opportunity to increase the comfort and skill of the new people which some unpublished data suggests can lead to less turnover, but also to help each experienced staff member feel better about what they themselves do. New staff learn the culture, how to feel more comfortable around disability, where the lunchroom is, how to treat other disciplines and patients, how to be one's own discipline, etc., by observing how their mentor accomplishes these activities and how they are treated by other disciplines.

Practical Applications

The main principle here is to see the team as a unit. Team morale and a unified approach may be more important to good treatment than an individual staff person's feelings.

A. ***Strengthening and Maintaining the Team*** [1]

1. **Support others**

   Supporting others is one of the major jobs that a team member can do for the team. We do that in a number of ways: by praising each other, by noting and applauding team function, by helping others to disown a problem, by defusing and reducing competition and splitting, by not rewarding tattletales, by not using the words "should" or "must," by recognizing multiple effective solutions, and by being a coping, not a mastery model.

   To be a good team member means to reduce one's ego and self-centeredness and the idea that only my discipline and I have THE answer. So, noting, in public, the accomplishments of others and of the team as a whole will encourage interdisciplinary functioning. Helping others (and ourselves) to disown the problem is the flip side of thinking that one has the answer. Many of us have an overdeveloped sense of responsibility, so feel guilty when an outcome doesn't occur the way we think it "should." Group process can assist with this harmful point of view by pointing out alternate rationales for the event not occurring the way the team planned. Being a coping model shows others that one can make a mistake and still be effective, that perfection is not the goal.

Avoiding the negative aspects of group activity also will support others by decreasing guilt, discouragement, and anger. "Shoulds" and "musts" imply that there are laws governing our behavior and that if we fail to accomplish teaching a patient a task, then we have not only failed, but we have also broken some unwritten rehabilitation law. On the other hand, if the patient accomplishes his goal, then we don't feel as good as we could because we are only following the law. Reducing competition and splitting by ignoring it and by not responding to tattletales will support others by letting all know that these ego-enhancing techniques just will not work in this team.

2. **Support group activity**

Any kind of group activity in a rehabilitation center offers a wonderful opportunity not only to accomplish tasks, but perhaps more importantly, to get to know each other as people (not just disciplines), understand roles, work together, grow to like other staff members, and build group spirit. Small subgroups of staff planning a task and carrying it out can learn to be a team and work out how best to facilitate team functioning. Having a team member who assumes or is given the job of noting the process and giving feedback on it will facilitate this learning.

Social gatherings such as Christmas parties, birthday celebrations, and potluck lunches all offer opportunities for group process in planning and actually getting to know people.

Planning and carrying out interdisciplinary patient classes and in-services gives more opportunities for discussing and planning what needs to be taught to families and patients thus learning more about each others disciplines and affirming team functioning. Similarly, team activities like preparing patient and family education manuals, doing a research project, preparing a presentation, or planning a party can facilitate team building.

Specific types of group activities such as team meetings and staff training groups will be discussed later in more detail.

3. **Use Appropriate Interpersonal Attitudes and Skills**

Since teams are composed of people, the team will profit if each team member possesses the interpersonal attitudes and skills to be a good team member. Some of these, like reflecting and celebrating team process are mentioned earlier, but an additional one is seeing the team as a whole and assessing this system: who is a strong team member, who needs support, what kinds of activities does the team do well or have trouble with, who is the task leader, who is the maintenance expert, etc.?

One also needs to realize that one can't just assume a position in the team by virtue of one's experience, age, or discipline. One needs the skills to "buy in" to the team by proving one's worth, being a valuable contributor to patient outcomes, and/or being a reinforcer and facilitator of team process.

One way of "buying in" and maintaining team functioning is to talk in a team manner. Using "we" and not "I," helping staff set realistic goals and responsibilities by giving information from the perspective of ones discipline, and predicting potential challenges are general principles to follow. Here are some examples:

1. "His discharge is certainly going to be a problem for him."
2. "It's too bad that spinal cords and personality disorders can't be fixed. I guess we'll just have to set limits."
3. "It looks like he doesn't have too many options."
4. "It will be better if we check out his communication with all the team."
5. "He's a man with whom we all may have difficulties."

4. **Develop Interdisciplinary Coordination Strategies**

   In spite of the interdisciplinary nature of rehab teams, so called transdisciplinary functioning or role blurring can be very helpful for staff satisfaction and good patient outcomes. Patients don't always choose the "correct" staff member to learn from, teachable moments don't always occur when the appropriate staff member is present, and provision of consistent interventions ensures coordinated care. All staff can contribute to decisions like which patients go in which room, what is the best approach to take, what kind of transfers work best for a particular patient, etc. Shared decision making spreads the responsibility and increases the quality of the decision by getting input from a number of sources who see the patient in a variety of situations.

   One good way to exchange disciplinary skills is to see the patient together. Psychosocial staff can learn how difficult transfers can be, how difficult the patient can be to teach, and how the interaction unfolds. Nursing and therapy can learn alternate ways of dealing with the patient and how the patient reacts in different situations. Observing how another staff member interacts with the patient increases consistency and facilitates good outcomes. Patients not only profit from the consistency, but also discover that the tricks of staff splitting will no longer work and their interaction with those staff members may improve.
5. **Use Environmental Influences**

   The environment in which we work and the external forces that beset us have an influence not only on our own morale and job satisfaction, but also on how the team functions. For example, construction, size of the space for team meetings, where therapy offices are located, patient room size, etc., all may contribute to team communication, morale, and functioning. It is helpful to notice our environment and try to adjust it to better fit the team process. If change is impossible due to external forces, we may need to increase the time we spend on team maintenance. Sometimes it is helpful to use external forces as a unifying force in the team. Staff shortages, small spaces for team meetings, a physician who is not a team player, a recalcitrant disciplinary supervisor, etc., all may be forces of nature, unresponsive to individual or team intervention. An "us vs. them" attitude can be helpful, when these external forces cannot be modified.
6. **Employ Team rounds**

   This material is taken from Dunn and Kuhn, [10]. Interdisciplinary team rounds are normally used for information gathering and patient planning, but they also can be profitably utilized for attitude change, assessment of team functioning, staff education, and team building. One who is more inclined to see the team as a system may also see team meetings as opportunities for Team Family Therapy. Regular support and praise delivered in public is very helpful for team morale and a good way to help maintain standards.
7. **Take Care of Yourself and Reduce Personal Stress**

This topic will be covered in more detail in another chapter, but for purposes of team functioning, the psychological state of yourself and each team member is also important. Thus, it is useful in interacting with others to seek feedback, embrace positive thinking and small steps, set realistic goals, and to tolerate inefficiency. In general, don't be your most difficult client.

B. ***Staff training***

Since graduate schools don't teach team functioning very well, if at all, it is up to the team itself to learn how to get along, how to work together and to inculcate new members into the culture of their new workplace, and be able to interact successfully and profitably with a host of unfamiliar disciplines. Not only that, what has been learned must be maintained. We all get a bit lazy and our team skills can slip, so regular maintenance of team functioning skills is useful for consistent, long-term functioning. Behavioral skills and attitudes, like muscles, need to be used to be maintained. Staff training is an excellent vehicle for such maintenance and starts with team meetings and rounds. Nancarrow et al. [1] suggest that data on patient outcomes and team performance should be regularly available to all team members. In addition, corrective feedback, rewarding good behavior, praising team functioning, asking questions of other team members, providing collegial information, and supporting others also can enhance and maintain team functioning.

More formal classes and courses offer a number of advantages; not only teaching new skills and strengthening old ones, but also allowing staff members to bond, learn more about each other as people and professionals, and practice interacting with each other in less stressful situations than patient care or team meetings may be. Nancarrow et al. [1], Cashman et al. [6], Strasser et al. [7], and others have discussed additional interventions to address general team functioning.

Specific topics that may be addressed are managing difficult behavioral situations in rehabilitation [11] and sexuality and disability [12]. All these courses may involve a thorough precourse needs assessment where specific areas of concern are identified and measured, lectures based on this material, group discussion of the material and, in some cases, demonstration and rehearsal in small groups of the specific situations which staff have encountered, expect to, or are nervous about. The latter activities are especially useful for becoming more comfortable with other staff and their disciplines, so ensuring that the same disciplines are not in the same small groups is helpful.

Finally, if resources exist, conducting staff groups [13] can be very helpful. Discussing troublesome patients or staff situations, how to deal with an uncooperative staff member, sharing experiences and strategies, and learning that one is not alone, can be very salutary.

In conclusion, team functioning, if effective can be beneficial and satisfying for the patient, the individual staff member, the discipline, and the institution. On the other hand, when the team struggles, rehabilitation can suffer, going to work can be a chore, disciplines experience conflict, and institutions can be more expensive. It is partly the responsibility of all interested parties to make it not so.

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Part V

Practice Management and Administration

CPT and Billing Codes

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Mark T. Barisa

Topic

Billing and coding activities provide rehabilitation psychologists the opportunity to identify the services (procedures) that have been provided to a patient in the context of a presenting problem or disorder (diagnosis). The specific procedures and associated diagnosis determine how, and if, the clinician receives payment (reimbursement) for the services provided. Having a good understanding of billing and coding activities relative to clinical services provided is critical for the financial success of clinicians and health care organizations. Key concepts in understanding billing and coding activities in rehabilitation psychology are outlined as follows:

A. ***Centers for Medicare and Medicaid Services (CMS)***
   - CMS is an agency within the US Department of Health & Human Services responsible for administration of several key federal health care programs.
   - In addition to Medicare (the federal health insurance program for seniors) and Medicaid (the state level needs-based program), CMS oversees the Children's Health Insurance Program (CHIP), and the Health Insurance Portability and Accountability Act (HIPAA), among other services.

B. ***American Medical Association (AMA)***

   As the largest association/organization of physicians and medical students in the United States, the AMA's stated mission is to promote the art and science of medicine for the betterment of the public health, to advance the interests of physicians and their patients, to lobby for legislation favorable to physicians and patients, and to raise money for medical education.

C. ***Current Procedural Terminology (CPT)***

   Initially developed and published in 1966, the AMA publishes and regularly updates the Current Procedural Terminology (CPT) coding system that is used to describe the health care assessment and treatment services provided to patients and to communicate uniform information about health care services and procedures among health care providers, coders, patients, accreditation organizations, and payors for clinical, administrative, financial, and analytical purposes.

D. ***International Classification of Diseases (ICD)***
   - Implemented in 1979, the International Classification of Diseases, Ninth Edition,

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_54

  Clinical Modification (ICD-9-CM) diagnostic coding system to classify diseases and a wide variety of signs, symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or disease.
  - The new tenth edition of ICD (ICD-10) has been developed for a number of years and after a long period of modifications for implementation, was adopted in October of 2015.

E. ***Local Coverage Determination (LCD)***
  - Local coverage determination (LCD) means a decision made by a fiscal intermediary or Medicare carrier under Medicare part A or part B about the services and items that are reasonable and necessary.
  - Medicare consists of two parts—Medicare Part A (hospital insurance) and Medicare Part B (medical insurance). Medicare Part A covers Medicare facility-based services, including care received while in a hospital, a skilled nursing facility, and through home health care. Medicare Part B covers services (like lab tests, surgeries, and doctor visits) and supplies (like wheelchairs and walkers) considered medically necessary to treat a disease or condition.
  - LCD also decides if a particular service should be covered.
  - LCD makes decisions about what services are reasonable and necessary for certain diagnoses and diagnosis codes.
  - LCD does not cover determination on which procedure code must be assigned to a service or a determination with respect to the amount of payment to be made for the service provided.

F. ***Medically Reasonable and Necessary***
  - As defined, clinical activities are justified as reasonable, necessary, and/or appropriate, based on evidence-based clinical standards of care.
  - By statute, Medicare may only pay for items and services that are "*reasonable and necessary* for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member," unless there is another statutory authorization for payment.

Importance

Billing and coding issues are often overlooked in clinical training settings. However, having at least a working understanding of appropriate billing and coding activities is imperative for a successful (i.e., financially responsible and beneficial) clinical practice. This is particularly important in light of the numerous changes in health care policy and procedures associated with the Affordable Care Act and associated changes in the health care marketplace.

Numerous documents from CMS, private insurance, and other third party payors outline appropriate billing; coding; and documentation policies, procedures, and requirements. However, at times these include inconsistent or unclear information that can change rapidly with little or no notice. Additionally, these "standardized" policies are subject to interpretation from local and regional organizations or customer service individuals that manage payments to providers. This results in additional inconsistencies and disagreements regarding appropriate activities. Finally, information set forth by individuals via professional e-mail listserves and through informal conversations often add to the confusion as rehabilitation psychologists attempt to discern the best way to manage this aspect of their practice. As a result, there is a high degree of variability in how psychologists conduct billing and coding activities and document their clinical service.

To demonstrate the scope of these difficulties and the relative high degree of stress associated with billing and coding activities, compare the attendance at presentations regarding billing and coding updates and other business activities to the attendance at more general CE presentations. Despite the explanations provided at these workshops, intelligent psychologists leave either in disagreement, disgust, or possibly more accurately, disbelief. This is a touchy area for many psychologists as much of the information presented is not in line with personal beliefs and desires. Still, it is important to understand the rules and regulations as much as possible and to structure activities in such a way as to minimize risk of audit or inappropriate billing while maximizing revenues and providing the highest quality of clinical care.

In an effort to avoid getting bogged down with the minutiae regarding the rules and regulations associated with CMS, private insurance, and other third party payors, this chapter presents information regarding billing and coding in a relatively conservative or basic fashion focusing on what we know and alluding to assumptions and concerns where limited or unclear information is available.

Practical Applications

A. ***Procedure Coding***

As noted earlier, CPT codes describe medical or psychiatric procedures performed by physicians and other health providers (Note: CPT does not identify "psychological" procedures. They are either medical or psychiatric). In 1983, CPT was adopted as part of the CMS Healthcare Common Procedure Coding System (HCPCS) and was mandatory in reporting services for Part B of the Medicare program. In 1986, this requirement was extended to state Medicaid agencies in the Medicaid Management Information System. The use of these codes for this purpose has since expanded to most managed care and other insurance companies. These codes have evolved over the years under the direction of the AMA, but continue to be used to describe the assessment and treatment services provided to patients, and to communicate uniform information about health care services and procedures among health care providers; coders; patients; accreditation organizations; and payers for administrative, financial, and analytical purposes.

There are a total of over 7500 CPT codes, but only about 50 are applicable for psychologists. For the purposes of this chapter, the more common codes are presented along with a few less common codes that may be useful in rehabilitation psychology practice settings. The presented codes fall into two main categories—assessment and intervention. Where appropriate, the codes will be presented as written in the CPT manual with additional information provided where applicable. In particular, codes are presented in terms of their congruence with medical versus mental health conditions. Special attention will be given to the Health and Behavior Assessment and Intervention codes as their use has become quite prevalent in coding clinical activities in rehabilitation psychology.

1. **Testing Codes**

For psychologists, assessment/testing CPT codes are those associated with neuropsychological and psychological testing. These are described in "sets" due to the fact that in 2006 the CPT codes for these activities were further specified to differentiate the work of professionals from technician- and computer-based administration. The testing codes are as follows:

- ***96118: Neuropsychological Testing by Professional***

  Neuropsychological testing (e.g., Halstead-Reitan Neuropsychological Battery, Wechsler Memory Scales, and Wisconsin Card Sorting Test), per hour of the psychologist's or physician's time, both face-to-face time with patient and time interpreting test results and preparing report.

  96118 is also used in those circumstances when additional time is necessary to integrate other sources of clinical data, including previously completed and reported technician- and computer-administered tests

- ***96119: Neuropsychological Testing Administered by Technician***

  Neuropsychological testing (e.g., Halstead-Reitan Neuropsychological Battery, Wechsler Memory Scales, and Wisconsin Card Sorting Test), with qualified health care professional interpretation and report, administered by technician, billed per hour of technician time, face to face

- ***96120: Neuropsychological Testing Administered by Computer***

  Neuropsychological testing (e.g., Wisconsin Card Sorting Test), administered by computer, with qualified health care professional interpretation and report.
- ***96101: Psychological Testing by Professional***

  Psychological testing (includes psychodiagnostic assessment of emotionality, intellectual abilities, personality, and psychopathology, e.g., MMPI, Rorschach, WAIS), per hour of the psychologist's or physician's time, both face-to-face time administering tests to the patient and time interpreting test results and preparing report.

  96101 is also used in those circumstances when additional time is necessary to integrate other sources of clinical data, including previously completed and reported technician- and computer-administered tests
- ***96102: Psychological Testing Administered by Technician***

  Psychological testing (includes psychodiagnostic assessment of emotionality, intellectual abilities, personality, and psychopathology, e.g., MMPI, Rorschach, WAIS) with qualified health care professional interpretation and report, administered by technician, per hour of technician time, face to face
- ***96103: Psychological Testing Administered by Computer***

  Psychological testing (includes psychodiagnostic assessment of emotionality, intellectual abilities, personality, and psychopathology, e.g., MMPI), administered by a computer, with qualified health care professional interpretation and report

Since the testing codes were adopted in 2006, they have been a source of confusion and frustration for psychologists as CMS and many other payors did not reimburse combinations of these codes for the same patient on the same day.

- To allow for the ***simultaneous use of professional and technician/computer*** a **-59 modifier** is used to identify the multiple codes as being distinct and separate services.
- When professional codes and technician/computer codes are used simultaneously the -59 modifier is used with the nonprofessional code (e.g., 96119 and 96120 or 96102 and 96103).
- This practice was recommended and outlined by the APA Practice Organization through an Information Alert in October of 2006.

  The acceptance of this practice has been inconsistent and variable by region and provider, despite the language in the 2008 AMA CPT manual stating that the professional codes were "also used in those circumstances when additional time is necessary to integrate other sources of clinical data, including previously completed and reported technician-and computer-administered tests."
- A new problem for rehabilitation psychologists is that in some settings and local areas, CMS has started to treat these testing procedures as a "bundled" service meaning that payment is made as a single procedure rather than multiple (per hour) units as defined in the AMA CPT manual. This has greatly reduced reimbursement for these services.
- ***Neurobehavioral Status Examination (96116)***
- Neurobehavioral status exam (clinical assessment of thinking, reasoning, and judgment, e.g., acquired knowledge, attention, language, memory, planning and problem-solving, and visual–spatial

abilities), per hour of the psychologist's or physician's time, both face to face with patient and time interpreting test results and preparing report.

- Activities involved in this service can include an interview by the professional; testing by the professional, technician, and/or computer; and interpretation and report writing by the professional.
- Time is billed together under the professional code assuming that different services are provided (no double billing) and a comprehensive/integrative report is generated.
- Some use 96116 as a neurocognitive "screening" prior to discharge from inpatient or rehabilitation units or as an admission assessment for outpatient rehabilitative programs preserving the neuropsychological testing codes for later comprehensive follow-up evaluation. If this is the case it is important to note the language that is used in the report.
- CMS typically does not reimburse for "screening" exams so the better terminology would be "abbreviated neurocognitive assessment" or similar verbiage.
- 96116 is also used as a nonpsychiatric (i.e., medical) interview to determine the need for further testing and what tests would be given rather than a testing code. In this sense, 96116 is sometimes used in conjunction with the neuropsychological evaluation test codes (96118–96120). If this is the case, a distinct documentation for each code is necessary to differentiate the services.

Frequency of Assessments

- The psychological testing, neuropsychological testing, and neurobehavioral status exam codes are administered once per illness condition or when a significant change in behavior and/or medical/health condition necessitates reevaluation.
- According to the AMA CPT Assistant (November 2006), if a repeat evaluation is to be attempted for the same condition, documentation should indicate why the service is medically reasonable and necessary. As such, a reevaluation should only occur when there is a potential change in diagnosis or the nature and/or severity of symptoms.
- Such a change is expected in rehabilitation settings so this is likely to be a common rationale for rehabilitation psychologists.

2. **Mental Health Assessment and Intervention Codes**

The AMA CPT Manual states, "psychotherapy is the treatment for mental illness and behavior disturbances in which the physician establishes a professional contract with the patient and through definitive therapeutic communication, attempts to alleviate the emotional disturbances, reverse or change maladaptive patterns of behavior and encourage personality growth and development." There are a variety of codes used for the initial assessment and treatment of mental health problems. It is important to note that these codes are specific to mental health diagnoses. Interventions for medical-based diagnoses are presented in the section addressing Health and Behavior Assessment and Intervention. The following listing of mental health CPT codes includes updates to some of the assessment and psychotherapy codes that went into effect as of January 1, 2013:

- ***90791: Psychiatric Diagnostic Evaluation***
  - Described as an integrated biopsychosocial assessment, including history, mental status, and recommendations.
  - The evaluation may include communication with family or other sources, and review and ordering of diagnostic studies.

  - ◦ This code replaces the prior diagnostic interview codes of 90801 and 90802.
- ***Psychotherapy Codes***
  - ◦ The prior distinction of different psychotherapy codes for inpatient and outpatient settings was eliminated with the new codes adopted on January 1, 2013.
    - – 90832: 30 min direct individual psychotherapy
    - – 90834: 45 min direct individual psychotherapy
    - – 90837: 60 min direct individual psychotherapy
    - – For 90 min or more, the CPT is yet to be determined. For now, it is best to use 60 min code plus -22 modifier or use 90837 in conjunction with the appropriate Prolonged Service Code (99354–99357).
- ***90785: Interactive Complexity***

  Interactive complexity is reported with add-on code 90785.
  - ◦ This refers to specific communication factors that complicate the delivery of certain mental health procedures (90791, 90832, 90834, 90837, 90853).
  - ◦ This must reflect a significant complicating factor (language barrier, aphasia, child play therapy, severe anxiety impacting communication, etc.) and be documented appropriately in the progress note. To report 90785 at least one of the following factors must be present:
    - – Maladaptive communication that interferes with the ability to assist in the treatment plan (e.g., high anxiety)
    - – The need to manage maladaptive communication among participants that complicates delivery of care (e.g., translator, interpreter, play equipment, device)
    - – Evidence or disclosure of a sentinel event and mandated third-party report with discussion of event/report with patient, other participants (e.g., abuse/neglect)
    - – The use of play equipment, devices, interpreters, and/or translators to assist with inadequate communication abilities on part of the patient
- ***90839 and 90840: Psychotherapy provided to a patient in a crisis state***
  - ◦ This code may not be reported in addition to a psychotherapy code (90832–90838) nor with psychiatric diagnostic, interactive complexity, or any other code in the psychiatry section
  - ◦ Code 90839 is reported only once for the first 30–74 min of psychotherapy for crisis on a given date, even if the time spent by the physician or other health care professional is not continuous.
  - ◦ Add-on code 90840 is used to report additional block(s) of time of up to 30 min each beyond the first 74 min reported by 90839 (i.e., total of 75–104, 105–134 min, etc.).
  - ◦ Crisis coding (90839) must be at least 30 min in duration. Otherwise, code standard psychotherapy.

  As of January 1, 2013, the earlier codes replace the previous psychotherapy codes 90804, 90806, 90808, 90810, 90812, 90814, 90816, 90818, 90821, 90823, 90826, and 90828.

3. **<u>Family and Group Psychotherapy Codes</u>**
   - Family therapy codes were not changed with the new individual assessment and psychotherapy codes.
   - Family therapy is described as reflecting "psychotherapy directed toward an individual and family to address emotional, behavioral or cognitive problems, which may be causative/exacerbating of the primary mental disorder or have been triggered by the stress related to coping with mental and

physical illness, alcohol and drug abuse, and psychosocial dysfunction."

- There also is a code for a multiple family group described as "therapy sessions for multiple families when similar dynamics are occurring due to a commonality of problems." This code is rarely reimbursed but is available for use under appropriate conditions.
- The group psychotherapy code is available for individuals being treated in a group session where "personal and group dynamics are discussed and explored in a therapeutic setting when similar dynamics are occurring due to a commonality of group problems."
- Family and group psychotherapy codes do not have a time or location component and are billed in single units.
- Family psychotherapy codes are differentiated based on whether or not the patient is present. Keep in mind that Medicare and other payors typically do not reimburse for services provided without the patient present.
- The family and group CPT codes are as follows:
  - 90846: Family Psychotherapy without patient present
  - 90847: Family Psychotherapy with patient present
  - 90849: Multi-family Group Psychotherapy
  - 90853: Group Psychotherapy

4. **Health and Behavior Assessment and Intervention Codes**

The focus of the intervention codes described thus far has been on patients with mental health diagnoses. In 2002, CPT codes were added that focus on acute or chronic medical illness rather than mental health disorders to match the biopsychosocial understanding of health, allowing psychologists to provide services for medical patients without having to make a psychiatric diagnosis. The purpose of the codes is to assess and manage medical issues such as adherence to medical treatment, symptom management, promotion of health-enhancing behaviors, reducing health-related risk-taking behaviors, and coping and adjustment to physical illness or injury. The purpose of treatment for a health and behavior code is the alleviation or mitigation of a medical condition. It is not for prevention, personal growth, or in response to a legal question.

It is not uncommon for a medical patient to have a comorbid mental health condition, and if the patient is being treated for a mental health problem and a medical problem at the same time, the mental health code (90801–90899) and health and behavior code cannot be used on same patient for same date of service. If both mental health services and health and behavior services are required on same date, report the principle service being provided as determined by the primary reason the patient is being seen. The following table adopted from Casciani (2004) [8] simplifies the distinction between health and behavior interventions and traditional psychotherapy and can be used as a guide to determine the appropriate CPT code to use (Table 1):

The health and behavior codes include both assessment and management services. It is important to remember that unlike the psychotherapy codes, they do not have specific time parameters associated with

Table 1 Differentiating health and behavior and psychotherapy codes

	H&B	Psychotherapy
Diagnosis	Physical illness/ injury (use ICD-10)	Mental illness (use DSM-V)
Primary focus	Education and/or behavior change	Insight and/or behavior change
Goal	Improve health and well being	Alleviate emotional pain or maladaptive behavior
Context	Emphasize collaboration with medical team and family	Emphasis on privacy and confidentiality

Adapted from Casciani (2004) [8]

each code. Instead, health and behavior services are billed in 15 min increments of face-to-face time for all of the available codes. The health and behavior CPT codes descriptions are as follows:

- ***96150: Initial Health and Behavior Assessment***

  The initial assessment of the patient to determine the biological, psychological, and social factors affecting the patient's physical health and any treatment problems.
- ***96151: Health and Behavior Reassessment***

  A reassessment of the patient to evaluate the patient's condition and determine the need for further treatment. A reassessment may be performed by a clinician other than the one who conducted the patient's initial assessment.
- ***96152: Individual Health and Behavior Intervention***
- ***96153: Group Health and Behavior Intervention***
- ***96154: Family Health and Behavior Intervention with Patient Present***
- ***96155: Family Health and Behavior Intervention without Patient Present***

While the health and behavior codes have been a useful addition for psychologists and neuropsychologists working in medical settings, they are not without their problems. Over the years, there have been and continue to be some difficulties with payor misunderstanding of the codes and denying or requesting a mental health diagnosis for services performed by a psychologist. Despite the efforts of the APA Practice Directorate and other professional organizations, this has not yet been totally resolved. Additionally, intermediaries/carriers may interpret the language differentiating health and behavior from mental health codes as meaning that a professional cannot bill the health and behavior code if the patient has a current or any previous mental health diagnosis. Finally, there has been some clinician misunderstanding that the codes are billed in 15 min increments of face-to-face time only and there is no allowance for additional information gathering and report writing.

