Handbook of Pediatric Psychology

Fifth Edition

edited by

Michael C. Roberts
Ric G. Steele

ebook

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HANDBOOK OF PEDIATRIC PSYCHOLOGY

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Preface

Pediatric psychology is a concept that has evolved over time, in both its research focus and its clinical applications. Our understanding of health and illness, psychological functioning, social and physical environments, and their multiple interactions has been refined and elaborated over the years. In the evolution of our field, pediatric psychologists have engaged in the fundamental developmental process of *adaptation*. That is, the field has constructively responded to changes in its environment through adaptation with processes of assimilation (using preexisting concepts for new situations) and accommodation (changing concepts to fit new situations). These processes have enriched our science and expanded the impact of our clinical work.

The field of pediatric psychology was originally defined by the *Journal of Pediatric Psychology* as encompassing "the interests and concerns of psychologists who work in interdisciplinary settings such as children's hospitals, developmental clinics, and pediatric or medical group practices" (Routh & Mesibov, 1979, p. 1). Although descriptive of the state of the science at that time, the definition of the field has been expanded greatly through the years (Roberts, La Greca, & Harper, 1988, p. 2). According to a more recent and comprehensive description of the field's scope,

> pediatric psychologists provide (1) psychosocial services for issues related to pediatric health conditions . . . ; (2) psychological services for mental health problems appearing in medical settings along with a pediatric problems . . . ; (3) assessment and treatment for psychological problems presenting in a medical setting without a concomitant medical condition; (4) programs for health promotion, disease and injury prevention, and early intervention; (5) assessment, intervention, and programming to improve functioning for children and adolescents with intellectual and developmental disabilities; and (6) advocacy for public policy supporting children and families and promoting public health advancements. (Roberts, Aylward, & Wu, 2014, p. 6)

Now, in the fifth edition of this *Handbook*, we are still discovering new concepts and approaches, new methodologies and applications. These have kept the field exciting and relevant. Roberts (1992) drew these conclusions about the literature in the *Journal of Pediatric Psychology* in regard to clinical practice, scientific research, and profes-

sional issues: (1) Pediatric psychologists provide competent services that are well appreciated by their professional colleagues and by parents; (2) pediatric psychologists clarify relationships of psychological and pediatric phenomena and evaluate interventions; and (3) pediatric psychologists examine issues of ethics and training that articulate pediatric psychology as a profession. As evidenced by the chapters of this *Handbook*, research in the field continues along this trajectory in terms of its questions, methodologies, and statistics, generating more accurate and useful scientific information. Clinical applications have more of a solid evidence base; as a result, pediatric psychologists provide more effective and efficient assessments and interventions in their various clinical roles in primary care settings, hospitals and clinics, and community programs. The organization and provision of clinical services are more comprehensive and integrated than at earlier stages in our history.

Despite the many advances that we have seen, many things have not changed substantially from the earliest days of the field in the late 1960s and early 1970s. Some of the same issues and problems remain for study and intervention, even if cast into new terminologies and concepts. Compliance with medical regimens has been an ongoing concern for research and applications since the 1970s and 1980s, even if the term "adherence" is *de rigueur* today. Adjustment and psychosocial functioning of children living with disease remain current issues, as evidenced by the robust literatures examining quality of life, coping, and resilience. Progress has been made toward changing what were "life-threatening diseases" into "chronic conditions" with which children and families cope; these remain today at the forefront of investigations and clinical applications. Pediatric psychologists, much as they did earlier, utilize concepts of family-centered, developmentally appropriate, and humane care for children through an understanding of the different systems affecting a child's life, such as family and peer relationships.

Despite these constants, the processes of assimilation and accommodation have shaped our understanding of many persistent threats to child outcomes. Nutrition and healthy eating as behavioral priorities have always been given attention by pediatric psychologists, who are concerned with health, development, and prevention of later problems. However, these areas of research and practice are now being enhanced by the study of genetic and epigenetic variables, as well as a greater appreciation for the impact of both built and social environments. Similarly, although safety and prevention of childhood injuries persist as significant causes of childhood morbidity and mortality, new technologies, such as the advances in virtual reality, enhance the way we understand the predictors of injury and open possibilities for preventive efforts. The concept of integrated primary care, recently championed by the Patient Protection and Affordable Care Act, is not a totally new idea; it was there in the early years (Schroeder, 1979) and was envisioned, then as now, as an ideal for the future. Some new problems have emerged over time (e.g., HIV/AIDS, the Zika virus), and some problems have become more salient (e.g., significant rises in diabetes and obesity). Adaptation processes will continue to ensure that pediatric psychology addresses these new and persistent issues in children's health.

This *Handbook*, like its predecessors, attempts to provide basic informational resources—in other words, to serve as a primer for pediatric psychology. Although we have endeavored to cover as many topics as possible in the broad swath of the field, we were inevitably limited by what could be packed into an accessible volume. Indeed, a multivolume set, encyclopedic in its coverage of detailed topics, would be necessary to

convey the comprehensive richness of the clinical practice and research. As with earlier editions, we sometimes had to make difficult choices. We were assisted in the arduous process of selecting and organizing the content by the thoughtful commentary and suggestions of the Editorial Advisory Panel (whose members are listed at the beginning of this *Handbook*). We appreciate their contributions to the overall architecture of the book.

Within the framework that was shaped in part by our Advisory Panel, we invited chapter authors who have special expertise in the chosen topics. This task was at once straightforward and challenging: The field has grown to the point at which, on any topic, there are many credible clinical scholars who could do the job well. We are appreciative that we had so many fine choices before us, and are indebted to the chapter authors, who devoted significant time and effort to the preparation and revision of the chapters.

The Society of Pediatric Psychology (Division 54 of the American Psychological Association) sponsors this *Handbook* as a peer-reviewed work similar to its two journals (*Journal of Pediatric Psychology* and *Clinical Practice in Pediatric Psychology*). In the case of this *Handbook*, each draft chapter was reviewed by a set of volunteer professionals and graduate students, contributing their own expertise and perspectives to improve the chapters. We thank the chapter authors and these reviewers (listed as the Board of Editors at the start of the book) for improving the chapters in this peer review process. Unfortunately, the chapter authors could not be given the page space necessary to trace the full historical development to today's situation on each topic. Thus readers may be tempted to conclude that where we are today is where we have always been. Reference citations in journal articles are often similarly limited, and thus too frequently cannot do justice to the historical contributions of conceptualizations and empirical research that have created the solid foundation of the field. We have lamented the lack of historical background, even as we had to impose page limits on the authors, and correspondingly had to limit bibliographic and historical references as well.

We thank Christina M. Amaro, our editorial assistant, for her organizational and editing prowess, which served us and the *Handbook* well throughout the production process. If the *Handbook* serves its purpose, it is to a large degree because of Christina's persistence and endurance.

The first four editions of this *Handbook* were dedicated to the founders of and early contributors to the field of pediatric psychology—Logan Wright (1933–1999), Donald K. Routh (b. 1937), and Lizette Peterson-Homer (1951–2002)—and more generally to the many pioneers who have shaped our field. These pioneers and their contemporaries have provided a remarkably solid foundation for our subsequent discovery, and have kept the field exciting and relevant for generations of professionals. Given our focus in this preface on the developmental processes that have shaped our field, it is fitting that we dedicate this edition of the *Handbook* to the future pediatric psychologists who will continue those traditions of excellence through their own assimilation and accommodation.

The chapters in the *Handbook* were written while the Patient Protection and Affordable Care Act was the law of the land in the United States. As we finished the book for publication, the incoming Trump administration began making significant changes to the law that could change health insurance for Americans, the kinds of services that are covered, and how health care is paid for. Even without knowing where this debate will ultimately lead, we expect whatever revisions are made to the current American health

insurance system will have significant implications for pediatric psychologists and the services they provide.

If history is our guide, we anticipate that the next generations of pediatric psychologists will have to face many new challenges. To be sure, there will be some of the same persistent conditions and problems that there have always been. However, there will also be new and unanticipated conditions, dilemmas, and issues that we can only guess at. We offer this *Handbook* in the hope that the information herein will stimulate the adaptation of pediatric psychology for a new generation.

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Contents

PART I. PROFESSIONAL ISSUES

PART II. CROSS-CUTTING ISSUES

PART III. MEDICAL, DEVELOPMENTAL, BEHAVIORAL, AND COGNITIVE-AFFECTIVE CONDITIONS

PART I

PROFESSIONAL ISSUES

CHAPTER 1

Historical Developments and Trends in Pediatric Psychology

Brandon S. Aylward and Jennifer L. Lee

The field of pediatric psychology includes both research and clinical practice that address a range of issues related to physical and psychological development, health, and illness among children, adolescents, and their families. As part of a multifaceted field, scientist-practitioners in pediatric psychology explore the relationships among psychological and physical health and the welfare of children and adolescents within a developmental perspective, considering the contexts of families, caregivers, health care systems, schools, peers, and community (Steele & Aylward, 2009). This chapter provides a brief history of the field, including organizational developments; describes research and training in the field; and makes projections for the future of pediatric psychology.

HISTORY OF PEDIATRIC PSYCHOLOGY

Conceptual Origins

Development in the field of pediatric psychology did not occur overnight; yet the field emerged over time, with remarkable growth since its early conception (Roberts, 1986, 1993). Collaborations between psychologists and pediatricians date back to the late 1890s and helped to shape the models of current pediatric psychology practice (Lee & Kazak, 2014). The benefits of these collaborations were first noted by Lightner Witmer, who established the first psychological clinic in the United States. Highlighting the opportunities for collaboration, Witmer stated that pediatricians could learn from psychologists how "normal, mental, and physical conditions manifest themselves in and out of the school-room" (1896, p. 391). On the other hand, psychologists could learn from pediatricians about "morbid and abnormal conditions that are frequently met with in childhood, and to acquire some knowledge . . . towards their amelioration" (1896, p. 391).

Witmer was pivotal in forming these early collaborations: He interacted with both pediatricians and schools to help children and their families with general and pediatric-related problems, served on a pediatric journal editorial board, and published case studies describing pediatric-related interventions (Routh, 1975, 1990). Arnold Gesell was another individual who bridged the fields of pediatrics and psychology; he was among the first to earn both a doctorate in psychology and a medical degree (Routh, 1990). As the scope of practice in pediatrics broadened, Gesell (1919) was one of the first to discuss the need for clinical psychologists to address the psychological issues of children in medical settings. John Edward Anderson (1930) reiterated the potential benefits of collaboration between clinical psychologists and pediatricians in an address to the American Medical Association. Specifically, Anderson highlighted the strong training of psychologists in child development, and the potential for psychologists to contribute to pediatric practice through intelligence testing, developmental assessments, and advice on child behavior training.

Despite these activities and other calls highlighting the benefits of cross-disciplinary interactions, growth in formal collaborations was slow in the early 20th century. Further, although early descriptions of the benefits of potential collaborative efforts were written mainly by pediatricians, others viewed this potential collaboration less favorably. For example, Joseph Brennemann was a prominent pediatrician who believed that pediatricians could meet the psychological needs of children and expressed his wariness of the emphasis on child development (Brennemann, 1933). Nonetheless, the involvement of psychologists in pediatric medicine continued throughout the 1940s with the shift to preventive medicine, including immunizations, nutrition, and the use of antibiotics (Connolly, 2011). However, pediatric psychology did not emerge in a more formal sense until the mid- to late 1960s, when pediatricians were being faced with increasing numbers of patients presenting with developmental, behavioral, and academic problems (McClelland, Staples, Weisberg, & Berger, 1973). Richmond (1967) emphasized that pediatrics was in need of the expansion and application of child development knowledge. Similarly, psychologists discovered that children with medically related problems and their families had needs that were not being met within the traditional psychologists' office or outpatient psychology clinic (Roberts, Mitchell, & McNeal, 2003). Ultimately, it became evident to both groups that a new model of practice was needed to meet the challenges of critical childhood problems (Roberts, 1986).

At about this time, two seminal papers communicated the need and set the terms and parameters for a new field (Genik, Yen, & McMurtry, 2015). In 1965, psychologist Jerome Kagan called for a "new marriage" between psychology and pediatrics in an article published in the *American Journal of Diseases of Children*. For psychologists, Kagan (1965) highlighted the beneficial role a psychologist might play in helping pediatricians identify early severe psychopathology and psychosocial problems, as well as the opportunities to use research inquiry to understand the mechanisms underlying the clinical presentations seen in practice. However, Kagan viewed the role of the pediatric psychologist as more research-oriented, and he seems to have underestimated the clinical role of the psychologist within medical settings (Mesibov, 1984).

The term "pediatric psychology" was first coined by Logan Wright in his 1967 article "The Pediatric Psychologist: A Role Model," and this article was pivotal in the early conceptualization and vitalization of the field (Roberts, 1993). Whereas Kagan's article portrayed psychologists as more research-oriented, Wright's paper was explicitly

programmatic and defined pediatric psychologists as more clinically focused. Wright (1967) urged psychologists to understand the requirements of pediatric practice and to use assessment and intervention practices that would fit with medical practice. To further the field's development, Wright stated the need for a clear role definition among psychologists, specific training for future pediatric psychologists, and a new knowledge base through applied research. Consistent with the needs outlined by Wright, pioneering pediatric psychologists focused their efforts on establishing successful clinical programs, training psychologists to work with pediatricians, and creating a core professional identity (Drotar, 2015); all these efforts helped lead to the emergence of the field of pediatric psychology as a distinct area in psychology (Roberts, 1993).

Organizational Developments

In its formative years, pediatric psychology faced the challenge of developing a professional identity (Drotar, 2015), which was a perceived need in Wright's early conception of the field. In 1967, George Albee, president of the Division of Clinical Psychology of the American Psychological Association (APA), recommended that the Section on Clinical Child Psychology (Section I) evaluate the increasing role of psychologists in pediatric settings and the potential for organizing a special interest group. A committee on pediatric psychology (including Logan Wright, Dorothea Ross, and Lee Salk) was formed, and letters were sent to the chairs of pediatrics departments in all U.S. medical schools, asking for the names of psychologists on staff. This survey resulted in over 250 psychologists' being identified as interested in a society for pediatric psychologists, and this group formed the basis for the founding of the Society of Pediatric Psychology (SPP) in August 1968 as an affiliate of the Section of Clinical Child Psychology. SPP focused on the delivery of psychological services to children in medical settings and on research in child health psychology (Routh, 1994). SPP was initially composed of members from university medical schools; however, other individuals from community hospitals and pediatric group practices also became involved as the society developed (Routh, 1994).

In 1968, the society's first newsletter, *Pediatric Psychology,* was organized by Lee Salk and edited by G. Gail Gardner. The first newsletter issue was distributed in March 1969 and provided an outlet to distribute information related to pediatric psychology research and practice. In October 1980, SPP became a section within the Division of Clinical Psychology (Section 5), and in 2001, SPP officially became a separate division as Division 54 of APA. As SPP has grown, it has also published professional texts, sponsored conferences, testified before the U.S. Senate, collaborated with other national organizations, and organized task forces on different issues important to children and families. Through these activities, SPP has fostered the development of professionals interested in the research and its applications at the intersection of psychology and pediatric medicine.

RESEARCH IN PEDIATRIC PSYCHOLOGY

Founding of the *Journal of Pediatric Psychology*

In his seminal article, Wright (1967) asserted that an accumulation of research was crucial to the development of the field. Early research on assessment, intervention, and out-

comes in pediatric populations provided a strong foundation of empirical evidence for the field (Drotar, 2015; see, e.g., Cassell & Paul, 1967; Friedman, 1972; Salk, Hilgartner, & Granich, 1972; Wright & Jimmerson, 1971; Wright, Woodcock, & Scott, 1970; Wright, Nunnery, Eichel, & Scott, 1968). In describing the early scientific research in pediatric psychology, Routh and Mesibov (1979) defined it as including developmental disabilities, neuropsychology, infant development, failure to thrive, noncompliance, toilet training, child abuse and neglect, death and bereavement, hospitalization, and psychological aspects of physical illness. Many of these early focal areas remain topics of continuing research within pediatric psychology today.

The original SPP newsletter, *Pediatric Psychology,* served as an outlet for disseminating research in the field. Eventually the newsletter became the *Journal of Pediatric Psychology* (*JPP*) in 1976, which solidified the foundation of SPP and established the field as "a truly scientific and professional enterprise" (Roberts, Maddux, Wurtele, & Wright, 1982, p. 198). *JPP* is considered isomorphic with research in the field, reflects the breadth and depth of research activities, and provides the scientific representation of the field (Roberts et al., 2003).

Founding of *Clinical Practice in Pediatric Psychology*

As pediatric psychology evolved as a field, and as *JPP* became a highly impactful and respected journal in the field, the focus of published articles shifted from a mix of practice-based articles and empirical research articles to predominantly explicative or interventional empirical research articles (Drotar, 2013). Discussion among the membership highlighted a need for an outlet for practice-based research and commentaries. Based upon these expressed needs, a proposal was submitted in 2010 to create a clinically focused journal for SPP (Tynan & Pendley, 2013). In March 2013, APA published the inaugural issue of this journal, *Clinical Practice in Pediatric Psychology* (*CPPP*), with editors Jennifer Shroff Pendley and W. Douglas Tynan; the journal continues to be published quarterly. Topics addressed include the results of randomized controlled trials for internet-based interventions, clinical case series evaluating treatment for rare or complex disorders, descriptions of models of clinical care in new settings such as primary care, and descriptions of procedures for billing and reimbursement in an evolving health care environment. Moreover, the, editors of *JPP* and *CPPP* have worked together to publish tandem issues, with *JPP* focusing on the empirical research surrounding evidence-based interventions in pediatric psychology, and *CPPP* focusing on real-world applications of these interventions.

Considerations for Future Research

A sound grounding in empirical research provides the field of pediatric psychology with credibility within the multidisciplinary health care system (Kronenberger, 2006). As research in pediatric psychology continues to grow, areas of future interest include a greater focus and emphasis on samples of individuals from diverse backgrounds, the addition of biological measures of functioning, and research focused on the integration of psychology in pediatric primary care (Drotar, 2012). Ultimately, an increased understanding of relationships between psychological and medical issues will assist in the development and provision of more effective prevention and intervention services (Roberts, 1993).

TRAINING IN PEDIATRIC PSYCHOLOGY

When Logan Wright first coined the term "pediatric psychology" in 1967, he emphasized the need for the development of the field as a specialty through concentrated training. Early in SPP's development, the membership roster represented several training areas; the majority of members were trained in clinical psychology, followed by educational, developmental, and counseling psychology (Routh, 1977). Since then, training in the field has expanded substantially, and SPP now consists of members with a variety of backgrounds (Roberts et al., 1982, 2003). Furthermore, present-day training in pediatric psychology includes a diverse array of graduate, internship, and postdoctoral programs (Drotar, 2015).

Prior to World War II, fewer than 12 medical schools had a psychologist on the faculty (Mensh, 1953); however, there was a significant increase in psychologists in medical school departments after the war (for additional reviews, see Buck, 1961; Matarazzo & Daniel, 1957; Routh, 1970). Although some clinical psychologists had completed practicums or internships in children's hospitals, none of these positions had been formally identified as posts in "pediatric psychology" (Routh, 1975). The first formal doctoral training program in pediatric psychology was started in 1966 by the Departments of Pediatrics and Psychology at the University of Iowa (Routh, 1969). Although the program had been created to increase the training of pediatricians in child development, no pediatricians elected to enroll in it. During the program's 5 years, it facilitated training in an interdisciplinary clinical setting for approximately 10 graduate psychologists, who Routh (1975) stated were "clearly identifiable as pediatric psychologists since their graduation" (p. 7).

Current Trends in Training

Historically, specialized training in pediatric psychology was provided through a variety of pathways. As stated by La Greca, Stone, Drotar, and Maddux (1987) in an official training brochure for SPP, it remains true that "there is no single path to becoming a psychologist" (p. 2), and training opportunities in pediatric psychology are increasing (Prinstein & Roberts, 2006). Many pediatric psychologists have backgrounds in areas such as special education, as well as developmental, school, health, and clinical child psychology. A survey conducted by Mullins, Hartman, Chaney, Balderson, and Hoff (2003) demonstrated that the majority of pediatric psychologists in the 1999 SPP membership list had graduated from doctoral programs in clinical psychology.

Several sets of recommendations have been developed over the years to provide a foundation for training (see La Greca & Hughes, 1999; Spirito et al., 2003). In 2012, SPP formed a Task Force on Competencies and Best Training Practices in Pediatric Psychology, to update and further develop recommendations for training (Palermo et al., 2014). Building upon the work of prior task forces (Spirito et al., 2003) and a Competency Benchmarks Work Group (Hatcher et al., 2013), the members of this task force worked to tailor the recommendations for pediatric psychology training and professional development. Six clusters of competencies were addressed: science, professionalism, interpersonal, application, education, and systems. A seventh cluster consisting of cross-cutting knowledge specific to pediatric psychology was added. Behavioral anchors of expected competencies in each cluster were provided that would demonstrate the readiness of an individual for different levels of training: entering practicum, internship,

and eventual practice. Focusing on specific domains of training allowed the task force members to provide concrete examples and recommendations for the guidance of programs and training directors of programs in pediatric psychology to prepare trainees for the multitude of research and practice opportunities that currently exist.

Undergraduate Training

Most undergraduates do not obtain exposure to pediatric psychology; this fact emphasizes the importance of increasing early exposure to this growing field by providing opportunities to gain knowledge about it (Drotar, Palermo, & Landis, 2003). Such opportunities include courses at the undergraduate level that are focused on health and pediatric psychology, student memberships in SPP, and chances for undergraduates to attend regional and national conferences in pediatric psychology (Drotar, 2012). In a study examining desirable characteristics of undergraduate applicants for graduate training, surveyed faculty noted that successful applicants typically had substantial experience in research methods and evaluations, as well as minimal to substantial experience with intervention strategies. Research fit with faculty interests and the fit with the general program were selected as the most important criteria for admission to graduate school in pediatric psychology (Karazsia & McMurtry, 2012). Information on programs offering training in pediatric psychology can be found on the APA Division 54 website.