5. **Feedback Session Codes**

Coding for feedback sessions has been a source of disagreement across practitioners. In general, there are several codes that have been described as "appropriate" or "possible" codes for feedback sessions including the following:

- *96118: Neuropsychological Evaluation (Professional)*
- *96152/96154/96155: Health and Behavior Intervention Codes*
- *9083x: Psychotherapy Codes* (using a comorbid or primary mental health diagnosis)
- *90846/90847: Family Psychotherapy Codes* (using a comorbid or primary mental health diagnosis)
- *90887: Feedback of Test Results* (using a comorbid or primary mental health diagnosis)
- *99211–215: E/M consultation codes*

I conducted a brief survey of members of the American Academy of Clinical Neuropsychology listserve regarding codes used for feedback. As summary of results of 30 respondents highlighted the variability noted in code usage:

- Most respondents use either 96118 (with multiple timeframes offered) or the H&B codes (9615x)
- Variability was noted in the reported use of 96118
  - ◦ Feedback provided on the same day with time added to the total 96118 units
  - ◦ Feedback provided on a different day, billed independently on the second day of contact
  - ◦ Feedback provided on a different day with total bill calculated on the second day of service
  - ◦ Feedback provided on a different day, but billed as part of the initial day evaluation (adding an additional

hour of 96118 on the day of testing for expectation of future feedback appointment)

- A few respondents indicated using the psychotherapy codes (with a mental health diagnosis code)
- No respondents indicated use of the E/M codes or other codes

  In my informal discussions with those who identify themselves as rehabilitation psychologists, the vast majority reported using Health and Behavior codes, although some described various scenarios of using 96118 as noted earlier.
- If a Health and Behavior code is used, there should be clear documentation of "intervention" as part of the feedback session to support the use of this code set.
- If a psychotherapy code is used, there should be an associated mental health diagnosis to support the use of this code set.

6. **Other Less Commonly Used Codes**

   To close out this section, the following additional codes are presented despite being less commonly used. Medicare may or may not recognize these as reimbursable codes, but other payors may, and they may serve for documentation for private pay, forensic, or other settings. Additionally, in institutional settings these codes may be useful in documenting productive time despite reimbursement limitations.

   - ***Assessment***
     - ***96110: Developmental Testing; Limited***

       Developmental testing; limited (e.g., Developmental Screening Test II, Early Language Milestone Screen), with interpretation and report
     - ***96111: Developmental Testing; Extended***

       Developmental testing; extended (includes assessment of motor, language, social, adaptive, and/or cognitive functioning by standardized developmental instruments) with interpretation and report
     - ***96020: Functional Brain Mapping***

       Neurofunctional testing selection and administration during noninvasive imaging functional brain mapping, with test administered entirely by a physician or psychologist, with review of test results and report.
     - ***95958: Wada activation test for hemispheric function***

       This includes electroencephalographic (EEG) monitoring so it is not used by psychologists with any regularity.
   - ***Intervention/Consultation***
     - ***90875 and 90876: Psychophysiological Therapy including Biofeedback***
     - ***90880: Hypnotherapy***
     - ***90882: Environmental intervention for medical management purposes*** **on a patient's behalf with agencies, employers, or institutions**
     - ***90887: Interpretation or explanation of results***

       Of psychiatric, other medical examinations and procedures, or other accumulated data to family or other responsible persons, or advising them how to assist patient (no patient present)
     - ***90889: Preparation of report***

       Of patient's psychiatric status, history, treatment, or progress (other than for legal or consultative purposes) for other health care providers, agencies, or insurance carriers
     - ***90899: Unlisted psychiatric service or procedure***
     - ***99366: Medical team conference***

       With interdisciplinary team of health care professionals, face to face with patient and/or family, 30 min or more, participation by nonphysician qualified health care professional (newly added in 2008)
     - ***99368: Medical team conference***

With interdisciplinary team of health care professionals, face to face with patient and/or family, 30 min or more, participation by nonphysician qualified health care professional (same as 99366 except that the patient is not present).

B. ***Putting Procedure and Diagnostic Codes Together***

To submit charges for any of the CPT codes described earlier, the procedure codes are linked to a diagnosis using the International Classification of Diseases, Clinical Modification (ICD-10M). The key for rehabilitation psychologists is to make sure that they link the appropriate diagnostic codes with the CPT codes submitted for reimbursement. In general, physical health procedures require physical health diagnoses, and mental health interventions require mental health diagnoses. Some of the CPT codes described previously are clearly for use with patients with physical health diagnoses and some are clearly for use with patients with mental health diagnoses. However, things are not always as easy as they appear.

Neuropsychology and rehabilitation psychology assessment and intervention services typically involve patients with physical health diagnoses, but it is important to understand some of the variability in the provision and interpretation (from a diagnostic standpoint) of such services as charges are reported to payors.

- Health and behavior codes were implemented to be used exclusively for physical health conditions
- Mental health assessment and psychotherapy treatment codes are to be used exclusively for mental health conditions.
- Some codes are available for use with patients with either physical health or mental health diagnoses.
    - These codes typically fall in the 96xxx series including the psychological evaluation codes (96101–96103) and neuropsychological evaluation codes (96118–96120).
    - As of 2006 the 96000 series codes could be used for the assessment of physical health patients without there being a diagnostic code mismatch.
    - This is an important (and potentially valuable) distinction that allows for use of the psychological testing codes for presurgical evaluations for bariatric surgery, spinal cord stimulator placements, or organ transplants; initial evaluations for chronic pain conditions; or other medical referrals.
- In determining the proper CPT procedure and ICD-10 diagnostic codes for services provided, it is important to consider the services provided as well as the condition being treated.
- It is possible that a patient will have both physical health and mental health diagnoses and the professional will need to identify the principle service being provided and the associated diagnostic group to determine the appropriate codes to assign to the service.
- Using multiple diagnoses can be useful, but understand that the "first diagnosis listed" has taken the place of "primary diagnosis." For most payors, this first diagnosis will serve as the basis for CPT/diagnosis determinations.
- It is important to note that, in some circumstances, adding a mental health diagnosis as a secondary to a physical health condition may result in mismatch issues for some CPT codes and may result in a charge being transferred to a behavioral health carve out agency rather than paid directly through medical benefits. This can result in a reduction in reimbursement or a denial depending on the service and the payor.
- It is important to note that CMS and third-party payors typically have a limited number of accepted diagnostic codes for any given procedure, and knowing their diagnostic "formulary" can save time, energy, stress, and money as appropriate reimbursement is sought.

- This has become particularly problematic for neuropsychological and psychological testing codes in some regions where LCD documents have rigidly applied a list of diagnostic codes required to meet the "medically reasonable and necessary" criteria.

C. ***Documentation***

According to the Office of the Inspector General investigating Medicare fraud, two of the primary problems encountered during audits are inappropriate/incomplete documentation and failure to document medical necessity. It is possible to address both of these issues simultaneously by developing a clinical documentation system that automatically and consistently incorporates appropriate documentation for the various CPT codes and related medical necessity. There are some general principles that apply to all documentation including the rationale for service, the procedure provided, the results or progress since previous contact, an impression and/or diagnosis, a plan of care or case disposition, and time (if applicable). It is important to remember that the information provided in this chapter reflects general guidelines. Local carriers and payors may have some variations that will need to be investigated further. Detailed information can be found in presentations provided by Tony Puente and available on his website listed in the reference section (http://psychologycoding.com). The following provides a summary of this information:

1. **General Documentation Guidelines**

Documentation should follow a logical progression including documenting medical necessity for services, maintaining records of a patient's evaluation results, plan of care, progress in treatment, and documenting the outcome of the services provided.

"Rationale for service" includes documentation of medical necessity in accordance with the definition provided earlier in this chapter.

Services or supplies are considered medically necessary if they:

- Are proper and needed for the diagnosis or treatment of the patient's medical condition;
- Are furnished for the diagnosis, direct care, and treatment of the patient's medical condition;
- Meet the standards of good medical practice; and
- Are not mainly for the convenience of the patient, provider, or supplier.

It is important to note that for every service billed, the specific sign, symptom, or complaint necessitating the service must be listed.

The structure, layout, and style of a professional's documentation are not as important as the content of the information. Some basic information is required across all codes whether they are assessment or intervention based. These include:

- Identifying Information
- Date(s) of Service
- Time, if applicable (total time or actual time—as appropriate)
- Identity of Observer (professional, technician, or other provider)
- Reason for Service (including medical necessity)
- Status
- Procedure(s)
- Results/Findings
- Impression/Diagnosis
- Plan for Care/Disposition

The patient's primary complaints as they relate to the presenting illness should be documented in terms of description of the symptoms present, the frequency and intensity, context of the complaints, modifying variables, and other associated signs. It is best to present these in the context of medical necessity for services.

For both assessment and intervention follow-up appointments, it is important to document any changes in the illness/condition as well as adherence to treatment recommendations. This is particularly noteworthy for repeat assessments using the same CPT code.

2. **<u>Assessment/Evaluation Documentation</u>**

   For assessment/evaluation documentation, the general guidelines earlier are used with some additional specifics. The following is a guide for assessment documentation:
   - Identifying Information
   - Reason for Service (including medical necessity)
   - Date(s) of Service
   - Time (amount of service time—total versus actual time)
   - Identity of Tester (professional, technician, other)
   - Tests and Protocols (include names and editions)
   - Narrative of Results
   - Impression(s) or Diagnosis(es)
   - Disposition or Plan of Care

   With the change in psychological and neuropsychological testing codes, some additional aspects of documentation need to be considered.
   - If more than one CPT code is used for an evaluation, each code should generate a separate report or at least a separate section appropriately and clearly labeled.
   - For the technician component (96119; 96102), the technician's name should be included along with the tests administered and the time for the face-to-face testing time.
   - For the professional component (96118, 96101, 96116), appropriate labels should be used for the various sections including obtained history (record review, interview, etc.), behavioral observations and mental status exam, tests completed by the professional, integration of findings, interpretation, and impressions/diagnosis. Time again is included based on the total <u>time for the professional's activities</u>.

3. **<u>Intervention Documentation</u>**

   Documentation for interventions is somewhat cleaner as there is typically a single code for a single service. Still, appropriate documentation is necessary including the following:
   - Identifying Information
   - Reason for Service (including medical necessity)
   - Date of Service
   - Time (typically face-to-face time only)
   - Status of Patient/Changes Since Previous Intervention
   - Intervention Performed
   - Results Obtained
   - Impression(s) and/or Diagnosis(es)
   - Disposition/Plan of Care

   If a computerized template is used for intervention documentation, it is easy to pull the most recent therapy note for a patient and use it as a basis for the current note. This allows a clinician to see the patient's previous status easily in comparison to the current status and make appropriate documentation easier and more time efficient.

4. **<u>It's About</u> <u>Time</u>**

   Time is measured by face-to-face contact for purposes of intervention (and health and behavior assessment/reassessment), and most intervention codes are time predetermined or billed in 15 increments of actual face-to-face time.

   For assessment purposes, time is less well defined.
   - Technician codes are specific in terms of time being the actual face-to-face time with the patient.
   - Professional codes can include time spent before, during, and after the actual face-to-face assessment.
   - It is helpful to develop a time monitoring form to document the provider, date(s) of service(s), service(s) provided, and the start and stop times of each activity.
   - This allows for more accurate reporting of actual time and will provide supporting documentation if questions arise in the future.

There will likely be an increased emphasis on the documentation of time in the future, possibly including exact start and stop times of all activities in the final report as well as a date and time for the signature on the final documentation.

5. **Final Thoughts on Documentation**

Complete and appropriate documentation does not have to be lengthy or cumbersome. Concise documentation can be achieved using this information as a guide.

Specific templates or boilerplates for each CPT code can be created to insure consistency in terms of the "types" of information included.

- These can be designed in a manner that allows for individual differences among clinicians within a practice or department while maintaining consistent documentation.
- Using a secured system or network drive allows for a MS Word version of a backup computerized medical record using this type of documentation.
- Similar documents can be created that can be filled in via handwritten entries, but typed documentation is preferred by most payors.

Documentation can be formatted in such a way that documents also serve as a marketing tool with departmental/practice logos and contact information are included as a letterhead.

Once the documentation process is established, occasional audits can be completed as a peer review/quality assurance measure to ensure that appropriate departmental/practice documentation is maintained.

Tips

Common CPT Codes for Psychologists

- **Assessment/Evaluation**
  - 90791: Psychiatric Diagnostic Interview
  - 96150: Health and Behavior Assessment—Initial
  - 96151: Health and Behavior Re-assessment
  - 96116: Neurobehavioral Status Examination
  - 96101: Psychological Testing—professional
  - 96102: Psychological Testing—Technician
  - 96103: Psychological Testing—Computer
  - 96118: Neuropsychological Evaluation—Professional
  - 96119: Neuropsychological Evaluation—Technician
  - 96120: Neuropsychological Evaluation—Computer
- **Intervention**
  - **Psychotherapy**
    - 90832: 30 min direct individual psychotherapy
    - 90834: 45 min direct individual psychotherapy
    - 90837: 60 min direct individual psychotherapy
    - 90785: Interactive Complexity
    - 90839 and 90840: Psychotherapy provided to a patient in a crisis state
    - 90846: Family Psychotherapy without patient present
    - 90847: Family Psychotherapy with patient present
    - 90849: Multi-family Group Psychotherapy
    - 90853: Group Psychotherapy
  - **Health and Behavior Interventions**
    - 96152: Individual Health and Behavior Intervention
    - 96153: Group Health and Behavior Intervention
    - 96154: Family Health and Behavior Intervention with Patient Present
    - 96155: Family Health and Behavior Intervention without Patient Present
  - **Other Codes**
    - 96110: Developmental Testing; Limited
    - 96111: Developmental Testing; Extended
    - 96020: Functional Brain Mapping
    - 90875 and 90876: Psychophysiological Therapy including Biofeedback

  - 90880: Hypnotherapy
  - 90882: Environmental intervention for medical management purposes
  - 90887: Interpretation or explanation of results
  - 90889: Preparation of report
  - 99366: Medical team conference with patient present
  - 99368: Medical team conference without patient present
  - 90899: Unlisted psychiatric service or procedure

Resources for Additional Information

- NAN PAOI webpage: www.nanonline.org/paio
- National Correct Coding Initiative: www.cms.hhs.gov/NationalCorrectCodInitEd
- Antonio Puente's webpage on CPT and Psychology Service Billing: http://psychologycoding.com
- Inter Organizational Practice Committee (IOPC) Health Care Reform and Neuropsychology Toolkit: http://neuropsychologytoolkit.com/
- http://www.psychiatry.org/practice/managing-a-practice/cpt-changes-2013
- Searchable CPT manual available free of charge on line from AMA at https://catalog.ama-assn.org/Catalog/cpt/cpt_search.jsp
- Information Regarding the Medical Physician fee Schedule: http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/index.html
- Consult the *Federal Register* for ongoing updates—www.gpoaccess.gov/fr along with regular review of regional Medicare carrier/intermediary websites
- The Medicare Learning Network (MLN) is the brand name for official CMS educational products and information for Medicare fee-for-service providers. For additional information visit the Medicare Learning Network's on the CMS website at www.cms.hhs.gov/MLNGenInfo.

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Burnout Prophylactics: Professional Self-Care

55

Mary G. Brownsberger and Preeti Sunderaraman

Topic

We all have our own definitions—our own experiences—of burnout, of fatigue borne of caring too much. We work with people who are sick, traumatically injured, dying. We work in environments with increasing administrative pressure for billable "productivity." We and our coworkers are equally stressed out and grappling with feeling helpless. The purpose of this chapter is to spark your own inner wisdom about how to take care of yourself, even in the midst of profound suffering. While the bulk of what follows is academic, or at least intellectual, including clinical definitions of key concepts, prevalence data, evidence base for various interventions, and concrete tips, the real "take away" is in cultivating your practice of listening to your own heart.

A. ***Key Concepts***

1. **Burnout**

   The adverse effect of long-term emotional, interpersonal, and physiological work demands on the self and on job productivity [1].

   Symptoms:
   - *Excessive distancing from patients*
   - *Diminished competence*
   - *Low energy*
   - *Increased irritability with colleagues, family, friends*
   - *Job dissatisfaction*

2. **Compassion Fatigue (also known as secondary traumatic stress)**

   Vicarious experience of individual or cumulative trauma resulting in increased tension, preoccupation with the trauma, feelings of hopelessness, anxiety and confusion, and decreased compassion [1].

   Symptoms:
   - *Exhaustion*
   - *Reduced ability to feel empathy or sympathy*
   - *Increased irritability*
   - *Increased substance use*
   - *Avoidance of working with certain patients*
   - *Increased arousal*
   - *Intrusive thoughts*
   - *Hypersensitivity to emotional information*

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_55

- *Absenteeism*
- *Impaired job performance*
- *Problems with intimacy, personal relationships* [2]

3. ***Consider this***

We are all, regardless of our specific professional discipline, helpers. Our job is to help people, and most of us derive immense personal satisfaction from knowing that we have done something that helped another human being. What happens when we are faced with situations in which we find ourselves unable to help—in which there is nothing that we can *do*? Are we perhaps more vulnerable to burnout or to compassion fatigue?

Importance

Warning: this is the academic/intellectual stuff. It's really great—lays the foundation for the practical tips. However, if you're currently experiencing high levels of stress or distress, skip this and go to "Tips." Come back to this later.

A. ***Job Productivity***

For those experiencing burnout, job productivity is impacted by higher rates of absenteeism, decreased job satisfaction, and poorer standards of care for the client [3]. In addition, physical health (poor cardiovascular health, pain), mental health (depression, anxiety, and addictions), quality of life (broken relationships, divorce), and participation in the community (early retirement) may be affected. On a macro level, such adverse effects translate into heavy economic losses ranging from 10 to 20% of the gross national product because of both direct and indirect costs [4]. Such costs are related to lowered work commitment and high worker turnover and the subsequent recruitment and training of new staff.

B. ***ICD Recognition***

Simply stated, burnout affects an individual's ability to work to his or her maximal potential while maintaining an effective work–life balance. Typically, burnout is experienced by health care professionals. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) classification does not consider burnout syndrome to be a disorder [5]. However, section **Z.73.0 of the International Classification of Diseases, tenth revision (ICD-10)** recognizes burnout as a "state of vital exhaustion" under "Problems related to life-management difficulty" [6]. Frequently, burnout syndrome has been associated with chronic depression in individuals and the intensity and nature of the symptoms in individuals experiencing burnout is similar to clinically depressed patients.

C. ***Prevalence***

1. **Burnout**

The prevalence of **burnout** in both developing countries and industrialized countries is relatively high [4]. In medical professionals, the rate of burnout ranged from 2.4 to 72% in European countries. Comparatively, the prevalence ranged from 37 to 74% in African countries, 7.4 to 24% in South America (primarily Brazil), and 42 to 71% in Asian countries. It has been suggested that a combination of socioenvironmental factors and a lack of focus or awareness on reducing work-related stress may exacerbate the rate of burnout. Socioenvironmental factors include poor literacy, limited resources at work, unevenly skewed professional to client ratio, poor working standards and work-related ethics, increased familial demands especially for females, and poverty [4, 7, 8].

2. **Compassion Fatigue**

Prevalence statistics for **compassion fatigue** are sparse. Studies conducted in Canada indicated that one-fifth of nurses participating in a national survey in 2005 reported that their mental health had impacted job performance, and 80% had accessed employee assistance programs (EAP) resources [2]. Other literature comments on how common compassion fatigue is among health care professionals but refrains from citing statistics [9, 10].

3. **Bottom line**

   Both burnout and compassion fatigue impact personal health and well-being as well as quality of job performance (and thus patient outcomes), and both are exceedingly common in medical rehabilitation settings. Literature describing prevalence and intervention models often discuss both burnout and compassion fatigue as similar constructs with similar intervention recommendations. For example, the model of burnout described later was used to understand protective factors among rehabilitation workers at risk for compassion fatigue [10]. Thus, we choose to forego any further discussion regarding definitions and focus on the practicalities of how to identify signs of both burnout and compassion fatigue and most importantly, ways to prevent these syndromes.

D. ***Models of burnout***

   Although several models of burnout syndrome have been proposed [3], the one proposed by Maslach et al (1996) is by far the most comprehensive and the most frequently used [11, 12]. These researchers developed the **Maslach Burnout Inventory (MBI)** which assesses three aspects of the burnout syndrome—**depersonalization (cynicism), emotional exhaustion,** and **low sense of personal accomplishment (work dissatisfaction**). Of the three, emotional exhaustion has been strongly related to mental disorders such as depression [3].

E. ***Attributes***

   Individual characteristics of health care professionals, client characteristics, and specific organization-related factors all interact and contribute to burnout. **Individual characteristics** associated with burnout include younger age, being female, a longer length of practice within an organization, Type A personality, perceived lack of control, and autonomy [7, 13]. **Client characteristics** contributing to a higher rate of burnout include a larger caseload, more severely and/or chronically ill clients, or potentially threatening clients, and more frequent direct contact with the client (versus indirect contact) [2, 4, 14]. **Organization-related factors** such as rigid and restrictive work demands, work overload, role conflicts, vaguely defined work responsibilities, inadequate supervision, and lower perceived support from supervisors led to burnout [13, 15].

Practical Application

A. ***Empircal Support for Prevention and Coping Strategies***

1. **Ethical Responsibility. Principle A—'Beneficence and Nonmaleficence'**

   The American Psychological Association (APA) states that, "Psychologists strive to be aware of the possible effect of their own physical and mental health on their ability to help those with whom they work" [16]. Specifically, **APA's Standard 2—'Competence'** makes it an ethical imperative for psychologists to engage in self-care by recognizing when personal issues impact competency. Despite the relatively extensive literature on the models and symptoms of burnout, there are still no standardized treatment or prevention regimens stipulated by medical or psychological organizations to prevent burnout. However, there is a growing number of treatment models across health care disciplines, all with the premise that a combination of individual- and organizational-based strategies can be utilized to prevent or help cope with burnout [12, 14].

2. **Two empirically researched treatments**
   (a) ***The Accelerated Recovery Program (ARP***) [17, 18] is a five-session manualized intervention program that teaches professionals coping skills and was found to significantly decrease symptoms of burnout in professional helpers.
   (b) Subsequently, the ***Certified Compassion Fatigue Specialist Training*** [19] was developed in which professionals learn the theory behind

burnout and compassion fatigue, in addition to learning to apply the ARP coping skills.

3. **Weekly support meetings**

   There is emerging evidence that weekly support group meetings to discuss and solve work-related issues in a nonjudgmental manner may decrease burnout [13]. Sharing work-related problems with coworkers has been especially identified as a critical factor for preventing burnout [13, 20] possibly because of the increased level of empathy and novel insights developed through those interactions [2].

4. **Time out**

   When faced with an extremely stressful situation, sanctioned "time-outs" can be employed whereby a professional can temporarily engage in some other (i.e., not client interaction based) activity [13]. Reducing sustained contact with one client or one type of diagnosis has also been found to decrease work overload, and thereby reduce burnout [3].

5. **Regular physical exercise** to maintain physical and emotional well-being has also been underscored [8].
6. **Stress management strategies** include psychoeducation regarding burnout syndrome, techniques to increase an individual's confidence and personal competency, encouraging the professional to develop hobbies outside of work, and conducting stress management training such as mindfulness training [13]. It has been suggested that psychoeducation is one of the most critical prevention strategies as it can help in the self-identification of symptoms by acting as an alerting mechanism [2] and thus preventing overwork and frustration [13]. Some of these strategies can also serve to make the job more exciting by decreasing monotony associated with a single work responsibility [13].
7. **Humor.** The ability to find humor and laugh easily when encountering certain work-related situations has also been identified as a buffer against burnout.
8. **Better organizational management** involves clearly defining roles and corresponding responsibilities; redistribution of heavy workload by rotating work-related responsibilities and making the schedules flexible; frequent assessment of the risk of burnout; regular supervision and provision for peer support; providing positive feedback with an opportunity to learn; increasing feelings of control and achievement; flexible working conditions; open communication at workplace including an ability to share ideas with supervisors, peers, and clients; supporting the worker and their family by providing low-cost, easily accessible childcare facilities and transportation services [3, 7, 8, 12, 19–22].
9. **Increasing the individual's connection with the organization.** Maslach et al. [12] suggest that ***six areas of one's work life***—workload, control, reward, community, fairness, and values—can be enhanced. Ultimately, such prevention and coping strategies will serve to increase one's resilience and work efficiency, decrease level of work-related idealism, and empower one to more fully engage in the professional community.

B. ***Preventing Burnout and Compassion Fatigue: To the point***

1. **Self-Awareness is Key!**

   We rarely take time to examine our personal values and life priorities, and how those are consistent (or not) with how we spend our time. We have expectations about how our lives and our work "should be." We feel we "should" be able to handle whatever comes our way; that's what we've had all this training for. Our idealized expectations are not reality based; the discrepancy between "ideal" and "real" creates distress.

   Examine your life [23]

   - What are your core values? For example:

Autonomy	Helping others
Challenge	Recognition/Status

Competition	Social Justice
Respect	Beneficence
Increasing knowledge	Being Right
Being around people	Being good
Freedom	Vitality
Authenticity	Growth

- What are your priorities? For example:
  - Work/Career
  - Family
  - Friends
  - Stability/Security
  - Physical/mental health
- How do you spend your time? For example:
  - Family time
  - Exercise
  - Leisure activities
  - Relaxation/meditation
  - Personal counseling/growth
  - Spirituality
  - Continuing Education/training
  - Health and nutrition
  - Friends, support team
  - Less than optimal coping strategies such as
    - TV
    - Video games
    - Alcohol
    - Comfort food
    - Illicit or misused substances
- What is the discrepancy between what you value and how you spend your time?
- If you had all the time you wanted, how would you spend your time?
- What aspects of the profession necessitate self-care?
  - What are some of the emotional rigors of the work that come to mind for you?
  - How were you prepared for the emotional rigors of the work?