Graduate Training

Graduate training for pediatric psychologists typically takes 4–6 years, typically culminating in a Doctor of Philosophy (PhD) or Doctor of Psychology (PsyD) degree. As described by Palermo et al. (2014), these years should include a mastery of skills in research and clinical training. Training can be provided through a number of means, such as coursework, directed readings, hands-on research experiences, and practicum placements, as well as involvement in professional development through membership in SPP and other relevant organizations. Research opportunities are often offered (i.e., journal reviews, publications) and can be obtained with the help of strong mentorship and institutional support (Drotar, Palermo, & Ievers-Landis, 2003). Specialty tracks in pediatric psychology may also emphasize developing competencies in multidisciplinary work by collaborating with local hospitals and medical schools for research and clinical opportunities (for examples of training programs, see Cohen, Rodrigues, Bishop, Griffin, & Sil, 2015; Eaton & Blount, 2015; Roberts & Steele, 2003).

Predoctoral Internships

About half of the 1999 SPP members surveyed by Mullins et al. (2003) had completed an internship with a major rotation in pediatrics; the trend was toward a greater number of interested students' completing internships focused on a breadth of pediatric psychology experiences. Internship sites tend to be at university-affiliated hospitals or children's hospitals (Mackner, Swift, Heidgerken, Stalets, & Linscheid, 2003). These locations offer access to training with a variety of disease groups, as well as a large number of clinical training opportunities in pediatric settings. All internship sites surveyed by

Mackner and colleagues provided opportunities in consultation–liaison services, providing a breadth of exposure. McQuaid and Spirito (2012) have expanded upon the desired opportunities for training in the internship year; they suggest that the internship year needs to include further training in research competencies, particularly the integration of research into clinical settings and the use of quality improvement methodologies (e.g., Lynch-Jordan et al., 2010).

Postdoctoral Fellowships

Although a postdoctoral fellowship is not required for licensure or practice in pediatric psychology, a fellowship offers additional training for expanding current competencies and increased preparation for entering the workforce (Palermo et al., 2014). Between the 1960s and 1990s, the number of SPP members completing postdoctoral fellowships in pediatric psychology tripled (Mullins et al., 2003). Such a fellowship can help to focus one's skills with specific clinical populations, treatment protocols, and/or research methodologies (Drotar, Palermo, & Ievers-Landis, 2003). Fellowships can last from 1 to 3 years, providing flexible opportunities for interdisciplinary teaching and supervision of psychology and medical students, grant and manuscript writing, and further professional development (e.g., career advice, networking).

Future Directions in Training

Although it is now possible to specify a more focused and formalized pathway for obtaining competency in the activities of pediatric psychology, there remains no single route to becoming a pediatric psychologist (Kaslow & David, 2003). Palermo et al. (2014) have designed their training recommendations to incorporate flexibility as to when and how competencies can be obtained, allowing students and training programs to design programs that fit their needs, interests, and resources. Furthermore, training should focus on enhancing competencies in interprofessional practice and interactions (Palermo et al., 2014), as well as in grant writing, implementing new technology in research and practice, and leading collaborative clinical and research teams (Drotar, 2015; Drotar et al., 2015).

PROJECTIONS FOR THE FUTURE OF PEDIATRIC PSYCHOLOGY

In an era when the complex connections between the mind and the body continue to be explored and supported, the future of pediatric psychology appears bright. The complementary relationship of psychology and medicine has grown and will continue to do so through systems of integrated health care. The field of pediatric psychology continues to adjust and adapt to the changing health care environment. For example, technology has expanded the reach of pediatric psychology, from the development of mobile health applications to the provision of clinical services via telehealth. As this market expands, it will be critical to evaluate the efficacy of these services through ongoing empirical research. In addition, the structure of the health care system and the nature of reimbursement are changing with the advent of health care reform. Making sure that psychologists have a "place at the table" in patient-centered medical homes and integrated

care services will be an ongoing effort, requiring psychologists to demonstrate the added benefit of their services. Roberts, Canter, and Odar (2012) note several other actions that will be needed to secure the future of pediatric psychology, including (1) making interprofessional efforts to create knowledge bases or practices across disciplines; (2) increasing practice in primary pediatric care; (3) demonstrating value through documented evidence-based practices in pediatric psychology; and (4) creating accountability of care through accreditation and board certification. These are just a few of the large changes facing pediatric psychology. As ever, the future of pediatric psychology rests in the hands of the next generation of pediatric psychologists.

CONCLUDING REMARKS

The dynamic field of pediatric psychology was developed to address unmet needs for psychological services seen in the pediatric setting. The early collaborations between pediatricians and psychologists paved the way for the emergence of pediatric psychology, and the field remains vibrant and viable. As the other chapters in this handbook demonstrate, pediatric psychology represents a wide range of topics, although most individual pediatric psychologists have more specific clinical and research interests. This new edition of the *Handbook of Pediatric Psychology* represents the ever-growing vitality of the field: It highlights the breadth of clinical and research activities in pediatric psychology, as well as the many services the field provides for children, families, and professionals.

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CHAPTER 2

Ethical and Legal Issues in Pediatric Psychology

William A. Rae, Donald Brunnquell, and Jeremy R. Sullivan

The ethics code of the American Psychological Association (APA, 2010) does not always provide explicit guidance for the unique ethical dilemmas encountered by pediatric psychologists. Like other professional psychologists, pediatric psychologists have expertise in assessment, intervention, and consultation, but the application of these proficiencies is complicated by the fact that they work with children, adolescents, and families. These complexities, along with the special vulnerabilities of minors, mean that pediatric psychologists should constantly strive to maintain the highest ethical and legal standards. Moreover, pediatric psychologists often work within institutions where they engage in institutional interventions, primarily in medical and health care settings, as a way of improving the psychosocial environment. These institutional settings require special ethical considerations that place special demands on pediatric psychologists. For example, pediatric psychologists often engage in professional practices that require frequent interdisciplinary interactions, which complicate the ethical decision-making process.

The purpose of this chapter is to describe ethical and legal issues that may affect pediatric psychologists in their multiple professional roles as mental health practitioners, as members of health care teams, and as researchers. The chapter is organized into three major sections to accomplish this aim. The first section describes general issues of mental health ethics, such as informed consent and confidentiality. The second section addresses bioethics within the context of problems confronted by pediatric psychologists in hospital settings. The third section outlines research ethics for pediatric psychologists.

MENTAL HEALTH ETHICS FOR PEDIATRIC PSYCHOLOGISTS

Informed Consent

The purpose of gaining informed consent from one's patients is to ensure that each patient is provided with sufficient information to make an informed decision about participating in a professional activity. Within the context of pediatric psychology, informed consent usually means "parental permission," since most patients seen by pediatric psychologists are minors. Permission from a parent or legal guardian is therefore required for a child's participation in clinical services or research, with assent or agreement obtained from the child or adolescent patient. Informed consent should be obtained by describing the procedures in a way that is clearly understandable to the patient and parent. This includes using developmentally appropriate language when working with children, and using an interpreter in order to provide information in a patient's or parent's native language if proficiency in English is limited (APA, 2010). Consent or assent should be documented in writing, and patients should have an opportunity to ask questions and gather additional information about the professional activity. The extent to which psychologists may legally provide services to minors in the absence of parental permission varies from state to state, with many states allowing for such services under explicitly defined and urgent circumstances (e.g., suicidal ideation, abuse, drug counseling).

Pediatric psychology training requires ethical adherence for research and for clinical applications (Palermo et al., 2014), which would include informed consent for research, assessment, intervention, and consultation services. Informed consent should cover the nature and likely course of the services, the situations that would limit confidentiality, and the experimental nature of the intervention if a new or developing treatment will be used (APA, 2010). Intervention services provided by pediatric psychologists might include individual, group, or family therapy based on a range of theoretical perspectives. Assessment includes the use of traditional assessment measures, but may include more specialized evaluation tools (such as measures of treatment adherence, pain, health beliefs, coping skills, family stress, and other issues related to medical treatments and outcomes). Especially important to pediatric psychology practice is consultation, which involves working with other professionals on behalf of child and adolescent patients and their families. A pediatric psychologist is often part of an interdisciplinary team of professionals who work together to provide a comprehensive program of care for a child and family (Spirito et al., 2003). With these consultative relationships, information about the patient must be shared among professionals in order to develop informed treatment approaches. The informed consent process should attempt to describe the purpose of consultation, identify anticipated interactions (e.g., among treatment team members such as physicians, nurses, specialists, and teachers), and explain the need for such interactions. The APA (2010) ethics code does not address consultation as a distinct treatment modality, but it does note that a psychologist engaging in consultation with colleagues should first obtain consent from the patient, and should share the minimal amount of information necessary to help the patient. As the consultative services change in response to the characteristics or needs of the child (e.g., an additional specialist is added to the treatment team based on changes to the child's diagnosis), parents should be kept consistently apprised of the interactions between the psychologist and other service providers.

Competence to consent involves elements of comprehension and decision-making capacity. As noted by Collogan and Fleischman (2005), adults are generally presumed to be legally competent to make decisions on behalf of themselves and their children unless proven otherwise (e.g., due to severe deficits in cognitive functioning). Children, on the other hand, are presumed to lack competence or decisional capacity, simply as a function of their developmental status as minors. These presumptions, however, have recently been met with some criticism, leading experts to call for more empirically based efforts to operationalize and assess these abilities. Several relevant standards have been described to assess decisional capacity for participation in psychological services or research. These include the patient's ability to actively reach a decision or express a preference, understand the factors that contribute to the decision (e.g., risks and benefits of participation), manipulate information, and apply information to his or her own circumstances. These abilities may be assessed via interview and observational methods; through the use of hypothetical scenarios and checking for understanding; or via more formal methods, such as relevant subtests from intelligence tests to estimate overall cognitive capacity (Collogan & Fleischman, 2005).

Confidentiality

Protecting confidentiality is a primary obligation for all psychologists and is the cornerstone of the therapeutic relationship (Koocher & Keith-Spiegel, 2008). Many patients and families would not divulge private information to a pediatric psychologist unless they were assured that the information would remain confidential, which could lead to assessments and interventions based on incomplete information. Confidentiality practices are not only legally grounded, but are also established by institutions, although it must be acknowledged that in medical settings the intricacies of psychological evaluation and treatment are often not well explained. A discussion of confidentiality issues should take place during the informed consent process at the initiation of the professional contact (and should be revisited as necessary), although this discussion is not always feasible in the chaotic medical environment. During the informed consent procedure, the pediatric psychologist should discuss the limits to confidentiality and describe how confidential information will be used.

Confidentiality issues for children and adolescents are different from those with adults. Adults expect that private information obtained from a mental health professional will be kept confidential except when they give their written consent to have information released. Young children, by contrast, do not expect broad confidentiality for private information, because parents are knowledgeable about many of these details anyway. On the other hand, adolescents require more assurances of confidentiality, because they may be suspicious of parental motives and intentions; they may also have issues they want to keep private. Many psychologists who treat adolescents require that confidentiality be maintained from parents, even though there is no legal basis for doing so. The pediatric psychologist must balance the right versus the need for the parents to obtain confidential information about their child.

Determining the limits of confidentiality can be problematic for pediatric psychologists. Conflicting expectations often exist for the patient, the parent, the referral agent (e.g., a physician), and the institution (e.g., hospital). In the same way, conflicting expectations may also occur for pediatric psychologists who work with families, because a

patient, parents, siblings, and extended family members can all have different expectations about what information should be shared with whom. Before initiating professional services, the pediatric psychologist should attempt to clarify the confidentiality issues for all the stakeholders involved. Even when these issues are clarified, there may still be different expectations. For example, primary care pediatricians commonly expect to be privy to the most confidential information, but patients may not want certain private information divulged. Ultimately, the parents and the child have to decide how information is shared with family members or health care providers.

Breaking confidentiality is legally mandated in all U.S. states under three circumstances. First, psychologists are required to break confidentiality if they suspect a child is being neglected or physically, emotionally, or sexually abused. In actual practice, the timing and manner of breaking this confidence can be influenced by statute and circumstantial variables that might affect the welfare of the patient. Second, psychologists must divulge confidential information if ordered to do so by a court. Finally, a pediatric psychologist should always break confidentiality to report imminent danger to a patient or to others. The pediatric psychologist must evaluate the potential danger and disclose that information only to appropriate public authorities, professional workers, potential victims, and/or parents as required by law or when it is prudent to do so, considering the legal statutes present. Pediatric psychologists appear to have little ambivalence about breaking confidentiality if a child or adolescent appears to be suicidal or homicidal, but they have considerable ambivalence when judging risky adolescent behaviors in such areas as sexual behavior and substance use, as these are affected by the intensity, frequency, and duration of the behavior (Rae, Sullivan, Razo, George, & Ramirez, 2002).

BIOETHICS FOR CHILDREN AND ADOLESCENTS

Ethics committees and consultation services are now well established in most hospitals, although the work and frequency of consultation vary widely. Generally ethics committees and services pursue the goals of education, policy development and revision, and consultation; some committees also address organizational ethics. Recent surveys of hospitals report that 95% have ethics committees, with 70% of pediatric hospitals providing 1–10 clinical ethics consultations per year (Kesselheim, Johnson, & Joffe, 2010). No standard format for consultation exists, although a task force of the American Society for Bioethics and Humanities (2011) has attempted to outline core competencies for consultation. The task force calls for core knowledge in the areas of bioethical issues and in concepts such as ethical theory; end-of-life decision making and advance care planning; the health care system; the local institution and its policies; beliefs and perspectives of patients and staff members; and relevant professional ethics codes and health care laws. Active engagement with their institutional ethics committees should be a goal of pediatric psychologists.

Medical Decision Making for Children

Issues of informed consent and assent have been discussed earlier in this chapter, but the discussion of who makes medical decisions for children is especially important. Pediatric psychologists can play a unique role in assessing decision-making ability and medi-

ating disputes, given their training in developmental issues, cognitive and emotional functioning, and family dynamics. Clearly, once children become the legal guardians of their own persons, they decide for themselves. Until that point (generally 18 years of age), their legal guardians (usually their parents) are responsible for the consent to treatment. Children should be involved in medical decisions to the extent of their capacity, even when they are not capable of understanding the entire situation or recognized as legally competent.

The most comprehensive review of children's understanding in the context of medical treatment and research decisions shows that there is no simple formula to assess understanding, and that age is not a sufficient standard for comprehension and therefore for children's capacity to make their own decisions (Miller, Drotar, & Kodish, 2004). Factors such as prior experience, cognitive and academic abilities, psychological problems, and the context of the decision must be examined carefully on a case-by-case basis. Assent to medical treatment is not a legal requirement, although pragmatically speaking, as children enter adolescence, treatment without assent is difficult. The parents are charged with the duty to act on their understanding of the best interests of the child, but it is the child's rights and interests (though not necessarily preferences) that should determine the decision, not the parents' interests or preferences. One formulation of this duty includes the responsibility to defend the child's "right to an open future." This is the thesis that maintaining a broad range of choices for the child until the child can make decisions for him- or herself (Feinberg, 1980). While parents are presumed to have the legal authority to act on their child's behalf, this is not an unlimited authority. The concept of children's inclusion in decisions to the extent of their capacity is broadly supported (American Academy of Pediatrics, 1995). A comprehensive review of how these ethical issues apply to many clinical conditions is available elsewhere (e.g., Diekema, Mercurio, & Adam, 2011). First steps include discussing the harm and benefit of including the child's viewpoints, assuring that all parties share a similar understanding of the facts, engaging in dialogue about the preferences of each party and the reasons for those choices, and (if necessary) seeking mediation by a third party such as a pediatric psychologist or ethics consultant.

Potential conflicts can arise when the religious or cultural views of the parents or other legal guardians limit the treatment options for the child. A fairly common situation of this sort occurs with the families of Jehovah's Witnesses, who specifically request that blood products from one person not be given to another (Watchtower Bible and Tract Society of New York, 1992). Pediatric psychologists can play an important role in eliciting and elucidating the perspectives of the legal guardians and integrating perspectives of the extended family, elders, and the community in which the child lives. State laws and local judicial practices differ with regard to cases where the parents are Jehovah's Witnesses. This results in using the courts to override the parents' judgment to refuse blood transfusions for their children in life-threatening situations, while at the same time recognizing the decision of legally competent patients to decline the treatment (Layon, D'Amico, Caton, & Mollet, 1990). The laws of each state bear on the status of the emancipated minor, but to the extent that a minor has capacity to understand, voice, and follow through on the decision, the basic principle of autonomy suggests that the minor should control the decision making. Even in areas such as forgoing life-sustaining treatment, many ethicists argue that mature minors should have the right, in most circumstances, to refuse life-sustaining treatment (Derish & Vanden Heuvel, 2000).

End-of-Life Care and Forgoing Life-Sustaining Treatment

End-of-life care for children is always an emotionally laden topic. Recent work by the Education in Palliative and End-of-Life Care (2014) initiative has outlined basic standards. Although this education is largely targeted to physicians, it is comprehensive and includes sections on ethical and psychosocial well-being for dying children and their families. Decisions to withhold or withdraw life-sustaining treatment have most often been discussed with regard to cardiopulmonary resuscitation, the so-called "do not attempt resuscitation" (DNAR) orders, and the issue of fluids and nutrition. General attempts to address this question (American Thoracic Society, 1991) indicate that there is no logical, philosophical distinction between withholding and withdrawing treatment. Those working with these patients confirm almost universally, however, that there is an emotional difference between the two situations. Exploration of this perceived difference is often helpful in discussions of particular cases.

The right to refuse resuscitation and other treatments is now among those guaranteed by the regulations of The Joint Commission (2015) and the federal government's Centers for Medicare and Medicaid Services. The right to refuse or have treatments withdrawn extends to all medical treatments, not only those involving resuscitation. Issues such as the invasiveness of the treatment, the pain and suffering entailed in the treatment, the short- and long-term prognosis for the patient, and the quality of life that can be achieved are all relevant to the decisions. Issues include the role of the family when patients are not by law competent (as is true of most children), and the general concern about a surrogate's (generally a parent's) making the decision. Also relevant are the patient's and family's fears of abandonment if a DNAR order is instituted, and the use of DNAR orders as a cost containment method. Generally the right to refuse treatment on behalf of someone else is recognized in law and ethics (Paris & Fletcher, 1987). As members of the health care team not directly involved in providing these services, psychologists can play an important role in assisting patients and families to ask questions and clarify the options open to them in the decision-making process. Pediatric psychologists can act to clarify the complex medical fact situation, to assist in clarification of values, to help a patient and family integrate their value systems into the fact situation, and to translate the patient's and family's view to the other members of the health care team.

The issue of withholding or withdrawing such treatments as medically provided nutrition and hydration is even more contentious. There is general agreement that oral nutrition and hydration should be offered unless these are specifically contraindicated. The symbolic importance of food, its place in human ritual, and the dependence of young children complicate decisions about the provision of medical nutrition and hydration. In general, there is agreement that in cases where the goals of the patient and purposes of life are not served, it is possible to overcome the presumption in favor of providing medical nutrition and hydration treatment and to withhold or discontinue nutrition and hydration (Nelson et al., 1995). Complete consensus regarding the requirement of provision of medical nutrition and hydration does not exist. Concerns about this position include the question of imposing suffering with feedings that cause medical problems, coercion of the patient, and prolongation of suffering in a terminal condition in which other treatments have been withheld. It is important to note that the life prospects of some children may be very similar to those of debilitated elderly individuals, for whom

a general consensus exists that forced feedings are not required. Forcing treatments on children that are optional for adults compromises the rights of children.

Emerging Issues

The question of the social versus the medical model of disability has been broadly debated. According to the social formulation, disability is not a characteristic of the individual person, but rather a characteristic of society's adaptation to the typical person. Vehemas (2004) has defined "disability" as disadvantage or restriction of activity caused by a contemporary social organization that does not account for impairment. In this view, the obligation of the professional is to fight against the discrimination of society in general, and to advocate for the rights and well-being of persons with disability. In contrast, the medical model identifies a defect in the individual that should be corrected by medical treatment. The medical model is criticized as seeing disability as a unitary category that does not recognize individual differences. Silvers (2001) has criticized the presumption that "normal" or "species-typical" is good, and that people must be cured of their differences. The debate extends to genetic screening for disability: Does such screening represent an attempt to limit suffering, a eugenic movement, or a form of genocide against people with differences (Scott, 2005)?

The issue of vaccination refusal has arisen over the past few decades (Opel & Diekema, 2011) and is generally understood to be a growing public health dilemma. More recently, it has elicited a public or legislative response as community outbreaks have occurred (Reiss & Weithorn, 2015). The "Disneyland measles" outbreak in 2015 (Halsey & Salmon, 2015) and numerous local pertussis outbreaks, along with public health awareness of emerging infectious diseases such as Ebola (Centers for Disease Control and Prevention [CDC], 2015a) and Middle Eastern respiratory syndrome (CDC, 2015b), may have begun to shift public sentiment toward greater adherence to recommended vaccination schedules. Sadaf, Richards, Glanz, Salmon, and Omer (2013) usefully explore approaches to minimizing vaccine refusal. The American Academy of Pediatrics (2013) has recently reiterated its position (Diekema, 2005) that pediatricians should work with parents who refuse vaccines and not dismiss them from their practices.

"Incidental findings" in research have received considerable attention and now constitute a growing issue in clinical work. This refers to unanticipated abnormal results uncovered by a test that the test was not intended to seek. For example, the increasing use of exome or whole-genome sequencing in diagnostic genetics leads to significant questions about what may or must be disclosed to parents if unanticipated current disease, later-onset disease, or predisposition to disease is discovered. Do parents have a right to all of this information or a duty to receive the information? Do clinicians have a duty to disclose the information, and if so, for only actionable findings or for all findings? At what age should the information be shared with children? Must it be shared when they become adults, and if so, what mechanisms exist to do so (Clayton et al., 2014)? Similarly, with advanced neuroscience technologies such as magnetic resonance imaging, clinical as well as research use can yield unanticipated findings. Kim, Illes, Kaplan, Reiss, and Atlas (2002) noted that 9% of children in neuroimaging studies were referred for further evaluation due to incidental findings.