2. **Take Responsibility: Develop a proactive self-care plan!**
   - Career
     - Consider importance of working somewhere that share your values and priorities
     - Reduce discrepancies between expectations and realities in your workplace
     - Gain support from supervisors, coworkers, key professional colleagues
     - Feel competent and good about what you do
     - Spend time on professional development and professional networks
   - Family
     - Balance need to care *for* family members with *receiving* care and support from family
   - Emotional/Psychological Health

○ Sense of Humor	Being in the moment
○ Cognitive Reframing	Organizing/Prioritizing
○ Sense of Purpose	Sense of effectiveness/control
○ Assertive communication	Personal therapy/peer supervision

   - Physical Health
     - Exercise
     - Sleep
     - Recreation
     - Nutrition
     - Preventive health care and treatment when needed
   - Financial
     - Do you feel financially secure?
     - Would you be able to handle an emergency?
     - When will you be able to retire? Reduce hours?
     - Recognize current habits
     - Take actions
       - Reducing/eliminating debt
       - Budgeting
       - Planning for emergencies
       - Insurance
       - Financial advisors/planners
   - Social
     - Are you happy with your current friendships and level of social support?
     - Do you want to improve quality or quantity of relationships?

    - How much time do you spend on these activities?
    - What types of activities would be most helpful for making improvements?
      - Phone calls, e-mails, cards/letters, compliments/verbalize appreciation, time together, etc.

  Spiritual
    - Meditation/Prayer
    - Participation in faith community if congruent with your values

3. **<u>Is there an urgent situation—immediate need to manage your response?</u>**
   - Ask the questions:
     - What is going on between the patient (or other person) and myself? For example, "attacking" "abandoning"
     - How do I feel about the situation?
     - Where is it in my body?
     - What will I do about it?
   - Can I take a "time out" or at least one deep breath?

Tips

- Get out of your head.
- Move the body.
- Breathe—with awareness and intention.
- Practice stillness, awareness without judging—whether mindfulness, contemplative prayer, meditation, or whatever label.
- Nutrition.
- Be with people whom you find supportive.
- Set boundaries—be clear what you choose and choose not to do—and remember—there is always a choice.
- Ask for help to complete the task—delegate when it's appropriate.
- Sleep hygiene.
- Ignore the stigma, even among health professionals, of taking a personal day or asking for professional help; we can't always heal ourselves.
- Stop before you drop.
- Read something calming and inspirational.
- Read something just for fun.
- Listen to your preferred music.
- Find an image of self-care that works for you. For example:
  - First, take your own pulse
  - Consider your heart a revolving door—take in the present moment fully, and then release it fully
- Find gratitude.

Our favorite resources which may not be yours (you're welcome to start here—but find what works for you):

Meditation/mindfulness retreats to replenish energy reserves and deepen self-care practice. One example (We're not marketing here—just a suggestion) is Insight Meditation Society, Barre, MA.

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Any poetry by Rumi or Mary Oliver

And **in closing**, from Sharon Salzberg's book, cited above:

> "No job is stress free…Happiness at work depends on our ability to cope with the obstacles that come our way and to bounce back, learn from mistakes, make amends when necessary, and—most important of all—begin again without rumination or regret…This is what we mean by resilience. No matter what happens to us at work (or elsewhere), we can learn to use challenges as opportunities to grow, increase our awareness, and learn methods for making future challenges more tolerable (p. 105)."

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Media Psychology: What You Need to Know and How to Use It

Pamela Rutledge

Topic

A. ***What is Media Psychology?***

- Media psychology is the use of psychology to bring people and media technologies together in a way that makes life better.
- People talk about media and technology as if they were different things. They are not. The lines are blurring among media channels—people routinely use more than one device simultaneously—and the concepts of online and offline will soon be obsolete.
- We live in a world where there are more cell phones than people over the age of 10. Today, 89 % of US residents have mobile broadband subscriptions that give them access to the Internet anywhere, anytime.
- Media technologies refer to any type of mediated communication including technology, from content to hardware. Media technologies are fully embedded in almost every aspect of life. Media technologies include the full range of tools we have at our disposal to help people get and stay well. Media psychology is figuring out how to use the right tools for the job.
- The goal of this chapter is to give you some ideas about how technology is being used in two ways: (1) as a treatment or intervention tool and (2) as a marketing and information tool to get a practitioner's name, services, and expertise out in the public.

B. ***Benefits of Media Technologies***

- Media technologies have powerful benefits. At a time when healthcare is expensive, media and technology can be used to extend reach, leverage quality care, and provide treatment that would otherwise be unavailable or cost prohibitive.
- Humans are social animals, and we crave connection, affiliation, and validation.
- The Internet and applications can:
  - ○ Provide a lifeline to treatment and social support for people with disabilities or to those who have limited mobility
  - ○ Allow people to stay connected to others in spite of difference in time zones or distant locations
  - ○ Provide timely information and diagnoses when resources are not available locally
  - ○ Provide reminders for taking medications and reinforcement for implementing new health behaviors
  - ○ Deliver treatment to those who would otherwise not receive it
  - ○ Empower and educate people to make positive changes or comply with treatment plans and protocols

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_56

C. ***Risks and Limitations of Media Technologies***:

Risks

- Media tools have potential risks; these include violations of patient privacy, inappropriate use, and resistance to technology adoption that can impact treatment adherence. These demand practitioners to take the time to learn best practices, legal and ethical rules, and the limitations of each type of technology (see section "Tips").

Limitations

- No tool can take the place of human judgment. Providers often have concerns that the use of technology will result in inferior therapeutic relationships with patients or that that technology is more trouble than its worth.
- In a perfect world, providers would be able to deliver hands-on, face-to-face services with no constraints as to time or equipment. While face-to-face is always preferable, particularly when it comes to diagnosis and treatment planning, it is not always possible.
- Media technology does not apply to all problems. For example, some treatments, such as exposure therapy for veterans with post-traumatic stress disorder (PTSD), would entail creating exposure environments that are neither feasible nor safe.
- Technology is not meant as a replacement to human contact. It is, however, a way to leverage resources, fill gaps, and provide treatment when perfect solutions are not available.

D. ***Terminology***

1. ***App***
   - An abbreviation for "application." An app is a stand-alone software program designed to do a particular thing. Typically, people referring to an app mean a program that is downloaded onto a mobile device.
   - There are hundreds of apps available that target specific behaviors, such as exercise and diet, and this makes apps valuable tools in rehabilitation programs.
2. ***Augmented reality***
   - Augmented reality (AR), also called "mixed reality," is the use of technology to overlay digital elements onto real experience. In contrast to virtual reality (VR), which completely immerses a user in a simulated environment, AR allows the user to see the real world and superimpose virtual objects on it in 3D. Through the use of technology like headsets, especially equipped eyeglasses or smartphones, people perceive the virtual and real objects as coexisting in the same space. AR enhances how we see and interact with the real world.
   - We see AR every day. From the TV weather forecaster standing in front of the weather map or televised football games superimposing down lines and team logos on the football field.
   - Both AR and VR have been explored for a variety of uses, including medical, manufacturing, education, entertainment, and military applications.

3. ***Bots***

- Bots are programs that automatically run tasks, like gathering email addresses, posting ads in the comment section of a blog, trying to spread viruses, or generating other mischief.

4. ***CAPTCHA***

- A CAPTCHA or Completely Automated Public Turing test to tell Computers and Humans Apart is a program that protects websites against computer-generated uploads and minimizes spam by asking a user to "prove" he or she is a human. The CAPTCHA program creates a challenge-response test using distorted letters and word strings that a computer or bot (see above) is unable to decode. This type of log-in device can be challenging for some patients, so be aware of the interface of any website or application you recommend to a patient.

5. ***Captology***

- Captology is a made-up word meaning the study of computers as persuasive technology. The word was coined by B.J. Fogg of Stanford University in 1996, but the concept of using technologies, from communications to marketing, to persuade is not new. Captology includes the design, research, and analysis of interactive computer technologies, from websites and video games to mobile phone apps, created to influence behaviors and attitudes [11].

6. ***The cloud***

- "The cloud" is a metaphor for the Internet and is a communications network that connects a large number of computers. The term has become popularized by marketers to mean services or software that are sold as a service, where the user can log on to the network without having to install anything on their personal computer or device.

7. ***Downloading and uploading***

- Downloading refers to the act of transferring information from a source to a user's device, such as software, music, videos, or raw data. It has become more common to transfer applications and content, such as music and videos, from online sources than to use other technologies, such as CDs or DVDs. Content can be transferred using cables, but increasingly content and data are transferred using wireless connections or Wi-Fi.
- Uploading refers to the act of transferring information from a user's device to a server that others can access. There are specialty sites that will allow you to upload a large file to their server (storage) so that authorized users can have secure access. Medical facilities have adopted complex and often proprietary systems to limit access in effort to protect patient confidentiality and rights.

8. ***Forums and chat rooms***

- An Internet forum or message board is a place online where people can have conversations with one another by posting messages, often text, but increasingly including images. The conversations happen asynchronously (at different times), so users can carry on conversations across time zones. Each conversation topic is called a thread and is started by a first post or question, and then all responses follow underneath in a hierarchical fashion. Forums vary in how they are managed. For example, forums can be open to anyone or they can be managed and require approval from a moderator or logging in with password to participate. Forums can range from allowing users to be completely anonymous to requiring verification of identity and have a range of rules for participation.
- A chat room happens synchronously, so that people who are chatting are doing it in real time. Chat rooms, like forums, are open or managed with various rules of conduct.
- Where forums allow for longer responses, chat rooms are typically short remarks similar to text messaging.

9. ***GPS***

- GPS stands for Global Position System. It is a space-based satellite system that provides time and location of a radio receiver on the earth's surface. While most commonly associated with car navigation systems, nearly all cell phones on the market include GPS capability. This functionality allows people to use their mobile devices for maps and directions, as well as to find services or other uses in their immediate location.
- Ethical considerations arise when location information is transmitted to second parties for real-time monitoring of people, such as for law enforcement and parolees or healthcare services and dementia patients.

10. ***LBS***

- LBS stands for location-based services. It is a type of computer program or app that uses location data from location-aware devices to control information and data features. This includes a range of technologies and systems or apps that allow people to find local services or connect with friends. The radio-frequency identification (RFID) tags that set off alarms when not removed from clothing prior to leaving a store is a common example. These tags help retailers track inventory and cut down on shoplifting.

11. ***Geo-fencing***

- Geo-fencing is the use of GPS tracking software to create boundaries around specific locations. They can be created dynamically as in a radius around a location or as a predefined boundary, such as a store or a specific school zone. When a location-aware device, such as a phone with GPS functionality, enters the area, a notice can be sent to the device owner or to second parties. These have been used in marketing, to send local offers to nearby shoppers as well as have the potential to notify parents when children enter or leave specific areas.

12. ***User interface***

- User interface (UI) is the term used to describe the design structure of any device that allows someone to interact with it. The user interface of an iPhone is the design of the device that allows you to accomplish the tasks it offers, such as calling, finding addresses, or posting to Facebook. A well-designed UI makes it easier to accomplish what you are trying to do; however, what people consider being well designed and accessible varies across individuals. For example, what seems obvious and intuitive to a 20-year-old may not seem so transparent to a 60-year-old.

13. ***User experience (UX)***

- User experience (UX) is the psychological impact of the user interface (UI). The UX is an evaluation of how something is experienced. UX looks at the user's behavior, emotions, and attitudes about using a product, system, or service. UX can apply to any interaction whether or not technology is involved, although it is most commonly associated with product and technology design. For example, we can evaluate the UX of the process of making an appointment with your office for rehab services. A good UX meets the needs of the customer or patient without problems or aggravation and leaves them feeling good about themselves and the interaction.

14. ***Smartphone***

- A smartphone is a mobile phone with more advanced capabilities. They generally include a variety of applications (apps), from productivity tools like address books and calendars, to entertainment, such as games and music players. The defining feature of a smartphone, however, is its ability to access the Internet and browse the web. Mobile technologies have untethered people from desktops, and the mobile access also allows the ability to install and use third-party apps (those not supplied by the phone manufacturer). Many of these apps target specific needs, such as stress relief training or memory development, and can be integrated into a rehabilitation program.

15. ***Social media***

- Web 2.0 is a set of Internet technologies that represents a shift in the way that information is created, stored, and distributed. The development of the Internet revolutionized communication by enabling social tools or social media, for collaboration, categorization, creation, and sharing.
- People often use social media to mean Facebook or Twitter. There are, however, different types of social media that have different characteristics and perform different functions. Some of the main distinctions are:
  - Self-publishing tools, like blogs (Wordpress.com) and micro-blogs (Twitter) which allow others to comment
  - Aggregators and social news sites, such as Technorati and Digg that draw on collective intelligence to find and promote stories or allow individuals to curate information for sharing, such as Scoop.it
  - Social networking sites, like Facebook, LinkedIn, and My Space, that allow users to set up boundaries that determine information flows
  - Content communities, such as YouTube, Flickr, and Instagram
  - Virtual worlds based on games or social connection, such as World of Warcraft and Second Life
  - Collaborative projects that create large bodies of crowd-curated information, called wikis, such as the well-known Wikipedia
- Search engines also have a less apparent social function in that the items returned in a search are promoted based on popularity as well as in response to your own search patterns.

16. ***Spam***

- Spam is unwanted email, texts, or posts. Most email programs have filters to cut down on the amount of unwanted email you receive. Blogs and forums often use CAPTCHAs to distinguish people from internet bots.

17. ***Trolls and flamers***

- An Internet troll is an abusive or troublesome user who disrupts or polarizes conversations or achieves attention by flaming (posting rude or shocking remarks). There are several theories about why people do this, including disinhibition that comes from Internet anonymity, the need for attention, and antisocial personality types. Many forums and chat rooms have moderators that monitor and police bad behavior and enforce the forum or chat room rules, which include banning abusers from the site.

- The existence of bad behavior online is a fact of life, just as it is offline. The difference is that online behaviors are permanent and searchable. As discussed in this chapter, under section "Tips: Creating a Social Media Strategy," it is important to have a plan in place in the event that something goes awry, for example, a patient posts a bad review on Yelp, a previous employee takes revenge on YouTube, or you are misquoted in the national press.

18. ***URL***

- A URL is the common abbreviation for the Uniform Resource Locator or web address of a website or document on the Internet. It is most commonly visible in the address bar of a web browser, such as Microsoft Explorer, Google Chrome, or Apple's Safari. This system of identifying locations on the web was standardized in 1994.
- The important things to know are:
    - The URL gives information about the protocol or scheme (such as **http://**), the domain name (registered name of the website that includes familiar endings such as .com, .org, .edu, and .net, such as **www.springer.com**) and the location within a given domain, which follows the domain name with a forward slash (such as **/psychology**). This information typed into the address bar on a browser will take you to the URL: **http://www.springer.com/psychology**).
    - URLs must be typed correctly—a mistake even by one letter or punctuation mark will interfere with where you want to go.
    - Make the URLs as simple and intuitive as possible, especially if you are creating web assets for clients and patients.
    - Whenever possible, include a live link (where the URL is connected to a word or phrase) so that a patient can click and be taken to the correct page and not have to type the address. You can include live links in any web document, including emails, word documents, and PDF files and, of course, on websites.

19. ***Wearable technology***

- As it sounds, wearable technology is a category of devices that can be worn by the user. Advances have increased the quality of tracking information, sensory information, and data manipulation capabilities while devices have become smaller and more usable. Currently, fitness trackers have dominated wearable consumer devices, but the introduction of devices like Google Glasses and the emergence of smart watches is a glimpse of the potential in personal computing power that lies ahead.
- Improved and lower cost wearable sensors can provide important physiological measures for rehabilitation patients, such as heart rate, respiratory rate, blood pressure, and muscle activity, the types of continuous monitoring that was restricted to medical settings. Potential uses include:
    - Safety monitoring
    - Health and wellness monitoring
    - Home rehabilitation
    - Assessment of treatment efficacy
    - Early detection of disorders or noncompliance [17]

20. ***Wikis***

- Wikis are one well-known example of collaborative software or groupware that lets people participate together to achieve a common goal. A wiki, which comes from the Hawaiian word for "quick," is a web application that allows people to easily add, modify, and delete content in collaboration with others. The best known is Wikipedia, but there are thousands online wikis creating knowledge bases of specialized content, such as heart conditions, postsurgical recovery and diabetes. Wiki software is available through multiple sources, is generally free, and can be installed and set up on websites and online learning centers quite easily. Providers can use wikis to develop a knowledge base of frequently asked questions (FAQs) in specific areas of rehabilitation, creating a collaboration of professional expertise with patient experience.

- Researchers studied the use of wikis to evaluate the difference between patient-generated information and that of professionals to improve peer support tools. Results indicated that patients offer substantial expertise that differs significantly from that of health providers. In contrast to concerns that patients would act as "amateur doctors," the researchers found that patients offered information and actionable advice of a more personal nature that providers are not always equipped to provide [15].

21. ***Virtual reality***

- Virtual reality (VR) is a computer simulation of an environment that completely immerses the user. The effectiveness of a VR system is the sense of presence, or "being there," that is, a combination of perceptual processes and intentional direction of attention. This combination subjectively transports the user into the experience. While enthusiastically embraced by the entertainment industry, VR systems have also been developed and tested for a number of healthcare applications, including surgical simulations and treatment for phobias and PTSD. Virtual reality environments have been created using various technologies, including head-mounted displays and data gloves. The goal in technology development is to improve the multisensory experience, including vision and touch, when people manipulate objects in virtual environments [3].

Importance

A. ***Augmented, mixed, and virtual realities***
   - Many VR and AR applications are still under development, but hold great promise. Some of the areas where important advances have been made include exposure therapy and patient education.
   - Virtual environments can create simulations of the real-life challenges people face. One of the most common virtual reality applications is flight simulators to train pilots. These have been developed, tested, and applied in a number of areas in rehabilitation, neuropsychology, and clinical psychology. Areas include fear reduction of simple phobias, PTSD, stress management in cancer patients, pain reduction, and physical therapy with painful procedures such as burn treatments, treatment of body image disturbances and eating disorders, training of motor skills in children and adults, functional rehabilitation in stroke recovery and central nervous system disorders, rehabilitation of attention, and improving memory and spatial skills.

1. ***Exposure therapy***

   A group of researchers employed AR systems to treat severe cockroach phobias using virtual exposure therapy. Patients were more amenable to exposure therapy using virtual methodology than the prospect of facing real cockroaches. After several sessions of manipulating virtual cockroaches with their hands, patients went from profound phobias to being able to pass a test with live cockroaches [4].

   Researchers have been working on virtual reality therapy aimed at providing relief for veterans suffering from PTSD. VR adds a new dimension to exposure therapy, where a patient faces traumatic memories guided by a clinician. Using VR, the treatments can involve virtual scenarios that include vibrations and smalls as part of the simulation. Young military personnel who grew up as with digital gaming technology may be more amenable to seeking out VR-based treatment than traditional therapies [20].

2. ***Patient education and marketing***

   AR can also be used to improve patient health and well-being. Quick response (QR) codes and bar codes can be used by patients to access more information about medications, instructions, or treatment protocols. QR codes, for example, can be printed on pamphlets or business cards and linked to instructional or inspirational YouTube videos.

B. ***Email***
   - Email communication between providers and patients is on the rise. Email may seem

old-fashioned compared to so many new technologies, but to many, email is still a radical departure from telephones and the US mail. While it is subject to the same concerns of privacy, judgment and boundary setting (see "Tips, D. Making Technology Safe"), email with patients can be useful and effective [2].

- The American Medical Association and other organizations recognize that there are several benefits:
  - ○ Follow-up on patient care and providing clarification of advice.
  - ○ Creating a written record of information.
  - ○ Providing patients with summary of useful information, including contact information for referrals, test results, and procedural information, such as how to take medication or other instructions.
  - ○ Educating patients with articles and links.
  - ○ Email also allows providers to have extended contact with patients beyond office visits that increase perceptions of quality patient care.

C. ***E-readers***

- E-readers, or e-book, is a general term for any digital electronic device designed for the purpose of reading books. Depending upon the device, it can also be used for reading magazines, newspapers, and any other documents that can be converted to a digital format, such as PDF or jpeg (photo file). Analysis of eye movements from reading e-books using a variety of reading tools suggests that the reading behavior is similar to reading from a printed book [28].

1. ***E-readers as low vision aids***
   - E-readers are portable, and many have several features that make them excellent low vision aids. They are often a more cost-effective option than CCTV.
   - They are portable.
   - Many have text-to-speech functions.
   - The font size and contrast are adjustable.
   - Some devices offer reversed polarity (white letters on black background).

2. ***Tablets and iPad***

   Like smartphones, tablets and iPads are portable, flexible devices with multiple functions due to the almost limitless number of apps. This can make them valuable tools supporting rehabilitation programs and functions. Some tablets and smartphones, such as the iPhone, iPad, and Android, have e-reader functions, but additional apps can expand their functionality. Some of the options include:
   - ○ The ability to magnify and illuminate text.
   - ○ The ability to identify the denomination of US paper money.
   - ○ Communicating vision changes to an ophthalmologist.
   - ○ Providing GPS guidance with voice commands.
   - ○ Using voice interface to check the weather, email, or time without having to visually navigate a device. Voice recognition also allows dictation of email and other texts.
   - ○ Note: You should always check the features of any device under consideration to make sure that it meets the specific needs of your patient.

D. ***Facebook***

- Facebook is a popular social network platform. Launched in 2004, it was originally intended to connect college-age students; in 2006 it was opened to anyone with an email address. Facebook has become the dominant social network in the world, with over a billion active users worldwide, 75 % of which are outside the USA. Nearly half are mobile users.
- Facebook has some distinct characteristics that are not shared by all types of social media:
  - ○ It requires membership—it is not a completely open system in contrast to a social network such as Twitter.
  - ○ It lets users to create a public or semi-public profile.
  - ○ It allows people to make social connections, that are called "friends," and a

    user's friends are visible to others in their network.
  - It gives user's access to streams of user-generated content, such as posts, images, and videos, from their connections within the Facebook network.
  - Anyone can search within the Facebook network to find an individual or organization. How much information is available will depend upon the privacy settings in place.

    Facebook operates on relationships and social connections. There are many rehabilitation organizations that use Facebook to create a human face for the public and their patients. They also use Facebook as a way to discuss general issues and questions and connect more personally than other channels.
  - Facebook is not a good place to interact with patients over specific health issues unless there is no need for privacy, and advice given is generally applicable. In spite of the privacy settings in Facebook, there is no way to guarantee privacy.

E. ***LinkedIn***

- LinkedIn.com is a professional networking site that is free to use, although LinkedIn does offer some premium options. Like Facebook, each user creates a profile page. Unlike Facebook, the people on LinkedIn are focused on professional development, industry networking, business promotion, keeping in touch with colleagues, job search, and recruitment activities.
- A quick search on LinkedIn returns nearly half a million professionals and organizations that have included "rehabilitation" in their primary title or organization's description; there are over four million affiliated with "healthcare."
- LinkedIn allows you to leverage your social connections by participating in special interest group and discussions related to your field. LinkedIn can help you stay abreast of new research, new career opportunities, and new ways of expanding your practice, connect you with other experts in your field as well as allow you to reconnect with previous colleagues.

F. ***Pinterest***

- Pinterest is an online pinboard. It is a curating tool that allows you to collect and display visual images. Pinterest has its own language, like most other social media sites.
  - Every image or bookmark you share is called a "pin."
  - If you share someone else's pin on Pinterest, it's called a "repin."
  - You can organize your pins together by topic onto a "pinboard."
- You can upload images directly onto Pinterest or you can share them from any webpage. You can also share your pins on Twitter and Facebook. Creating a Pinterest account is free, but you do not have to join to look around.

G. ***Text messaging and mobile communications***

- As of January 2014, 90 % of American adults had a cell phone. Smartphones are owned by 58 % of Americans and are represented by higher percentages of African Americans (59 %) and Hispanics (61 %) than whites (53 %) [19]. Mobile devices are redrawing the lines among communication channels, becoming functional second screens, and information portals, not just "telephones." The shift from location bound to person linked elevates mobile devices to extensions of identity and self-presentation. Mobile devices are fully embedded in even the most mundane aspects of daily life and are something we carry at all times. Thus mobile devices feel private and personal [21].
- Text messaging solves these problems because it is perceived as being less invasive due to privacy, brevity, asynchronicity, and accessibility and yet is timely. The widespread use of mobile devices makes sending text messages a quick, easy, and socially comfortable way to communicate for a large part of the population.

- Texting for teens in crisis:

  The average teen sends and receives around 4000 texts per month. These are not spam. The "open rate"—or how many texts actually get opened and read—is 96 % among teens. Recognizing this trend, DoSomething.org created the Crisis Text Line, which works like a traditional hotline with experienced accredited counselors, but all counseling is over text messaging.
  - Text messaging has several advantages over other forms of communication. It allows for communications without fear of embarrassment, it is succinct, and it allows for a more direct form of communication.
  - Text messaging cannot be guaranteed to be completely confidential, so all programs need to implement HIPAA-compliant guidelines such as those used for voicemail messages [25].

H. ***Twitter***

- Twitter is a microblog service with messages limited to 140 character messages. Posts or "tweets" on Twitter are part of a public timeline. Accounts are free and can be set up by individuals or organizations. Twitter is searchable, and people use the hashtag (#) in front of keywords to make it easier to search. Hashtags are frequently used to tag group events, such as during conference proceedings, and to identify breaking news.
- Twitter can serve different functions in a professional practice:
  - Network with other professionals.
  - Share professional information and best practices.
  - Market your practice.
  - Help spread the word on new research and regulations or other industry issues.
    1. **Finding people worth following on Twitter**

       People will often post links to new blog posts, articles, research, events, and conferences. There are several "Twitter directory" tools you can use to identify people in your area of interest.
    2. **Being someone worth following on Twitter**
       - When you find good resources, share. There are a number of extensions that can add to your web browser that will let you add a tweet from any web page with the click a button.
       - Ask questions to other experts in your area of interest. Sharing works both ways.
       - Twitter is public. Never discuss patients or have an exchange with someone that violates confidentiality.

I. ***Websites***

- Websites are the storefronts of the digital age. A website is a "place" or "page" on the Internet with their own address (or URL). Every business advisor and marketer will tell you it is essential to have a web presence. Websites function in place of brochures and business cards; they give people information about your practice and organization, as well as about any products and services you offer and your perspective about the work you do.
- Websites can be simple, or they can have added functionality, such as the ability to book appointments, get information, or even have password-protected membership areas. Creating password-protected areas is common for websites that provide patient-/client-only information or access to forums and chat rooms where people can gather and have conversations about personal topics.
- Websites should be current and give the patient the information they need. A clear and well-designed website reflects on your practice. It has psychological and practical benefits. According to recent data, 72 % of Americans have looked online for health information online. This includes everything from researching diseases and conditions to checking out reviews of providers and facilities.

- A website of your practice can:
  - ○ Increase the patient's comfort with you.
  - ○ Increase knowledge about potential treatment paths and the extent of the services you offer.
  - ○ Show photographs of you, your staff, and office locations.
  - ○ Promote a positive experience and enhance likability through increasing familiarity, both through knowledge and image [7].
- From a practical perspective, an effective website with adequate security increases the quality of patient care and can decrease costs, by allowing patients to:
  - ○ Make appointments online.
  - ○ Ask providers questions using an information request form.
  - ○ Request things like medication refills.
  - ○ See upcoming appointments and previous reports.
  - ○ Get hours and directions.
  - ○ Access and download new patient forms.

J. ***YouTube***

- YouTube is a video-sharing website that allows anyone to upload, view, and share videos. Founded in 2005, YouTube has more than one billion unique users each month from around the world, and 100 h of video are uploaded every minute. The ability to record and watch videos has had broad social impact, challenging entertainment models, creating YouTube celebrities, impacting world events, and facilitating the dissemination of education and culture, as well as "how-to" and technical instruction.
- Video communication is a powerful form of connection because it engages multiple senses. The human brain processes image and sound differently than it does text. Thanks to mirror neurons, our brains automatically mimic movements, expressions, and emotions. Video communication is a much richer media and a more powerful means of disseminating information of every kind compared to text or still image.
- For practitioners, YouTube can be used as a resource for patient information or social modeling in the same way that cinema therapy is used. Practitioners can also create their own videos to:
  - ○ Demonstrate rehabilitation techniques
  - ○ Provide general information about a service or type of rehabilitation approach and process
  - ○ Deliver instruction, explanation, and education as part of a larger therapeutic program
  - ○ Provide inspiration and encouragement

Practical Applications

A. ***How to use Pinterest in a healthcare practice***

Many healthcare organizations are using Pinterest for a range of goals, from marketing to patient education. Here are some of the things that you can pin:

- ○ Patient/client photos and testimonials (with permission)
- ○ Introductions or explanations how to use products and services
- ○ Pictures of facilities, staff, and events to show your organization's culture
- ○ Conference and workshop activities
- ○ History and plans for the future that you can show
- ○ Inspiration that you can provide and knowledge that you can share
- ○ Health and well-being that you can promote
- ○ Examples to check out:
  - – The Summit Medical Group of New Jersey[1]
  - – Baylor Health Care System[2]
  - – St. Luke's Medical Center Acute Rehabilitation[3]
  - – Restorative and Rehabilitative Exercises[4]

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[1] http://www.pinterest.com/summitmedicalnj/

[2] http://www.pinterest.com/baylorhealth/

[3] http://www.pinterest.com/stlukesmc/acute-rehabilitation/

[4] http://www.pinterest.com/jetdsf/restorative-rehabilitative-exercises/

B. ***How to use text messages in practice***:

1. **Appointment changes and reminders**
    - Many providers find text messaging an easy way to make or change appointments with current patients. Some larger organizations, such as Kaiser Permanente, use text message appointment reminders, treatment reminders, and notification of lab results. Using text messaging has a number of benefits for both the practice and their patients, through improved patient relations, lower postage and labor costs for things like reminder mailings, and fewer missed appointments [9].
2. **Prescription refills**
    - In 2012, research showed that 73 % of patients would prefer to use their mobile phones to order prescriptions. Pharmacy chains such as CVS add to the convenience of mobile ordering by alerting customers when their prescriptions are ready for pick up. This practice also decreases the prescription abandonment rate.
3. **Lifestyle changes**
    - Text messaging has been successful in multiple lifestyle change programs, including smoking cessation, improving diet and exercise, diabetes monitoring, and providing nutrition education, by tailoring messages for relevance, tone, and language in support of the program goals.
    - A study from University of Michigan used tailored text messages to help teens adopt healthier eating behaviors. It was particularly effective for those who had trouble adhering to behavior change recommendations [26].
    - To overcome health inequalities among the Maori, Australian researchers tested a mobile phone text-based smoking cessation program finding that using text allowed successful recruitment among Maori and was equally effective for Maori and non-Maori [6].

C. ***There is an app for that***

- The expression "there is an app for that" is no joke. Look on the iTunes or Android store, and you will see that human creativity and entrepreneurship knows no bounds. There are both free and paid apps that can be very useful to a practitioner. Mobile technology has the advantage of being context sensitive—it is with us wherever we are.
- Availability does not mean that every health and wellness app works. According to researchers, only a small portion of the app-based interventions for physical activity are grounded in behavior change theories that bridge education and formation of intentions with motivation [8].

1. **Facilitating behavior change**
    - Tablets' and iPads' size makes them appropriate for a wide age range, providing instruction is provided. Useful apps are:
        - ○ Journals and logs
        - ○ Exercise plans
        - ○ Alarms and reminders
        - ○ Stress reduction programs
        - ○ Cognitive training for nearly every cognitive rehab goal
    - Specialized software is also available for tablets and iPads that allows clinicians and practitioners to have access to records and make notes from any location.
2. **Using technology to change behavior**
    - According to social scientist B.J. Fogg's captology model, how we interact with computing systems, whether it is a smartphone or a desktop, influences technology's ability to impact behavior and facilitate behavior change. Technology can function in one of three ways:
        - ○ Tools that extend or increase our abilities by giving us resources or knowledge
        - ○ Tools that give us a new understanding or perspective that enables behavior change, such as simulation or virtual reality

  - Tools that replicate social connection that simulates emotion, such as providing encouragement or warnings

D. ***Seeing humanity in technology***

Humans have an innate tendency to anthropomorphize objects, ascribing them humanlike qualities, which increase their persuasive ability. Neuroimaging studies have shown that most people have the same neural responses to human behavior as they do to the behavior of robots. We also tend to behave toward technological devices with the same social conventions we use when we interact with humans. This has positive and negative effects:

  - On the positive side, anthropomorphic computer interfaces and designs increase engagement and likeability, making us more likely to use them. Our brains respond with genuine pleasure when our iPhone app issues words of encouragement.
  - On the negative side, projecting humanlike intentionality to computer devices increases the likelihood that we treat technology as scapegoats, feel less responsible for achieving tasks, and may have unrealistic expectations for the device capabilities.

E. ***Picking the right apps***

- Carefully evaluating the desired target attitude or behavior is important in identifying an app that can effectively provide interventions that support behavior change goals. Depending on the aptitude and interest of the patient, apps can be combined to achieve the desired support; for example, a smartphone-based activity monitor using GPS such as RunKeeper can be used with a wearable technology fitness tracker such as the JawboneUp or the Fitbit. These tools link seamlessly with some food log apps, such as MyNetDiary, and together provide extensive and user-friendly feedback on activity, diet, and sleep habits.
- Technology does not replace the psychological steps necessary for behavior change, such as acceptance of the need for change and motivation and willingness to engage in new behaviors. Technology can, however, provide timely, tailored, and context-relevant support in ways that people are not able.
- The best interventions are easy to use and facilitate small changes so people feel successful.
- Behavior change through technology is enhanced when the:
  - User finds an intuitive app that is easy to use for data entry and setup.
  - App allows for realistic targets broken down into achievable goals and time spans and provides appropriate feedback. In a 2001 report on behavior journaling, nearly 80 % of those surveyed wanted to get analysis and feedback from the information they were entering [9].
  - App facilitates social support. Many apps allow users to link to friends or others with similar goals and even opportunities for healthy competition.

F. ***Cinematherapy and bibliotherapy***

- Cinematherapy involves a health professional selecting a commercial film for a patient to view either alone or with others that provides the patient with opportunities for healing or growth. Films can be a powerful catalyst for inspiration to overcome obstacles, provide information, show examples of behaviors to practice on their own, communicate a new attitude or perspective, or trigger an experience of emotional release or understanding. Used in group settings, cinematherapy can enable useful discussions.
- Bibliotherapy is the use of literature in the same capacity. Cinematherapy and bibliotherapy can be used to support an ongoing therapeutic program. Both are story based, and the narrative format allows a message to be delivered in a way that opens the door for the patient to relate to the story, thus experiencing elements of the film with more impact. Research on the power of narrative shows that it can increase empathy and lower resistance to persuasive messaging, making the viewer more amenable to cognitive change [14].

G. ***Attitudes and barriers to technology adoption in seniors***

- Technology adoption is often associated with younger age; however, the primary drivers for adoption are trust, perceived ease of use, and perceived usefulness. Seniors are often unaware of the resources and benefits that technology brings. Many seniors are anxious about digital tools and devices, and 77 % say they would need someone to help them in order to use it. However, 23 % of older adults have a physical or health condition that makes reading difficult, and 29 % have a disability that keeps them from participating in many common daily activities where technology could make a difference in their quality of life and well-being [22].
- Once seniors have begun using the Internet and digital tools, they begin to view them as essential parts of their daily life; 79 % of seniors online agree that people without Internet access are at a disadvantage because of the information they are missing.

H. ***Telehealth and telemedicine***

- Telehealth is the use of any kind of technology, from information transfer to telecommunications, to support health-related services. It can refer to both clinical and nonclinical services. Some people make the distinction between telehealth, defining it as the broad field of technologically mediated health-related activities and information, versus telemedicine, defining it as the more specific field of technologically mediated delivery of health services and treatments
- Telehealth has three main characteristics:
  - ○ Video or voice conferencing for remote real-time consultations
  - ○ Remote monitoring where electronic devices transmit information to practitioners
  - ○ Storage and forwarding of digital images and information among providers, medical staff, and institutions
- Tele benefits:
  - ○ Telehealth is particularly valuable to connect practitioners and specialists with patients in remote locations. Telehealth promotes patient-centered care due to the increased availability of:
    - – Patient-practitioner communications and consultations
    - – Provider feedback on self-management protocols and behaviors
    - – Health education and literacy
    - – Medication management

I. ***Video conferencing***

- Telehealth via video conferencing provides new ways to deliver various healthcare and rehabilitation services, such as real-time consultations at much lower cost in time and money. Video conferencing is especially helpful when patients have physical disabilities that make travel a challenge (e.g., spinal cord injury). While video conferencing was once available only with expensive specialty equipment, there is now a full range of equipment, from using smartphone cameras to sophisticated video conferencing facilities. The variation in the equipment demands that consideration be given to perceptual limitations due to technology, from clarity of picture and sound to behavioral cues that may be misinterpreted. For example, the patient can easily misunderstand and misattribute the meaning of things like volume and eye contact, hesitate to ask questions, or experience undue concern when a practitioner looks away to make notes or is interrupted.
- Video Conference for PTSD:
  - ○ In studies using video conferencing for delivery of prolonged exposure therapy for PTSD, consisting of weekly sessions over several months, results demonstrated high completion rates and suggested a high acceptance rate of telehealth as a delivery system [12].
  - ○ Some practitioners believe that aspects of telehealth are well suited to veterans and others who suffer from PTSD because they overcome some obstacles of delivery and compliance, such as:
    - – Making treatment available to those living in rural areas or where local facilitates do not have fully trained treatment providers

    - Helping patients overcome difficulties, anxieties, and cost of traveling long distances
    - Alleviating the need for patients to deal with crowded waiting rooms and hospital lobbies and systems

J. ***Social support online***

- Understanding the impact of social networks can contribute to the design of effective treatments and interventions. Social networks are not only online; they are the web of relationships that surround the patient, and the impact on health behaviors comes from the amount of positive support they generate. Social support has been broken down into four main components:
    - ○ Empathy, trust, and caring
    - ○ Tangible aid and services
    - ○ Information
    - ○ Constructive feedback and validation for self-evaluation [16]
- Where offline social support is often one-on-one, online social networks offer the advantage of group interrelationships and participation, increasing the sense of affiliation and meaning through participation in a larger unit.
- There are an almost infinite number of online support group forums and chat rooms; they range from those sponsored and managed by large organizations such as the Mayo Clinic to self-organizing groups using platforms such as Yahoo Groups. Online groups offer the advantages of providing social connection and understanding to people who do not have positive emotional support at home. It also provides an opportunity to exchange experiences and information with those who are facing the same issues, such as symptoms, treatments, progress, or emotional and social adjustment.
- Empirical research on the benefits of online groups has examined structured and unstructured group formats, level of participation, educational components, and time-limited group experiences across a number of mental and physical health issues with mixed results. In addition, some researchers believe that online social support groups generate a sense of empowerment and better meet cultural and social needs due to their more inclusive and cooperative approach [5].
- Many healthcare organizations now include access to online support and information forums and communities as part of their patient services. As with self-organizing groups, the goal is to make patients feel emotionally supported. One meta-analysis of 122 studies from 1948 to 2001 found a significant relationship between treatment compliance and social support [10]. For online communities sponsored by healthcare organizations, the study found that the ability to easily find information had a greater impact on the patients' perception of empathy that did social support provided in this context.
- Social support can have benefits beyond the targeted intervention. For example, researchers found that hearing aid users with unresolved hearing problems who participated in an online education program that included interaction with an audiologist, compared to the control group who participated only in an online forum, had reduced symptoms of depression both immediately and 6 months after the program [24].

1. ***What to look for in online support***
    - Online support groups vary in quality, as does the amount of help they provide to participants. Differences among individual needs, group dynamics and type of issue, disorder or health challenge make creating a surefire checklist impossible.
    - The only way to know for sure is to join a group—most are free—and "listen" for a while, read past posts, and see how the group feels. Here are some general guidelines:
        - ○ Supportive group environment—Look for groups where members express concern and compassion for each other in a nonjudgmental way. Avoid groups that focus on the neg-

    atives to one another or that fall into the "poor me" trap.
  - Activity—Groups should be active with frequent posting. Check for the number of members and if the group has an active moderator or leader.
  - Community—See how long people have been members of a group and if they appear to have formed bonds with one another.
  - Respect for individual differences—A Google search for keywords "rehab support groups" returned over 18 million responses. Whether it is substance abuse, stroke recovery, or PTSD, most support groups are tailored to meet the needs of a certain group within that area. For example, breast cancer support groups may be organized around an age group, people at a certain stage of treatment, or those dealing with life as a breast cancer survivor. Patients should not be discouraged if the first group or two they check out are not a good fit.
- Practitioners can help patients by taking note of the support groups that other patients have found helpful and by investigating a few in anticipation of a patient's need.
- It is always an option to start a community around your area of practice to support your patients. Be forewarned that keeping a community vibrant and positive takes some work, and the best ones use community managers who monitor and post on a regular basis. Sometimes these are volunteers; often this is a paid position. There are two important things to consider:
- Are you reinventing the wheel? It is possible that something very similar to what you want to create exists.
- Are you clear on your goals? What are you trying to accomplish and how much money and time are you willing to spend to pursue them? Like websites, creating an online community can be easy and inexpensive or time-consuming and costly.

K. ***Wii-Hab: Video games and rehabilitation***

- Video game systems that detect motion and require physical activity to interact, such as Nintendo's Wii and Microsoft's Kinect, can be used for different types of physical therapy and can provide a valuable adjunct to traditional therapy [27]. Motion-detection games, dubbed "WiiHab" by some, have the social and entertainment benefits of game play, such as competition, rewards, and continual feedback, thereby increasing patient engagement while improving endurance, strength, and coordination.
- Wii therapy, using off-the-shelf games such as boxing and tennis, has been put to multiple uses. Some applied examples are:
  - Helping elderly patients improve hand-eye coordination
  - Improving visual-perceptual processing, postural control, and functional mobility in a young boy with cerebral palsy
  - Supporting balance and mobility activities in burn patients
- Microsoft is developing a *Stroke Recovery with Kinect* system to help stroke victims improve upper limb motor functioning.
- Anecdotal evidence and case studies provide encouraging results. There is still a need for research in larger-scale studies [23].

Tips

A. ***Multiscreen world***

- The Internet is new enough that people still tend to make the distinction between online and offline or real and virtual. These borders are disappearing. Media engagement and interaction flow across technologies. Thanks to mobile devices, the USA is a nation of multiscreen users, and smartphones are the backbone of media activities. According to Pew Research's health fact sheet, 87 % of US adults use the Internet, 90 % own cell phones, and 72 % looked online for health information within the past year. Latinos and African Americans are significantly more likely than other demographics to have mobile Internet access. In contrast to concerns about "information overload," for many, multiple screens increase the sense of efficiency and accomplishment [13, 18].

- What does this mean for you as a practitioner?
    - Patients have access to a wealth of information of varying quality on conditions, diagnostic criteria, treatment approaches, costs, and outcomes. This access can be empowering for patients and their families and can have a positive impact on outcomes.
    - However, practitioners need to be prepared to deal with the balance between respecting patients' ability to advocate on his or her own behalf and the potential for the patient using found information to challenge the practitioner's expertise or experiencing unwarranted fear and distress.

B. ***Tell people what to expect***

- **Setting boundaries**
- Your communication style can be interpreted as a sign of respect that translates into perceptions about quality of care. The ubiquity of technology means it is not just your words and tone of voice but the tools you use and how quickly you respond.
- Create written communication policies for your patients that describe how you will communicate with them. This establishes expectations as well as boundaries.
- Think through what makes sense for your patients based on the way they manage their lives.
- Do not dismiss anything out of hand until you think it through because technology has changed the standards we use to judge how people communicate.
- Advise patients about the privacy risks of different forms of communications.

C. ***Communications policy***

- We live in a socially connected world. Have a policy in place about how you handle communications between you and your patients—from answering text messages and phone calls to friend requests on Facebook—to create defined healthy boundaries for both you and your patients.
- The American Psychological Association (APA) has a published guidelines for telepsychology that covers many of these issues in detail.
- The American Medical Association (AMA) has also published guidelines on the appropriate use of communications channels for both patient-related and public relations/advertising activities under Section 5 of the AMA Code of Ethics [1].
- Many practitioners are embracing new communications technologies, beyond the office phone, fax, and US mail service. These include:
    - Cell phone
    - Email
    - Texting for appointments, information, or support
    - Website or blog
    - Twitter
    - Facebook
    - Skype
- Several organizations offer electronic communications guidelines and best practices. Learn the benefits and limitations of each tool before you use it. Make it clear where patients can have a presumption of privacy and where you cannot guarantee it, such as email, texting. Make sure your staff are equally well informed as to your expectations and practices.
- Questions to answer:
    - How can a patient contact you or your staff?
    - How quickly can they expect a response?
    - What type of information is appropriate for each channel?
    - Where do they call during emergencies?

D. ***Making technology safe***

- The Internet, telephone, and video conferencing, desktop computers and mobile apps, and other emerging technologies can be an effective way to provide information and services and connect with your patients. In fact, providers' use of social media and virtual communication is expected to increase under the Accountable Care Act. Before you launch a site, recommend an app, text your patients, or begin consulting using online video tools; consider the following:

E. ***Privacy and security***

- There are many regulations protecting medical information. The Office for Civil Rights enforces the Health Insurance and Portability and Accountability Act of 1996 (HIPAA) Privacy Rule and the Patient Safety and Quality Improvement Act of 2005 (PSQIA). HIPAA was designed to protect individual privacy of health information. PSQIA was created to assess and resolve patient safety and healthcare quality issues. As technology changes, the concerns and regulations will also change. Stay current. Be sure you understand your responsibilities as a healthcare provider.
- If you collect any information online, you must meet security standards and confidentiality provisions. This means being thoughtful about the design of the site's security, how the information is accessed and if it is downloaded for other use (such as patient files), and who can access and see the data at every step of the way. Perform your own audit with the "eyes of an outsider." Do not skimp on the cost of professional help to set up adequate security systems.
- Understand the limitations of practice insurance.

F. ***Ethics***

- While privacy and security are primary ethical concerns, there are other ethical issues to consider if you are publishing online:
- **Accountability and responsible conduct.** When you are creating an online site, be aware of promising things you cannot deliver and of giving advice that is ethically inappropriate and should be saved for a therapeutic relationship.
- **Intellectual honesty and copyright.** Be aware of publishing information or images without permission or proper citation
- **Provide equal access**. Recognize that not all sociodemographic groups have equal access to web services, whether it is age, income, or language barriers.
- **Informed consent**. Obtain and document with informed consent the issues unique to telehealth and telepsychology services. A lot of consent forms are full of unintelligible legalize. It is good practice to help your patients understand the facts. Translate the permissions into main points for any educational level.

G. ***Tips for patient technology use***

- **Suitability: Does it fit the patient's situation?**
- Determine whether specific technologies are suitable for your patients based on current information, research, and best practices.
- If you are consulting or doing therapy using the phone, video conferencing, or texting, this includes being familiar with inter-jurisdictional practices so that you remain in compliance with relevant laws and regulations across both jurisdictional and international borders.
- ***Accessibility: If you build it, can they come***?

Access comes in three ways:

- Do people have the right technology, such as Internet access or mobile devices?
- Can they easily use the technology to achieve what you intend?
- Will they use technology?
- **Simple to find**
- If you are creating web assets for clients and patients, such as website, logs, forums, or documents, make the URLs as simple and intuitive as possible. This is particularly important when dealing with aging patients or those who have cognitive challenges.
- Whenever possible, include a live link (where the URL is connected to a word or phrase) that someone can click and be taken to the right page. This avoids a patient having to type the correct address. You can include live links in any web document, including emails, word documents, PDF files, and, of course, on websites.

- **Simple to use**
- If you are integrating apps into your practice, provide training to your patients using different modalities—written instructions, video instructions, and face-to-face support. Do not forget your staff may need training, too.
- Build in an accountability procedure, such as follow-up phone calls or data monitoring, to confirm that people are able and willing to use the technology you prescribe once they get started. Compliance comes in all sizes.
  - **Make action easy**
    - If you want people to do something, make it easy and clear so they can take action: "click here," "donate here," "check here," "go here." Use big buttons and a clean design.
  - **Design**
    - Consider the age and cognitive ability of your users as well as the type of device used to access your materials. Gestalt psychology says that we process information holistically by automatically looking for patterns to make sense out of things. While you do not have to know the gestalt principles to create media, you should be aware that everyone has a tendency to attribute meaning to things like size, placement, and color. The old adage "less is more" holds true when you are creating media of any kind, from pamphlets to iPhone apps. There are several things to consider, such as:
      - ○ The size of the type you use—is it legible?
      - ○ Where you place text—will it appear in the main screen or the main page or will the user have to scroll down or flip to find something?
      - ○ Have you thought out the organization and pathways? How can the patient get the information they need, whether it is online or in print?
      - ○ Are the colors conducive to readability?
      - ○ Do images support the information or distract? Our understanding of information is "primed" by images appearing near it, whether it is related or not.
      - ○ Are you requiring people to go through a lot of steps, such as to create an account before they can enter your website? Are any instructions clear and understandable? Are users informed of the privacy risks and steps you are taking to protect them?

H. ***Guiding principles for using social media as a healthcare provider***

- The Internet and social media raise a host of new questions about setting use guidelines and boundaries. Healthcare professionals of all kinds need to have clear policies about what is public and what is private.
- Educate your staff and colleagues. Making your policies and procedures clear to your employees, co-workers, and patients is essential for practical, ethical, and legal reasons. Writing them down allows you to think through various scenarios and articulate your policies clearly to those around you.
- Everything you post on a social media site is potentially public, even with the strictest privacy settings.
- Everything is searchable and permanent.
- Your personal life and your professional life are not distinct. Online conduct, however unrelated to your professional life, can reflect on your profession and practice. This is true for you and any employees or co-workers.
- The golden rule applies online: Treat others with respect.
- Support friends and colleagues.
- Share expertise not advice.
- If something bad happens or someone posts something unfavorable, do not ignore it. Address it honestly and move on.

The best way to get rid of negative information online is to "bury" it with new content.

I. ***Creating a social media strategy***

- All service providers face competition from other offices in the area. Social media tools, like Facebook, Twitter, and collaborative tools like blogs and wikis can provide places for keeping a vibrant social media presence, although, they can be a lot of work, it can also be very rewarding. These will help you identify your goals to develop an effective social media strategy:
  - ○ Identify your audience.
  - ○ Clarify the purpose of your social media presence. Sharing information? Creating relationships? Establishing a professional presence? Making yourself accessible to patients?
  - ○ Be realistic about the amount of time and money you want to devote.
  - ○ Identify the practical and ethical restrictions and constraints.
  - ○ Evaluate any technology-based tools, from social media to mobile apps, to see if they fit your goals.

    Write out a strategy, including your criteria for determining what works and what does not.
  - ○ Do some research; listen to what people are saying about your area.
  - ○ Start slowly; do not jump in all at once.
  - ○ Adjust to feedback.
  - ○ Stop what is not working; do more of what is.
  - ○ Leverage your efforts. There are tools you can use that will let you leverage your efforts, such as linking your social media platforms together, so, for example, a new blog post is automatically announced on Twitter and posted on Facebook.
  - ○ Create an "emergency response" plan for when something goes wrong or when someone publicly complains.
  - ○ Social media is about relationships; it is not about selling or broadcasting.

J. ***Have an open mind***

- We live in a world with 24/7 connectivity. People have new expectations of response time, adaptability, and being "heard."
- The world of social media has introduced a new standard of authenticity and transparency that demands a different, more human approach to engagement. People make all kinds of assumptions and attributions about communication methods. How and when you respond to your patients will impact how they perceive your empathy and the quality of care.
- A lot of people do not like text messaging, social media, technology, or the Internet. If you are one of those, that is okay, but recognize that not all your patients will agree with you. If connecting with people in a meaningful way is your goal, then it is worth your time to explore your patients' engagement with technology.

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Commission on Accreditation of Rehabilitation Facilities (CARF) Accreditation

Christine M. MacDonell

Topic

The Commission on Accreditation of Rehabilitation Facilities (CARF) is a private, nonprofit organization that accredits health and human services across the lifespan and continuum of care. Accreditation opportunities are available in the fields of Aging Services, Behavioral Health, Child and Youth Services, Employment and Community Services, Medical Rehabilitation, Opioid Treatment Programs, and Vision Rehabilitation Services. CARF also accredits One-Stop Career Centers, Business Networks, Service Management Networks, Continuing Care Retirement Communities, Aging Services Networks, and Durable Medical Equipment, Prosthetics, Orthotics and Supplies (DMEPOS). Accreditation is based on application of practical and relevant standards of quality through a peer-review process to determine how well an organization is implementing practices designed to result in quality services to consumers. The standards are developed with the input of the persons served, professionals, purchasers of services, and other stakeholders with expertise and experience in the areas accredited by CARF and refined through external field review.

CARF currently accredits more than 52,000 programs at more than 20,000 locations internationally. In 2015, more than 8.7 million persons of all ages were served annually by more than 7000 providers in the United States, Canada, Europe, the Middle East, Southeast Asia, Africa, China, Mexico, and South America. CARF conducts more than 2500 surveys annually. The CARF International family includes CARF, CARF Canada, CARF–CCAC, and CARF Europe with offices in Tucson, Arizona; Washington, D.C.; Edmonton, Alberta, Canada; Toronto, Ontario, Canada; and London, England.

Hundreds of governmental, insurance, workers compensation, and private entities have accepted, mandated, or endorsed accreditation by CARF. CARF is financed by fees from accreditation surveys, workshops and conferences, sales of publications, and grants from public entities. The survey fee is determined on the size and number of locations for which the organization is seeking accreditation as well as the country the organization is located in. These fees include all costs associated with the surveyors' travel, lodging, and meals. The fee also covers the survey itself, the survey report, and the certificate of accreditation, if accreditation is achieved. There are no annual fees associated by CARF. There are both direct and indirect costs in preparing for a survey which

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_57

can be discussed with CARF staff we interested in accreditation.