"Neuroethics" is the exploration of the ethics of neuroimaging, technologies that manipulate neurological function, and neurosurgery. Emerging areas of research moving

toward clinical application include the use of brain imaging in clinical and legal settings; brain stimulation for behavior control; and cognitive, affective, or behavioral enhancement by pharmaceutical, surgical, or brain–computer interface (see Farah, 2012, for an overview). The precautionary principle argues for restraint until good data exist for both the efficacy of benefit and minimization of risks of specific technologies, but these considerations must be balanced against progress in health care. Pietro and Illes (2013) discuss in a research setting issues that are equally relevant to clinical settings. There are numerous ethical challenges, relevant to both genetic and neuroscientific work. These include the clinical utility of findings; the degree to which the possibility of incidental findings has been discussed, and to which informed consent regarding such findings has been given; and the psychological risks of disclosure. In addition, how should disclosure occur and to whom, what is the economic burden of additional tests, and what are the physical risks (e.g., sedation)? Also, is there a duty to look for incidental findings, are there confidentiality risks to the disclosure, and how may the therapeutic conceptions and misconceptions affect all parties?

RESEARCH ETHICS FOR CHILDREN AND ADOLESCENTS

Many of the issues related to informed consent and confidentiality within the contexts of assessment, intervention, and consultation are also relevant to planning and conducting research in pediatric psychology. At the same time, the world of research also presents some unique ethical issues and challenges, which we address briefly here. For more thorough discussions of these issues, the reader is referred to Alderson and Morrow (2011), Miller (2008), and Rae and Sullivan (2003). Readers would also benefit from familiarity with the "Common Rule," which is also known as the Federal Policy for the Protection of Human Subjects (Protection of Human Subjects, 1991). The Common Rule has been adopted by 15 different U.S. federal agencies, including the Department of Health and Human Services and the Department of Education, as the foundation for protecting research participants. As such, the policy includes guidelines for institutional review boards (IRBs), general requirements for informed consent, and considerations for including children (see Subpart D) and other vulnerable populations in research studies.

Within the context of research, it is important that the informed consent process describe the purpose of the study; the nature of procedures or interventions that will be provided during the study; time commitments (e.g., frequency and duration of meetings or sessions); the potentially sensitive nature of topics discussed; the limits of confidentiality; procedures used to assign participants to different groups; potential risks and benefits of participating; and other characteristics of the research that could influence willingness to participate (APA, 2010). The informed consent process should also describe any incentives or compensation that participants will receive for their commitment to the study. In order for consent to be truly voluntary, incentives for participation must not be so great as to coerce participation among children and family members who would not participate in the absence of incentives. This issue is especially salient when families have scant financial resources, and therefore are more vulnerable to coerced participation that may be an attempt to collect compensation; however, researchers must also be sensitive to the fact that research projects demanding great time com-

mitments from participants, requiring expenses such as bus fare, or posing numerous inconveniences (e.g., multiple visits to a hospital or clinic, invasive procedures) may have difficulty recruiting participants if some type of compensation is not offered (Alderson & Morrow, 2011). One solution has been to offer a small amount of payment at each point of data collection rather than a large one-time payment, so that incentives are spread out over the course of the study and are less likely to contribute to coerced participation (Rice & Broome, 2004).

Collogan and Fleischman (2005) noted that securing informed consent for research is complicated by the fact that a child or family may or may not benefit from participation (depending on the efficacy of standard-care and experimental interventions). This differs from consenting to psychological services such as therapy or consultation, in which there is a clear expectation of benefit due to the clinician's obligation to act in the best interest of the patient's therapeutic progress. Thus researchers must make clear the possibility (or, in some cases, the probability) that participation in the research project will not result in any direct benefit to the child or family, although their participation may benefit society at large. In a related issue, researchers must take care not to overestimate the potential benefits or impact of an experimental intervention just to increase the number of participants (Miller, 2008; Rae & Sullivan, 2003). Parents and children should feel safe to decline participation, and must receive assurance that they will still be provided appropriate treatment if they elect to decline participation in a research project.

As noted by Fisher (2004), psychologists who conduct research often face the dilemma of functioning in dual roles: researchers and service providers. This dual relationship becomes problematic when a psychologist's role as service provider interferes with the voluntary nature of research participation, thereby leading to potential exploitation of patients (APA, 2010). For example, children and families working with a psychologist in assessment or intervention services may feel pressure to participate in clinical research conducted by the psychologist. Similarly, the psychologist's interactions with patients may be influenced by a desire to recruit participants and successfully complete the research study, in order to receive continued funding for the research program (Miller, 2008). Thus these dual relationships should be closely monitored, or avoided altogether, if they hold the potential to cloud the psychologist's objectivity or unduly influence individuals' ability to provide consent voluntarily. Recent research by Miller, Luce, and Nelson (2011) suggests that the informed consent process should include opportunities for parents to describe whether they feel any external pressures to provide consent to participate in treatment studies, in addition to a more general discussion of factors influencing their decision, so that researchers can take steps to address or mitigate these perceived pressures.

To conclude our brief discussion of research ethics, it is important to note that an IRB acts as a key monitoring system in order to ensure that researchers consider the ethical issues described herein. Institutions that conduct research, such as universities and health science centers, have their own IRBs that govern research conducted by faculty at their institution. At such an institution, researchers must submit a proposal to the IRB that describes the research in detail, including procedures for selecting participants, obtaining informed consent/parental permission (e.g., the IRB must approve the actual consent forms to be used in the study), maintaining confidentiality, assigning participants to experimental groups, and analyzing data. Pediatric psychologists

must be especially careful to clearly describe any experimental procedures or manipulations with which members of the IRB may be unfamiliar, as IRBs vary with regard to their knowledge and understanding of pediatric psychology research protocols (Drotar, 2011). The IRB approval process provides an important opportunity for the proposed research to be evaluated by an objective and external source that has no vested interest in the research; such an evaluation presents the possibility for identifying ethical issues that the researchers may have missed. This system is especially important with research involving child and adolescent participants, given the vulnerability of this population.

CONCLUSION

Applying ethical and legal standards to the care and treatment of children, adolescents, and families can be very complex for pediatric psychologists. It is critical for pediatric psychologists to recognize that children and adolescents represent a vulnerable population, and therefore that assessment, intervention, consultation, and research in pediatric psychology require special care and sensitivity to the participants' welfare. In addition, the context of practice (e.g., hospital, clinic, inpatient) and the other professionals involved must be considered. All psychologists must strive to be ethical, but pediatric psychologists also have the additional role of being advocates for pediatric patients and their families.

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CHAPTER 3

Professional Development, Roles, and Practice Patterns

Lisa M. Buckloh and Lisa M. Schilling

Pediatric psychology continues to evolve to encompass a variety of clinical settings and innovative methods of delivering evidence-based interventions. There is significant variability in pediatric psychologists' positions, the administrative models under which they function, the activities for which they are responsible, and their revenue-generating activities. Their training and careers often include the integration of clinical care, teaching and supervision, research and grant writing, and practice or university administration, and often encompass balancing work in multiple settings (Roberts, Aylward, & Wu, 2014). The successful pediatric psychologist also must monitor and respond to changes brought about in the practice of psychology by market forces, such as health care reform and increased accountability for generating revenue. In the first part of this chapter, we focus on the professional roles and practice patterns of pediatric psychologists. We then review professional development issues that affect practice, including training, licensure/certification, and coding/billing.

PROFESSIONAL ROLES AND PRACTICE PATTERNS

The settings in which pediatric psychologists typically practice include inpatient units in children's hospitals or in specialized treatment facilities, outpatient medical clinics or clinics with a developmental focus, and community support agencies (Roberts et al., 2014). As part of a study to establish benchmarks for performance for pediatric psychologists (Opipari-Arrigan, Stark, & Drotar, 2006), members of the Society of Pediatric Psychology (SPP) were surveyed about their primary work settings. The majority of the 356 respondents (63%) indicated that they worked in a hospital, with half in academic medical centers. Most of those working in hospital settings had academic appointments. Private practice settings also accounted for a significant number of respondents (22%).

Other primary work settings included academic departments of psychology, mental health service agencies, outpatient clinics, school systems, and academic departments other than psychology. These data are currently being updated as part of the SPP Workforce Survey.

Pediatric psychologists routinely provide services with physicians and other medical service providers within the biopsychosocial model (Engel, 1980). Interdisciplinary care (psychological and medical providers sharing information and engaging in collaborative treatment planning) and transdisciplinary care (members of various disciplines synthesizing their knowledge bases into a unique, comprehensive scientific focus) are described in detail by Armstrong (2009). The term "interprofessional" is now often preferred in place of "interdisciplinary" or "transdisciplinary," to highlight the application of shared professional competencies in an integrated manner (e.g., Rozensky & Janicke, 2012).

Inpatient Settings

Overview of Hospital-Based Services

Hospital-based pediatric psychologists may work in general hospitals, trauma centers, and children's specialty hospitals, such as rehabilitation hospitals. The pediatric psychologist in an inpatient medical setting may have such a range of clinical, research, and educational roles that the term "pediatric psychological hospitalist" has been deemed appropriate, paralleling the growing role of physicians providing clinical care primarily or exclusively to hospitalized patients (Carter, Thompson, & Thompson, 2014).

Inpatient clinical work may be focused on a specific behavioral goal, such as developing a plan to increase adherence or addressing procedural anxiety or oppositional behaviors interfering with effective care. Consultation may involve evaluating a potential stress component to neurological, pain, or gastrointestinal symptoms. Consultation also may be requested to evaluate severity of depression or generalized anxiety in a hospitalized patient. Other significant pediatric psychology inpatient services include facilitating adaptation to a new diagnosis or treatment protocol; enhancing productive communication about treatment-related issues among the family, patient, and medical team; and promoting a positive transition back to and adherence in the home environment (Carter, Kronenberger, Scott, & Ernst, 2009). The pediatric psychologist may take a lead role in coordinating care across disciplines, such as participating in case conferences; engaging parents, siblings, and peers in interventions; encouraging collaborative, interdisciplinary relationships with other medical professionals; and remaining an educational resource for medical staff, such as by participating in grand rounds lectures or resident training.

Consultation–Liaison

Clinical care in a hospital setting typically involves consultation–liaison in regard to children who have been admitted for management of acute or chronic conditions. The psychologist in this role must conduct a diagnostic assessment; conceptualize the presenting problem; and develop and communicate recommendations to the medical team, patient, and family—all in an expeditious manner. Such consultation is often complicated by difficulty in obtaining parent input, difficulty in scheduling or completing comprehensive assessment because of required medical procedures, and varying levels of

child participation (because of medication, pain, and/or overall anxiety). Inpatient setting interventions are summarized by Lassen, Yu, and Roberts (2014) and include planning and implementing cognitive-behavioral strategies to enhance coping, adherence, and management of pain and anxiety; managing environmental factors in the hospital milieu; and preparing for the transition to home and community. Comprehensive information regarding consultation–liaison may be found in another chapter of this book (see Carter et al., Chapter 9, this volume).

Critical Care Settings

Pediatric psychologists in a hospital-based setting may work with a specific care environment (such as the neonatal or pediatric intensive care unit, the burn unit, or the bone marrow transplant unit) or with a specific patient population (such as the oncology or neurology service). Clinical services in these environments may encompass individual therapy, family-based therapy or supportive services, and interdisciplinary case management. Psychologists may design, implement, and evaluate interventions to decrease stress caused by painful procedures, excessive stimulation, lack of diurnal variation, isolation, and frequently changing caregivers, all of which are inherent in such settings.

In a joint report, the American Academy of Pediatrics and the American College of Emergency Physicians emphasized the vital position of the emergency department (ED) in managing pediatric patients with mental illness, developmental delay, and behavioral and emotional disorders (Dolan & Mace, 2006). Assessing immediate risk of harm, evaluating and providing intervention to victims of trauma, assisting children in unfamiliar medical procedures, and conducting research related to ED utilization are potential tasks for pediatric psychologists. Providing education to parents and staff in appropriate management of disruptive or aggressive behaviors, and assisting staff in determining ongoing care needs, may also be among a psychologist's roles in the ED (Lassen et al., 2014).

Rehabilitation Settings

Pediatric psychologists also are actively involved in rehabilitation hospital settings, which typically provide comprehensive long-term treatment for children with chronically impairing medical conditions or conditions with permanent physical and/or cognitive impact, such as traumatic or congenital brain injury or recovery from brain tumor resection. Rehabilitation services require an integrated, multidisciplinary approach that considers chronic medical needs, cognitive impairment, family factors and school placement (Prigatano & Naar-King, 2007). Interventions may include behavioral plans to decrease acting-out behaviors, increase social responsiveness, and improve compliance, and/or instruction in cognitive-behavioral anxiety/stress management.

Outpatient Settings

Twenty-five percent of pediatric psychologists surveyed about their primary work settings indicated that they worked in outpatient clinics or private practices (Opipari-Arrigan et al., 2006). Most notably, however, many who identified themselves as hospital-based psychologists (63% of respondents) worked in a combination of inpatient and outpatient settings. Outpatient settings can be diverse and encompass the following: outpatient clin-

ics housed within or sharing practitioners with a hospital or medical center; outpatient clinics within or closely associated with primary care practices; private practices with a focus on health promotion; or integrative community-based clinics or "medical homes" (Kleinsorge, Roberts, Roy, & Rapoff, 2010). In a medical outpatient setting, pediatric psychologists may work with a particular medical specialty and provide consistency of follow-up both in and out of the hospital, or may provide services in a multidisciplinary clinic (e.g., weight management, continence).

Medical Clinics and Primary Care

Studies examining referral characteristics of patients referred to outpatient clinics within hospitals or medical centers indicate that the most frequent referral problems are not medically related. Common referral problems include noncompliance with parental requests, tantrums, and aggression (Charlop, Parrish, Fenton, & Cataldo, 1987); cognitive evaluation and externalizing behavior problems (Rodrigue et al., 1995); and assessment of school problems (Sobel, Roberts, Rayfield, Barnard, & Rapoff, 2001). Pediatric psychology involvement in primary care provides an ideal setting for screening and can result in effective resolution of the referred problem (e.g., Lavigne et al., 2007) and decreased rates of health care utilization (e.g., Finney, Riley, & Cataldo, 1991). In addition to assessment and treatment, psychologists are involved in training pediatric residents (Applegate, Kelley, Applegate, Jayasinghe, & Venters, 2003), and in program development and treatment evaluation (e.g., the Chapel Hill Pediatric Psychology Practice; see Schroeder, 2004). Pediatric psychologists may also be involved in programmatic evaluation of interventions within a health care system (e.g., Svoren, Butler, Levine, Anderson, & Laffel, 2003).

Community Settings

School

Approximately 20% of school-age children with chronic illnesses are absent from the school environment due to treatment demands for lengthy or repeated periods of time (Weiner, Hoffman, & Rosen, 2009). In such cases, pediatric psychologists play a critical role in school reintegration, which requires establishment of an effective family, school, and hospital team; individualized assessment of learning and environmental needs; development of an intervention plan (e.g., an individualized education plan or 504 plan); the provision of resources to assist parents in their roles as advocates for their children's needs; and preparation of teachers, peers, and staff (Alderfer & Rourke, 2014). Research and clinical work in the school setting may focus on areas such as assessing and increasing teachers' knowledge of chronic illness care, evaluating and reducing barriers to care in school, and assessing and impacting social competence and peer support (e.g., Wagner, Heapy, James, & Abbott, 2006).

Health Care Transition Programs

A particular challenge for pediatric psychologists is the transition of adolescent patients with specialized medical and psychological health care needs to appropriate adult care. The Agency for Healthcare Research and Quality provides a comprehensive review

of transition guidelines for children with special needs (McPheeters et al., 2014). The review suggests that, in the few empirical evaluation studies examining transition, educational materials, a specialized transition clinic, and a transition coordinator were common components, but that quantitative outcome measures must be better defined and potential methods of funding must be identified. Moreover, a multidisciplinary team approach appears critical to designing effective transition programs.

Other Community Settings

Additional community settings are being evaluated for their clinical effectiveness and ease of utilization. Pediatric psychologists have implemented trials of home-based family systems therapies, primarily targeting diabetes adherence (e.g., Harris, Harris, & Mertlich, 2005; Ellis et al., 2005). Telemedicine and eHealth interventions are additional community based interactive technologies used by pediatric psychologists for a variety of medical conditions (see reviews in Van Allen, Davis, & Lassen, 2011, and Palermo & Wilson, 2009). Involvement in camps for children with medical challenges and membership on advisory boards for local and national medically focused organizations are other common pediatric psychologist roles.

PROFESSIONAL DEVELOPMENT

Training, Licensing, and Credentialing

Pre- and Postdoctoral Training

The broad field of professional psychology (Fouad et al., 2009) and the specialty of pediatric psychology (Palermo et al., 2014) are both continuing to move toward competency-based education, training, and credentialing. Specific recommendations for the training of pediatric psychologists (Spirito et al., 2003) have been expanded to include competencies in six cluster areas: science, professionalism, interpersonal, application, education, and systems and knowledge competencies (Palermo et al., 2014). In addition, research-based competencies in pediatric psychology have been proposed (Madan-Swain et al., 2012). For further review of these training recommendations, see Palermo, Janicke, Beals-Erickson, and Fritz (Chapter 5, this volume).

Predoctoral internship and postdoctoral training are generally required in the United States and Canada for licensure. The Association for Psychology Postdoctoral and Internship Centers (*www.appic.org*) generates an online directory of internships and postdoctoral programs, which includes information such as populations served, major rotations (including pediatric psychology), and treatment modalities. In addition, the American Psychological Association (APA) Divisions 54 (the Society of Pediatric Psychology, or SPP) (*www.societyofpediatricpsychology.org/training*) and 53 (the Society of Clinical Child and Adolescent Psychology) (*www.clinicalchildpsychology.org/internships_postdocs*) provide lists of graduate programs and internships in pediatric psychology. Mentoring relationships in pediatric psychology extend from graduate school through postdoctoral training and throughout career development, with most pediatric psychologists identifying multiple mentors and ongoing exchanges within these networks (Aylward, Odar, Kessler, Canter, & Roberts, 2012).

Licensure/Continuing Education

Pediatric psychologists practicing in the United States and Canada are required to be licensed in their specific state or province to provide clinical services (Reaves, 2006). The general purpose of licensing is to protect the public from incompetent practitioners by ensuring that the professional meets the minimum standards of competency. Each state in the United States, and each province or territory of Canada, has its own psychology licensing board and requirements. The Association of State and Provincial Psychology Boards (ASPPB) is the alliance of these licensing boards. Although the ASPPB does not govern the process of psychology licensing, it coordinates the cooperative efforts of the boards and facilitates communication, maintains responsibility for the standardized written Examination for Professional Practice in Psychology (EPPP), and facilitates mobility for psychologists moving between states or provinces (Van Horne, 2006).

The requirements for psychology licensure in the United States vary by state, but typically include (1) a doctoral degree in psychology from an APA- or Canadian Psychological Association (CPA)-accredited program or the equivalent; (2) 3,000–4,000 hours of supervised clinical experiences, through predoctoral, internship, and postdoctoral training; and (3) passage of the EPPP examination (DeAngelis, 2006; Vaughn, 2006). Some states and provinces do not require postdoctoral training (ASPPB, n.d.-b). However, to ensure future mobility, it has been recommended that students get the maximum required hours in most states: 2,000 hours in an APA- or CPA-accredited internship and 2,000 hours of postdoctoral supervision (DeAngelis, 2006). In addition, most state and provincial licensing boards have additional oral or written examinations on ethics, area of practice, and/or the specific laws and rules of their jurisdictions (e.g., Melnyk & Vaughn, 2006). Specific requirements for licensure for each state, province, and territory, including information on the EPPP, can be found in *The ASPPB Handbook of Licensing and Certification Requirements* (ASPPB, n.d.-b).

Most U.S. states require licensed individuals to complete a certain number of continuing education (CE) hours per licensing period, with most states requiring an average of 20 per year (ASPPB, n.d.-a). Some states require CE credits in specific topic areas, such as ethics and legal issues, reducing medical errors, and domestic violence (ASPPB, n.d.-a). Continuing education hours can be obtained through attendance at national, regional, or local conferences, workshops, or individual presentations sponsored by an agency accredited to provide CE credits (e.g., APA, SPP). CE hours can also be obtained through accredited online resources.

Board Certification

Psychologists have the opportunity to identify their specialty by becoming board-certified by the American Board of Professional Psychology (ABPP) in one of 15 specialty boards. Eligibility requirements for ABPP Specialty Certification can be found at the ABPP website (*www.abpp.org*). Pediatric psychologists are strongly encouraged to apply to the American Board of Clinical Child and Adolescent Psychology, because at this time there is not a separate board certification in pediatric psychology (e.g., Rozensky & Janicke, 2012).

There are many reasons why board certification for psychologists is essential. With the exponential growth of psychological knowledge and skills, specialization has

become a necessity (Packard & Simon, 2006). Practice environments require specialization, given work demands and reimbursement policies, and the generic nature of licensing in North America requires additional specialty credentialing to protect consumers. Increasingly, hospitals and medical centers are requiring board certification for approval of privileges, and health insurance companies are routinely asking about board certification as part of their network application processes (ABPP, n.d.). With the implementation of the Patient Protection and Affordable Care Act (ACA), board certification will likely become even more important to pediatric psychologists (Rozensky & Janicke, 2012).

Work Performance

Health Care Reform

Pediatric psychologists must be able to respond to the changes in the health care delivery system as dictated by ACA. Health care providers must be prepared to offer interprofessional (application of shared competencies in an integrated way), team, evidence-based, and integrated care in an efficient, high-quality, and cost-effective manner (Rozensky & Janicke, 2012). Pediatric psychologists are well equipped to deliver such care, as they have long been involved in multidisciplinary teams (Roberts, Canter, & Odar, 2012). However, pediatric psychologists need to continue to prepare for the future of health care in a number of ways, as suggested by Rozensky and Janicke (2012): continuing to expand the role of psychologists in primary care settings; establishing more collaboration with public health colleagues; demonstrating patient satisfaction, cost offset, and clinical significance; obtaining board certification; and advocating for psychologists' roles and reimbursement. To take advantage of the opportunities offered by health care reform, pediatric psychology should have workforce analysis studies, a database of evidence-based treatments, updated training recommendations, and a strong professional identity (Rozensky & Janicke, 2012).

Benchmarks/Salaries

Opipari-Arrigan et al. (2006) provided data on benchmarks of work performance for pediatric psychologists, including salaries and activities, in their survey of members of SPP. Over two-thirds of the respondents reported clear productivity expectations, which are consistent with the increasing demands for financial accountability and viability in hospital settings. The authors indicated that high clinical demands within hospital settings were reported, with over 80% of the sample participating in clinical work. Research also was reported as a revenue-generating activity by over 50% of the sample (Berry, 2006). Updated benchmarks of pediatric psychologists are being compiled in the SPP Workforce Survey, currently in preparation (*www.societyofpediatricpsychology.org/spp-workforce-survey*).

Pediatric psychologists will need to continue to find creative avenues for income generation, including specialized managed care contracts, contracts with schools, subsidy of services with hospitals or departments, government and foundation grants and training grants, and fundraising/private donations (Drotar, 2004). Strategies for advocacy have been recommended, such as working with APA to meet the goals of more

comprehensive reimbursement codes, legal and health care reform, increased coverage from managed care contracts, and increased government funding (Drotar, 2004).

Billing

Therapy CPT Codes

As of January 1, 2013, there were major changes to the Current Procedural Terminology (CPT) psychological and neuropsychological testing codes, which must be used for billing and documentation for all insurers (APA Practice Organization, 2012). There are now just three timed psychotherapy codes that are used by psychologists in all settings (inpatient or outpatient): 90832 (30 minutes), 90934 (45 minutes), and 90837 (60 minutes). Changes to the CPT effective January 1, 2017 clarify use of the codes and add a modifier code for telemedicine services (APA Practice Organizations, 2016). There are add-on codes for interactive complexity, and there is a code for a patient in crisis (90839).

HEALTH AND BEHAVIOR CODES

Pediatric psychologists may use health and behavior codes (H & B codes), which may be more accurate than using psychiatric diagnoses and billing codes for children with medical problems. The six codes are billed in 15-minute increments and are associated with a child's medical diagnosis, not a psychiatric diagnosis (American Medical Association, 2007). H & B codes can be used for such issues as pain management, improving adherence to medical regimens, treating adjustment problems related to the medical condition, and enhancing health-promoting behaviors or reducing health-related risk behaviors (Noll & Fischer, 2004). They can be used in inpatient or outpatient settings and are appropriate for consultation–liaison services. Because it is beyond the scope of their practice for psychologists to diagnose physical health conditions, the existing medical diagnosis by a physician is used, supporting integrated care models (APA Practice Organization, 2006).

Pediatric psychologists' experiences with H & B codes are summarized by Drotar (2012) and highlight the inconsistency in reimbursement for the codes across a range of settings. Although these codes provide some reimbursement, it is not sufficient to cover the costs of delivering pediatric psychology services. Drotar (2012) has called for continued advocacy at the local and national levels for appropriate reimbursement, a demonstration of cost-effectiveness/offset, and tracking of reimbursement rates. With the ACA, there should be continued opportunities to enhance the use and reimbursement of H & B codes to provide interprofessional and integrated psychological services.

CONCLUSIONS

As the field of pediatric psychology continues to mature, professional roles and development issues will continue to evolve. The successful pediatric psychologist must be ready to face the challenges of the changing health care needs of children, adolescents, and families, as well as the broader market forces that influence this field. Pediatric psychologists must become active participants in shaping the future of their practice

through developing exemplary training programs, supporting specialty credentialing and enhancing mobility efforts, advocating for appropriate reimbursement and expansion of services in health care, conducting cutting-edge applied research, and implementing empirically supported assessment and intervention protocols. To continue to enhance the field's financial viability, pediatric psychologists will need to continue to be flexible, creative, and collaborative, and to seek out new opportunities for reimbursement and income generation.

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CHAPTER 4

Research Design in Pediatric Psychology

The State of Our Science, Recommendations, and Future Considerations

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The mission of the Society of Pediatric Psychology is to "promote the health and psychological well-being of children, youth, and their families through science and an evidence-based approach to practice, education, training, advocacy, and consultation" (*www.societyofpediatricpsychology.org/leadership*). This core statement communicates clearly that research design and statistical applications are of critical importance and value to the field of pediatric psychology. The generation, application, dissemination, and integration of the pediatric psychology literature transcend and inform nearly all facets and aspects of our work. Simply stated, it has been argued that scientific research is the foundation of pediatric psychology (Holmbeck, Zebracki, & McGoron, 2009). In light of this core value, the purpose of this chapter is to provide a brief overview of research design, methodologies, and statistical applications in the field of pediatric psychology. We want to make it clear here that we strongly advocate for what has been termed "methodological pluralism." Methodological pluralism reflects a willingness to utilize, develop, and embrace whatever approach, methods, or strategies are necessary for understanding the phenomena of interest (Richters, 1997). This approach assumes that no single research method, approach, or strategy is inherently superior or inferior; rather, these approaches are to be evaluated only with specific reference to the research questions being asked and the phenomena of interest (Richters, 1997).

We begin by highlighting how theory and previous empirical work mutually inform how we think about, hypothesize, and formally test these research questions, as well as the methodologies chosen. We then provide a summary of the research questions and methodologies that have appeared in the flagship publication of our field, the *Journal of Pediatric Psychology* (*JPP*), since the previous edition of this chapter (Holmbeck et al.,

2009). Throughout the text, we highlight some newer developments that have yet to be adopted widely within our field and thus offer rich potential for researchers seeking new approaches to thinking about research questions, accessing pediatric populations, and analyzing data. Whenever possible, we refer readers to practical tutorials or exemplary papers that illustrate these methodologies.

OVERVIEW OF RESEARCH QUESTIONS AND METHODOLOGIES

Theoretical frameworks, conceptual models, clinical hunches, and previous research (among a host of other factors) can all guide the research questions we ask. A sound grounding in research methodologies can shape *how* we ask these questions and the types of data we collect, while ensuring that we are aware of potential confounds or alternative explanations. Although research questions, methods, and statistical analyses appear distinct, they are often highly intertwined, in that they are mutually informative and reciprocally related (Karazsia & Berlin, 2014; MacCallum, Zhang, Preacher, & Rucker, 2002). As such, our awareness of methodologies and statistical analyses informs the questions we ask, and the nature of the questions informs the development and utilization of various methodologies and analyses. In practice, one would rarely focus on these components separately and without consideration of the others, but we do so here for ease of presentation.

The types and combinations of research questions asked and methodologies used to answer them are potentially limitless. This fact is not surprising, given that the field of pediatric psychology has a broad and ever-developing range of relevant issues, topics, content, frameworks, theories, and approaches. For example, both the previous and present editions of this volume include nearly 50 chapters related to professional and cross-cutting issues; specific medical, developmental, behavioral, and cognitive-affective conditions; public health issues and systems; and other special topics. Furthermore, the vast array of training experiences and theoretical orientations endorsed by pediatric psychologists (Mullins, Hartman, Chaney, Balderson, & Hoff, 2003) contributes to the diversity of questions asked and methods utilized. In this respect, the breadth of our field reflects the general trends in the broader disciplines of psychology (Freier & Aylward, 2007).

To document the state of our science since the preceding edition of the *Handbook* was published, we reviewed a random sample of approximately 20% (n = 138 of 588) of the abstracts appearing in *JPP* from January 2009 to October 2014. We used a procedure drawn from Holmbeck et al. (2009) and Tabachnick and Fidel (2013): Coders (who exceeded our reliability criterion of kappa >.80; mean kappa = .86, SD = .19) coded the broad types of research questions asked (degree and type of relationship among variables, significance of group differences, prediction of group membership; structure and time course of events; other) and the methodologies employed (experimental/randomized clinical trials, quasi-experimental designs; single-participant designs; meta-analyses/systematic reviews; longitudinal designs; cross-sectional designs; and/or qualitative designs). These categories are not mutually exclusive, in that many studies could have used many methodologies to answer several research questions within one paper. In the following sections, we review these questions and methodologies, and provide information on their relative frequency.

Types of Research Questions

Questions Regarding Between-Groups and Between-Persons Differences

DEGREE AND TYPE OF RELATIONS AMONG VARIABLES

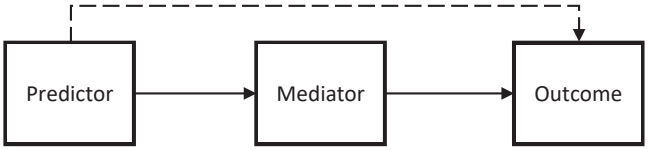
The most common (64.5% of studies reviewed) research question beyond basic descriptive statistics is about the relation between two or more variables. For example, Jensen and Steele (2012) examined associations between health-related quality of life and teasing at various time points in a longitudinal investigation of youth seeking treatment for overweight and obesity, and Morrongiello, Kane, and Zdzieborski (2011) examined associations between parental supervision and in-home injury occurrences among elementary-school-age children.

Questions of association generally assume a relation without a presumed cause. For reasonable inference of a cause-and-effect relation, five general conditions are typically required (Kline, 2011, 2016; Mulaik, 2009; Pearl, 2000): (1) "temporal precedence" (the cause occurs before the effect); (2) "association" (the variables relate to [covary with] another); (3) "isolation" (the association between the presumed cause and effect is not due to any other plausible explanation); (4) "effect priority" (the direction of the effect is specified correctly); and (5) "known distributional form" (the effect meets the appropriate statistical assumptions of the variable's distribution). When there are data or theory to support a presumed cause, it is helpful to think about the *type* of effect or role this variable has in relation to other variables of interest. More specifically, does this variable affect another, and if so, in what way? Is it directly or indirectly through its impact on another or other variable (e.g., mediation)? Alternatively, perhaps this variable exerts its influence by affecting how other variables relate to one another (e.g., moderation). Depending on the nature of this role and its effect, a variable could be considered a moderator, a mediator, a risk versus vulnerability factor, or a protective versus resource factor (Holmbeck, 2002; Karazsia, Berlin, Armstrong, Janicke, & Darling, 2014; Rose, Holbeck, Coakley, & Franks, 2004). Graphic depictions of, definitions of, and methods for delineating these roles are presented in Figures 4.1 and 4.2. From our perspective, a clear delineation of the specific role(s) that variables play, couched in the context of relevant theory, is a marker of maturity of a discipline (Karazsia & Berlin, 2014; Karazsia et al., 2014).

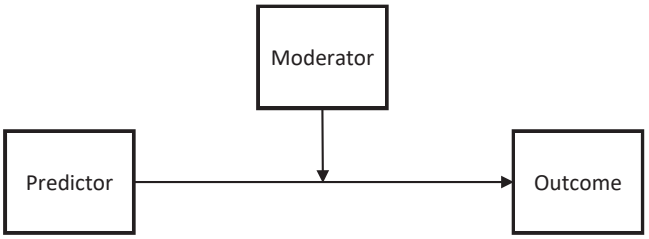
SIGNIFICANCE OF GROUP DIFFERENCES

Group comparisons (35.5% of the reviewed studies) offer an apparently "simple" way to determine the direct effect of group membership on an outcome or outcomes of interest. This research question is a variant on "the degree of relations among variables," in which the predictor variable represents membership in inherently discrete groups (e.g., males vs. females, youth with diabetes vs. youth without diabetes) rather than associations between continuous variables (Holmbeck et al., 2009). For example, Holbein et al. (2015) compared children with and without spina bifida on observed peer interaction styles. Kaczynski, Claar, and LeBel (2013) examined differences in various psychosocial symptoms (e.g., anxiety, depression, pain coping) across adolescents with tension-type headaches versus those with migraine headaches. Naturally, examination of group differences requires the existence of distinct groups in one's dataset, and we echo the concerns raised by several methodologists over the years who have noted the various shortcom-

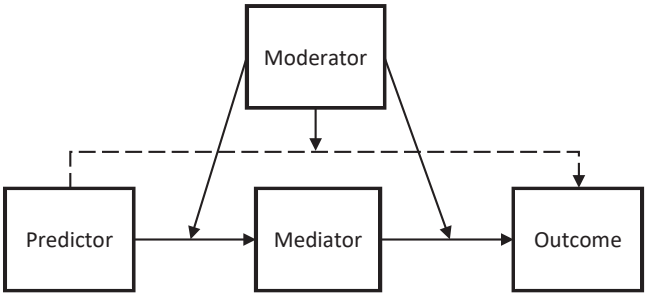
Mediator: Accounts for or explains (at least partially) the relation between a predictor and an outcome. Answers the questions of how or why a predictor influences a criterion.



Moderator: Affects the strength or direction of a relation between a predictor and outcome. Answers questions of under what conditions a predictor affects an outcome.



Mediation and Moderation: Strength of a mediating pathway (depicted with a dashed line) varies as a function of a moderator variable, which may alter the direction or strength of the path between the predictor and outcome (when modeled), the predictor and mediator, or the mediator and outcome.



Multifinality (left): Similar initial states may yield disparate outcomes across development.

Equifinality (right): Many disparate causes or factors may lead to a common outcome.

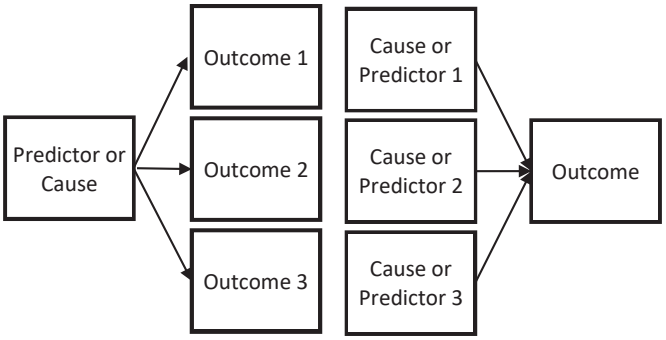
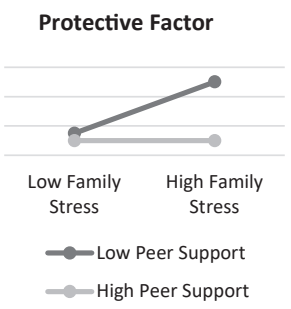
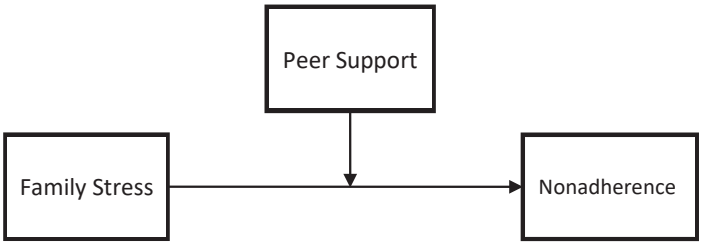


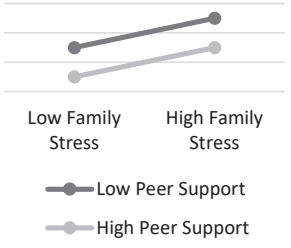
FIGURE 4.1. Graphic depictions of mediation, moderation, equifinality, and multifinality.

ings of creating such groups artificially via median splits or other forms of dichotomization solely for the purpose of examining group differences (Cohen, 1983; Dawson & Weiss, 2012; MacCallum et al., 2002; Preacher, Rucker, MacCallum, & Nicewander, 2005; Royston, Altman, & Sauerbrei, 2006). Simply stated, analysis of group differences should take place due to naturally occurring differences (e.g., the presence or absence of a diagnosis), rather than to artificially generated differences (e.g., median split).

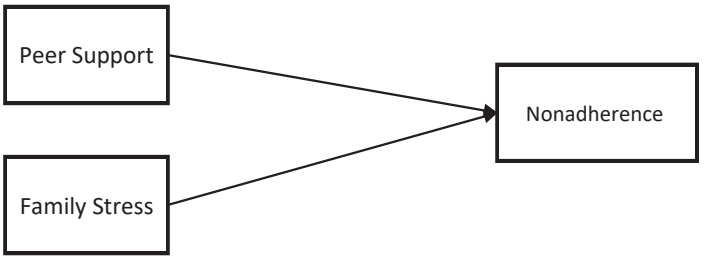


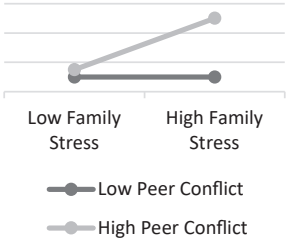
Protective Factor: a moderation effect in peer support has a positive impact only in the high family stress condition



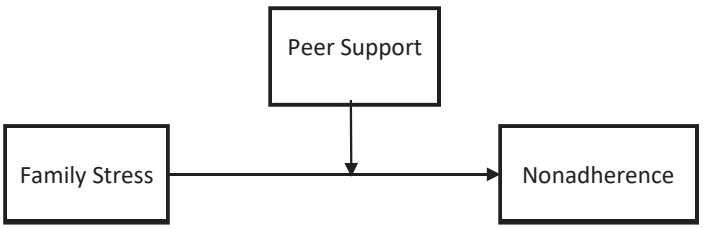


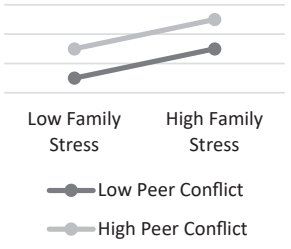
Resource Factor: Peer support has a direct positive impact in both the high and low family stress condition





Vulnerability Factor: A moderating effect in peer support has a negative impact only in the high family stress condition





Risk Factor: peer conflict has a direct negative impact in both the high and low family stress condition

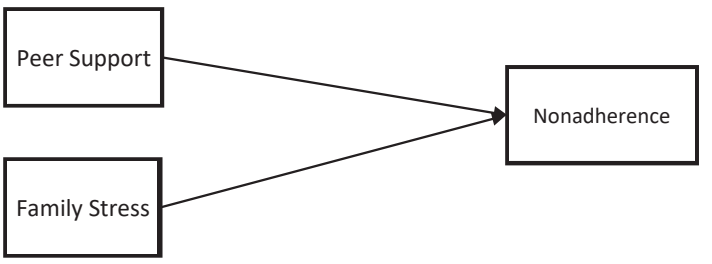


FIGURE 4.2. Graphic depictions of protective versus resource factors and of vulnerability versus risk factors.

Despite the articulation of a seemingly straightforward research question, great care must be taken to guard against the possibility that the effects of groups on outcomes are not due to any other plausible explanations, such as unmeasured differences in groups or unexamined moderators (i.e., interactions among variables). For example, if a researcher finds an effect of biological sex on adherence, this effect might be due to sex differences in adolescent depression (Klein, Torpey, & Bufferd, 2008) or to an interaction with sex and depression that, when controlled for, makes the effect of sex "disappear." Including possible confounding variables in the analyses, matching participants (both of which can use the promising approach of propensity scores), and/or random assignment to groups when possible (e.g., randomized controlled trials, discussed later) helps to minimize bias and strengthen claims when researchers are asking these types of questions (Boutron et al., 2008; Tumlinson, Sass, & Cano, 2014). Selection of relevant variables to control for should be guided by relevant theory.

PREDICTION OF GROUP MEMBERSHIP

Questions of another kind focus on the prediction of a discrete outcome such as group membership from a set of predictors that may be a mixture of continuous, discrete, and/or dichotomous variables. That is, prediction of group membership can be phrased as "What variables affect the likelihood of belonging to a particular group?" These types of research questions were the most infrequent in our survey, appearing in 2.9% of the reviewed studies. In the pediatric psychology literature, questions such as this might be prediction of groups of individuals with versus without disease activity, those above versus below established clinical cutoffs, intervention responders versus nonresponders, or a host of other types of groupings. An example in *JPP* is a recent investigation by Berlin, Williams, and Parra (2014) of what predicted membership in groups representing differential obesity risk patterns. In an effort to rule out alternative explanations, Berlin, Rabideau, and Hains (2012) found that age, sex, grade, and illness duration did not predict membership in any diabetes-related stress groups. This type of question may also appear in studies where outcomes have a preponderance of extreme scores at either the lowest (floor) or highest (ceiling) possible values of the measure, such as count or censored data. In such cases, appropriate analyses can simultaneously determine (1) what predicts whether the score is extreme versus not (i.e., that an individual is in the group with the floor or ceiling effect); and, if the score is not extreme, (2) variability in the outcome (Karazsia & van Dulmen, 2008; Long, 1997).

In addition to questions related to *what* predicts membership, studies examining the accuracy of prediction, or *how well* variables predict groups, can be of equal or greater interest to researchers (Youngstrom, 2014). These questions, for example, can utilize diagnostic efficiency statistics to inform clinical decision making by means of checklists or assessment instruments. In these cases, receiver operating characteristic (ROC) analyses provide useful information on the accuracy of positive and negative results (positive predictive value and negative predictive value, respectively), and the sensitivity (accuracy of test among those who have a condition) and specificity (accuracy of test among those who do not have the condition). Guidelines for researchers are available (e.g., Standards for Reporting of Diagnostic Accuracy; Bossuyt et al., 2003), as is a practical demonstration of ROC analyses (Youngstrom, 2014) for interested readers.

Measure Development and Validation

Among the important aspects of advances in the science of pediatric psychology are the development, refinement, and validation of assessment instruments (questionnaires, observational coding schemes, structured interviews, etc.) (Blount et al., 2008; Cohen et al., 2008). Of the studies reviewed for this chapter, 11.6% focused on such efforts. For example, Pagé, Fuss, Martin, Escobar, and Katz (2010) developed and subsequently validated a measure of children's pain anxiety symptoms. Similarly, Fedele, Grant, Wolf-Christensen, Mullins, and Ryan (2010) examined the factor structure of a parenting measure in populations of parents with a child diagnosed with a chronic illness.