Since its inception in 1966, CARF has benefited from national organizations joining together in support of the goals of accreditation. These organizations, representing a broad range of expertise, sponsor CARF by providing input on standards and other related matters through membership in CARF's International Advisory Council (IAC). Psychologists are well represented by organizations such as the American Psychological Association, American Congress of rehabilitation Medicine, Brian Injury Association of America, and Veterans Health Administration. A list of current IAC members is available on the CARF website, http://www.carf.org/members.

CARF is governed by an international Board of Directors, composed of individuals elected based on their expertise, experience, and perspective on matters of importance to CARF. The Board develops the strategic direction of CARF in conjunction with CARF leadership and approves corporate policies, including policies regarding standards development, the accreditation process, and fiscal matters.

Mission: The mission of CARF is to promote the quality, value, and optimal outcomes of services through a consultative accreditation process that centers on enhancing the lives of the persons served.

Vision: Through responsiveness to a dynamic and diverse environment, CARF serves as a catalyst for improving the quality of life of the persons served by CARF accredited organizations and the programs and services they provide.

Values: The CARF Board of Directors has identified that the persons served shall be the moral owners of CARF. Persons served are the primary consumers of services, who may be referred to as clients, participants, or residents. When these persons are unable to exercise self-representation at any point in the decision-making process, *persons served* is interpreted to also refer to those persons willing and able to make decisions on behalf of the primary consumer. The persons served as the moral owners of CARF means that CARF cannot fail to protect those owners through the CARF accreditation process. CARF believes in the following core values:

- All people have the right to be treated with dignity and respect.
- All people should have access to needed services that achieve optimal outcomes.
- All people should be empowered to exercise informed choice.

CARF's accreditation, research, and educational activities are conducted in accordance with these core values and with the utmost integrity. In addition, CARF is committed to:

- The continuous improvement of both organizational management and service delivery.
- Diversity and cultural competence in all CARF activities and associations.
- Enhancing the involvement of persons served in all of CARF's activities.
- Having persons served be active participants in the development and application of standards for accreditation.
- Enhancing the meaning, value, and relevance of accreditation to the persons served.

Purposes

In support of our mission, vision, and values, CARF's purposes are as follows:

- To develop and maintain current, field-driven standards that improve the value and responsiveness of the programs and services delivered to people in need of rehabilitation and other life enhancement services.
- To seek input and to be responsive to persons served and other stakeholders.
- To provide information and education to persons served and other stakeholders on the value of accreditation.
- To recognize organizations that achieve accreditation through a consultative peer-review process and demonstrate their commitment to the continuous improvement of their programs and services with a focus on the needs and outcomes of the persons served.

- To conduct accreditation research emphasizing outcomes measurement and management and to provide information on common program strengths and areas for improvement.
- To provide consultation, education, training, and publications that support organizations in achieving and maintaining accreditation of their programs and services.

Importance

The Commission on Accreditation of Rehabilitation Facilities (CARF) is a voluntary, peer review, external evaluation process that health and human service providers choose as a means to review the functioning and practices of their organizations, programs, and services. CARF has engaged with rehabilitation providers and psychologists since 1966 to ensure quality and accountability throughout the continuum of services provided for individuals rehabilitation needs. Providers around the world have chosen to pursue accreditation as "it is well recognized that application of the principles of accreditation on an ongoing basis facilitates continuous quality improvement" [1]. Accreditation can create social capital, provide a learning environment for change in practice, encourage both formal and informal relationships and communication, and through shared values may enhance care for individuals with rehabilitation needs. [2]

CARF accreditation standards and the survey process provide programs with a template to organize a quality rehabilitation program. While the CARF standards are a template of how to organize good rehabilitation care, it does appear that improving an overall organization by using CARF standards results in a number of areas which determine quality including health and safety practices, reduction of risk, performance measurement, management, and improvement, collaborative team work, and person-centered practices to name a few. In a Veterans Health Administration (VHA) study, it appears the following had a significant positive impact on the programs surveyed caused by preparing for a CARF survey: communication with members of the rehabilitation team, program quality overall, medical record documentation practices, communication with Veterans Administration Medical Center (VAMC) management regarding mission and/or actual performance of the rehabilitation program, and quality of information provided to the patient and family regarding the care plan. [3].

CARF has a long history of working with organizations in different countries to prepare for surveys and become accredited. CARF accreditation in Canada dates back to 1969 and now includes a wide spectrum of programs and services. In 2002, the CARF Canada office was opened in Edmonton, Alberta and soon after an office in Toronto, Ontario. In 2014, the CARF Europe office opened in London, England.

The field of human service providers and technology has made the world a smaller place, and CARF continues to expand its borders. Since 1996, CARF has accredited a growing number of organizations and programs outside of North America. The first Comprehensive Integrated Inpatient Program was accredited in 1996 in Lund, Sweden at the University of Lund. In 2014, CARF-accredited organizations and programs included providers in Europe, the Middle East, Africa, China, Southeast Asia, and South America. There is increased interest from the international community to review and participate in CARF activities. CARF regularly conducts training sessions in Europe and elsewhere to meet the growing demand for accreditation information. Individuals from the international community participate in CARF standards development, contributing to a global emphasis on quality service provision.

CARF is committed to ensuring that all surveyors who travel internationally are well prepared and educated about the markets they will be surveying. Surveyors from other countries who conduct surveys in the United States also are provided with information to assist them in the survey process. There are over 1500 peer-review CARF surveyors representing eight countries.

CARF's work in the international markets has demonstrated that the differences in services are minor and the process of person-centered services, good business practices, outcomes management systems, and performance improvement are international in scope. CARF is committed to continuing its work with international communities that embrace quality and demonstrate value for all persons served. For international providers, the use of standards can be tools to assist with the development of continuums of care, establish links with providers outside of their countries to increase learning opportunities, and establish partnerships and collaborations for research and clinical practice.

International providers have many reasons to seek CARF accreditation; most are related to the intrinsic value to the development of their programs and organizational structures. These providers continually state that peer review, consultation, and the ability to revise standards are critical components. A unique aspect of the international market is that there may only be one or two rehabilitation hospitals or limited community-based providers in a country, so there is not a volume of providers to seek accreditation. In countries outside of the United States, the eagerness to be part of an international network of like providers, have outside review and consultation, develop a continuum of services, and be able to tap into multiple resources are the drivers for those seeking accreditation.

Psychologists are encouraged to participate in one of the key functions of CARF: standards development. The CARF standards, which are central to the entire accreditation process, have evolved and been refined over more than 49 years with the active support and involvement of providers, persons served, purchasers of services, and advocacy groups. The standards were originally established and have been maintained as international consensus standards. The standards define the expected input into, processes for, and outcomes of programs and services for persons served.

CARF convenes its International Advisory Council (IAC); International Standards Advisory Committees (ISAC); and regional, national, and international focus groups to systematically review and revise CARF's standards and to develop standards in new areas as warranted by the needs of the field. Composed of individuals with acknowledged expertise and a broad base of experiences, including persons served, these committees and groups make recommendations to CARF concerning the adequacy and appropriateness of the standards.

The work of these groups is a starting point in standards development and revision. Recommendations from the survey development and revision process are consolidated and made available to persons served, accredited organizations, surveyors, regulatory agencies, national professional groups, advocacy groups, third-party purchasers, and other stakeholders for review and comment. Field input is reviewed by CARF. Changes are made if necessary from input received. At the completion of this standards development process there is either a new or revised set of standards published and copyrighted by CARF.

Practical Applications

Psychologists should become familiar with the structure of the CARF Medical Rehabilitation Standards Manual to better understand and appreciate the depth and breadth of the CARF standards. Psychologists in CARF accredited organizations may wish to consider becoming a CARF surveyor.

Achieving CARF accreditation involves demonstrating conformance to standards of quality in the provision of programs and services as evidenced through observable practices, verifiable results over time, and comprehensive supporting documentation. To determine conformance to the CARF standards, CARF peer surveyors:

- Observe the environment and interactions among staff members, management, and the persons served.
- Conduct interviews with persons served, personnel, and other stakeholders.
- Study the organization's policies and procedures.

- Observe practices and service provision.
- Review documentation.
- Provide consultation

The role of the CARF peer surveyor is not that of an inspector or auditor, but rather a consultant. The goal is not only to gather and assess information to determine conformance to the standards, but also to assist the organization in improving its programs and services and its business operations. The entire CARF accreditation process is focused on continuous improvement of the organization, programs, and service delivery.

Medical Rehabilitation organizations that seek accreditation demonstrate conformance to a variety of standards. The first section of standards are the ASPIRE to Excellence standards which apply to all organizations seeking CARF accreditation. Since CARF's inception in 1966 the standards have not just focused on clinical/service practices, but also the running of the organization using a robust business and performance improvement model. CARF's ASPIRE to Excellence model crosswalks with ISO 9001, Six Sigma, LEAN, and Baldrige criteria. The advantage for medical rehabilitation providers is the language of the CARF standards reflects the daily practices of providers as well as the concepts of most modern quality frameworks. Many CARF organizations use multiple systems (CARF ISO, CARF Baldrige, etc.). Those using more than one quality system express that the CARF standards make the intentions of the quality framework become practical in the provision of services, make sense to personnel on all levels of the organization, and requires them to look at their results not just their processes.

The business model includes the structure of leadership and governance, development and use of an integrated strategic planning process dynamic listening to the individuals they serve, personnel and stakeholders to analyze and use ideas and thoughts in the organizational functions. The listening process engages all parties in a sense of shared future that promotes long-term organizational excellence.

The organization demonstrates compliance with legal requirements, financial planning and management, and human resource requirements that promote the competency of staff and their performance reviews, an active risk management plan, a healthy and safe environment for persons served, personnel, and stakeholders as well as a strong technology plan. The rights of the person served and the promotion and practice of these rights is a critical component of the ASPIRE section. CARF standards promote the removal of all barriers for person served, personnel, and stakeholders in the key domains of architecture, environment, attitude, communication, financial, transportation, community integration, and any other area where anyone from the key groups (person served, personnel, or stakeholder) identifies a barriers. This is a dynamic process that is also linked with reducing potential risks and performance improvement.

The last two sections of the ASPIRE to Excellence section of standards focus on establishing the measurement of key performance indicators in both business and clinical practices. This sets the stage to review data collected regarding reliability, validity, completeness, and accuracy. CARF standards make an organization establish targets for their performance and measure against it. If targets are not met, performance improvement plans are developed and implemented. Performance measurement is done again to see if improvement is gained. There is no finish line with quality, only the raising of the bar for the delivery of optimal quality. CARF standards require organizations to be transparent with their results and share this information with persons served, personnel, and stakeholders in meaningful ways. Medical rehabilitation programs that are CARF accredited should be able in a variety of mechanisms to share their results. This can be done via web, handouts, charts, focus groups, newsletters, one-on-one discussions, town hall meetings, residential councils, staff meetings, etc.

The second section of CARF standards, applied to all medical rehabilitation programs is Program Structure and the Rehabilitation Process for the Person Served. This section devotes itself to standards that formulate the day-to-day process of providing case-managed care for those in medical rehabilitation programs, and addresses scope of services, admission, transition and discharge criteria, the role of the interdisciplinary team, the communication and collaboration of the team, education and training for persons served and families/support systems, equipment, supplies, physical plant, behavior programs, medical records, conferencing, and a variety of other topics related to the rehabilitation process.

The third section of CARF standards is the specific location standards (e.g., Comprehensive Integrated Inpatient Rehabilitation Programs (CIIRP)) and the specific diagnostic category standards (e.g., stroke, spinal cord system of care, cancer rehabilitation).

A. ***Becoming a Surveyor***

Individuals who are selected, trained, and assigned to conduct site surveys for CARF are designated as surveyors. They are selected on the basis of their professional experience, expertise, and program leadership. CARF surveyors are committed to the principle that accreditation is essential in ensuring that organizations offer programs and services of demonstrated value to the persons served.

Currently, there are more than 1500 CARF surveyors throughout all 50 states, Canada, Europe, Middle East, and South America. They have expertise in all program and service areas in which CARF accredits organizations.

Psychologists interested in becoming CARF surveyors should apply online at the CARF website. Each applicant is required to submit several items, including a résumé and professional references. After all required materials have been received, the candidate is considered for acceptance into the pool of applicants.

Tips

Psychologists may be in charge of preparing for a CARF survey or on a team that is tasked with preparing for CARF. Critical to either role is a current knowledge and understanding of CARF standards. CARF staff attend and present at many professional meetings which is one way to stay current. CARF staff also hold sessions called “CARF 101” that are held in different locations and review all the standards. This is an excellent way to quickly learn all the standards and also interact with other rehabilitation providers. Web casts and webinars are also offered throughout the year. Finally, at any time, a psychologist can call CARF staff and discuss standards, a process, or changes/additions/deletions that they feel need to be made to standards and or the process.

We encourage organizations and individuals to use a systematic approach to preparation for a CARF survey. On the CARF website you may find useful tips on successful preparation for a CARF survey.

CARF encourages psychologists to interact with CARF and the standards development process to improve, revise, and update standards to reflect the needs of consumers, providers, payers, and government agencies. CARF looks forward to future interactions and collaborations with rehabilitation psychologists around the world to continue to enhance the lives of persons with rehabilitation needs.

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Websites

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Incorporating the Standards Established by The Joint Commission (TJC)

Laura M. Tuck and Sigmund Hough

Topic

The Joint Commission (TJC), formally the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) [1], has the following goals:

Mission: To continuously improve healthcare for the public, in collaboration with other stakeholders, by evaluating healthcare organizations and inspiring them to excel in providing safe and effective care of the highest quality and value.

Vision: All people always experience the safest, highest quality, best-value healthcare across all settings.

Accreditation by TJC indicates that a healthcare organization meets the standards of care for safety and quality [2]. TJC was founded in 1951 and provides site visits and accreditation for more than 20,500 healthcare organizations and programs in the United States. Working with TJC provides guidance to create structures and management practices for quality improvement and survey preparation as well as maintenance of high-quality care and compliance with the most recent standards. Accreditation formerly acknowledges that the standards are met by agencies, both public and commercial. Accreditation lasts for 3 years, with the exception of laboratories. With a growing number of psychologists practicing within medical centers, particularly those who are embedded in the same setting as their medical colleagues, understanding the standards of care for accreditation is increasingly important for advocacy of persons served, stakeholders, and the healthcare system in which one works [3].

As part of the accreditation process, national patient safety goals are reviewed in several medical settings where psychologists practice in an interprofessional model of care. Ambulatory care, behavioral healthcare, critical access hospitals, home care, hospital care, laboratory service, and nursing care centers are common sites [4]. These programs may be housed in hospitals, doctor's offices, office-based surgery centers, behavioral health treatment facilities, and home care services. Tenets of patient safety broadly include confirmation of patient identity, safe medication use, infection prevention, prevention of surgical mistakes, identification of patients with safety risks, timely staff communication, use of equipment with alarms to notify staff of patient and equipment alerts, and fall prevention.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_58

An important element of a site review is the utilization of tracer methodology in integrative healthcare settings [5]. Individualized tracer activity is conducted by a thorough and systematic chart review where the patient's experiences are "traced" throughout their time with an organization. Typically these traces are conducted for high-risk patients or practices. This is a preferred form of evaluation to review daily care practices, processes, and adherence to standards. System tracer activity is the review of a specific process within a hospital and is conducted via a meeting with a surveyor and relevant staff members that is based on information provided by the individualized tracers. The process, communication, and interprofessional coordination are evaluated in the areas of data management, infection control, and medication management. The data management tracer is always reviewed, while the other two areas vary depending upon the survey. Program-specific accreditation tracers identify high-risk areas and safety concerns across the continuum of care that is relevant to the organization. These reviews are common in high-risk and high-volume areas. Lastly, the second-generation tracers offer an even more detailed evaluation within a specific area, process, or subject. Areas for review may range from sanitization practices to how professional practices are evaluated through ongoing and focused reviews.

Surveys are typically unannounced, unless the site is a large organization, or there are unique factors involved in the survey such as the necessity for surveyors to obtain advanced security clearance [6]. In these situations advanced notice is generally within 7 days of the intended site visit. Although organizations are often unaware of the planned survey date, they can estimate a survey will occur between 18 and 36 months after the last survey. This ensures the process can be completed before existing accreditation expires. Leadership will often apprise staff of the likelihood of upcoming visits and will prepare staff to address quality improvement efforts that took place in the interim since the last visit and areas to be aware of in regard to patient safety that a surveyor may ask about during a visit.

In addition to accreditation, TJC offers Disease-Specific Care (DSC) certification. This program was established in 2002 to evaluate healthcare organizations for nearly any chronic disease or condition. Nonaccredited organizations, such as disease management companies and health plans with disease management services, can also participate in this type of certification. Similar to accreditation surveys, an on-site review is performed by a field reviewer. Performance and outcome measures, adherence to guidelines in daily practice, and the program's commitment to continual improvement to safety and care are evaluated during site reviews. TJC also reviews how programs educate patients in engagement in disease self-management. Tracer methodology is utilized to examine these areas.

Advanced certification is also offered for organizations that meet additional clinically specific requirements and expectations. Advanced certification can be sought in the following areas: chronic kidney disease, chronic obstructive pulmonary disease, heart failure, inpatient diabetes care, lung volume reduction surgery, primary stroke center, and ventricular assist device destination therapy. Certification lasts for 2 years with a required conference with TJC at the end of the first year to demonstrate ongoing compliance. Performance measures are routinely submitted to TJC to assist with the evaluation process. Measures are standardized for the stroke and heart failure certification, whereas the other domains select program-specific measures based upon their goals for improvement.

TJC surveyors are experienced healthcare professionals who provide expert advice and educational services during the on-site survey. Feedback can be expected within a 2-week to 2-month time frame. Customized feedback from the extensive survey provides valuable information based on the surveyors' diverse background experience working in variety of healthcare settings and training areas. To provide tailored reviews, surveyors are matched to sites reflective of their own areas of expertise. This ensures the feedback provided is relevant to the organization. TJC is invested in the growth of facilities and therefore provides continuing support and education services to accredited organizations to assist with ongoing efforts for performance improvement.

Importance

During the 1980s psychologists' work in medical settings became more prevalent and recognized. Psychologists began serving not only patients with mental health diagnosis, but health concerns as well under Engel's biopsychosocial model. Roles changed beyond that of a clinician to administrators and teachers in medical settings for both mental health and medical service lines. Psychologists work within several team models on the continuum of interprofessional practice including consultative, multidisciplinary, interdisciplinary, and transdisciplinary teams. Psychological services are provided on a larger systems level based on expertise in behavior, ethics, advocacy, interpersonal relationships and team dynamics, and contributions from the field of industrial-organizational psychology. TJC established standards for psychologists regarding credentialing and privileging as part of the hospital boarding process and subsequent professional practice evaluations [7]. These standards are refined as the field of psychology and healthcare structure continue to evolve.

Being aware of the TJC standards helps psychologists work alongside leadership to organize and strengthen patient safety efforts to carry out the organization's mission and TJC standards in a way that improves patient care. Psychologists can enhance the quality and safety of services offered in their facility beyond their clinical contributions by assisting with data management and analysis, as a large component of TJC surveys is the review of performance and accountability measures. Expertise in measurement and data analysis can be invaluable to an organization. Psychologists can translate data into action, determining what aspects may be failing and turning the information into a strategic performance improvement plan. These plans can improve risk management and risk reduction through continual and structured performance improvement initiatives to reduce the risks of error or low-quality care.

Practical Applications

A. ***Marketing/Patient Retention Aspects***

Working for an accredited agency is beneficial to psychologists to ensure employment by a reputable and sound organization. The public will generally have greater trust in accredited hospitals and likely increased service utilization compared to hospitals that do not carry the same reputation for quality, safety, treatment, and services offered. For those working in the civilian sector, this is beneficial for marketing and client referrals. For those working in government agencies, the quality of service implied by accreditation communicates to persons served that the agency meets the set standards of care and strives for continual improvement. This is increasingly important for retention of persons served because recent legislations such as the Affordable Care Act and the Veteran's Choice Program provide more competition for services. There may also be an economic advantage for a psychologist to work in or provide consultative services in an accredited hospital because it may reduce liability.

B. ***Human Resources Aspects***

Many organizations across the country face challenges with hiring staff due to financial limitations. TJC is one of the most recognized names in healthcare, which helps organizations further innovative integrative care by hiring high-caliber staff. Competitive recruitment packages may be easier to provide with TJC accreditation due to the additional opportunities for staff to develop their skills and knowledge. The Accreditation Council for Graduate Medical Education (ACGME) requires healthcare organizations sponsoring or participating in graduate medical education (residency) programs to be accredited by TJC or another recognized body with reasonably equivalent standards.

C. ***Administrative Aspects***

For psychologists practicing in the role of administrators, seeking TJC accreditation can make it easier to obtain Medicare and Medicaid certification. The facility may already qualify for these certifications if it is accredited by TJC, thus minimizing duplicative administrative tasks by not having to undergo a separate quality inspection from the government. Accredited rehabilitation hospitals are recognized by insurers and other third-party payers, which is increasingly becoming a requirement for reimbursement and participation in managed care plans or contract bidding. To increase efficiency, administrators may consider a blended survey where the organization undergoes evaluation by two different accrediting bodies [8]. The opportunity to coordinate a blended survey comprising concurrent accreditation review by both TJC and the Commission on Accreditation of Rehabilitation Facilities (CARF) can be beneficial in terms of the organization's focused energy, actual time spent under review, and unified actions of response corrections. This is an opportunity to hear the good things the organization is doing and planning to do in the future. A blended survey with TJC and CARF may seem overwhelming due to perceived increased oversight; however, if an organization is well prepared, there may be greater potential benefit in the long run despite initial anxiety.

Tips

- Utilize TJC as a source of support and shift thinking about site visits from a mission to uncover suboptimal practices to a collaborative approach. As a not-for profit organization, TJC is invested in the successful performance of accredited facilities.
- Utilize consultants to bring an objective review of systems and operations with "fresh eyes" to help with quality improvement. Feedback often includes practical tools to strengthen or maintain performance, which should be taken seriously.
- When interacting with surveyors, respect their role of fact finding and education. The question to ask is "What do we learn to improve?" instead of "How do we get the task done to get the survey completed?" Make interactions as comfortable and pleasant as possible.
- Discuss accreditation and standards throughout the year by making it a part of the environmental culture. Organization, monitoring for compliance, accountability, learning opportunities, and communication with staff members to keep them informed and feel invested in being a part of ongoing compliance with established standards of care are ways to establish this culture.
- TJC website provides a number of resources [9]:
  - The Leading Practice Library includes good practices submitted by accredited organizations.
  - The Targeted Solutions Tool is an interactive web-based tool created by TJC Center for Transforming Healthcare where organizations can check their performance online and search for customized solutions to address growth areas.
  - The Certification Publicity Kit assists with marketing.
  - Free online education courses qualify for continuing education credits for medical providers.
  - The website hosts information about prominent topics in rehabilitation as well as timely daily updates.
  - Measures for specific expectations outlined in the manuals are reviewed on the website. Further guidance is offered in the online toolkits.
  - The Annual Report-Improving America's Hospitals and the Top Performer on Key Quality Measures are noteworthy resources to view how successful facilities run their programs.

  - The Joint Commission standards are available for purchase on their website; however, standards are likely readily available at your facility. Administration may have electronic copies posted on the intranet or on a network drive.
- Fundamentals of accreditation [10]:
  - **J** for JOIN (everyone participates).
  - **C** for CLARITY and COMMUNICATION (empower through knowledge and understanding).
  - **A** for ATTITUDE (focus on ways to accomplish versus reason you cannot).
  - **H** for HUMOR (humor has always been the best medicine).
  - **O** for ORGANIZED (organizational skills and accountable systems are the foundation for building quality and maintaining quality care).
- There has been a shift in conceptualization of accreditation from completing the minimal requirements to striving to complete the process as well as possible. Fundamentals of successful accreditation:
  - **T** for TAKE opportunity to accomplish accreditation in an organized manner with humor and respect.
  - **J** for JOIN the accreditation process as a team, not just a team member.
  - **C** for COMMUNICATE the standards clearly and empower the staff to have control for accomplishment.

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Part VI

Research and Self Evaluation

Research Made Useful for Busy Rehabilitation Providers

59

Scott D. McDonald, Paul B. Perrin,
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Topic

"Evidence-based practice" (EBP) has become the standard in rehabilitation medicine and psychology in recent decades [1, 2]. EBP is an approach to health care in which clinical decisions are based on (1) the best available research evidence, (2) clinical judgment and expertise, and (3) the values and preferences of the patient. Although EBP is often discussed in the context of treatment, it also applies to assessment, diagnostics, the therapeutic relationship, and other aspects of direct patient care. A large literature base supports the idea that the best quality patient care happens when scientific evidence is part of the decision-making process, leading psychology and other health-care professions (e.g., American Occupational Therapy Association, American Speech-Language-Hearing Association) to support the EBP framework as the standard of care and professional competency. By employing EBP, clinicians strive to provide the best possible care, maintain professional credibility, and demonstrate accountability to stakeholders and third-party payers. However, despite the wide acceptance of EBP, health-care practitioners and programs often do not follow best available practices. In part, the use of EBP in routine practice is hampered by a perception among some clinicians that the research literature is inaccessible to clinicians, too time consuming to approach, and difficult to understand. In this chapter, we provide readers resources and encouragement for how to effectively find and employ research evidence to inform their use of EBP in the context of rehabilitation medicine.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_59

Importance

A. ***Evidence-based practice and the role of research***

EBP combines three critical elements: an understanding and incorporation of the *research evidence* with good *clinical judgment* and *patient preference* (see Fig. 59.1, EBM Triad) [3]. A foundational article in defining EBP includes an oft-cited definition: "Evidence-based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" [4]. As such, at the core of EBP in psychology and in rehabilitation, medicine is the stance that best practices will be identified through *evidence* provided by rigorous and systematic study of clinical practices [2, 5].

Randomized controlled trials (RCTs), intervention studies that randomly allocate participants into treatment groups, are generally considered the highest level of evidence for interventions. Unfortunately, RCTs are challenging to conduct in rehabilitation medicine, as they require large sample sizes in relatively homogeneous groups under well-controlled conditions. Given the sometimes small sample size of many patient groups, medical comorbidities, and concurrent treatments, other research designs such as prospective observational cohort and single-subject experiments often provide the best available evidence in rehabilitation [6]. Although several psychological interventions have been examined in rehabilitation settings, cognitive rehabilitation has the strongest evidence base, and a stronger evidence base in other areas of rehabilitation psychology is needed. Clinicians considering the application of interventions and practices that have significant support in general outpatient mental health settings will need to consult the research evidence and draw from clinical expertise to determine applicability to rehabilitation settings.