One review concluded that many existing pediatric psychology measures lacked supporting psychometric data (e.g., basic indices of reliability and validity), limiting a complete evaluation of these measures (Holmbeck et al., 2008). These results prompted the development of specific criteria (with several subpoints and specific recommendations) and a checklist for measure development papers appearing in *JPP* (Holmbeck & Devine, 2009). The checklist was designed to guide authors as they work on measure development. In this respect, it is a checklist for the research process, not just for manuscript development. The checklist also helps standardize the presentation of psychometric studies in *JPP*. Briefly summarized, the nine major criteria presented by Holmbeck and Devine (2009) are as follows: A researcher or group of researchers developing an instrument (1) establishes a scientific need for the instrument; (2) attends to content validity during initial measure development; (3) evaluates reliability; (4) develops norms for the measure; (5) presents a quantitative item analysis; (6) conducts factor analyses; (7) evaluates validity; (8) evaluates diagnostic utility, clinical utility, and cost-effectiveness; and (9) translates the measure into other languages (Holmbeck & Devine, 2009). Given the availability of this practical checklist, it will be important to see whether the frequency of validation efforts continues to increase, particularly as the field continues to broaden into new domains where current measures may not exist yet.

Time Course of Events, Sequences, and Modeling Change

Among the most important, though relatively infrequent, studies (5.1% of those we reviewed) are those involving repeated measurements, events unfolding over time, and longitudinal changes in variables of interest. Recent examples in the pediatric psychology literature include a longitudinal examination of health-related quality of life in youth with spina bifida (Murray et al., 2015) and an investigation into the ways in which self-concept evolves across time among adolescents with and without chronic illness (Ferro & Boyle, 2013). There are numerous strengths to longitudinal research, including (1) investigation of the onset, duration, termination, and trajectories of outcomes and processes; (2) examination of the continuity, discontinuity, and escalation of adaptive and maladaptive behaviors; (3) prediction of later outcomes from earlier factors; (4) identification of developmental sequences and trajectory subtypes; (5) examination of how specific developmental periods and processes interact over time to differentially affect among at-risk youth; and (6) identification of what predicts prevention and interventions outcomes and the maintenance of change (Holmbeck, Bruno, & Jandasek, 2006; Loeber & Farrington, 1994). We add to this list (7) investigation of the timing and rate of events (Stoolmiller & Snyder, 2014); and (8) examination of event sequences

and behavioral contingencies over time (Chorney, Garcia, Berlin, Bakeman, & Kain, 2010).

All of these aforementioned questions are closely tied to the core principle in developmental psychopathology that multiple pathways to adaptation exist. More specifically (see Figure 4.1 for graphic depictions), many disparate routes may lead to a common outcome ("equifinality"), and similar initial states may yield disparate outcomes across development ("multifinality") (Cicchetti & Cohen, 2006; Hinshaw, 2008). Five useful tutorials have appeared in *JPP* that may be of interest to those interested in practical introductions to statistical and quantitative data-analytic approaches for longitudinal research: (multilevel) individual growth curve modeling (DeLucia & Pitts, 2006); latent growth curve modeling/growth mixture modeling, and latent class growth analysis (Berlin, Parra, & Williams, 2014); and modeling change with structural equation modeling, (Barker, Rancourt, & Jelalian, 2014), multilevel survival analyses (Stoolmiller & Snyder, 2014), and time-window sequential analysis (Chorney et al., 2010).

When developing studies that investigate constructs across time, scholars need to be careful to decide whether a prospective or a truly longitudinal study is more appropriate for their intended purposes. Generally, a prospective study is used to predict some outcome or event that occurs after knowledge of one or more predictors. In such a study, the predictors are different constructs from the outcome or event of interest. This type of study is different from a truly longitudinal study, in which repeated measurements of the same construct (with or without other predictors or outcomes) are made across time.

Specific Methodologies

Experimental/Randomized Clinical Trials and Quasi-Experimental Designs

Often considered the "gold standard" methodology for examining outcomes of specific interventions, randomized clinical trials (RCTs) are important for generating an evidence base for the interventions that we use with pediatric populations, and 15.3% of studies in our review were RCTs (with an additional 2.2% of studies being quasi-experimental designs, where true randomization was not possible for logistical reasons). Recent RCTs reported in *JPP* include investigations of behavioral pediatric obesity treatments (Berkowitz et al., 2013; Saelens, Lozano, & Scholz, 2013), supervision training for siblings of younger children (Schell, Morrongiello, & Pogrebtsova, 2015), and interventions for various other chronic illnesses and conditions (Stehl et al., 2009). The Consolidated Standards of Reporting Trials (CONSORT) checklist was developed to maximize the complete and transparent reporting of essential information in RCTs to facilitate methodical critiques and interpretations (Boutron et al., 2008). CONSORT was modified in 2012 to include "noninferiority" and "equivalence" designs (Piaggio, Elbourne, Pocock, Evans, & Altman, 2012). Whereas the primary purpose of most RCTs is to determine whether one intervention is superior to another, the purpose of equivalence trials is to determine whether one intervention is similar to another. A related trial type is a noninferiority trial, which focuses on whether one treatment is not worse than another treatment by more than an acceptable amount. These trials often use the language of "margin of superiority" (or "margin of noninferiority"), which reflects the magnitude of difference that is required for practical importance (Cipriani, Girlanda, & Barbui, 2009; Greene, Morland, Durkalski, & Frueh, 2008; Kraemer, 2011; Leon,

2011; Piaggio et al., 2012). In other words, these trials seek to determine the clinical significance of one treatment versus another treatment that has also been shown to be effective. Similar standards and guidelines are available for nonrandomized designs. In these cases, the use of Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) statements is encouraged (Des Jarlais, Lyles, & Crepaz, 2004).

Single-Participant Designs

Studies with an *N* of 1 (or only a few participants) may be particularly useful in the field of pediatric psychology (Rapoff & Stark, 2008), though they represented only 2.9% of published studies in our review. Pediatric psychologists often serve clients with very unusual conditions or presenting problems. Approaching such cases with a single-participant research design in mind can help assess response to intervention and offer a quantified approach to summarizing intervention effects in the research literature. However, single-case methodologies are not very common in our field at present, perhaps due to concerns of limited generalizablity. A recent example of a well-conducted *N*-of-1 study is an investigation of a token economy for exercise adherence in youth with cystic fibrosis (Bernard, Cohen, & Moffett, 2009). It is worth reiterating that *N*-of-1 methodologies may be perfectly well suited for practicing psychologists who are working a very specialized population (such as very rare conditions or disorders). Scholars interested in incorporating *N*-of-1 studies in their work are encouraged to consult two practical tutorials published recently in *JPP* (Cohen, Feinstein, Masuda, & Vowles, 2014; Cushing, Walters, & Hoffman, 2013) and an earlier *JPP* paper on examining clinical trials with single-subject analyses (Powers et al., 2006).

Meta-Analyses/Systematic Reviews

Meta-analyses and systematic reviews can be very useful for summarizing existing research related to interventions for a particular field, or associations among important constructs, and they represented 12.4% of studies we reviewed. Illustrative didactic papers are available in *JPP* regarding effect sizes, including those for conducting a meta-analysis (Durlak, 2009), and confidence intervals (Finch & Cumming, 2009). In addition, *JPP* publishes a recurring special issue on evidence-based treatment, in which a recent guest editor (Palermo, 2014) ensured that all reviews on evidence-based treatments now adopt the methodologies of meta-analyses and systematic reviews. Importantly, these reviews are abiding by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) criteria, which is a consensus-based minimum set of items for reporting in systematic reviews and meta-analyses (Moher et al., 2015). Palermo (2012) offers guidelines specific to *JPP* regarding the process of conducting and publishing review articles (including systematic reviews and topical reviews).

Qualitative Designs

Appearing in only 4.4% of research studies published in *JPP,* qualitative designs may be among the most underappreciated methodologies in our field. This fact may not be surprising, given that pediatric psychologists have always had an affinity for quantifi-

able evidence (Mesibov, 1984). Because psychologists are heavily trained in quantitative methods, pediatric psychologists may feel unable to evaluate or incorporate qualitative methodology in their own research (Fiese & Bickham, 1998). Given the complex nature of chronic illness, however, qualitative methods may be necessary to gain a better understanding of the impact of chronic medical conditions on youth and their families (Fiese & Bickham, 1998; Wu, Thompson, Aroian, McQuaid, & Deatrick, 2016).

Beyond limitations in pediatric psychologists' training, the underutilization of qualitative research in the field may be due to the challenging nature of this methodology. There may be a need to educate readers about qualitative research—which involves carefully identifying the intent of the research and the role(s) of the researcher, drawing themes from multiple types of data sources, using specific protocols for recording data, analyzing data through multiple steps, and using additional strategies to ensure the validity of the collected data (Creswell, 2014). Consistent with many scientific disciplines, the preference for empirical evidence often leads to a pursuit of both internal and external validity; however, since the general focus of qualitative research is on particularity and not generalizability, external validity may be threatened (Creswell, 2014). Instead of starting with internal validity, qualitative methods begin with the phenomenological experience of the population under study (Fiese & Bickham, 1998). Therefore, qualitative methodologies are extremely important for keeping the gap between science and practice as narrow as possible, and for providing key insights into the actual experience of the participants and clients whom we serve.

Although qualitative methodologies have potential reliability and validity concerns (Creswell, 2014), these designs also have several strengths. Qualitative research allows the in-depth examination of phenomena that may be impossible to measure with quantitative methods. For example, Valenzuela et al. (2011) used semistructured interviews to explore the difficulties experienced in youth with behaviorally acquired HIV who were making the transition to adult care, and to identify possible areas of improvement. These qualitative interviews provided rich data regarding the most difficult aspects of adult care transition, highlighting the need for future research in this area. Qualitative methodology can also be implemented to tailor preexisting intervention programs to culturally diverse groups. Cassidy et al. (2013) conducted focus groups with rural African American youth, their parents, and community leaders regarding eating and weight gain issues, to gain insight into how previously existing prevention programs might be adapted to this specific population. In addition to cultural tailoring, qualitative designs can be used to enhance the initial development and/or refinement of prevention and intervention programs (Rounsaville, Carroll, & Onken, 2001). Wilson, Williams, Evans, Mixon, and Rheaume (2005) used focus groups of underserved youth to identify preferences for exercise and motivational programs to increase physical activity. Qualitative research also allows for exploration of new areas to generate hypotheses and the ability to build novel theories; it is not limited to rigidly defined variables (Fiese & Bickham, 1998; Creswell, 2014). For instance, Jacobson et al. (2013) adopted a qualitative design to assess the validity of a self-report measure of chronic pain. Whereas the majority of measure development research consists of purely analytical approaches (e.g., factor analysis, reliability analysis), this qualitative study helped the researchers ensure that item development was consistent with the actual experience of the target patient population. Researchers wishing to adopt qualitative methods in their own research programs should refer to overviews of qualitative methodology (Fiese & Bickham, 1998; Wu et

al., 2016) and of using focus group data in qualitative research (Heary & Hennessy, 2002), as well as to the articles highlighted in this section.

Person-Centered Approach to Research Questions

The previously reviewed research questions most generally explore the effects of one or more variables across an entire sample and assume that observed heterogeneity in the sample can be accounted for by variables included and measured in the study. Alternatives (and complements) to these approaches are "person-centered designs." Such designs consider unique subgroups, marked by homogeneity, that exist within an overall population marked by heterogeneity (Bergman, von Eye, & Magnusson, 2006). Person-centered approaches assume that variability (heterogeneity) in a total sample may be due to the presence of unobserved "mixtures" of homogeneous subpopulations, sometimes called "latent classes," which are commonly derived through latent variable mixture modeling (LVMM; (Berlin, Parra, et al., 2014; Berlin, Williams, et al., 2014; Muthén, 2001).

To illustrate with a hypothetical example, let us consider a population of pediatric patients diagnosed with cancer. Naturally, we would expect to observe substantial variation (heterogeneity) in patients' psychological adjustment to diagnosis and treatment. This variation could potentially be explained by the existence of two or more subgroups within this population, presumably demonstrating adaptive versus maladaptive adjustment. Further, within the subgroup with maladaptive adjustment, marked heterogeneity may still exist—and thus more refined subgroups may still exist, such as those manifesting internalizing versus externalizing maladjustment. The methodologies within the person-centered approach to data analysis are designed to discover and then model these homogeneous clusters that exist within a larger, more heterogeneous sample.

Person-centered questions may focus on patterns of stress or co-occurring developmental and medical diagnoses influencing outcomes (Berlin, Lobato, Pinkos, Cerezo, & LeLeiko, 2011; Berlin et al., 2012); identification of differential longitudinal trajectories of medical outcomes (Helgeson et al., 2010); or patterns of adherence over time among youth with recent diagnoses (Modi, Rausch, & Glauser, 2011). Although these groups are most often defined by differences in the means or proportions of a collection of variables (via latent class and/or latent profile analyses), these models can extend to include differential patterns of the research questions previously discussed. For example, a person-centered or LVMM approach to understanding the degree of relation among variables might posit the existence of subgroups based on a differential relation between two variables (e.g., mixture regression). An example of this approach might consist of subgroups in which stress is positively related to adherence (e.g., a subgroup in which stress cues an approach coping style) and others for which this relation is negative (e.g., a subgroup in which stress prompts avoidance). While this LVMM approach is similar to cluster analysis, its primary benefit is the flexibility researchers have in the role of latent class membership in their research questions and the ability to integrate variable and person-centered approaches. For example, latent classes can have direct, indirect, and moderating effects, as well as serve as outcomes in their own right in the context of both cross-sectional and longitudinal designs (Berlin, Parra, et al., 2014; Berlin, Williams, et al., 2014). For practical tutorials on cross-sectional and longitudinal mixture modeling,

readers are encouraged to review Berlin and colleagues' introductory papers on LVMM in *JPP* (Berlin, Parra, et al., 2014; Berlin, Williams, et al., 2014).

BEST PRACTICES IN PEDIATRIC PSYCHOLOGY RESEARCH DESIGN (GENERAL CHARACTERISTICS OF "STRONG" STUDIES)

While a truly "perfect" study does not exist, there are certain methodological and statistical considerations that greatly improve a project's rigor and impact while guarding threats to validity or incorrect conclusions. Reflecting on our review of existing methodologies adopted in our field and existing recommendations in research methodology literature, we have developed the following nonexhaustive list of "dos and don'ts." We believe that these recommendations can help pediatric psychologists remain mindful of best practices in methodology.

1. Do not (unnecessarily) use fancy statistics to win friends and influence people (Wilkinson & the Task Force on Statistical Inference, 1999); do match your research question with an appropriate quantitative methodology.
2. Do not improperly care for your data before using your statistical program (Kline, 2016); do take care to clean, inspect, and explore missing data with the same precision as if you are conducting inferential statistics.
3. Do not confuse statistical significance with clinical significance, or vice versa (Jacobson, Roberts, Berns, & McGlinchey, 1999; Kraemer et al., 1999; Kraemer & Kupfer, 2006; Kraemer et al., 2003); do integrate findings within clinical contexts to aid the audience in clinical translation of research findings.
4. Do not ignore missing data and the potential pattern of "missingness" (Little, Jorgensen, Lang, & Moore, 2014); do embrace the inevitability of missing data proactively, and plan your research methodology and statistical analyses accordingly.
5. Do not ignore child development (Holmbeck, Greenley, & Franks, 2003); do base research questions and study designs on current developmental theory and literature.
6. Do not rely on unvalidated measures; do use (and if necessary, develop and refine) psychometrically sound measures with excellent reliability and validity.
7. Do not ignore the presence of confounds; do rule out (or address) alternative explanations and theories throughout all phases of studies (design, analysis, and interpretation), including measurement (e.g., reliance on multiple informants via multiple methods; Holmbeck, Li, Schurman, Friedman, & Coakley, 2002).
8. Do not ignore statistical power; do be mindful of your sample size, statistical power, and effect sizes, and let these be important considerations as you design studies and analyze data.
9. Do not go it alone; do ask for help! Just as practicing clinical psychologists are often encouraged to utilize networks of other clinicians for consultation (e.g.,

Clayton & Bongar, 1994), so should applied researchers utilize consultations for methodological and statistical issues in all phases of the research process (not just when analyzing results).

CONCLUSION

While research methods and statistical applications have long been in the forefront of research conducted by pediatric psychologists, there has been a remarkable trend toward special issues of *JPP* devoted solely to these topics, including issues focused on methodology/research design (Noll, 2002), quantitative methods (Karazsia & Berlin, 2014), longitudinal research (Holmbeck et al., 2006), and direct observation research (Wysocki, 2014). In this chapter, we have reviewed the current state of our science, in terms of frequencies of existing methodologies as sampled from past *JPP* articles. Although our review is based on papers published in our discipline's flagship journal, pediatric psychologists do publish in many outlets, so the sampling for this chapter should not be considered exhaustive or representative of the full pediatric psychology literature. That said, our review has revealed that pediatric psychologists use a variety of methodologies to answer the complex questions they face. Furthermore, the review has revealed that several methodologies have yet to be widely embraced by pediatric psychologists. Two such approaches include single-subject methodologies (e.g., Rapoff & Stark, 2008) and qualitative methods (e.g., Fiese & Bickham, 1998; Wu et al., 2016). We believe that further adoption of these techniques could provide a basis for bridging the research–practice gap. Both of these approaches focus more on individual patients and their experiences, and thus more closely approximate the experiences of practicing pediatric psychologists who treat the patients that do not meet *inclusion* criteria in a research trial. We hope that the review offered in this chapter stimulates the creativity of pediatric psychologists, so that our field can continue to ask important questions and answer them in creative ways that will translate into enhanced functioning for the youth and families we serve.

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CHAPTER 5

Training and Competencies in Pediatric Psychology

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Within the field of pediatric psychology, there is a long history of commitment to training. In 1967, Logan Wright published a paper in the *American Psychologist* that discussed the specialized knowledge, training, and roles required in the subspecialty of pediatric psychology. At that time, a pediatric psychologist was defined by experience in providing evaluation and treatment to children in a medical setting, rather than by the training or education that he or she had received. Once the Society of Pediatric Psychology (SPP) was formed in 1969, this organization began to put forth descriptions of the specific training needed for the practice of pediatric psychology. Historically, these efforts included surveys of predoctoral, internship, and postdoctoral training programs to describe pediatric and/or clinical child psychology experiences, current training opportunities, and suggestions for progression in training (Drotar, 1975; La Greca, Stone, Drotar, & Maddux, 1988; Routh, 1977; Tuma & Grabert, 1983). More formal efforts to develop training guidelines for pediatric psychology grew in response to national policy efforts to improve mental health services for youth and families. Roberts et al. (1998) produced clear guidelines and justification for general recommended experiences and skills needed for training psychologists to work with children and adolescents. Building from this model for training, in 2003 the SPP Task Force on Recommendations for Training of Pediatric Psychologists provided a comprehensive overview of the critical knowledge areas important to the development of specific skills in pediatric psychology (Spirito et al., 2003).

In recent years, a cultural shift has occurred in the expectations for the education and training of all health care professionals (including psychologists) to emphasize

accountability for professional competencies. Since then, the field of professional psychology broadly has addressed this call to identify core competencies for psychologists and psychology trainees (Fouad et al., 2009). To respond to this movement, the SPP convened a new Task Force on Competencies and Best Training Practices in Pediatric Psychology, to articulate specific competencies necessary for optimal functioning as a pediatric psychologist. Several other groups have also expanded on the core set of professional psychology competencies to tailor specialty-specific competencies, such as those for clinical health psychology (Masters, France, & Thorn, 2009), clinical child psychology (Jackson, Wu, Aylward, & Roberts, 2012), and psychology practice in primary care (McDaniel et al., 2014).

The 2014 SPP Task Force paper (Palermo, Janicke, et al., 2014) was intended not only to identify core competencies in pediatric psychology, but to provide specific benchmarks at different training levels to identify mastery and specific competency achievement in domains specific to pediatric psychology. Identification of competencies is important, because the availability of published competencies in our subspecialty allows us as pediatric psychologists to uphold the same standards of competency attainment as other health service professionals. Moreover, training programs can identify both general and subspecialty competency expectations to represent the goals and learning outcomes of their programs of instruction to pediatric psychology trainees.

SUMMARY OF THE 2014 COMPETENCIES

The competencies in pediatric psychology published in 2014 include 10 cross-cutting knowledge competencies, as well as 6 competency cluster areas identified in the "benchmarks" document for training health service psychologists (Hatcher et al., 2013) and tailored for pediatric psychologists. Behavioral anchors identify specific performance expectations across training levels, from practicum level to entry into professional practice.

Cross-Cutting Competencies

The cross-cutting competencies form a foundational knowledge base applicable to all pediatric psychologists, despite differences in roles and settings. These competencies include (1) understanding of the scientific foundation underlying the practice of pediatric psychology; (2) knowledge and appreciation of the core facets of clinical child psychology; (3) multifaceted, contextual understanding of influences on child health and illness; (4) grasp of medical literature and basic tenets of medical management of acute and chronic child illness; (5) understanding of familial influences on child health and illness; (6) understanding of the effect of socioeconomic and cultural factors on health and health disparities in youth; (7) understanding of the relative influence of systems and contexts (e.g., schools, state/federal policy) on child health and illness; (8) knowledge and appreciation of roles across disciplines involved in health service delivery; (9) awareness of the functions of health information technology; and (10) familiarity with the process of helping pediatric patients make the transition to adult health care networks (Palermo, Janicke, et al., 2014).

Competency Cluster Areas

The six cluster areas include science, professionalism, interpersonal, application, teaching, and systems (Palermo, Janicke, et al., 2014).

1. The science cluster includes the ability to apply research methods in a range of pediatric psychology settings, to engage in ethical conduct in research with children, and to effectively disseminate research findings. In addition, knowledge and skills in interdisciplinary research are needed to integrate expertise from multiple disciplines to study child health and illness.