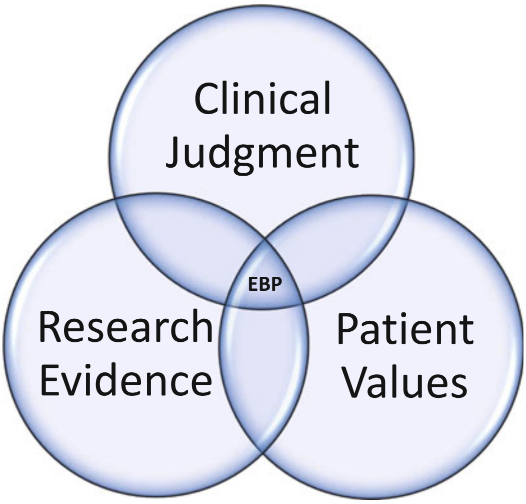

Fig. 59.1 The Evidence-Based Practice Triad

Clinical expertise and patient preferences are also essential components of the EBP clinical triad. *Patient preferences* are perhaps the least developed aspect of EBP but are crucial for *shared decision-making*, a tenet of rehabilitation medicine. *Clinical expertise* refers to proficiency and judgment that is developed through training and experience, expressed through diagnostic skills and thoughtful integration of patient preferences and situational factors in clinical decision-making. Foundational clinical competencies such as communication skills, self-appraisal, and ability to develop relationships, trust, and alliances with the patient are all aspects of clinical expertise and, to varying degrees, are part of training curricula across health professions. Familiarizing oneself with the research literature allows the practitioner to bring clinical judgment into treatment decisions. Being a critical reader and consumer of the research—that is, knowing how to evaluate the literature and whether the research is with quality and relevance to your practice—enhances clinical practice. A critical skill to develop is recognizing whether an EBP makes sense in your practice: a treatment may be empirically supported, but the context of that support or the type of patient treated may differ markedly from those seen in your practice.

B. ***Importance of utilizing evidence-based practice in rehabilitation psychology***

Keeping up with the evidence base informs best practice in EBP for several reasons. First, (1) it *enhances the quality of care*. Knowledge of the available empirical evidence will point toward best practices for patients given a particular clinical presentation, setting, and patient preference. This includes not just information about specific evidence-based treatments (EBTs) but also knowledge about potential treatment moderators (e.g., patient characteristics and institutional factors), trends in patient preferences, and best practices for developing a therapeutic alliance. Given that ESTs are not available for every clinical presentation, and patients will often not fit well into discrete disease classifications, it is critical for clinicians to have knowledge of the best available practices, their limitations, and parameters of their application.

Secondly, (2) it *demonstrates accountability*. When the evidence base is ignored in health care, it can lead to misappropriation of resources, inefficient care, and missing opportunities to benefit the patients we serve. Incorporating EBP into our work is not only important for patient care but also demonstrates that our services are of substance and an equitable use of tight health-care dollars. This is useful for reimbursement and policy development but also for demonstrating our worth as members of interdisciplinary teams and as consultants. Whereas quality patient care is the ultimate aspiration of the rehabilitation professional, the interdisciplinary nature of rehabilitation necessitates that we also function as ambassadors for our profession or specialized discipline.

Thirdly, (3) it *diminishes the propagation of medical myths*. A scientifically informed practice reduces medical myths that can propagate ineffective or harmful treatments. In some cases, myths are remnants of previously accepted practices or treatments that have become popular with limited evidence of effectiveness. For example, although psychological debriefing has become a common practice in emergency medicine and often recommended after traumatic events, evidence for its ability to minimize psychological distress and reduce the development of post-traumatic stress disorder (PTSD) is lacking. Reviewers highlight that not only is there a lack of studies but additionally that methodological shortcomings of existing studies have made it difficult to demonstrate the utility of this intervention [7, 8].

Myths may also persist as they are part of clinical lore. Pertinent to rehabilitation psychology, Elisabeth Kübler-Ross's "stages of grief" (denial, anger, bargaining, depression, and acceptance) have been popularly revised to suggest that there is a stepwise, predictable progression of adjustment phases, and emotional healing requires passing through each stage successfully. However, after decades of research, it has become clear that not everyone follows the same adjustment trajectory, and the stages identified by Kübler-Ross are not necessarily universal [9]. Potential harms from applying an unproven stage model to patient care include inaccurate assessment of a patient's current process (e.g., assuming an emotionally stable patient is in denial) and unwittingly guiding patients and family members to what they "should" be experiencing.

Utilizing EBP also (4) *improves shared decision-making with patients*. Sharing decision-making responsibilities with the patient is a tenet of rehabilitation medicine, aids in compliance and positive outcomes, and is essential in EBP. A clinician who is knowledgeable will be better able to help patients make informed decisions about treatment options [2] and dispel potentially harmful medical myths.

Fifth, it (5) *enhances interdisciplinary communication*. Good communication is essential for effective interdisciplinary teams. EBP introduces common terms and standard protocols, improving opportunities to collaborate across health professionals who often use discipline-specific terminology [10]. By employing EBP, we demystify the therapeutic process and solidify our position on the treatment team by speaking the same language as our colleagues.

Finally, using EBP in rehabilitation psychology (6) *has benefits to the clinician*. There is growing awareness that practicing evidence-based psychology can cultivate expertise and promote the clinician's professional satisfaction and well-being. An awareness of the evidence base helps to hone our skills and reduce errors and biases by making us aware of the limits of our knowledge and skills that can affect clinical judgment [2, 11]. In addition, embracing EBP is linked to clinician satisfaction and well-being [12]. For example, trauma specialists employing EBP reported less compassion fatigue and greater compassion satisfaction [13]. Although mediators of the process have not been well defined, both self-efficacy and staff training are known to improve well-being, so it stands to reason that employing the best available practices will improve job satisfaction by providing a sense of competence.

Practical Applications

In the section above, a description and case for the importance of EBP were given. How does one go about actually practicing evidence-based rehabilitation psychology? This section describes a process for formulating a question related to your practice, finding relevant evidence from the research literature, and how to critically appraise those findings.

A. ***Formulate a question***

The first step in incorporating new evidence-supported practices into one's clinical work often involves formulating a clear and *answerable*—i.e., searchable—question. Formulating this type of question presupposes that the rehabilitation professional or clinician has an appropriate background and at least basic familiarity with the keywords needed for the literature search. For example, to be able to ask questions such as "What are the effects of opiates on cognition?" or "Is there more support for behavioral activation or cognitive therapy as a brief treatment for depression after spinal cord injury?," one must already have a basic knowledge about opiates, cognition, and depression treatments. If this turns out not to be the case, consulting with colleagues, textbooks, review articles, or even websites addressing the general topic can help zero-in on the appropriate search terms.

Once these terms are identified, formulating the specific research question is best understood through a series of steps known as the **Patient-Intervention-Comparison-Outcome or "PICO" procedure** [14]. In the *patient* step, the clinician asks what specific demographic characteristics are relevant for the patient, including race/ethnicity, age, gender, socioeconomic status, health condition, and medical issues. In the *intervention* step, the clinician identifies the specific intervention under consideration with as many details as possible, such as frequency, dose, intended purpose, and type of provider. In the *comparison* step, the clinician asks what the treatment is being compared to, including a control group, usual care, placebo, or no treatment. And finally in the *outcome* step, the clinician asks how the effectiveness of the intervention is measured in terms of a reduction in symptoms or increase in function or quality of life. The best research question—and as a result, the search term—involves all four PICO components, especially when the general body of research on that topic is extensive. For example, a good search term derived from the PICO steps addressing the above research question could be "spinal cord injury; behavioral activation; cognitive therapy; depression." On the other hand, when the topic area is new or under-researched, general or fewer terms may prove more useful.

B. ***Search the literature***

After formulating a clear and answerable question, one must decide how to efficiently find trustworthy information. Busy clinicians do not generally have the time and expertise to seek out and critically appraise individual research articles. Instead, systematic reviews and clinical practice guidelines offer good-quality summaries of the evidence base and recommendations.

1. **Systematic reviews** on a specific topic, and especially those including meta-analysis, tend to provide the highest level of evidence for answering a research question. These typically summarize and critically evaluate a body of research and therefore transcend many of the methodological and generalizability limitations of single-sample studies. These reviews are "systematic" because they conduct a thorough review of all published findings (and, ideally, unpublished studies as well) using prespecified criteria for inclusion. This methodology helps reduce confirmation bias on the part of the investigator, that is, a tendency to look for confirmation of existing beliefs and exclude those studies that challenge them. Systematic reviews are often published in peer-reviewed journals and can be found in general or discipline-specific databases, as described in detail below. Online databases of systematic reviews include:
   - Cochrane Database of Systematic Reviews (www.thecochranelibrary.com)
   - Campbell Systematic Reviews (www.campbellcollaboration.org/lib/?go=monograph)
   - Mental health-specific National Registry of Evidence-Based Programs and Practices (www.samhsa.gov)
   - The rehabilitation-specific Registry of Systematic Reviews of Disability and Rehabilitation Research (www.ktdrr.org/systematicregistry)
2. **Clinical practice guidelines (CPGs)** help clinicians make decisions about interventions for a specific condition based on the cumulative evidence to date on a topic. They are generally informed by systematic reviews and grade the relevance and level of evidence of recommendations, but may introduce expert consensus to fill in gaps or resolve inconsistencies in the findings of systematic reviews. It is important for clinicians to differentiate between evidence-based guidelines and merely consensus guidelines, with the former commanding more weight [14]. CPGs are often published by professional organizations (e.g., American Psychiatric Association) and government agencies (e.g., US Department of Veterans Affairs). Many such CPGs are freely available on the Internet. There are several searchable databases of CPGs available, most of which screen for inclusion based on quality indicators and current relevance. The National Guideline Clearinghouse may be the most comprehensive database to date, although there are many:
   - AHRQ Comparative Effectiveness Reviews: www.effectivehealthcare.ahrq.gov
   - American College of Physicians: www.acponline.org/clinical_information/guidelines
   - American Psychiatric Association: www.psych.org/practice/clinical-practice-guidelines
   - Institute for Clinical Systems Improvement: www.icsi.org/guidelines__more
   - National Guideline Clearinghouse: www.guideline.gov
   - National Institute for Health and Care Excellence (UK): guidance.nice.org.uk/CG
   - VA/DoD Clinical Practice Guidelines: www.healthquality.va.gov
   - World Health Organization: www.who.int/publications/guidelines/en
3. **Search tools.** At times, it may be advantageous to seek out nonsystematic reviews, peer-reviewed journal publications, patient-oriented evidence that matters (POEMs), or book chapters to find information on relatively unique groups or that is otherwise not available in systematic reviews or CPGs. Computer-based search tools provide an efficient method of exploration, although results are often limited to abstracts, that is, a summary of the full article. When using such computer search tools, the clinician has the choice as to

whether he or she wants to use a *discipline-specific database*, such as PsycINFO for psychologists, or a more *general database*, such as PubMed or EBSCOhost. Discipline-specific databases often provide a thorough, and also more specific, search for articles that are within one's discipline, excluding many of the articles outside of the discipline. These types of databases are especially good if a clinician has identified a very specific question with concrete search terms in a particular discipline. For example, PEDro (physiotherapy), OTseeker (occupational therapy), and speechBITE (speech pathology) are specific to evidence-based practice in rehabilitation medicine. If the clinician has a less-specific question or one likely spanning multiple disciplines, a more general database may be more suitable because many cross-discipline articles will be included in the search. PubMed (pubmed.gov), maintained by the National Center for Biotechnology Information (NCBI) at the National Library of Medicine® (NLM), is an excellent source of journal article and chapter titles, online articles from PubMed Central, and other biomedical literature. Although there is a notable learning curve to fully appreciate the most useful search strategies, it is easy for novices to conduct a broad keyword search and find information of interest. American Psychological Association's (APA) Librarian's Resource Center (www.apa.org/pubs/librarians) offers tutorials and other useful resources to optimize the use of PubMed and other information sources.

In recent years, Internet search engines such as Google Scholar have emerged as popular, powerful, and comprehensive search tools that capture articles from nearly all disciplines. However, it is not always easy for the untrained eye to determine the *quality* of articles found in Google Scholar, given search hits from almost all possible sources of information on the Internet. The recent growth of open-access "vanity" and "pay for press" online journals has increased the number of articles of dubious quality that are freely available on the Internet. In one of several recent examples, a science journalist was successful in publishing a bogus scientific paper, complete with devised, serious design flaws, in 157 of 304 (52 %) open-access journals to which he submitted [15]. Not only new open-access publishers but also several established publishers of peer-reviewed print and open-access journals also fell prey to the demonstration. Shockingly, 70 % of those journals that utilized peer review accepted the paper.

4. **Accessibility and electronic resources.** Whether a clinician decides to use a general or discipline-specific database, many times clinicians' access to the full text of journals is limited by whether they have an affiliation with a university or major research institution. Even then, institutions do not always purchase access to all of the journals that a clinician might be interested in accessing. The recent National Institutes for Health Public Access mandate for federally funded studies to post peer-reviewed journal manuscripts on PubMed Central and trends in open-access journals has made it easier to find articles of interest. Additionally, it is not uncommon for an author or his or her institution to post a PDF of the manuscript on an institutional website. Contacting the author for a reprint may be fruitful, but the requester should know that publication agreements may restrict dissemination of reprints by the author. When these sources fail and the abstract alone does not provide needed information, the full text of the individual article can be purchased from the publisher.

C. ***Critically appraise your findings***

After identifying sources of information that address the question, the clinician must critically appraise the findings. First, **(1) is**

the information relevant to the setting and patient at hand? Patient demographics and comorbidity, clinical resources, and patient preference are some of the important considerations. For example, treatment recommendations in a CPG for the treatment of combat-related post-traumatic stress disorder in a US Veterans Affairs medical center may not transfer well to a spinal cord injury inpatient rehabilitation unit at a private hospital. If not adopting the practice as written, it may be appropriate for adaptation, with consideration of the local practice setting and patient characteristics. Clearly, modifications to evidence-based recommendations may invalidate or strengthen effectiveness; tracking of outcomes can help to better understand the applicability of a treatment to a particular setting or patient group as well as the impact of modifications for local use.

Secondly, **(2) is the information current?** The National Guideline Clearinghouse considers CPGs older than 4 years to be obsolete, though others have recommended reappraisal after only 1–3 years [16]. Third, **(3) is it easy to use?** Information that is succinct, direct in its recommendations, and easy to follow will be more likely to be used. Many CPGs use flow charts to illustrate recommendations, and quick-reference "pocket cards" are also frequently available for the busy clinician.

Finally, **(4) is it of good quality?** Systematic reviews and CPGs generally report well-defined search strategies for the primary articles and a description of evidence ratings employed. There are several established guidelines for systematic reviews and accompanying quality rating scales for systematic reviews (e.g., PRISMA Checklist and AMSTAR) and for CPGs (e.g., the AGREE Instrument and the WHO Handbook for Guideline Development). Short of utilizing these formal evaluation instruments, readers are encouraged to consider *several indicators of quality*, including the source and funding for the systematic review or CPG, the expertise of the authors, the descriptiveness of the methods, comprehensive discussion of report limitations, and the degree to which recommendations are based on research findings vs. consensus.

Nonsystematic reviews, book chapters, and individual articles may succinctly provide accurate information that is useful for EBP. However, critical appraisal of these sources can be difficult without modest familiarity with an article's field and research methods employed. It is important to consider that these sources are not always peer reviewed, and without systematic methods of data aggregation, they may be susceptible to selection bias and opinion. Trusted information sources, such as peer-reviewed book reviews or professional organization newsletters and websites, may highlight high-quality articles and provide critical reviews. For example, the aforementioned PEDro database includes a rating of quality for articles describing clinical trials.

When critically reviewing any source of information, there are many aspects to consider. First and foremost in importance **(1) is the source of the information**. Peer review provides some assurance that independent reviewers have already critically appraised the work, but as mentioned above, it provides no promise of a good-quality paper. A high acceptance rate, a low or unrated impact factor (an index of the average number of times the journal's articles are cited each year), having no known content experts on the editorial board, and giving misleading information on the journal's website are all warning signs [17].

Another important consideration is **(2) who financed the study and wrote the article.** Although not markers of quality per se, the source of funding and author's potential conflicts of interest may indicate possible biases in the research or presentation of results. Regarding the paper itself, **(3) evaluate whether it has good flow, structure, and absence of grammatical errors. (4) The aims, methods, and results should be clearly stated and consistent. (5) Interpretation of results and subsequent discussion should be accurate and follow study aims**. Do not only consider the statistical significance of effects reported in empirical articles, but more importantly consider *effect size estimates* and the *confidence intervals for those effect size estimates* to evaluate precision. Also, if the study is an intervention study, the clinician should ascertain whether the study involved a randomized controlled design and whether there were any critical side effects of the treatment or treatment moderators that would impact applicability to a particular population or setting.

Finally, guidelines have been developed for the conduct and reporting of certain kinds of studies, including the CONSORT Statement (www.consort-statement.org) for the reporting of randomized controlled trials and the STARD Statement (www.stard-statement.org) for the reporting of diagnostic accuracy studies. Associated websites provide straightforward checklists to assist the reader in evaluating study quality.

D. ***Conducting Your Own Research***

Many psychological interventions that are established in other settings have limited evidence in rehabilitation. Rare conditions, complex comorbidities, and saturated therapy schedules can make it difficult to study the impact of psychological treatment while the patient is engaged in rehabilitation. Still, it is this very reason that even small efforts to add to the empirical literature on psychological treatment effectiveness can be extremely valuable. Many clinicians express that they do not have the time or the skills to be involved in research activities. However, whether or not trained as a scientist or scholar, it is vital for all professionals functioning in an interdisciplinary rehabilitation climate to maintain an appropriate level of awareness of, and involvement in, activities related to the promotion of EBP. For all interdisciplinary providers, there is an importance of knowing that professional value may transcend relative value units and billable hours: longer-term alignment of activities with institutional outcome metrics may represent a valuable longer-term investment by the sponsoring organization.

There are many ways the rehabilitation professional can become involved in research. Depending on professional identity, these activities may range in terms of intensity of involvement, from systematic program evaluation of one's own practice to designing an RCT. In almost all settings, clinicians have the opportunity to perform *program evaluation* and *quality improvement projects* using clinical outcome measures as well as institutional performance measures. Program evaluation refers to the systematic assessment of program implementation and delivery and can be distinguished from research by the latter's focus on advancing scientific knowledge or theory. An advantage of tracking one's own clinical data is that it can provide insights into best practices but does not generally require the same institutional approvals as does a formal research project. Providers may look to the local administrative structure to become better informed about outcome metrics of value to the sponsoring institution. Most sponsoring institutions have a quality management department, and there may be ways to learn more about the outcome metrics of the institution and then to speak with supervisors about how clinically related involvements may help or hinder adherence to health-care quality of effectiveness metrics. These activities may or may not lead to publication of results, but will ultimately lead to better evidence-based care.

Providers interested in getting more directly involved with research may look to the local research service to unearth historical, ongoing, and pending research activities that may be pertinent to clinical involvements. Developing a relationship with an investigator who can serve as a research mentor can also help you develop basic research skills and present opportunities. Specific ideas for involvement include the following:

- Write a newsletter article or internal report that describes your patients and setting.
- Collaborate with team members on a case study.
- Become a study interventionist for an RCT.
- Contribute as a clinical content-area expert for a grant proposal.

- Contribute to a clinical tracking database with regard to clinical outcomes, using established metrics of access, efficiency, effectiveness, and satisfaction.
- Develop a questionnaire or rating tool that describes a clinical feature or outcome that does not have an available measure.

Developing and actively sustaining a network of colleagues both within (if possible) and beyond the host institution can lead to opportunities to participate in research. This network will contribute to a broader perspective and help you stay grounded if the immediate work environment becomes stressful. Consider reaching outward to make connections with other colleagues in areas of overlapping interest, or clinical concern, and making meaning from those connections through collaborative professional involvements (e.g., developing a symposium together). Introducing yourself to research project staff and remaining open in interpersonal posture may create degrees of freedom for involvement in RCTs as a clinician or other research projects.

Lastly, actively share your approaches to clinical care with a larger professional audience. Dissemination efforts may take the form of local, regional, or national presentations, local in-services, or submission of manuscripts to appropriate journals. Not only do such activities directly promote best practices and add to the knowledge base, they also open doors to collaboration and the exchange of new ideas.

Tips

1. **Start with common and important conditions**. Start with a condition that you see frequently in your clinic to increase the chance of finding information and making it easier to understand the literature given your expertise. Practice using PICO to formulate a question and become familiar with sources of relevant literature. Critically appraise your findings and adopt or adapt the best practices to boost your EBP.
2. **Set time aside to read**. Just one lunch hour a week set aside to read newsletters and magazines, websites and blogs, and LISTSERVs provided by professional organizations can help keep you aware of current trends in EBP. For example, APA's Division 22 (Rehabilitation Psychology) maintains a LISTSERV and a rehabilitation psychology newsfeed (www.apadivisions.org/division-22). Another useful resource is the National Library of Medicine-funded www.ebbp.org, a website dedicated to news and resources about evidence-based behavioral practice.
3. **Remember that your own clinical judgment is essential.** Expertise is a key component of EBP and is essential for integrating evidence into your work.
4. **Know your research basics.** Regardless of your health profession, it is likely that all rehabilitation health professionals took at least one research-oriented course in their training. Staying mindful of the research basics makes one better able to comprehend, critique, and apply the scientific literature to practice. For example, a basic understanding of research methods, research ethics, and terminology (e.g., effect size, causation vs. correlations, efficacy vs. effectiveness) will enhance your ability to practice EBP.
5. **Become an advocate for EBP**. Despite the widespread acceptance of the importance of EBP, clinicians often report significant institutional barriers to practice. Each interdisciplinary team member can contribute toward removing local barriers to implementing evidence-supported treatments, fostering the growth of clinician expertise, and practicing collaborative care that takes into consideration patient preference. For example, providing clinical supervision within an EBP framework, facilitating a discussion of EBP during interdisciplinary team meetings, hosting journal club meetings with presentation and discussion of recent publications, engaging in clinical research, and, of course, actively practicing EBP are all opportunities to promote the best possible treatment environment for your patients.

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Using Information and Knowledge Technologies to Practice Evidence-based Rehabilitation Psychology

Elaine C. Alligood

Topic

When stakes are high, decisions critical, and time short, the knowledge resources provided here focus on enabling clinicians to rapidly access and retrieve the evidence needed to identify appropriate clinical strategies.

These days, clinical questions or information deficits occur at the point of need, at the bedside, in the emergency department, even in the hospital hallway, rather than in a traditional brick and mortar library. Thus, it is likely librarians or informationists are already clinical team members: rounding, attending morning report, teaching, and answering queries as they arise.

Importance

This chapter addresses how to get the evidence you need, when you need it, rapidly—at your fingertips in real time.

A. ***<u>Healthcare Runs on Information</u>***: Knowledge Tools Empower You **Evidence-based practice** is clinical decision-making based on peer-reviewed, methodologically sound clinical research evidence derived from systematic reviews, meta-analyses, evidence-based guidelines, and randomized clinical trials.

The evidence-based resources here are not the only ones available; rather they are the go-to, reliable, evidence-based, highly regarded options. Most are accessible by computer, laptop, mobile phones, or tablets.

Each resource/database/application is described, search options identified, and tutorial links included along with mobile access links and free or fee-based resources.

Practical Applications

1. **<u>PubMed Clinical Queries—Free from the US National Library of Medicine: NLM</u>**
    a. **<u>Description</u>: PubMed Clinical Queries** provides three sets of search filters, developed by McMaster University Department of Clinical Epidemiology and Biostatistics, to filter: **Clinical Studies:** etiology, diagnosis, therapy, prognosis, and clinical prediction guides. The **Systematic Reviews** filters: systematic reviews, meta-analyses, reviews of clinical trials, evidence-based medicine, consensus development conferences, and guidelines. The **Systematic Reviews** filter retrieves reports that describe methods, results, outcomes, clinical consensus, or the

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_60

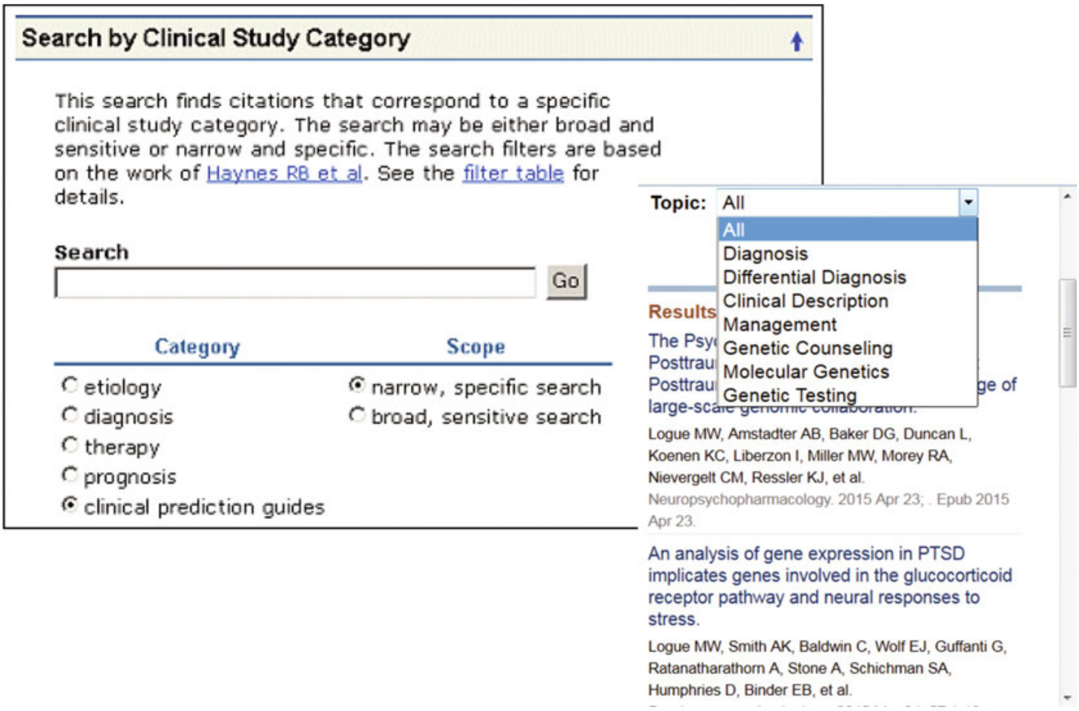
need for additional research—and can enable clinicians to quickly incorporate evidence results into their clinical decisions and tactics. The third category, **Medical Genetics** filters: the genetics aspects of diagnosis, clinical descriptions, molecular genetics, management, genetics counseling, and testing (Fig. *60.1*).

b. **Website:** http://www.ncbi.nlm.nih.gov/pubmed/clinical

c. **Handheld-Mobile Access:** http://pubmedhh.nlm.nih.gov/ mobile accessible website, also available as an iOS iPhone App or as a Google Play Android App. Additional National Library of Medicine mobile apps are available: http://www.nlm.nih.gov/mobile/

- **Search Tips:** Search using the phrases that pop up.
- Create a phrase to try: ***PTSD drug treatment* OR *drug treatment PTSD***
- Try several search approaches until you find what you need; check article titles.
  1. ***Behavioral pharmacology stress disorder* [truncate using * for disorders, disordered]***
  2. ***Behavioral pharmacology [account for language/spelling differences]***
- Try using the **Related Citations** feature as well—gives you additional options (Fig. *60.2*).
- Search using the important or most specific concept first:
  1. ***Atypical antipsychotics PTSD***
  2. ***PTSD treatment AND (sertraline OR fluoxetine)* use AND or OR** to combine concepts as needed**.**
  3. Try several approaches for comprehensiveness: ***PTSD AND sertraline* OR *PTSD AND fluoxetine***

d. **Tutorials:** http://www.nlm.nih.gov/bsd/disted/pubmedtutorial/020_570.html http://www.ncbi.nlm.nih.gov/books/NBK3827/#pubmedhelp.Medical_Genetics_Search_Filte or http://www.ncbi.nlm.nih.gov/books/NBK3827/#



Search by Clinical Study Category

This search finds citations that correspond to a specific clinical study category. The search may be either broad and sensitive or narrow and specific. The search filters are based on the work of Haynes RB et al. See the filter table for details.

Search

Category
○ etiology
○ diagnosis
○ therapy
○ prognosis
● clinical prediction guides

Scope
● narrow, specific search
○ broad, sensitive search

Topic: All

The Psy… Posttrau… Posttrau… …ge of large-scale genomic collaboration.

Logue MW, Amstadter AB, Baker DG, Duncan L, Koenen KC, Liberzon I, Miller MW, Morey RA, Nievergelt CM, Ressler KJ, et al.
Neuropsychopharmacology. 2015 Apr 23; . Epub 2015 Apr 23.

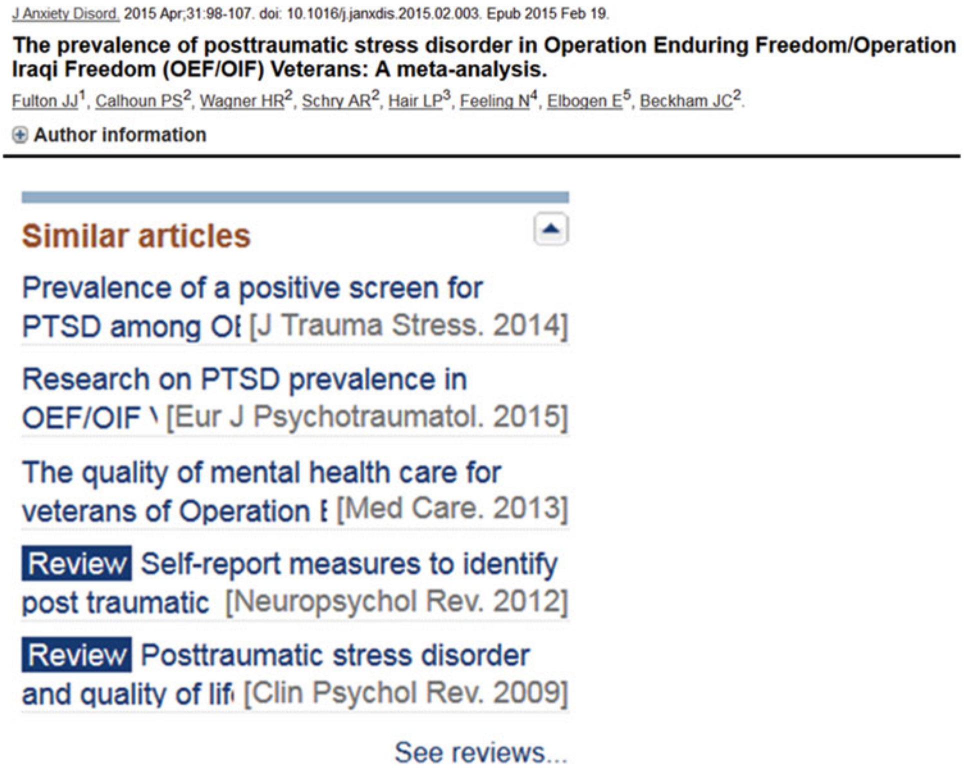
An analysis of gene expression in PTSD implicates genes involved in the glucocorticoid receptor pathway and neural responses to stress.

Logue MW, Smith AK, Baldwin C, Wolf EJ, Guffanti G, Ratanatharathorn A, Stone A, Schichman SA, Humphries D, Binder EB, et al.

Fig. 60.1 PubMed Clinical Queries Clinical Study Categories. Reprinted with permission from National Library of Medicine pubmedhelp.Is_there_anything_special_for Many medical libraries have created their own YouTube clinical queries tutorial clips.

   e. **Notes**: This is a reliable and powerful tool on a mobile device. More mobile applications are available from the NLM http://www.nlm.nih.gov/mobile/index.html

2. **PubMed Health—Free From the US National Library of Medicine**
   a. **Description: PubMed Health** is a free resource that helps the entire healthcare team from health professionals to patients and families find clinical effectiveness research. PubMed Health includes an online database gathering together systematic reviews that can help determine whether a treatment method works, weigh the benefit or harm of the intervention, and show how much is still unknown about a type of care—PubMed Health answers the question, what works? **PubMed Health** contains systematic reviews from the last 10 years that focus on health interventions, diagnosis, diagnostic tests, policy, and public health. They are selected from DARE Reviews, Database of Abstracts of Reviews of Effects, Cochrane Database of Systematic Reviews, and the Health Technology Assessment (**HTA**) systematic reviews in partnership with international HTA agencies (Fig. 60.3).
   b. **Website: http://www.ncbi.nlm.nih.gov/pubmedhealth**
   c. **Handheld-Mobile Access:** There is no app for PubMed Health; rather the website is mobile friendly and enables mobile, handheld searching.
   d. **Search Tips:** Keep your mobile searches brief and specific. For example, search ***implementation AND team* AND quality improvement AND diabetes***; keep it



J Anxiety Disord. 2015 Apr;31:98-107. doi: 10.1016/j.janxdis.2015.02.003. Epub 2015 Feb 19.

The prevalence of posttraumatic stress disorder in Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) Veterans: A meta-analysis.

Fulton JJ[1], Calhoun PS[2], Wagner HR[2], Schry AR[2], Hair LP[3], Feeling N[4], Elbogen E[5], Beckham JC[2].

⊕ Author information

Similar articles

Prevalence of a positive screen for PTSD among OI [J Trauma Stress. 2014]

Research on PTSD prevalence in OEF/OIF [Eur J Psychotraumatol. 2015]

The quality of mental health care for veterans of Operation [Med Care. 2013]

Review Self-report measures to identify post traumatic [Neuropsychol Rev. 2012]

Review Posttraumatic stress disorder and quality of lif [Clin Psychol Rev. 2009]

See reviews...

Fig. 60.2 PubMed Clinical Queries Clinical Study Categories. Reprinted with permission from the National Library of Medicine simple and direct. Use common or likely specific phrases that identify your topic: ***quality improvement AND routine diabetes care***. Build the search one concept at a time; start with the most specific words/phrases for your need, i.e., if routine care is what you seek, say that and not ***healthcare***. If you need quality improvement team-based articles, then use that: ***quality improvement team**** (use the * to truncate and pull the plural, teams). If that retrieves too many citations to manage, try using only words appearing in the **title: *quality improvement* AND *diabetes[title]*.**

e. **<u>Tutorial</u>**: http://www.nlm.nih.gov/nichsr/outreach.html brings you to multiple resources for health services researchers.

f. **<u>Notes</u>**: **PubMed Health** contains what is called Grey Literature, that is, systematic reviews, evidence reports, guidelines, technology assessments, meta-analyses, etc. published outside formal publisher channels, by government, nonprofit, hospital, or academic entities. Peer reviewed for the most part, yet not commercially published.

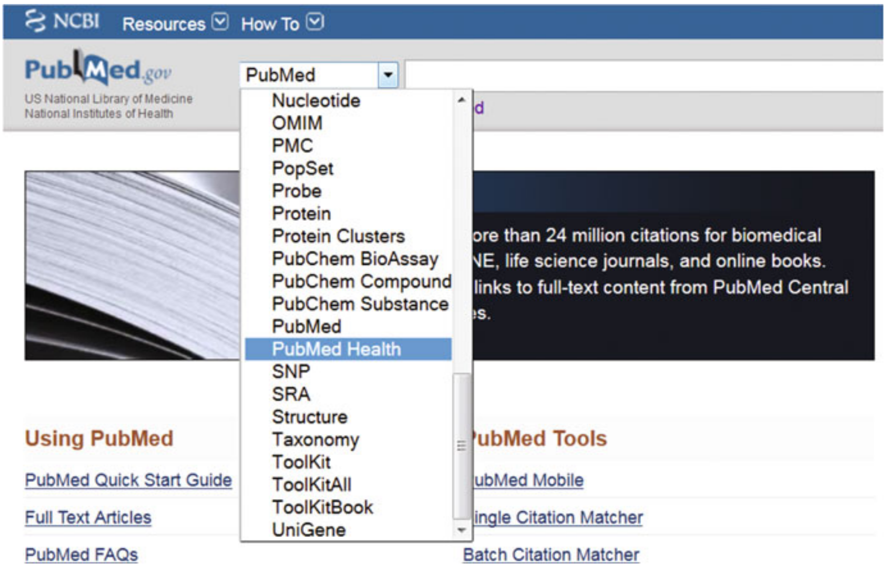
3. **<u>MedlinePlus</u>** **<u>Free from the National Library of Medicine</u>**

   a. **<u>Description</u>:** MedlinePlus is the National Library of Medicine's website and knowledge portal for patients, families, and clinicians. It contains reliable, up-to-date information about diseases, conditions, and wellness issues in accessible, easily understood language. MedlinePlus offers authoritative information on the latest treatments, drugs, or supplements, along with dictionaries, medical videos, and illustrations. As well, it links to the latest medical research and clinical trials.

   b. **<u>Website</u>:** **http://www.nlm.nih.gov/medlineplus/**

   c. **<u>Handheld-Mobile Access</u>:** There is no app for MedlinePlus; rather the website is mobile friendly and enables mobile, handheld searching.

   d. **<u>Search Tips</u>:** Search the disease or condition first: ***breast cancer treatment*** to see what resources and information portals are generally available. Next if one is specifically seeking clinical trials for metastatic breast cancer, then search specifically: ***clinical trials for metastatic breast cancer*.**



ore than 24 million citations for biomedical
NE, life science journals, and online books.
links to full-text content from PubMed Central
s.

Fig. 60.3 PubMed Health Launch Point Reprinted from US National Library of Medicine

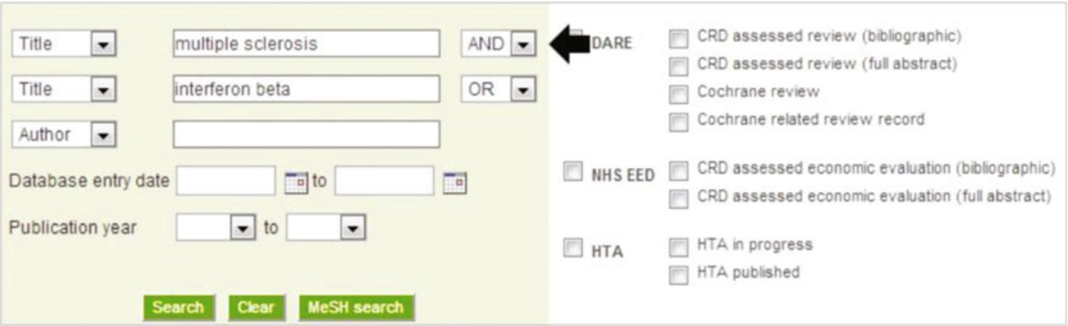
The resources of the entire National Institutes of Health and associated US health-related agencies are connected to **MedlinePlus**, including substantial information on the entire range of drugs of abuse: crystal meth, LSD, marijuana, and others.

e. **Tutorial:** http://www.nlm.nih.gov/medlineplus/training/trainers.html takes users to an array of training resources. The most useful is the 2.5-min video overview, http://www.nlm.nih.gov/medlineplus/tour/tour.html

f. **Notes**: **MedlinePlus** is actually available to add to electronic health records (**EHRs**). You can request your **EHR** managers to add **MedlinePlus for EHRs** to your local **EHR**. http://www.nlm.nih.gov/medlineplus/connect/overview.html. Interestingly, 40 % of **MedlinePlus** usage is by clinicians. Put it in your toolbox!

4. **HTA—CRD—DARE Databases Free from the University of York**
   a. **Description**: The UK **University of York Centre for Research and Dissemination, CRD,** offers (free-of-charge) three databases to the world's clinicians and researchers. The **CRD** databases: **DARE**, **NHS-EED**, and **HTA**, are updated daily, providing clinicians access to thousands of quality assessed systematic reviews, economic evaluations, and summaries of ongoing technology assessments/systematic reviews.
      1. The **DARE (Database of Abstracts of Reviews of Effectiveness)** contains over 30,000 reviews of systematic reviews—grading the methods, quality, evidence, and relevance of each review. Recently the funding was stopped for these important "reviews of reviews." This shouldn't deter you from using them over the next several years. There is value in reading them, as they thoughtfully critique the reviews, thus providing readers with knowledge on what to look for when scrutinizing reviews on their own. Learning to quickly recognize good and bad systematic reviews saves time and clinical errors.
      2. The **NHS-EED (NHS Economic Evaluation Database)** focuses primarily on the economic evaluation of healthcare interventions. It aims to help clinical and policy decision-makers interpret the increasingly complex and technical literature for best practices and effective therapies derived from methodologically sound studies. Economic evaluations compare two or more interventions or therapeutic alternatives to examine costs and outcomes—using cost-benefit analyses, cost-utility analyses, and cost-effectiveness analyses.
      3. The **HTA Database (Health Technology Assessment Database)** is an international database that gathers reviews and evidence-based reports produced by national healthcare agencies around the world whose technology assessment groups systematically study the evidence for using the health technologies provided through their national healthcare systems.
   b. **Website:** http://www.crd.york.ac.uk/CRDWeb/
   c. **Handheld-Mobile Access:** While not sized for mobile access, these databases are searchable from a handheld device.
   d. **Search Tips:** Check out **PROSPERO** to identify ongoing or new systematic reviews. http://www.crd.york.ac.uk/PROSPERO/ **PROSPERO** is an international database of prospectively registered systematic reviews in healthcare. It contains new and ongoing systematic review protocol in order to publicize systematic reviews as they are begun to avoid unplanned research duplication and enable comparison of reported review methods.
   e. **Tutorial:** The guide to searching is available on the CRD website, http://www.crd.york.ac.uk/CRDWeb/GuideToSearching.asp
   f. **Notes:** Search CRD databases with TITLE words and/or phrases or MeSH terms, select specific report/review types, or retrieve from all types (Fig. *60.4*).

5. **<u>TRIP Database Free or Fee-Based Premium Version</u>**
    a. **<u>Description</u>: TRIP's *'Find evidence fast'*** motto describes the search engine approach that TRIP uses to connect users to high-quality research evidence to support evidence-based practice and/or care. Online since 1997, **TRIP** has fine-tuned the search engine to retrieve all types of evidence-based reviews, reports, syntheses, critical appraisals, meta-analyses, and more. It is free and one must register; an expanded version is available to individuals at $40.00 per year.
    b. **<u>Website</u>: https://www.tripdatabase.com/ https://www.tripdatabase.com/info/**
    c. **<u>Handheld-Mobile Access</u>:** The **TRIP** database is mobile enabled and mobile friendly. It has a handy yet sparse look (Fig. *60.5*).
    d. **<u>Search Tips</u>: TRIP** is a straightforward resource, whether on a mobile or on a laptop. TRIP offers three ways to search: quick search, a PICO search approach (**P**roblem, **I**ntervention, **C**omparator, **O**utcomes), or an advanced search page as well.
    e. **<u>Tutorial</u>**: TRIP Database tutorial https://www.tripdatabase.com/how-to-use-trip
    f. **<u>Notes</u>: TRIP** Database is about 10 years old; it's improved greatly over time, has a very well done mobile interface—great for users who prefer a handheld—and has rapid access. If users are willing to create a private account for about $40.00US, they are promised access to even more content.
6. **<u>Cochrane Library: Fee Based from Wiley and Available on Additional Search Platforms</u>**
    a. **<u>Description</u>:** Cochrane Library is the compilation of systematic reviews, economic evaluations, meta-analyses, clinical trials, and technology assessment reports. All are produced by a variety of government healthcare agencies and organizations such as the Cochrane Collaboration that produce in-depth evidence-based reports using high-quality clinical trials results, aggregating the study data so as to identify treatment and/or clinical efficacy of any sort of healthcare technology from knee prostheses to drugs to health interventions of all sorts. The Cochrane Library as available from Wiley has the added benefit of the Cochrane Study Groups, Journal Club, and additional resources such as the Cochrane Podcasts, plus the ability to comment on Cochrane reports.
    b. **<u>Website</u>: http://www.cochranelibrary.com/ The Cochrane Collaboration** website contains substantial useful additional information about their work: http://www.cochrane.org/ (Fig. *60.6*).
    c. **<u>Handheld-Mobile Access</u>:** While not sized for mobile access, these databases are easily searchable from a handheld device. Just recently Cochrane has enabled



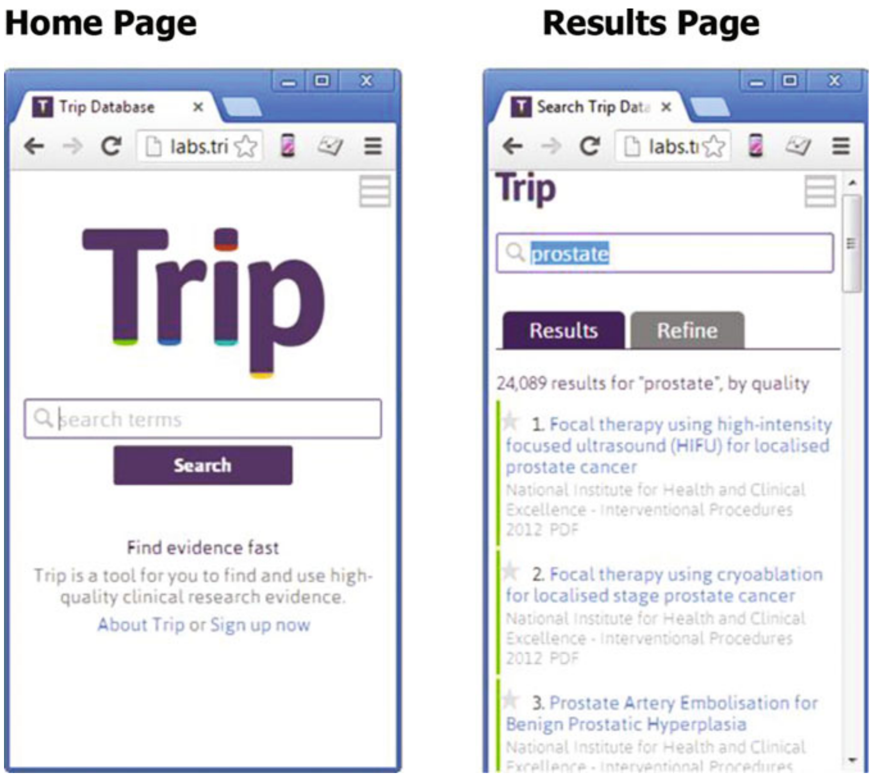
Title ▾ multiple sclerosis AND ▾
Title ▾ interferon beta OR ▾
Author ▾
Database entry date to
Publication year ▾ to ▾

DARE
☐ CRD assessed review (bibliographic)
☐ CRD assessed review (full abstract)
☐ Cochrane review
☐ Cochrane related review record

☐ NHS EED
☐ CRD assessed economic evaluation (bibliographic)
☐ CRD assessed economic evaluation (full abstract)

☐ HTA
☐ HTA in progress
☐ HTA published

Fig. 60.4 CRD Multiple Database Search Screen Reprinted with permission by the University of York Centre for Reviews and Dissemination


Home Page

Trip Database

labs.tri

Trip

search terms

Search

Find evidence fast

Trip is a tool for you to find and use high-quality clinical research evidence.

About Trip or Sign up now

Results Page

Search Trip Data

labs.tr

Trip

prostate

Results Refine

24,089 results for "prostate", by quality

1. Focal therapy using high-intensity focused ultrasound (HIFU) for localised prostate cancer
National Institute for Health and Clinical Excellence - Interventional Procedures
2012 PDF

2. Focal therapy using cryoablation for localised stage prostate cancer
National Institute for Health and Clinical Excellence - Interventional Procedures
2012 PDF

3. Prostate Artery Embolisation for Benign Prostatic Hyperplasia
National Institute for Health and Clinical Excellence - Interventional Procedures

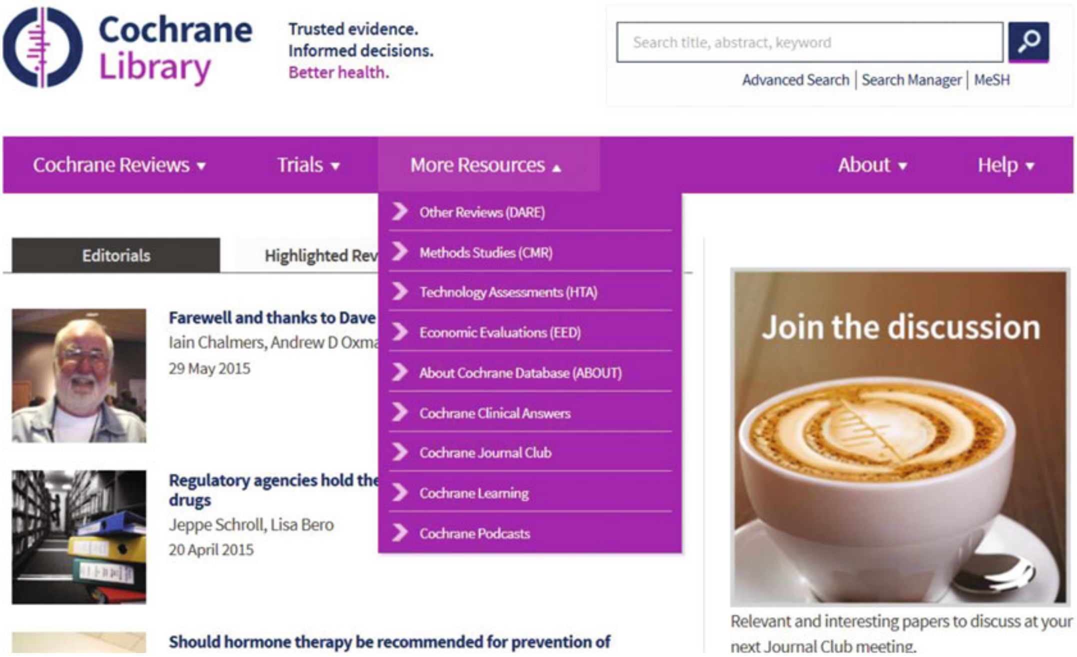
Fig. 60.5 TRIP Mobile. Reprinted with permission by TRIP Database

an easy-to-read version of reports and documents. Called Anywhere Systematic Reviews are actually mobile/handheld friendly HTML-enabled articles created by Cochrane. http://www.cochranelibrary.com/help/anywhere-systematic-review.html

d. **Search Tips:** As with all these databases, the best approach when time is short and stakes are high is to search using the variations on the key words or phrases you seek. Thus, if what you want is evidence-based information for a newer topic such as **_Kennedy Terminal Ulcer*_** or **_antibiotic stewardship_**, simply use the explicit phrase first. But, if you want quality improvement for pressure ulcer care programs (a large body of literature), then try a few search variations **_quality improve* AND pressure ulcer* treat*_** or **_pressure ulcer* care AND quality improve*_** or other synonymous phrases such as **_prevent* AND pressure ulcer*_** As your search skills improve try combining concepts such as: **_pressure ulcer* AND prevent* AND (quality OR improv*)_** or perhaps **_pressure ulcer* AND (care OR treat* OR therap*) AND (quality OR improv*)_**.

e. **Tutorial:** Tutorials, user support, printable search guides, and saved or upcoming webinars are all located at this website, http://www.cochranelibrary.com/help/how-to-use-cochrane-library.html

f. **Notes:** Take a look at the main Cochrane website, http://www.cochrane.org/ to sign up or listen to the Cochrane Podcasts http://www.cochranelibrary.com/more-resources/cochrane-podcasts.html, or scan the Cochrane Review Groups to identify groups that cover your practice or research interests, or sign up for the Cochrane Journal Club, http://www.cochranelibrary.com/more-resources/cochrane-journal-club-.html



Farewell and thanks to Dave
Iain Chalmers, Andrew D Oxma
29 May 2015

Regulatory agencies hold the
drugs
Jeppe Schroll, Lisa Bero
20 April 2015

Should hormone therapy be recommended for prevention of

Relevant and interesting papers to discuss at your next Journal Club meeting.

Fig. 60.6 Cochrane Library Resources. Reprinted with permission by The Cochrane Library, John Wiley & Sons, Inc.

7. **GUIDELINE.GOV Free from the US Agency for Healthcare Quality and Research. DHHS**
   a. **Description:** The NGC **http://www.guideline.gov/** mission is to provide physicians and other health professionals, healthcare providers, health plans, integrated delivery systems, purchasers, patients, and others an accessible web-based resource for accessing evidence-based, objective, detailed information on clinical practice guidelines and to further their dissemination, implementation, and use. Created and hosted by the Agency for Healthcare Research and Quality (AHRQ) in partnership with the American Medical Association and the American Association of Health Plans (now called America's Health Insurance Plans [AHIP]). http://www.guideline.gov/ accepts guidelines from agencies around the world that meet the inclusion criteria: http://www.guideline.gov/about/inclusion-criteria.aspx and fulfill the IOM definition of a clinical practice guideline: *Clinical practice guidelines are statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options*.
   b. **Website: http://www.guideline.gov/** and the main AHRQ Agency for Healthcare Research and Quality (AHRQ).
   c. **Handheld-Mobile Access:** At the moment, access on a smartphone is possible but it is not yet mobile enabled; tablet access is a better option. AHRQ will likely address this with an app in the future. The recently AHRQ created the **ePSS** Electronic Preventive Services Selector. http://epss.ahrq.gov/PDA/index.jsp is designed for primary care clinicians to identify US Preventive Services Task Force (USPSTF) recommendations for clinical preventive services that are appropriate for their patients.
   d. **Search Tips:** Keep searches simple; one or two words will easily retrieve guidelines useful to your practice. Take note of all the additional resources available on the

guidelines' website below. Especially the opportunity to set up email alerts by topic (Fig. 60.7).

e. **Tutorial:** AHRQ provides a variety of YouTube video tutorials on how to Search & Browse, along with these Guideline.Gov Technical Assistance Videos and how to set up your own account My NGC: National Guideline Clearinghouse account (Fig. 60.8).

f. **Notes:** Setting up your own account ensures new guideline alerts, expert commentaries, and more drop right into your email account as soon as possible. The AHRQ website contains information, abundant research reports on a wide range of health services research, and clinical practice effectiveness and is worth spending time exploring the breadth of content related to your research and practice interests.