2. Professionalism is a core tenet of training in pediatric psychology that fosters respect for the complex issues that arise in work with children and families on managing health and illness. Pediatric psychologists should demonstrate the ability to grow and adopt the values/attitudes of appropriate clinical, educational, and research relationships and work ethics; demonstrate appreciation and respect of diversity; adhere to standards and policies within their work setting and ethical code; and engage in ongoing self-reflection and self-care.

3. Interpersonal skills include both communication and relational proficiency. Both of these subdomains are essential for successful interdisciplinary functioning within health care systems (American Psychological Association [APA], 2013).

4. Application, or the day-to-day activities involved in clinical service provision (Rodolfa et al., 2005), includes competencies in evidence-based practice in assessment, intervention, and consultation roles.

5. Teaching and supervision reflect the role that pediatric psychologists occupy as educators of future psychologists and other health professionals.

6. Systems functioning includes developing interdisciplinary system skills (e.g., abilities to communicate with other disciplines, awareness of overlapping and separate team roles), as well as professional leadership and advocacy efforts. This is consistent with previous SPP recommendations for interdisciplinary training, to improve working relationships with other health care providers and to advocate for more pediatric psychologist positions in interdisciplinary settings (Spirito et al., 2003).

Over time, we anticipate that the 2014 competencies will be further expanded and refined as trainers begin to incorporate these competencies into their training programs.

DEVELOPMENTAL STAGES OF TRAINING IN PEDIATRIC PSYCHOLOGY

Following the structure provided by Fouad et al. (2009), the SPP Task Force also identified specific examples of measurable behaviors that would demonstrate competence at different training levels. These are referred to as "behavioral anchors" and can be considered developmental milestones that reflect increasing levels of expertise and independence across training levels (practicum, internship, entry into practice). Although there are many paths to becoming a pediatric psychologist (Palermo, Janicke, et al., 2014), and individual interests will shape career development and experiences, we review a

common developmental trajectory of training in pediatric psychology with examples of competency attainment at each stage.

Undergraduate Training

Undergraduate psychology students rarely receive exposure to pediatric psychology's core competencies as part of their curriculum. Introduction to the field of pediatric psychology often comes from proactively seeking out mentorship, which opens up opportunities such as joining SPP as a student member, participating in SPP's mentorship program, contributing to ongoing studies by their mentors, or presenting research at regional or national conferences (Aylward, Bender, Graves, & Roberts, 2009). Students interested in pursuing a graduate degree are encouraged to seek out additional experience in child-focused settings. Faculty members in graduate programs are most interested in admitting undergraduate students who have research methods coursework and research experience (e.g., completion of an independent research project such as an honors thesis or conference presentation), preferably related to pediatric topics (Karazsia & McMurtry, 2012).

Graduate Training

In graduate training, competency assessment historically focuses on breadth of training and acquiring general clinical child psychology skills (Spirito et al., 2003); however, recent shifts allow graduate students opportunities to increase their experiences with core competencies in pediatric psychology. During graduate training, many programs offer pediatric tracks, electives, or specialized programs that students may pursue, as well as increased pediatric research opportunities and clinical practicum experiences. Incorporating competency-based training and assessment provides valuable opportunities to establish specialization early.

Graduate students are encouraged to join professional societies in order to present data and increase their exposure to the field (Aylward et al., 2009). Competencies in science are also addressed by collaborating on specialized research projects across disciplines and developing advanced data analysis skills (Aylward et al., 2009). Behavioral anchors appropriate at the graduate level are completing literature reviews, giving presentations at conferences or conventions, participating in journal article reviews, and contributing to scientific papers in relevant pediatric and psychology journals (Palermo, Janicke, et al., 2014; Roberts & Steele, 2003).

Clinical practicum training provides important opportunities for building competencies in multiple domains (e.g., interpersonal, professional, application, and systems; Palermo, Janicke, et al., 2014). In addition to developing general professional psychology skills in practicum experiences, students may have opportunities for collaboration with local providers (including hospitals and medical schools) that provide critical training with multiple mentors and pediatric populations (Aylward et al., 2009). Pediatric-oriented practicum sites may include participation in inpatient or outpatient consultation or therapy, interdisciplinary evaluations for children with a range of health conditions, and group therapy experiences (Roberts & Steele, 2003). Students should demonstrate familiarity with ethical issues in clinical work with children and families, show awareness of the value of evidence-based practice, and demonstrate knowledge

of health and behavioral intervention strategies (Palermo, Janicke, et al., 2014). Competency at the graduate level also considers students' demonstration of professionalism and interpersonal skills through their ability to maintain appointments, show insight into the impact personal experiences can have on service delivery, and present with a professional and appropriate demeanor (Palermo, Janicke, et al., 2014). Graduate training is important in pediatric psychology career development, as it provides a breadth of experience that serves to guide future training specialization and may determine students' choices in priorities for clinical internship (Roberts & Steele, 2003).

Internship Training

The predoctoral internship period of training allows for continued breadth of experience with increased specialization through more programmatically intensive pediatric exposure (Spirito et al., 2003). Internship is an opportunity to continue to develop professional competencies and to pursue more advanced specialization in clinical skills than graduate training provides (Steele, Borner, & Roberts, 2014). Behavioral markers at the internship level reflect a student's maturation in abilities in pediatric psychology across all competency cluster areas and cross-cutting competencies (Palermo, Janicke, et al., 2014).

Internship sites in pediatric psychology are often at children's hospitals or other university-affiliated hospitals, which provide opportunities for gaining experience with integration in interdisciplinary treatment settings (Aylward et al., 2009). Programs often provide opportunities for competency attainment through the combination of direct clinical service experiences, supervision, and didactics. More recently, many internship sites have begun offering varied and specialized pediatrics rotations (e.g., in condition-specific areas as well as in primary care), with a corresponding increase in pediatric psychologists' completion of such rotations during their internships (Aylward et al., 2009). These specialized rotations have expanded to include rotations with diverse teams, such as pain management, hematology/oncology, organ transplant, pulmonology, craniofacial anomalies, rehabilitation, and diabetes, among others. Didactic training opportunities vary and can include attending seminars or case conferences that may provide interdisciplinary exposure (Aylward et al., 2009).

Competency expectations increase in a number of areas during predoctoral internship, particularly in application in assessment, intervention, and consultation. Trainees should demonstrate participation in interdisciplinary teams in both research and clinical settings, flexibly adapt interventions to a range of different patient presentations and situations, show increasing knowledge of evidence-based research practices, and demonstrate the ability to formulate a thorough case conceptualization—all while taking into account a range of issues pertinent to health and illness (Palermo, Janicke, et al., 2014). After their internships, many trainees seek out further specialization as they consider career direction.

Postdoctoral Training

Postdoctoral training is typically 1–2 years in duration. The postdoctoral experience allows for further gains in competency and specialization in a research or clinical area in pediatric psychology, and also assists with fulfilling licensure requirements (Aylward

et al., 2009). Presently, postdoctoral training is a common expectation for employment as a pediatric psychologist. In fact, pediatric psychology postdoctoral training opportunities have significantly increased over the years, with three times as many SPP members completing specialized postdoctoral training in the 1990s as in the 1960s (Mullins, Hartman, Chaney, Balderson, & Hoff, 2003). Even early in the field's history, postdoctoral training was recommended to pediatric psychologists as an ideal way to develop their skills (Routh, 1977).

Postdoctoral training may focus on clinical practice, research, or a combination of activities. Trainees may choose a clinical setting that provides an opportunity to gain proficiency with a particular population or in a specific area (e.g., pain management, primary care, program evaluation; Spirito et al., 2003). At this level of training, a pediatric psychologist should be rapidly moving toward complete independence in day-to-day core activities in the application, systems functioning, interpersonal, and professionalism competencies. A pediatric psychologist in a research-based postdoctoral training position should also be moving toward independence in the science competencies (e.g., designing studies, supervising research staff, and writing grants). Competency assessment continues to be important at this stage for ensuring proper preparation for independent practice as a pediatric psychologist within research, teaching, and/or clinical activities.

Licensure/Board Certification

Candidates for licensure or board certification must demonstrate achievement of the core competencies in professional psychology. National competency requirements (e.g., the Examination of Professional Practice in Psychology [EPPP]) are necessary for providing independent psychological services (Aylward et al., 2009). State-level requirements vary, but licensure assessments generally evaluate knowledge and familiarity with state and provincial mental-health-specific statutes (Aylward et al., 2009). Ongoing postlicensure competency assessments remain a focus in the field (Aylward et al., 2009; Palermo, Janicke, et al., 2014).

Board certification through the American Board of Professional Psychology (ABPP) is a national means of identifying specialties. Although the field of pediatric psychology is not recognized by ABPP as a specialty, pediatric psychologists make up approximately half of the psychologists certified by the American Board of Clinical Child and Adolescent Psychology (Aylward et al., 2009). While board certification is not required for practice, benefits associated with this measure of competency include license mobility, financial incentives, and recognition of achieving the highest level of competency in the field.

STRENGTHS AND CHALLENGES IN PEDIATRIC PSYCHOLOGY TRAINING

Given the evolving emphasis on integrated, interprofessional care and the critical role of patient-centered medical homes in the delivery of services, there is a strong need for pediatric and clinical child psychologists to serve in a variety of health service provider roles and settings (Janicke, Fritz, & Rozensky, 2015; Rozensky & Janicke, 2012). Although challenges exist in preparing trainees to function as health service providers

and researchers in this new system, fortunately there is a strong network of training sites where graduate students, interns, and postdoctoral trainees are afforded opportunities to work on interdisciplinary teams with health service professionals from many backgrounds. There continue to be many different pathways of training offered at all levels. Ideally, these opportunities will continue to expand, so that our trainees will learn alongside other disciplines' degreed professionals as well as their trainees in interprofessional environments (Health Service Psychology Education Collaborative, 2013). For example, there are joint training programs that provide education and training to pediatric residents and psychology fellows in behavioral health care and collaboration in primary care settings (Pisani, leRoux, & Siegel, 2011).

Despite the strengths that have emerged with the concerted focus in pediatric psychology on training, there are also inherent challenges across all levels of training. One challenge concerns access to pediatric populations, particularly at the undergraduate and graduate levels, in order to provide experience to students learning to conduct applied research, to perform evaluations, and to apply evidence-based interventions with children and adolescents in medical settings. At the undergraduate level, there are few opportunities for coursework in pediatric psychology, to allow exposure to the field or guidance from mentors in the field. However, when such opportunities are available, undergraduates can obtain critically important exposure to the activities of pediatric psychologists and can begin to develop knowledge-based competencies and develop interest in pursuing graduate training in pediatric psychology. Similar challenges may exist at the graduate level of training, where pediatric psychology mentors may not be readily available and/or graduate programs do not have close proximity to pediatric populations for research or for clinical placements. Reimbursement issues can also restrict access to pediatric populations for clinical practica. This may result in students' obtaining only limited hands-on experience with pediatric populations until later in training or on the job.

There are ongoing debates regarding the appropriate point in training to initiate specialization (Palermo, Janicke, et al., 2014; Spirito et al., 2003; Steele et al., 2014). Graduate training balances general requirements with opportunities for pursuit of specialization. Creating a specific pediatric psychology track within a department allows students to do general clinical child psychology coursework, as well as to specialize in pediatric-focused courses. In programs where an independent track is not possible, departments can offer electives and focused practica in pediatric psychology (Roberts & Steele, 2003). The balance between offering necessary training (including lifespan developmental psychopathology, research methods, and assessment) and providing graduate students with opportunities to pursue specialized interests can be particularly challenging (Roberts & Steele, 2003; Steele et al., 2014). Partnership with other departments is one option for increasing specialization opportunities by providing electives that allow students to collaborate and participate in interdisciplinary training (Roberts & Steele, 2003). Another option is to offer opportunities to participate in focused programs such as grant-writing courses (Roberts & Steele, 2003) or pediatric-psychology-specific seminars (Ievers-Landis, Hazen, & Fehr, 2015). Optional, focused programs give students opportunities for increasing specialization without mandating it across the department.

There also remain challenges in interdisciplinary roles for pediatric psychologists. Although the field of pediatric psychology has historically focused on collaboration with pediatricians and other physicians, students in most educational programs receive

the bulk of their teaching, mentoring, and supervision from psychologists, and there is limited early exposure to other disciplines (Drotar, 2012). In the present health care environment, interdisciplinary roles must be expanded beyond collaboration with physicians to include a range of other health care professionals (e.g., case managers, medical aides, physical therapists, social workers, nurses); this will result in broader exposure to the field. Science has also expanded considerably to include diverse teams of investigators from many different backgrounds (e.g., epidemiology, computer science, bioethics, health economics). Students receiving contemporary training in pediatric psychology will benefit from an expansive introduction to the roles and values of a diverse range of professionals. A related benefit from early exposure to interdisciplinary roles is that other health care professionals and research investigators will learn the value and skills of pediatric psychologists on such teams.

FUTURE DIRECTIONS FOR THE EVOLUTION OF TRAINING

Given the importance of competency attainment as described by Palermo, Janicke, et al. (2014) and as noted in this chapter, it will be increasingly important to develop and implement reliable and valid methods of assessing competency attainment, both for trainees and for advanced professionals. The competency assessment toolkit for professional psychology developed by Kaslow et al. (2009) encourages multimethod assessment of competencies and provides a wide array of potential strategies for assessing competency attainment. As we better define and measure competencies, a logical next step is for training programs to examine, determine, and evaluate best training practices. This helps trainees and current professionals acquire and demonstrate the competencies identified as important at various levels of training and practice. Determining what combinations and types of coursework, practica, and interprofessional training experiences, delivered in what order, lead to optimal competency attainment and training outcomes will be crucial. There is no one "best path" for training, and certainly training practices will differ according to each program's (and individual's) unique goals and available resources. Ongoing dissemination and discussion via journals, workshops, and conference presentations will be vital as the field strives to evolve best training practices in line with the changing health care environment. As a first step toward this goal, the SPP Task Force on Competencies and Best Training Practices in Pediatric Psychology produced a special issue of the journal *Clinical Practice in Pediatric Psychology* in 2015, to showcase examples of programs that have developed practices fostering competency attainment in pediatric psychology (Palermo et al., 2015).

Several specific competencies and areas of training will deserve particular focus in the evolving health care system. First, as our understanding of health has become increasingly biopsychosocial, and as we work with teams of health service providers for integrated practice, we will need a broad knowledge base across disciplines. Training in pathophysiology, biogenetics, and psychopharmacology will be increasingly important. Notably, if we want to be better able to advocate for patients and for our services as pediatric psychologists, we will need to improve our knowledge of health policy and our health insurance literacy (APA, 2015; Janicke et al., 2015).

Increased opportunities for interprofessional education and training opportunities will also be essential. Interprofessional training is defined as occurring "when students

from two or more professions learn about, from and with each other to enable effective collaboration and improve health outcomes" (World Health Organization, 2010, p. 10). As this training model becomes more prevalent in other health professions, we psychologists cannot expect to be added to health care teams when team members did not train with our students (Belar, 2012). Our training programs must continue (or need) to reach out to other health care settings and disciplines for more advanced training, and to refine our competency guidelines to reflect joint training goals.

Given the emphasis of the new health care system on integrative care and primary care patient-centered medical homes, pediatric psychology must be proactive in expanding its role in integrating behavioral and physical health care in primary care settings (Rozensky & Janicke, 2012). Training for the next generation of pediatric psychologists should include a focus on developing competencies needed to function successfully in primary care settings. This includes a strong emphasis on brief targeted assessment and therapy, as well as practice-based research models enhanced by developing collaborations and primary care practicum placements that will allow for hands-on clinical experiences.

With the increased emphasis on accountability in the current health care system, policy makers and payers are increasingly focused on quality *and* cost of care. Research and data documenting quality of care, as well as cost-offset and cost-effectiveness for our services, will be essential as pediatric psychologists advocate for service inclusion and reimbursement in the integrated health care arena (Rozensky & Janicke, 2012). It will be beneficial for aspiring pediatric psychologists to receive training in conducting cost-offset and cost-effectiveness research, as well as defining and measuring patient-centered outcomes.

Finally, advocacy will be increasingly important as the parameters of the new health care environment continue to evolve. Psychologists, including pediatric psychologists, must be included when team-based reimbursement structures are defined within legal statutes, Medicare and Medicaid rules, insurance company policies, and local hospital settings (Rozensky, 2011). Pediatric psychologists must become strong advocates for our profession by displaying confidence in the excellent, data-based services that we uniquely provide. We cannot rely on physician colleagues to support and promote our profession. Many pediatric psychologists may not have experience serving in this role, but do have the requisite knowledge to communicate to policy makers the importance of services to children and their families. Training and encouraging our trainees and professional colleagues to develop skills in selling our "value added" will help us to ensure that we can best advocate for children and families, as well as our profession.

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CHAPTER 6

Quality Improvement and Cost-Effectiveness

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As part of the Patient Protection and Affordable Care Act (2010), the U.S. Department of Health and Human Services (2014) was tasked with establishing "a national strategy to improve the delivery of health care services, patient health outcomes, and population health" ("Overview of the National Quality Strategy," para. 1). In response, the Agency for Healthcare Research and Quality has established an agenda, the National Quality Strategy, focusing on three aims: (1) better care—improving the overall quality of care; (2) healthy people/healthy communities—improving the health of the U.S. population by supporting evidence-based interventions; and (3) affordable care—reducing the cost of health care (U.S. Department of Health and Human Services, 2014). Efforts to achieve these aims have resulted in an increased focus on quality, defined by the Institute of Medicine (1990) as the "degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (p. 37). In addition, these efforts have led to significant shifts in health care payment models, including the growth of value-based reimbursement ("pay for performance") and bundled care (American Psychological Association, 2009; Medicare Payment Advisory Commission, 2014).

For pediatric psychology to align with efforts to improve quality and continue to grow in the era of new payment models, it will be essential for the field to answer systems-level questions such as "How can the quality of behavioral health care be improved?" and "Can a behavioral intervention reduce health care spending?" (Chassin & Galvin, 1998; Rozensky & Janicke, 2012). Arriving at these answers can be accomplished by moving beyond the randomized clinical trial (RCT) framework typically used to test behavioral interventions, and incorporating methods originally developed in industry

and economics. Specifically, leaders in pediatric psychology have highlighted the potential of quality improvement (QI) and cost-effectiveness (CE) frameworks to determine the impact of interventions on the quality and cost of health care (Rozensky & Janicke, 2012; Stark, 2010).

In contrast to RCTs, which are designed to determine efficacy, QI methods focus on quantifying the delivery and impact of evidence-based interventions on "real-world" practices and patients. QI methods include a series of iterative improvement cycles known as "plan, do, study, act" (PDSA) cycles, in which data are continuously collected and reevaluated to test interventions and inform refinements (Berwick, 1998). Pediatric psychologists can use QI methods to implement behavioral interventions within routine clinical care and assess their impact on patient outcomes and health care quality (e.g., Ernst et al., 2010).

The quality of health care should not be interpreted in isolation, as "high-quality health care is useful only when people find it affordable" (U.S. Department of Health and Human Services, 2014, p. 12). As a result, health care administrators and insurance companies selecting among interventions to improve specific health outcomes and quality indicators may utilize CE analyses. CE analyses compare the outcomes and costs of two or more interventions (Muennig, 2002). Typically, the intervention of interest is compared to an alternative intervention or control condition (i.e., treatment as usual). An incremental cost-effectiveness ratio (ICER) quantifies the relative cost per additional desirable outcome (e.g., symptom-free day) obtained. For example, a CE analysis of the Coordinated Approach to Child Health school-based intervention program targeting childhood obesity produced an ICER of $900 (2004 U.S. dollars) per quality-adjusted life year (1 year lived at perfect health) saved (Brown et al., 2007). If administrators were considering implementing this intervention, they would have to decide whether a gain of a quality-adjusted life year for a child is worth a $900 investment.

Pediatric psychologists can use QI and CE methods to demonstrate how behavioral interventions improve health care quality and reduce costs. The purpose of this chapter is to provide an overview of the design and interpretation of QI and CE methods as relevant to pediatric psychologists. Potential applications and recommendations for further education are also provided.

CLINICAL CARE EXAMPLE

To envision how a pediatric psychologist could apply QI and CE methods to evaluate a behavioral intervention, consider a pediatric psychologist providing care in a clinic for children with sickle cell disease (SCD). Consistent with the larger population of children with SCD, many patients served by this pediatric psychologist suffer from unpredictable and recurrent pain episodes that ultimately result in emergency department (ED) visits. The pediatric psychologist may be interested in implementing evidence-based behavioral pain management strategies that have been demonstrated to reduce pain episodes and health care contacts (Gil et al., 1997, 2001). Utilizing QI and CE methods could enable the psychologist to determine (1) the most effective methods for implementing a home pain management plan (HPMP) that includes empirically based behavioral pain management strategies; and (2) whether it would be economically feasible to provide the HPMP intervention to all children with SCD.

QUALITY IMPROVEMENT

QI is a theory-based approach to developing, testing, and implementing new processes to improve patient outcomes and the quality of care. A QI approach is most appropriate when the goal or global aim is to (1) design or implement a process (e.g., provide routine assessments of and interventions for self-reported pain among children with SCD); (2) replicate or disseminate a process (e.g., apply an HPMP in another SCD clinic); or (3) generate new ideas for solving a systems-level challenge (e.g., develop and implement an HPMP to help children with SCD manage their pain at home). QI also requires a team that can directly change the targeted process, measure baseline functioning, and track progress. For example, a QI approach would not be appropriate if a multidisciplinary health care team wanted to develop and test a process to change how pain is treated in the ED, but was not able to modify ED procedures or collect data on how pain is currently being treated in the ED.

Design

Once the team verifies that the global aim can be achieved by using QI methods, the project should proceed in accordance with the QI roadmap (Figure 6.1). First, a "specific, measurable, actionable, relevant, and time-bound," or SMART, aim is developed. For example, a multidisciplinary team implementing a pain management intervention for children with SCD, with the global aim of minimizing ED visits and hospitalizations for pain (Crosby et al., 2014), developed the following SMART aim: Increase the percentage (from 0 to 85%) of sickle cell patients 5 years and older who have an individualized HPMP by November 2012 (Figure 6.2). An outcome measure is then selected to assess progress toward achieving the SMART aim. In the aforementioned example, the outcome of interest was the percentage of patients receiving an HPMP. Typically, the primary outcome variable reflects the degree to which changes within the health care system have been implemented, or the magnitude of changes in patient outcomes.

After process and outcome measures have been established, baseline data are collected (e.g., percentage of patients currently receiving a HPMP intervention) and used to inform the development of a "key driver" diagram or learning structure. Key driver diagrams are comprised of three or more levels (Figure 6.2). The first level includes the global aim, the SMART aim, and relevant process or outcome measure(s). The second level includes the key drivers, or high-level factors driving the targeted process, that need to be influenced in order to achieve the SMART aim (e.g., family education and engagement in pain management; Crosby et al., 2014). The third level includes potential interventions that may influence the key drivers (e.g., develop a comprehensive, individualized HPMP, provide pharmacological and nonpharmacological strategies).

Next, potential interventions are tested using a series of small tests of change or PDSAs with small groups of patients (N = 1–5). The team implementing an HPMP in an SCD clinic used PDSAs to develop and implement the intervention of using standard assessment tools (Crosby et al., 2014). For example, the first PDSA tested potential procedures for completing a pain assessment during clinic visits (Figure 6.3). Specifically, procedures were developed (plan) to ensure that the assessment tool was available, identify who would administer the assessment, and detail how the assessment would be introduced. This process was then tested ("do") with three patients during one clinic.

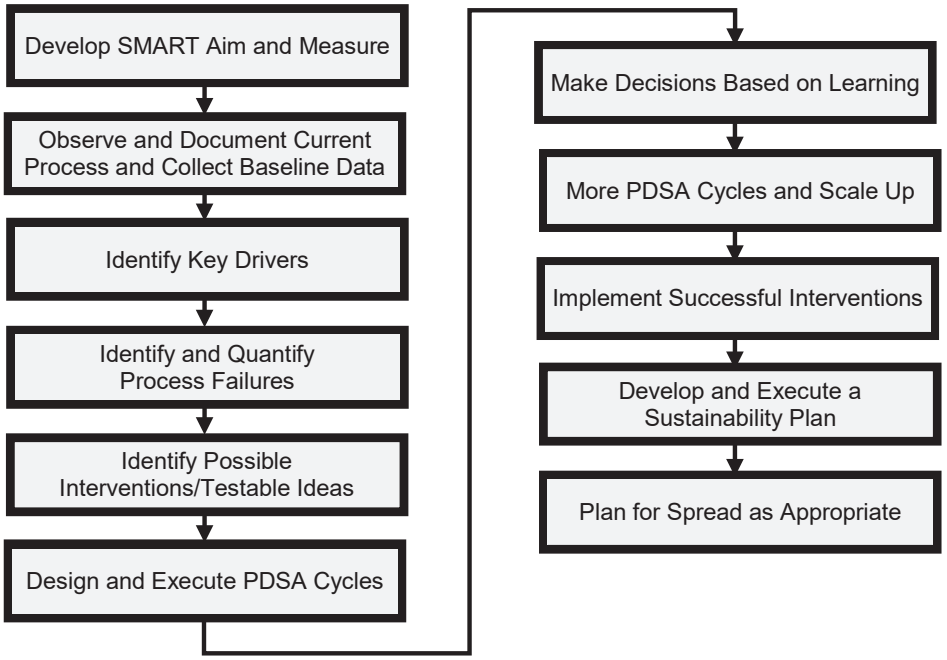

FIGURE 6.1. Quality improvement (QI) roadmap. SMART, "specific, measurable, actionable, relevant, and time-bound"; PDSA, "plan, do, study, act." Copyright © 2015 Cincinnati Children's Hospital Medical Center. Used with permission.

As results indicated that the assessment could be completed in 5 minutes and did not disrupt clinic flow ("study"), the team decided to adopt this process ("act").

Interpretation

Results of QI efforts are depicted by plotting the outcome of interest as measured at regular intervals (often a time scale such as weeks or months). These figures are termed "run charts" or "control charts." To facilitate interpretation, run charts also include a goal line representing the predetermined SMART aim (e.g., 85% of eligible patients will have an HPMP) and notation of intervention components (e.g., list of patients needing an HPMP). For example, Figure 6.4 depicts the run chart used to monitor weekly progress on the percentage of eligible patients with an HPMP; it indicates that the SMART aim was met in May 2013, when 88% of patients had an HPMP. Probability-based rules can also be used to compare data points to the baseline median and test for nonrandom patterns (i.e., shifts, trends, runs) (see Perla, Provost, & Murray, 2011, for an overview). Results are then used to inform whether an intervention will be adopted, adapted, or abandoned. Once procedures are finalized, plans for sustainability and dissemination are implemented as appropriate.

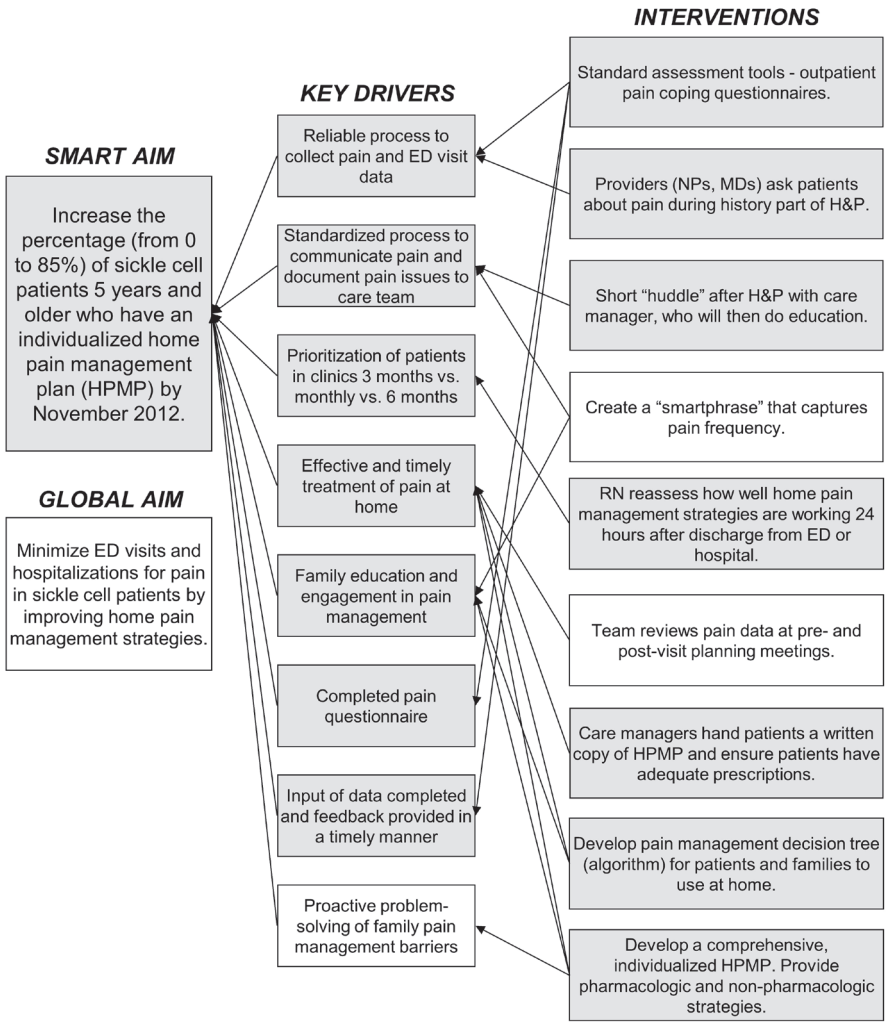

FIGURE 6.2. Key driver diagram. ED, emergency department; H&P, history and physical; HPMP, home pain management plan. Copyright © 2015 Cincinnati Children's Hospital Medical Center. Used with permission.

Applications

QI projects facilitate the development, implementation, and dissemination of systems-level changes that can improve the quality of health care and lead to better patient health outcomes (Langley et al., 2009). As illustrated in the example above, pediatric psychologists can use QI methods to systematically develop and implement evidence-based interventions. In this instance, using a QI approach resulted in the dissemination of an evidence-based intervention (i.e., the HPMP) into standard clinical care for patients with SCD. Ernst et al. (2010) also successfully used QI methods to develop a multidisciplinary

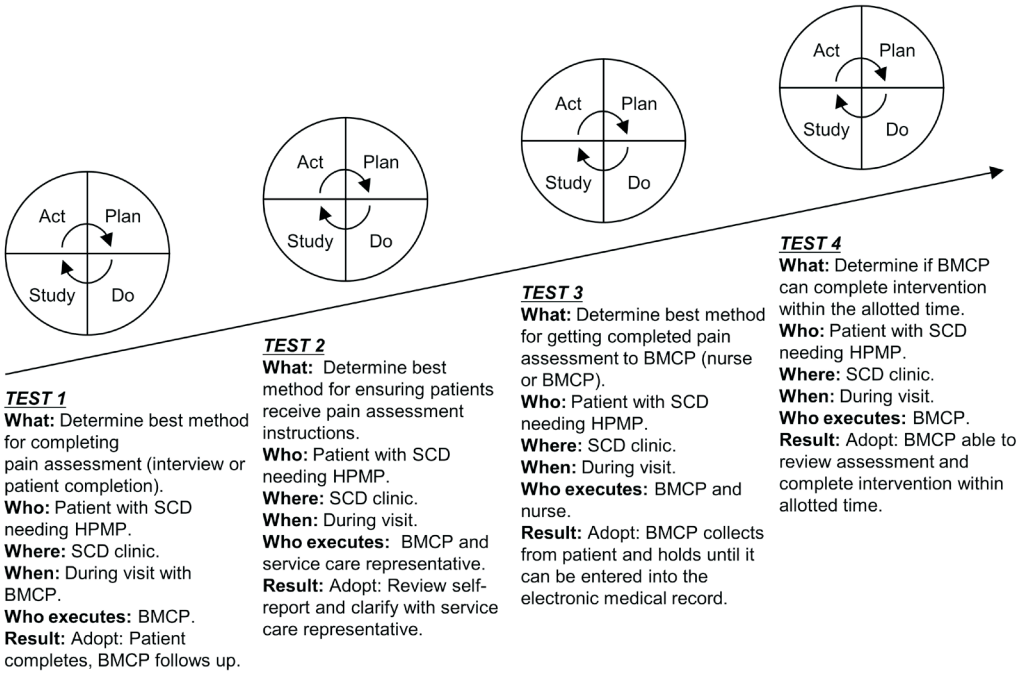

FIGURE 6.3. PDSA ramp. SCD, sickle cell disease; BMCP, behavioral medicine and clinical psychology provider; other abbreviations as in earlier figures. Copyright © 2015 Cincinnati Children's Hospital Medical Center. Used with permission.

intervention to increase the occurrence of best-practice airway clearance therapy among adolescents with cystic fibrosis receiving inpatient standard clinical care.

Once a new procedure is developed, pediatric psychologists can also use QI methods to monitor implementation by answering such questions as "Are eligible patients receiving the appropriate assessment/intervention?" (Crosby et al., 2014). Reed-Knight et al. (2015) tracked the percentage of patients with SCD who were assessed for pica, and used this information to inform refinements to clinical procedures. Following QI project implementation, assessment of pica behaviors increased from 36 to 100% among patients with SCD.

Finally, pediatric psychologists can use QI methods to monitor patients' response to treatment and inform potential modifications. In a QI pain management initiative, Kline et al. (2010) monitored treatment response to nonpharmacological interventions among children admitted to a pediatric intensive care unit. Data were used to refine intervention content and ultimately informed a new training protocol for pediatric intensive care unit nurses, medical residents, and fellows.

In sum, QI methods have multiple potential applications in pediatric psychology. To ensure that QI methods are conducted in accordance with best practices, interested teams are encouraged to refer to previously published methodological (Taylor et al., 2014) and reporting (Ogrinc et al., 2008) guidelines.

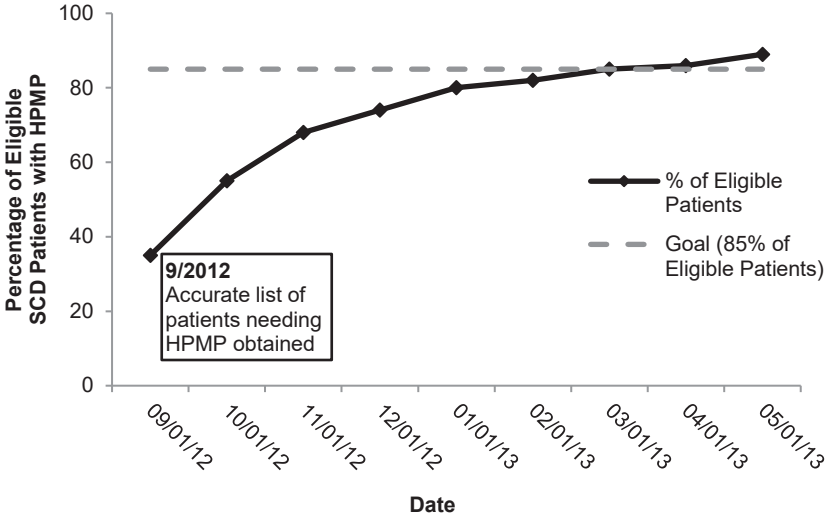

FIGURE 6.4. Run chart of percentage of eligible patients with SCD and a home pain management plan (HPMP). From "Using quality improvement methods to implement an electronic medical record (EMR) supported individualized home pain management plan for children with sickle cell disease" by L. E. Crosby, K. Simmons, P. Kaiser, B. Davis, P. Boyd, T. Eichhorn, . . . K. A. Kalinyak, 2014, *Journal of Clinical Outcomes Management, 21,* p. 11. Copyright © 2014 Turner White Communications. Used with permission.

COST-EFFECTIVENESS ANALYSES

Once the impact of a behavioral intervention on health outcomes has been established, CE analyses may be used to understand the costs and outcomes of the intervention of interest relative to another intervention.

Design

Muennig (2002, 2008) described seven primary steps in a CE analysis: (1) develop a research question; (2) design the analysis; (3) obtain data; (4) adjust data; (5) construct a model; (6) test the model; and (7) conduct sensitivity analyses. A CE analysis begins with a research question indicating the intervention, population, and clinical outcome of interest. The clinical outcome should be a variable that is relevant to the target population, is expected to change as a result of the intervention, and is ultimately expected to lead to changes in economic outcomes (Ramsey et al., 2005). Returning to the earlier example, a CE analysis could be used to compare the costs and pain episodes (clinical outcome) associated with an individualized HPMP (intervention) for children with SCD (population) to those associated with standard clinical care (no intervention). Pain episodes meet the aforementioned criteria, as they are commonly experienced by patients with SCD and account for up to half of all ED visits, and thus their associated costs (Crosby et al., 2014). In addition, previous research has demonstrated that psychosocial

interventions reduce pain episodes (Chen, Cole, & Kato, 2004) and ED visits (Crosby et al., 2014) among children with SCD.

Next, the analysis is designed by collecting required data elements. Required data elements include relevant clinical outcomes and costs, and can be identified by using previously described frameworks (Muennig, 2002; Luce, Manning, Siegel, & Lipscomb, 1996). These data can be collected as part of ongoing intervention studies or based on estimates from previously published studies, expert opinion, or national databases (see Muennig, 2008, for a list of resources). Data should be adjusted for inflation and time preference as recommended by the Panel on Cost-Effectiveness in Health and Medicine (Weinstein, Siegel, Gold, Kamlet, & Russell, 1996). A model is then selected to test the research question. As detailed in previous reviews (Kim & Goldie, 2008; Stahl, 2008), the most appropriate model for a given CE analysis depends on a number of factors, including the duration of the treatment effect (e.g., short-term vs. long-term) and the natural progression of the medical condition (e.g., static vs. dynamic). Finally, sensitivity analyses are used to test how variations in inputs (e.g., HPMP reduces pain in 50% vs. 70% of patients) may change the results (Briggs et al., 2012).

Interpretation

Results of a CE analysis represent the differences in cost and effectiveness between two interventions, or the incremental cost-effectiveness ratio (ICER). If the psychologist in the earlier example was interested in examining the cost-effectiveness of the HPMP, an ICER could be calculated to determine the differences in costs and impact on pain episodes between the HPMP and no intervention. This ICER would be expressed as follows:

$$\text{ICER} = \frac{(\text{total cost of HPMP} - \text{total cost of no intervention})}{(\text{pain episodes, HPMP} - \text{pain episodes, no intervention})}$$

The ICER can be represented graphically on a CE plane developed by Black (1990), where the *x*-axis represents differences in intervention effects (pain episodes) and the *y*-axis represents differences in costs. The ICER will fall in one of four quadrants: (I) increased effectiveness, increased cost (HPMP is *more* effective and *more* costly than no intervention); (II) increased effectiveness, decreased cost (HPMP is *more* effective and *less* costly than no intervention); (III) decreased effectiveness, decreased cost (HPMP is *less* effective and *less* costly than no intervention); or (IV) decreased effectiveness, increased cost (HPMP is *less* effective and *more* costly than no intervention) (Muennig, 2002, 2008). Interventions falling in quadrant II can be categorized as "cost-effective," while interventions falling in quadrant IV can be categorized as "not cost-effective." Interventions in these quadrants do not require a tradeoff between cost and effectiveness, because both the cost and effectiveness of the intervention represent positive (quadrant II) or negative (quadrant IV) outcomes. Conversely, interventions in quadrants I and III require a consideration of the acceptable cost-effectiveness ratio (Black, 1990). For example, interventions in quadrant I elicit questions such as "How much are we willing to pay to prevent a pain episode for a child with SCD?" Similarly, while interventions in quadrant III are generally not considered, as they are predicted to be less effective, determining whether or not they are "cost-effective" requires answering the question:

"How much would we have to save to be willing to provide an intervention that may result in increased pain episodes for a child with SCD?"

Applications

In countries other than the United States, results of CE analyses are often a component of health care policy decisions (Neumann, 2004; Neumann, Rosen, & Weinstein, 2005; Williams, Bryan, & McIver, 2007). Although Medicare does not formally consider CE when determining coverage, pediatric psychologists can still use these results to advocate for their services. In the most favorable scenario, the individualized HPMP would be more effective and less costly than no intervention in reducing pain episodes, allowing a psychologist to show how he or she could not only improve patient outcomes, but also reduce health care costs. For example, Wang, Crossett, Lowry, Sussman, and Dent (2001) compared the costs and health outcomes of Project Toward No Tobacco Use, a school-based tobacco-use prevention program, to those resulting from no intervention. Results indicated that the intervention was more effective in preventing students from becoming established smokers and (as a result of averted medical costs) less costly than no intervention. The program, thus, was considered "highly cost-effective."

Perhaps more likely, the individualized HPMP (or another intervention developed or delivered by a pediatric psychologist) may be more effective but also more costly than standard care (quadrant I). In this scenario, the services provided by the psychologist have the potential to improve patient outcomes, but still require additional financial support. Equipped with the results of a CE analysis, however, the psychologist would be able to estimate how much the institution or insurance company would need to invest in psychological services to reduce pain episodes. A number of published CE analyses estimate the costs required to improve health outcomes by implementing behavioral interventions targeting healthy eating and physical activity (e.g., Moodie et al., 2013), alcohol use (e.g., Neighbors, Barnett, Rohsenow, Colby, & Monti, 2010), and sexual behavior (e.g., Cooper et al., 2012).

While CE analyses of pediatric behavioral interventions are promising, the published literature is largely limited to large-scale examinations of interventions targeting "healthy" children and adolescents (McGrady & Hommel, 2016). Additional research is needed to determine if similar economic benefits extend to behavioral interventions including other populations (i.e., children with chronic medical conditions) and delivered in other settings (i.e., outpatient clinics). Guidelines for conducting (Ramsey et al., 2005) and reporting (Husereau et al., 2013) such research have been established by the International Society for Pharmacoeconomics and Outcomes Research (*www.ispor.org*).

EDUCATION

To ensure that QI methods and CE analyses are conducted in accordance with published guidelines, individuals interested in utilizing these methods are encouraged to seek specialized training. The Institute for Healthcare Improvement, the National Association for Healthcare Quality, and the Quality Innovation Network provide training and networking opportunities in QI; the Society for Medical Decision Making and the Inter-

national Society for Pharmacoeconomics and Outcomes Research offer training and networking in CE. In addition, pediatric psychologists may wish to consider developing collaborations with experts in other fields specializing in these methods (for QI, health care administrators/managers; for CE, health economists).

LIMITATIONS AND FUTURE DIRECTIONS

Despite the promise of QI and CE methods, pediatric psychologists should be aware of their potential barriers and limitations. To use QI methods, psychologists must have access to practice data (e.g., patient characteristics, number of patients receiving assessment/intervention) and outcome data (e.g., number of ED visits for SCD pain). Similarly, in order to conduct CE analyses, researchers must have access to economic data. Despite national efforts to facilitate access to health care price data, the types of economic data (i.e., costs, charges, reimbursements) collected by institutions differ by state (Health Care Incentives Improvement Institute, 2015). In addition, procedures for the release of patient-level data are likely to vary across institutions. Psychologists should work with relevant financial services or billing departments at their institution to understand local policies and procedures.

CONCLUSIONS

In sum, QI and CE methods are valuable tools that pediatric psychologists can use to disseminate behavioral interventions and demonstrate their utility and economic benefits. In this era of health care reform, QI and CE methods are likely to play a crucial role in the continued advocacy for the unique role of pediatric psychologists.

ACKNOWLEDGMENTS

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PART II

CROSS-CUTTING ISSUES

CHAPTER 7

Culture and Diversity in Research and Practice

Daniel L. Clay

The importance of culture and diversity in mental health care, health care, and pediatric populations has been well documented. Decades of research have demonstrated links between diversity-related variables and disease prevalence rates, access to care, treatment quality, and health and mental health outcomes. In fact, racial and socioeconomic status (SES) disparities in health care have been identified by the U.S. Congress and the National Institutes of Health (NIH) as critical problems requiring significant increases in funding to improve research and practice (*http://report.nih.gov/nihfactsheets/viewfactsheet.aspx?csid=124*).