8. **Rehabilitation Reference Center—Fee Based Knowledge Portal from EBSCO**

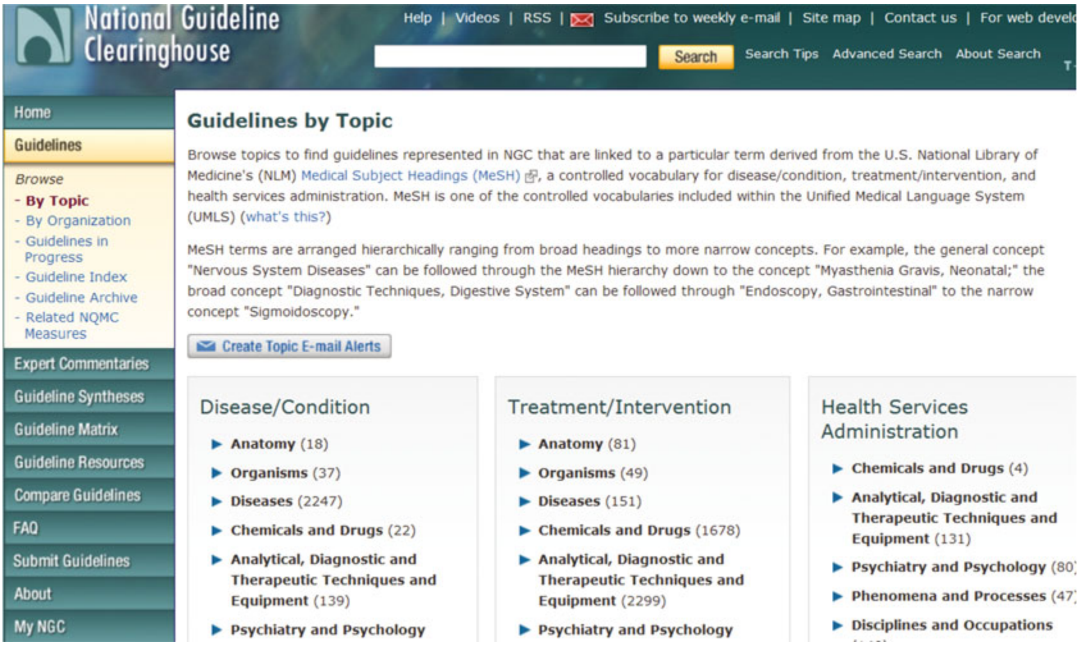
a. **Description:** Rehabilitation Reference Center™ is an evidence-based, point-of-care resource for physical therapists, occupational therapists, speech therapists, and rehabilitation professionals. It's a portal to clinical practice techniques, guidelines, articles, books, clinical reviews, research instruments, information from the AHFS on over 11,700 drugs and their manufacturers, exercise images, reference handbooks, patient education topics, breaking news, relevant clinical updates, continuing education, and more (Fig. 60.9).

b. **Website:** Rehabilitation Reference Center https://health.ebsco.com/products/rehabilitation-reference-center

c. **Handheld-Mobile Access:** At the moment EBSCO has not presented a mobile application for users. Yet, the website is mobile accessible from smartphones, handhelds, and laptops; nevertheless, one is likely to appear soon.

d. **Search Tips:** Be sure to take advantage of the wide range of content types, CEUs, clinical reviews, guidelines, images, drug and patient information, research instruments, and news. Search simply here, start with one or two words, and scan the titles for additional ideas: ***cognitive rehabilitation*** (Fig. 60.10).

e. **Tutorial:** Take the Rehabilitation Reference Center Tutorial to get the most



Guidelines by Topic

Browse topics to find guidelines represented in NGC that are linked to a particular term derived from the U.S. National Library of Medicine's (NLM) Medical Subject Headings (MeSH), a controlled vocabulary for disease/condition, treatment/intervention, and health services administration. MeSH is one of the controlled vocabularies included within the Unified Medical Language System (UMLS) (what's this?)

MeSH terms are arranged hierarchically ranging from broad headings to more narrow concepts. For example, the general concept "Nervous System Diseases" can be followed through the MeSH hierarchy down to the concept "Myasthenia Gravis, Neonatal;" the broad concept "Diagnostic Techniques, Digestive System" can be followed through "Endoscopy, Gastrointestinal" to the narrow concept "Sigmoidoscopy."

Fig. 60.7 Guidelines by Topic Search. US. DHHS. AHRQ. National Guideline Clearinghouse

My NGC

Save favorite summaries and organizations by browsing the site. Create custom e-mail alerts by selecting content

Note: E-mail alerts are issued weekly. You will only receive an e-mail if your specific content has changed (i.e., sum updated, or withdrawn).

My Alerts

Topic Alerts

You have not selected any topic alerts.

Expert Commentary Alert

Alert me when a new Expert Commentary is published.

My Favorite Guideline Summaries

You do not have any favorite guideline summaries.

NOTE: To save a favorite guideline summary, search or desired guideline, and click 'Save to Favorites' on the up page.

My Favorite Organizations

You do not have any favorite organizations.

NOTE: To save a favorite organization, select an organi Organization browse, and click 'Save to Favorites' on th

Fig. 60.8 My NGC Account Setup Page. US. DHHS. AHRQ. National Guideline Clearinghouse

Find: Cognitive Rehabilitation

Fig. 60.9 Rehabilitation Reference Center Search Box. Reprinted with permission by EBSCO Information Services

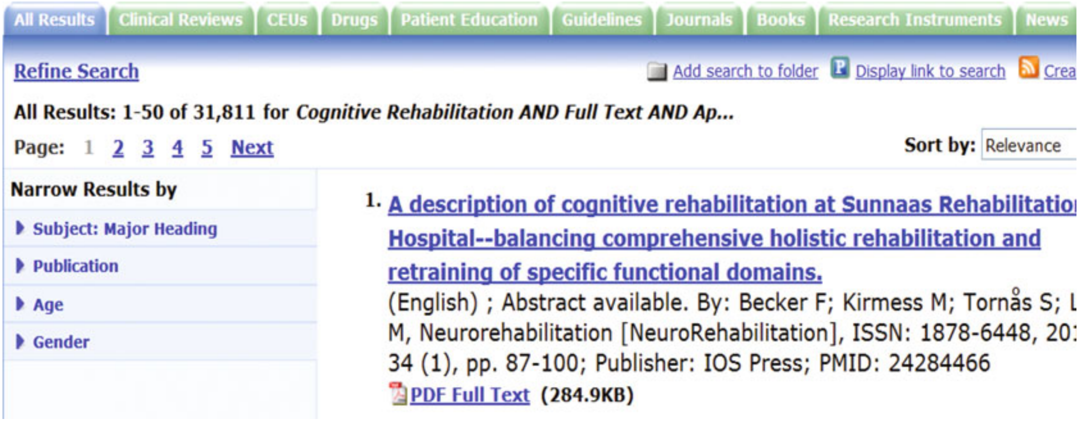
power out of the wide variety of database components. Particularly useful are the physical therapy photos and images demonstrating yoga poses. http://support.ebsco.com/training/flash_videos/rrc/rrc.html

f. **Notes:** Full-text articles come with most of the citations. You can set up alerts on topics or resources. The Rehabilitation Reference Center brochure can be downloaded here (Fig. *60.11*).

Tips

Search is iterative! It is a process that improves over time, with experience: the more you do, the better you get.

- Ask your librarian for help whenever you can!
- Never give up! Try synonyms, phrases, and spelling variations; flip the word order to accommodate variations in English native speakers and non-English speakers.

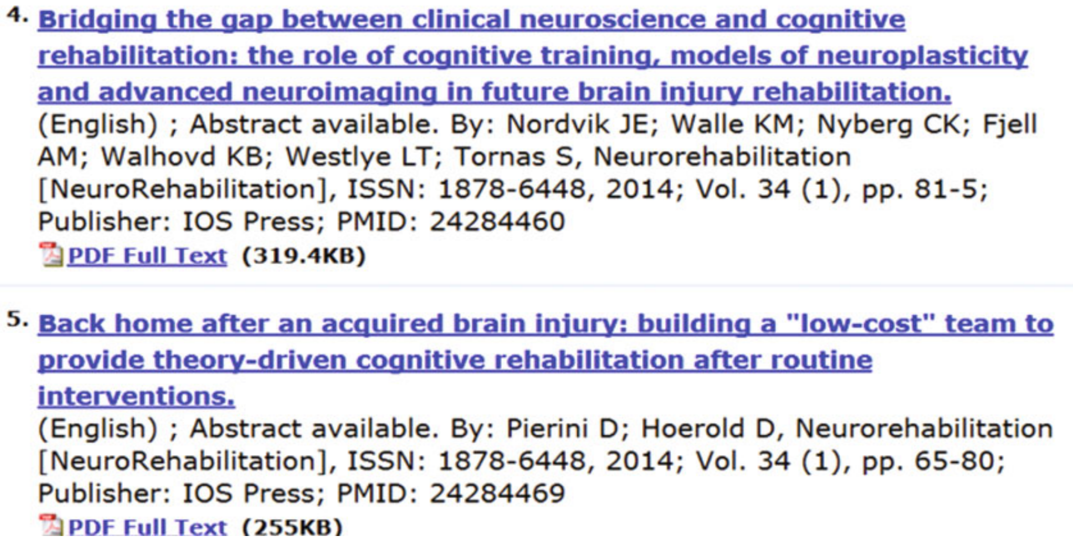


All Results: 1-50 of 31,811 for *Cognitive Rehabilitation AND Full Text AND Ap...*

Page: 1 2 3 4 5 Next

1. A description of cognitive rehabilitation at Sunnaas Rehabilitatio Hospital--balancing comprehensive holistic rehabilitation and retraining of specific functional domains.
(English) ; Abstract available. By: Becker F; Kirmess M; Tornås S; L M, Neurorehabilitation [NeuroRehabilitation], ISSN: 1878-6448, 20 34 (1), pp. 87-100; Publisher: IOS Press; PMID: 24284466
PDF Full Text (284.9KB)

Fig. 60.10 Rehabilitation Reference Center Search Results Display. Reprinted with permission by EBSCO Information Services



4. Bridging the gap between clinical neuroscience and cognitive rehabilitation: the role of cognitive training, models of neuroplasticity and advanced neuroimaging in future brain injury rehabilitation.
(English) ; Abstract available. By: Nordvik JE; Walle KM; Nyberg CK; Fjell AM; Walhovd KB; Westlye LT; Tornas S, Neurorehabilitation [NeuroRehabilitation], ISSN: 1878-6448, 2014; Vol. 34 (1), pp. 81-5; Publisher: IOS Press; PMID: 24284460
PDF Full Text (319.4KB)

5. Back home after an acquired brain injury: building a "low-cost" team to provide theory-driven cognitive rehabilitation after routine interventions.
(English) ; Abstract available. By: Pierini D; Hoerold D, Neurorehabilitation [NeuroRehabilitation], ISSN: 1878-6448, 2014; Vol. 34 (1), pp. 65-80; Publisher: IOS Press; PMID: 24284469
PDF Full Text (255KB)

Fig. 60.11 Rehabilitation Reference Center Retrieval with free full text. Reprinted with permission by EBSCO Information Services

- Begin a search with the phrases you have in mind. If that doesn't quite retrieve the topic you seek, scan the titles you did retrieve, (not only those on the first page!) for phrasing ideas and then try them.
- Try starting with a "scoping" phrase search using the full PubMed (not Clinical Queries) search—24 million citations give a good chance your topic will emerge.
- When searching your concept in PubMed, always begin with the **Clinical Queries** search first. Check the Systematic Reviews in the middle column of Clinical Queries; the systematic reviews will provide immediate access to a synthesis of research, ideally with a recommendation of a treatment strategy or clinical practice guideline.
- Try a Google Scholar search **only** to see if other, better, phrases emerge as possibilities—then try them in your chosen database. Keep in mind Google Scholar is an undefined database; users have no way of knowing what exactly is in there—as opposed to a database like PubMed that clearly identifies the journals

it indexes. Many less reputable publishers supply their citations to Google Scholar, presenting them as if they are peer reviewed, when they are not.

- When time permits take the tutorials! Check out the search tips or the how-to-search assistance the databases offer. Over time you will be rewarded by robust, relevant results!
- The more you know, understand, and practice, the more effective your searches!
- As the App World continues to explode, clinicians and the librarians who teach and work with them will employ more and more of them in our daily practice.

References

Additional Resources (free unless otherwise labeled)

- **Introduction to Evidence-Based Practice Tutorial:** http://www.hsl.unc.edu/Services/Tutorials/EBM/index.htm
- **Cochrane Library Tutorials:** http://www.thecochranelibrary.com/view/0/HowtoUse.html
- **Comparative Effectiveness Tutorial:** www.nlm.nih.gov/nichsr/htawebinars/index.html
- **HTA Glossary:** http://htaglossary.net/HomePage
- **Joanna Briggs Institute:** http://www.ovid.com/site/catalog/databases/11299.jsp Evidence-based nursing research reports from the JBI in Australia, a fee-based OVID Database
- **CINAHL:** Fee-based nursing literature databases available from EBSCO
- **Suicide Safe APP:** Created by the Substance Abuse and Mental Health Administration **SAMHSA.gov** Suicide Safe App http://store.samhsa.gov/apps/suicidesafe/?WT.mc_id=EM_20140916_SUICIDESAFE_00
- **AHRQ ePSS:** The Electronic Preventive Services Selector (ePSS) is an application from the Department of Health and Human Services (HHS), Agency for Healthcare Research and Quality (AHRQ). It assists primary care clinicians to identify the screening, counseling, and preventive medication services appropriate for their patients. The ePSS information is derived from recommendations of the US Preventive Services Task Force (USPSTF). The ePSS is available as a mobile web-enabled application: http://epss.ahrq.gov/
- **National Institute for Clinical Excellence:** The **NICE.ORG** Clinical Guidance App can be downloaded on Google Play and iTunes.
- **McMaster Evidence Updates:** McMaster University's Health Information Research service provides access to current best clinical evidence from research, tailored to each user's healthcare interests. They deliver a searchable database and email alerts tailored by a user-created subject profile, often with links to additional evidence-based resources: https://plus.mcmaster.ca/evidenceupdates/

ACCESSSS Federated Search: McMaster University's federated search portal enables users to search for the best evidence-based answers to clinical questions by simultaneously searching the leading evidence-driven medical publications and the high-quality clinical literature. https://plus.mcmaster.ca/ACCESSSS/Default.aspx?Page=1

Performance Measurement and Operations Improvement Using Lean Six Sigma

61

Charles D. Callahan and Todd S. Roberts

Topic

A. ***Performance Measurement and Operations Improvement Using Lean Six Sigma***

1. **Lean Six Sigma (LSS)**

A powerful, data-driven method for improving quality, service, efficiency, and value in healthcare. Refined over many decades in high-demand industries (manufacturing, military, nuclear safety), this approach has only recently been applied to healthcare improvement. When implemented as part of a quality and safety culture, the results are dramatic. Lean Six Sigma is both a philosophy and a technology for redesigning the healthcare delivery system and for maintaining those results. A process exhibiting "6-sigma" performance is one that is 99.9966 % effective.

Lean Six Sigma is based on the following ideas:

- Managing by fact through the use of a reliable measurement system
- Understanding the voice of the customer (what does the customer really want?)
- Understanding the voice of process (how does the work get done?)
- Removing non-value added steps, waste, and hassles
- Removing process variation that leads to unwanted, unreliable outcomes
- Applying a systematic, scientific approach to improvement **(DMAIC)** to produce real and lasting gains [1, 2]

B. ***Key Concepts***

1. **DMAIC Process Improvement Framework**

DMAIC refers to five-step framework for understanding, improving, and maintaining any work process:

Define	Inputs from customers, stakeholders, frontline workers, and external sources (e.g., research literature, accrediting agencies, payers) prompt a laser-like focus to identify the scope of the real problem
Measure	Data replace assumptions, impressions, and guesswork and establish the baseline performance of the existing system or process
Analyze	Powerful statistics (like Statistical Process Control Charts) optimized for real-time, small N operations improvement problems, identify key root causes and opportunities
Improve	A set of evidence- and data-based improvement actions are implemented and tested to ensure desired outcomes without unintended consequences or suboptimization of other parts of care delivery system

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0_61

Control	Standard work specifications that operationally define the new optimized delivery process(es), measurement specifications defining process performance, and action steps for process owners to maintain (“hardwire”) the new system over time

2. **Lean**
   - Operations improvement philosophy that emphasizes the creation of value for the customer through the reduction of waste in the process. Waste comes in many forms: defects, overproduction, waiting, neglected talents of staff, transporting materials, inventory, excess movement/motion by staff, and excess handling/processing of materials. It is commonly reported that in a typical organization, up to 30 % of gross revenues are lost to waste [3].
   - Lean and Six Sigma combine to create high performance by (1) removing wasteful process steps and (2) making those that remain as close to 100 % reliable as possible.

C. ***Terminology***

1. **Voice of Customer**

   The stated or unstated needs or requirements of the customer (typically the recipient and/or buyer of healthcare services). Can be captured in many ways: interview, survey, observation, and complaints. Understanding the voice of the customer ensures that any process improvement actions are intended to satisfy the recipient, versus the provider, of the service or product. In healthcare, often reflect elements of **STEEEP** (see below).

2. **Voice of Process**

   A comprehensive understanding of the performance characteristics and capabilities of any process. Best depicted via a graphical **Statistical Process Control Chart** (see below) that portrays process measurements sequentially over time, with reference to both the central tendency and the normal variation inherent in the process.

3. **STEEEP**

   The six healthcare customer requirements highlighted as paramount by the Institute of Medicine: Safe, Timely, Effective, Efficient, Equitable, Patient Centered [1].

   Safe: Avoid injury to patients from the care that is intended to help them

   Timely: Reduce waits and harmful delays

   Effective: Provide services based on scientific knowledge to all who could benefit and refrain from providing services to those not likely to benefit (avoiding underuse and overuse, respectively)

   Efficient: Avoid waste (of time, motion, materials/resources)

   Equitable: Provide care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographical location, and socioeconomic status

   Patient Centered: Provide care that is respectful of and responsive to individual patient preferences, needs, and values

4. **Statistical Process Control (SPC) Chart**
   - A powerful statistical measurement and analytic tool for graphically portraying the performance of a process over time. A plot of time-series data, its central tendency, variation, and statistically derived “control limits” that allow the operator to distinguish normal **common cause** variation from non-normal **special cause** variation in the process.
   - Common cause variation: All processes exhibit common cause variation; it is “noise”—part of the process. It is normal and predictable.
   - Special cause variation: Some processes exhibit special cause variation. It is “signal”—not part of the process. It is non-normal and unpredictable. Typically reflects changes to manpower, machine, materials, methods, or management [4]. Special cause is detected using three primary empirical rules: (1) ***Ones*** (any point outside the control limits), (2)

Runs (seven or more consecutive points all above or below the central tendency line), and (3) **Trends** (seven or more consecutive points moving up or down crossing the central tendency line) [5, 6].

5. **Benchmark**

   An external performance standard or specification against which one's own process or system can be compared.

6. **Healthcare-Acquired Condition (HAC)**

   Negative patient safety outcomes acquired during the course of receiving healthcare services that reasonably could have been prevented through the application of evidence-based guidelines. The Centers for Medicare and Medicaid Services recognizes the following categories of HAC: surgical site infection, foreign body retained after surgery, air embolism, blood incompatibility, stage III and IV pressure ulcers, falls and trauma, manifestations of poor glycemic control, catheter-associated urinary trait infection (UTI), vascular catheter-associated infection, deep vein thrombosis/pulmonary embolism, and iatrogenic pneumothorax [7].

7. **High Reliability Organization**

   Organization that executes safely and effectively in an environment/demand known to be complex and risk prone. Examples include commercial airlines, nuclear power plants, and military operations. Such organizations are marked by a preoccupation with the potential for failure and a culture of supported communication, teamwork, and learning. Such organizations accept that errors or defects may occur. What is not acceptable is refusal to act on actual or potential errors/defects.

8. **Culture of Quality and Safety**

   High reliability organizations consistently minimize adverse events despite carrying out intrinsically complex and hazardous work. Such organizations maintain a commitment to safety at all levels of organization; acknowledge the high-risk nature of the work and commit to achieve consistently safe operations; establish blame-free environment where individuals are able to report errors or near misses without fear of reprimand or punishment; encourage collaboration across departments, disciplines, and sites to seek solutions to patient safety problems; and sustain organizational commitment of resources to address safety concerns. Culture produces results far more powerful than tactics or strategies alone [7].

Importance

Patient Protection and Accountable Care and Accountability Act (PPACA)

Commonly referred to as "Healthcare Reform Act" or "Obamacare," this is a far-reaching US federal statute passed in 2010 intended to transform the country's healthcare delivery system, by (1) increasing access to care for millions of American's currently without health insurance, (2) reducing the per unit cost of delivering healthcare, and (3) improving healthcare quality and safety. Embedded among its many features is the concept of pay for performance. Known as "value-based purchasing," program whereby Medicare payments to healthcare organizations and individual providers are reduced by penalties for poor outcomes, low satisfaction, and high relative cost. Additional governmental payment reductions also accrue from higher-than-expected rates of healthcare-acquired conditions (HACs) and hospital readmission. By Federal Fiscal Year 2017, up to 6 % of a hospital organization's annual Medicare payments may be at risk under the combination of these pay-for-performance programs; similar programs are in development for independent practitioners billing Medicare as well [7, 8].

Practical Applications

- **Kotter Eight-Step Change Management Model**
- Kotter [9] described an eight-step model of organizational behavior change that encourages cycles of learning and innovation. The model provides a framework deploying healthcare Lean Six Sigma in emphasizing vision, data-based decisions, teamwork, and standardization.

Create the conditions for change	1. Increase urgency
	2. Build coalition
	3. Create vision
	4. Communicate
Introduce new practices	5. Empower action
	6. Short-term wins
Maintain momentum	7. Don't let up
	8. Make it stick

- **Sigma Score (Z-Score)**
- Statistical measure of how much a process varies from perfection, based on the number of defects per one million units of product or service.

Sigma score (Z)	% yield	Defects per million opportunities (DPMO)	% defects	Category
1.0	31	691,462	69	Non-competitive
1.5	50	500,000	50	
2.0	69	308,538	31	
2.5	84.1	158,655	15.9	
3.0	93.3	66,807	6.7	Industry average
3.5	97.7	22,750	2.3	
4.0	99.38	6210	0.62	
4.5	99.87	1350	0.13	
5.0	99.977	233	0.023	
5.5	99.9968	32	0.0032	
6.0	99.99968	3.4	0.00034	World class

- **Defining Lean Six Sigma Process Improvement Team Members**

Role	Role definition
Master Black Belt (100 % time)	**Extensive training** and experience, trains, **certifies**, and coaches Black and Green Belts. Functions at LSS **program level** to develop key metrics and strategic direction. Acts as a strategist, technologist, and internal consultant
Black Belt (100 % time)	**Significant training** and experience, operates under Master Black Belts. Applies LSS methodology at **project level**. Leads, trains, and coaches project teams
Green Belt (5–20 % time)	**Intermediate training**, operates under Black Belts. Functions at the **process level** assisting Black Belt with data collection and analysis, leads smaller scope projects or teams, along with regular job duties
Executive White Belt	**Accelerated basic training** in LSS method for executive and physician leaders. Functions as a **project sponsor or champion** to help team maintain focus and momentum
White Belt	**Basic training** in LSS tools. Functions as the **product level** as a team member supporting process improvements
Employees	**Little formal training**, frontline knowledge workers who assist local problem-solving that support projects. **Awareness** of LSS philosophy
Executive sponsor	**Owns vision, scope, and integration** of project results, leads high-level **culture** change efforts, overcomes organizational barriers to project success
Project champion	**Process owner and/or content expert**, provides strategic direction to project team, assists with implementation and hardwiring of new processes
Team member	**Contributes knowledge/ideas/efforts** that significantly impact success of project

- **Healthcare Quality Priorities in Era of Reform:** Lean Six Sigma methods can effectively be deployed to address these key areas of focus under National Health Reform:
  - ✓ Reducing healthcare-acquired conditions (HACs)
  - ✓ Reducing avoidable readmissions
  - ✓ Standardizing clinical processes of care
  - ✓ Increasing patient safety and outcomes
  - ✓ Enhancing patient experience of care
  - ✓ Streamlining care continuum to reduce delays and readmissions
  - ✓ Increasing cost efficiency of care

Tips

- ***A 30% Solution*****:** Across a variety of industries and settings, most work processes can be improved by at least 30% using Lean Six Sigma methods. Yields will occur in reduction of waits and delays, costs, and errors/defects and increase in productivity, revenue, customer, and staff satisfaction. Many projects will produce positive yields in more than one domain (quality, service, and finance).
- ***Map It Out***: Draw a process flow map showing the sequence of steps required to execute the work. A powerful technique to visually identify delays and non-value-added steps in any process.
- ***Avoid Average Thinking*****:** Measuring and reporting only central tendency (mean, median, mode) obscure most of the valuable information in understanding any process, yet it is the most common approach in healthcare (e.g., average length of stay, average mortality). Understanding variation in the data, and detecting change using statistical process control, is the key to operations improvement.
- ***Rule of 24*****:** 24 data points (e.g., consecutive patients, days, months, trials) provide an almost undisputed test for process stability, allowing statements to be made about process position, stability, and detection of significant change. Always seek 24 data points.
- ***Ones*****,** ***Runs*****,** ***and Trends***: Remember the three-decision rules for detecting change (special cause) in an SPC chart: **Ones** (any point outside the control limits), **Runs** (seven or more consecutive points all above or below the central tendency line), and **Trends** (seven or more consecutive points moving up or down crossing the central tendency line).
- ***Change is a Team Sport*****:** Gathering team perspectives on care helps build cohesion, enhances understanding of the problem, guides development of effective interventions, and strengthens organizational adoption of new more effective practices. Change is about more than techniques; it's about advancing a culture of quality, safety, and performance.

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M.A. Budd et al. (eds.), *Practical Psychology in Medical Rehabilitation*,
DOI 10.1007/978-3-319-34034-0