The purpose of this chapter is to summarize issues of culture and diversity related to conducting research in pediatric psychology and providing services to pediatric populations. The literature on these topics is expansive and growing, so here I focus on summarizing the literature, highlighting critical issues, and identifying recommendations for future efforts. (Please see Lescano & Rahill, Chapter 38, this volume, for a thorough review of health disparities and related issues, such as access to care and quality of care.) First, I highlight a few of the diversity concepts and issues related to both research and practice that provide a context for specific issues within each of those areas. Next, I focus on issues of conducting research with diverse populations, including research methods and recommendations for advancing our scientific understanding of culture and diversity in pediatric psychology. Finally, I review treatment issues, such as models of cultural competence in providing services, as well as guidelines for education and training.

DEFINITIONS/CONCEPTS IN CULTURE AND DIVERSITY

There currently exist differences of opinion among researchers and practitioners regarding what exactly "culture" refers to and how it can be measured, although there is

universal agreement about its importance. Jahoda (2012) extensively reviews definitions of culture and concludes that there is little agreement; in fact, some definitions are mutually exclusive of each other. Asad and Kay (2015) have examined interpretations of culture among officials in government and health care organizations. They have found that culture is defined and interpreted in many different ways, and that these interpretations influence health interventions.

Much of the early research in culture and diversity in health care focused on race and its relationship to disease prevalence rates and outcomes. Racial disparities and differences continue to dominate the literature and professional discussions. However, the current discussion of diversity has significantly broadened to include SES, religiosity, sexual orientation, ability status, gender, and geographical (urban vs. rural) variables, as well as acculturation and language. The broadening of this scope occurred because research has demonstrated that *within*-group differences are often greater than *between*-group differences, and that these within-group variables are often associated with psychological and health outcome variables of interest. For example, acculturation can account for greater differences in outcomes than membership in an ethnic or cultural group can. Jadalla, Hattar, and Schubert (2015) found that acculturation was the most important predictor of health-promoting behaviors among Arab Americans. These issues are complex and interactive, which makes research and application to evidence-based practice even more difficult (Asad & Kay, 2015; Clay, Mordhorst, & Lehn, 2002).

Understanding diversity in relation to health outcomes in children is increasingly important because of the increasing diversity of the United States. U.S. Census Bureau data suggest that the United States will become a "majority-minority" country within the next 30 years (*www.census.gov*). That is, the black, Asian, and Hispanic populations are expected to increase significantly, while the white non-Hispanic population is expected to decrease. These demographic changes and their associated increases in health disparities require that researchers and health care providers focus on cultural competence (Yali & Revenson, 2004). Research has linked these specific populations to poorer health outcomes in asthma, heart disease, diabetes, and cancer, to name only a few areas (see Lescano & Rahill, Chapter 38, this volume). However, much of the research to support evidence-based treatments in pediatric psychology fails to account for critical cultural variables in these groups (Clay et al., 2002), and failure to account for such variables can negatively influence the design, implementation, and evaluation of large-scale public health projects (Asad & Kay, 2015). Other forms of diversity, such as sexual minority status, have also been related to health care access and outcomes (Mink, Lindley, & Weinstein, 2014).

Any discussion of cultural variables within the mental health or health care context must also account for historical influences. For example, many populations within the United States have experienced and continue to experience oppression, marginalization, and prejudice. Recent racially charged events in Ferguson, Missouri, and elsewhere (see, e.g., *www.cnn.com/2014/11/25/us/national-ferguson-protests*), as well as nationwide protests on university campuses (see, e.g., *www.nytimes.com/2015/11/12/us/racial-discrimination-protests-ignite-at-colleges-across-the-us.html?_r=0*), provide clear evidence of the continuing influence of oppression and its current importance in today's political and interpersonal environment. The infamous Tuskegee Experiments of the 1930s, in which treatment was intentionally withheld from African American men, constitute just one example of abuses that have occurred in research and health care (Gamble, 1997). This legacy of abuse is one of several reasons why trust in health

care researchers and providers is a major barrier to addressing disparities in health outcomes among various racial minority groups (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). Boulware et al. (2003) examined trust in physicians, hospitals, and health insurance plans, and found that black patients were significantly less likely to trust physicians. In addition to racial discrimination, health care discrimination against other groups, such as those with disabilities, has been well documented (Bognar, 2010).

RESEARCH

Race, ethnicity, and SES are among the most widely researched cultural variables, yet there remains a lack of agreement on how to define and measure these variables. Entire volumes have been written on various definitions, methods, measurements, and approaches to analysis of cultural variables in health research. Ford and Kelly (2005) have published a comprehensive article examining conceptualization, definition, measurement, and design in regard to race and ethnicity in health research. They discuss race and ethnicity as social constructs, review specific issues with measurement of these constructs, and provide recommendations for health services researchers on the use of self-report categories of race and ethnicity. Stansfield and Dennis (2003) published a comprehensive text on definition and measurement issues, and Stansfield (2011) has followed up with a revised text incorporating more recent research on measuring race and ethnicity.

Historically, health studies, including pediatric psychology studies, have failed to include racial/ethnic minorities and other underrepresented groups appropriately (Clay et al., 2002). The NIH (2001) now provides specific guidelines and requirements for including women and minorities in research. The NIH website includes a comprehensive set of resources for researchers to identify best practices; podcasts on utilizing resources and best practices; and forms and Frequently Asked Questions pages to aid researchers. NIH has also created the National Institute of Minority Health and Health Disparities, which coordinates all health disparities research and promotes the training of a diverse workforce (*www.nimhd.nih.gov*).

There are numerous challenges, however, in conducting health-related research with racial/ethnic minorities and other underrepresented groups. As previously mentioned, the mistrust resulting from historical abuse and discrimination constitutes a major barrier to recruitment (Penner et al., 2009). Recruiting and retaining participants; using culturally appropriate measures for independent and dependent variables; and overcoming language barriers, social stigma, and financial difficulties (e.g., costs of participation due to travel or missing work) can all be significant obstacles to research (Huang & Coker, 2010). Yancey and colleagues (2006) conducted a thorough literature review of studies examining strategies to improve minority recruitment and participation in research. They provided specific recommendations to researchers (e.g., telephone follow-up with African Americans for surveys), in addition to macro-level recommendations for improving policy to enhance minority participation.

Researchers have typically used quantitative methods to examine culture and diversity variables in relation to health. Correlational, between-group, and quasi-experimental designs are the most common of these methods, with randomized clinical trials the gold standard for treatment research. However, strict use of quantitative research designs in examining the complex relationships between culture and health

fails to account for the cultural context of data (Greenfield, 2007) and the uniqueness of cultural issues within and between groups (Asad & Kay, 2015). Increasingly, mixed-methods designs (i.e., studies utilizing both quantitative and qualitative methodologies) are used to examine empirical relationships, while also providing a context for interpreting and understanding results. Bartholomew and Brown (2012) provide an extensive review of the literature on mixed methods in cultural research; they conclude that mixed-methods designs can advance research on culture and psychology. Likewise, such designs can effectively examine cause–effect relationships and determine treatment efficacy, while simultaneously clarifying the within-group determinants of health outcomes and the patients' experiences.

Mitchell, Patterson, and Boyd-Franklin (2011) provide an excellent overview of issues related to increasing cultural diversity in family assessment research. They review barriers such as mistrust, difficulties in recruitment and retention, lack of sensitivity on the part of researchers, language barriers, lack of research instruments normed on diverse populations, and study criteria that disproportionately affect minority and low-SES families (e.g., single-parent households). They provide numerous recommendations, such as using measures validated in diverse populations, removing barriers to family participation, ensuring generalizability to diverse groups, and conducting research that allows translation into effective treatments for those patients and families that need it most.

Effectively translating science into practice is essential to ensure optimal outcomes for children with health problems and their families. The development and improvement of treatments must be based upon the growing body of scientific literature that helps us understand the active ingredients in therapeutic approaches and their relationship to individual differences, disease characteristics, and cultural variables. So-called "evidence-based treatments" are those that have a sufficient body of research to support their efficacy, safety, and cost-effectiveness. Increasingly, third-party payers will only pay for treatments deemed "evidence-based" or "empirically supported."

We (Clay et al., 2002) reviewed 71 research studies cited as evidence of empirically supported treatments within the *Journal of Pediatric Psychology,* to determine the extent to which they addressed issues of cultural diversity. Studies were selected if they were cited in support of treatments for asthma, cancer, diabetes, and obesity, because all of these health conditions have been consistently linked to cultural variables. Only 27% of the studies reviewed even reported the race or ethnicity of study participants; only 18% reported SES; and inclusion (or even mention) of cultural variables as potential moderators was virtually nonexistent. Clearly, the research used to support evidence-based treatments failed to account for cultural variables, suggesting that much work remains to be done in this regard.

We (Clay et al., 2002) made several specific recommendations for future research to address cultural issues in pediatric psychology treatment research, which are adapted and listed below:

1. Examine family factors associated with culture and their relationship to treatments, including adherence, treatment acceptability, and outcomes.
2. Explore how culture influences health care beliefs, practices, utilization, and adherence.

3. Examine the independent and interactional effects of health and minority status on development and health.
4. Identify cultural variables that may serve as protective factors or as strengths that enhance treatment effects and improve outcome (e.g., Fisher, Burnet, Huang, Chin, & Cagney, 2007).
5. Include a discussion of cultural assumptions and biases whenever appropriate when reporting treatments used in efficacy research with minority populations.
6. Address cultural appropriateness of measures and methodologies when examining variables related to culture.
7. Consider the influence of culture and the cultural context of results when discussing study findings.

Health and health outcome disparities among minority populations become even more important as North American society becomes more racially and ethnically diverse. Although recent advances in research and treatments have better accounted for cultural issues, clearly more research is needed to address health disparities and the cultural influences impacting outcomes. Next, I focus on the application of our research knowledge to the provision of health care to improve outcomes in diverse populations.

PRACTICE

It is clear that many complex factors contribute to differences in health care outcomes in children from diverse backgrounds. To address these disparities effectively, health care providers must understand the complexities, acquire knowledge, and develop skills to provide effective treatments that will lead toward optimal outcomes for all (National Center for Cultural Competence [NCCC], 2002). Much of the early focus in practice was on the development of evidence-based treatments that would lead to better outcomes. However, comprehensive reviews of these treatments revealed significant problems when they were used with diverse samples, due to the limitations in research. The rigid focus on internal validity of these treatment studies, as well as methodological issues, call into question the ecological validity of these so-called evidence-based treatments with diverse populations (Clay et al., 2002). Clearly, more research in diverse pediatric populations is necessary to understand the ecological validity of evidence-based treatments.

Asad and Kay (2015) propose a multidimensional model to explain the impact of culture on health interventions. They identify three dimensions that influence practical applications of interventions: "cultural knowledge," "cultural practice," and "cultural change." They also provide specific and practical examples regarding design of interventions, use of social networks, and integration of cultural beliefs to facilitate and encourage participation in these interventions. This systematic framework is helpful in understanding the potential role of culture in disparities in health care utilization.

More recently, the focus has been on practitioners and their ability to provide treatments within specific cultural contexts, instead of the development of specific treatments. Research has focused on the cultural competence of health care professionals, with the goal of providing culturally and linguistically competent services (NCCC,

2002). There are numerous articles on cultural competence in providing mental health services to children (e.g., Clay, 2007), but here I focus on definitions and models of cultural competence, and on recommendations for education and training to ensure cultural competence within health care settings.

Definitions and Models of Cultural Competence

"Cultural competence" has been defined at both the systems level and the individual level, although definitions are evolving as our knowledge of cultural factors in health care increases. At the systems level, cultural competence typically refers to knowledge of institutional processes and policies that can create barriers to access and quality of care (e.g., Lescano & Rahill, Chapter 38, this volume), and to knowledge of ways in which institutions can improve the care of diverse populations through modification of policies and systems. Cultural competence at the individual level focuses more specifically on patient–provider interactions, provider interpretations, and modifications of treatments (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). In the remainder of this chapter, I focus more specifically on the cultural competence of individual providers—first by reviewing models of cultural competence, and then in the next section by making recommendations on education and training for health care professionals.

Chi-Yue, Lonner, Matsumoto, and Ward (2013) provide a comprehensive review of cultural competence history and theory. Although there is still some debate about specifics, the current general consensus among researchers suggests that cultural competence is characterized by analytical and relational skills—that is, the abilities to understand the worldviews of others and to leverage that understanding to provide effective interventions at the interpersonal level. These attributes of cultural competence are often operationalized as attitudes, knowledge, skills, and abilities. "Attitudes" refers to beliefs, assumptions, biases, and stereotypes about specific cultural groups. "Knowledge" refers to learning about aspects of cultures that help inform analysis. "Skills" and "abilities" refer to the uses of this information within patient–provider interactions in ways that lead to improved outcomes.

Numerous comprehensive models of cultural competence have emerged. Godel and Carter (2013) have proposed a cultural competence model for addressing mental health problems in pediatric settings. Drawing on models from child development, public health policy, and health psychology, Godel and Carter have proposed a systematic and sustained approach to relationship development and treatment implementation. One important factor they discuss is "goodness of fit," which refers to the shared understanding and cultural congruence of the diagnosis and treatment approach. They also discuss sociocultural considerations related to providers' cultural competence, such as providers' self-awareness of their own cultures, identities, and beliefs, and the ways in which these factors may influence the providers' approaches to treatment with diverse families.

McFarland, Mixer, Webhe-Alamah, and Burke (2012) have proposed the use of cultural care theory as a context for using research findings to provide culturally competent nursing treatment. Among the valuable contributions of their work are the definition and articulation of "culturally congruent care" and "cultural competence" within a continuum of types of care (see Table 7.1 for definitions of various terms within their model). Although this model was developed for use in nursing care, these definitions and

applications are helpful for pediatric psychologists and physicians as well. McFarland and colleagues' definition of cultural competence requires that practitioners work within the cultural contexts of patients and their families, thereby ensuring that care is provided in a culturally congruent manner. Their article also includes recommendations for using culture care theory and qualitative methodologies to better understand cultural issues influencing the success of health care treatment.

The NCCC (2002) has proposed a comprehensive model of cultural competence in health care settings. This center, a collaboration between Georgetown University and multiple federal agencies, aims to reduce health and mental health disparities through identification and use of best practices. The NCCC (2002) has also developed a self-assessment checklist for practitioners to evaluate their level of cultural competence; this checklist focuses on the practitioners' environment and resources, communication styles, and values and attitudes. The NCCC website (*http://nccc.georgetown.edu*) provides valuable resources for both administrators and practitioners to identify best practices; these resources include assessment instruments, informative publications, and reviews of promising practices, as well as a list of consultants who can help individuals and organizations improve services through increased cultural competence.

Education and Training

As research has improved our understanding of cultural issues and the importance of cultural competence for providers, a call for education and training guidelines that address cultural competence has followed. In 2003, the American Psychological Association

TABLE 7.1. Orientational Definitions

Term	Definition
Care	Assistive and supportive actions, attitudes, and practices to help others toward healing and well-being.
Generic care	Culturally learned and transmitted care. Folk/lay care. Traditionally based care. People's/informants' ways of knowing.
Professional care	Formally taught and learned care. Professional health care providers' ways of knowing.
Culture care	Conceptual, global, cognitively learned and transmitted professional and indigenous folk values, beliefs, and patterned lifeways.
Culturally congruent care	Actions and decisions that fit with people's lifeways to support satisfying health care and promote well-being or dignified death.
Cultural competence	A process in which nurses strive to work successfully within the cultural context of individuals, families, and communities (Andrews & Boyle, 2012, p. 268). Reflected through the provision of culturally congruent care.
Health	A state of well-being that is culturally defined, valued, and practiced, which reflects the ability of individuals or groups to perform their daily role activities.

Note. Adapted from *Culture Care Diversity and Universality: A Worldwide Nursing Theory* (2nd ed., pp. 10–16), by M. M. Leininger and M. R. McFarland, 2006, Sudbury, MA: Jones & Bartlett. Copyright © 2006 Jones & Bartlett Publishers. Adapted with permission.

(APA) published a comprehensive review and set of recommendations for education, training, practice, research, and systems change to address cultural issues. Table 7.2 lists the specific recommendations of the APA (2003) task force. Importantly, the first two guidelines include a commitment to cultural self-awareness and to learning about other cultures; as such, they are consistent with the models of cultural competence reviewed above. With self-awareness, psychologists are then encouraged to recognize important cultural characteristics of those with whom they work.

Tervalon (2003) provides a thorough overview and recommendations for education and training of medical students to address cultural issues in provision of health care services. A thorough description of culture in the context of health is followed by a focus on specific tools and skills for physicians, many of which also apply to pediatric psychologists. Tervalon notes that it is also important to consider institutional policies and processes, which can have a significant impact on care for diverse patients.

Moreover, it is important for novice psychologists to receive effective clinical supervision in practicum and internship placements, to ensure that knowledge is applied and skills are developed in ways leading to cultural competence. In the early stages of practice, it may be helpful to use a structured approach to incorporating cultural issues into diagnosis, treatment planning, and treatment implementation. Table 7.3 provides a framework for guiding decision making (Clay, 2007). Supervisors must provide culturally competent supervision in the supervisor–supervisee relationship, just as providers must furnish culturally competent services in the provider–patient relationship (Johnson, 2014).

TABLE 7.2. American Psychological Association (APA) Guidelines

Domain	Guideline
Commitment to cultural awareness and knowledge	1. Psychologists are encouraged to recognize that, as cultural beings, they may hold attitudes and beliefs that can detrimentally influence their perceptions of and interactions with individuals who are ethnically and racially different from themselves.
Commitment to cultural awareness and knowledge	2. Psychologists are encouraged to recognize the importance of multicultural sensitivity/responsiveness to, knowledge of, and understanding about ethnically and racially different individuals.
Education	3. As educators, psychologists are encouraged to employ the constructs of multiculturalism and diversity in psychological education.
Research	4. Culturally sensitive psychological researchers are encouraged to recognize the importance of conducting culture-centered and ethical psychological research among persons from ethnic, linguistic, and racial minority backgrounds.
Practice	5. Psychologists are encouraged to apply culturally appropriate skills in clinical and other applied psychological practices.
Organizational change and policy development	6. Psychologists are encouraged to use organizational change processes to support culturally informed organizational (policy) development and practices.

Note. Adapted from APA (2003).

TABLE 7.3. Five Steps to Guide Culturally Competent Decision Making in Work with Pediatric Patients

1. Evaluate which, if any, cultural aspects are relevant. Evaluate own beliefs and assumptions.
2. Determine the level of skills and information necessary for competent treatment and possible referral.
3. Determine how much, when, and how to incorporate cultural issues.
4. Examine potential treatments and understand the cultural assumptions of each.
5. Implement the treatment, using cultural strengths.

Note. Adapted from "Culturally competent interventions in schools for children with physical health problems" by D. L. Clay, 2007, *Psychology in the Schools, 44,* p. 392. Copyright © 2007 John Wiley and Sons. Adapted with permission.

There are a multitude of guidelines for training to ensure cultural competence in other fields, including nursing, social work, physician assistants, and physicians. The Association of American Medical Colleges (2005) has published comprehensive guidelines for cultural competence education with medical students. Likewise, a focus on cultural competence training in pediatric clerkships (Mahalic, Dobbie, & Kinkade, 2007) has led to a validated cultural competence curriculum for use during such clerkships (Mahalic, Morrow, Long, & Dobbie, 2010). Pediatric psychology students doing clinical practica or internships in health care settings may benefit from an interdisciplinary focus on cultural competence with other health care providers in training, including medical clerks and residents. Indeed, pediatric psychologists have much to offer interdisciplinary teams in health care settings with respect to culture and its influence on health outcomes.

SUMMARY

Research has demonstrated clear links between health outcomes and cultural variables such as SES, language, sexual orientation, religion, race, and ethnicity, to name only a few. More research is needed to reach a better understanding of these complex relationships, however. Effective and ethical practice requires that pediatric psychologists have knowledge of, awareness of, and skills in diversity issues to ensure culturally competent care. The recommendations discussed in this chapter provide a context for understanding and incorporating cultural issues into assessment, treatment, and clinical supervision.

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CHAPTER 8

Evidence-Based Practice in Pediatric Psychology

Timothy D. Nelson and Maren Hankey

Evidence-based practice in psychology (EBP) is a broad organizing framework for professional psychology, and provides essential context for practice in pediatric psychology. EBP, as defined by the American Psychological Association (APA) Presidential Task Force on Evidence-Based Practice (2006), highlights the importance of three critical components in psychological practice: (1) best available research; (2) clinical expertise; and (3) consideration of patients' characteristics, cultures, and preferences. The integration of these components represents the ideal for modern psychological practice and the guiding standard for pediatric psychology practice and training. As such, the current chapter describes EBP specifically as it pertains to pediatric psychology, including both progress toward this ideal and challenges for the field in implementing EBP.

A BRIEF HISTORY OF EBP

Although formal and endorsed definitions of EBP are a relatively recent development, the field of clinical psychology has long grappled with core issues of how science and practice should be integrated in professional practice and training (e.g., Hilgard et al., 1947; Witmer, 1907). The "empirically supported treatment" (EST) movement of the 1990s brought these issues to the forefront of the field, triggering much debate about the relative roles of research evidence and clinical expertise in psychological practice. APA Division 12 (Clinical Psychology) played a central role in this movement, creating the Task Force on Psychological Interventions and the Task Force on Promotion and Dissemination of Psychological Procedures (1995). These task forces developed specific criteria for defining treatments as ESTs (Chambless et al., 1998; Chambless, 1993), as well as lists of treatments with varying levels of support (e.g., Chambless & Hollon, 1998;

Chambless et al., 1996). Early lists focused on ESTs for adults, but similar efforts in the child and adolescent domain soon followed (e.g., Chambless & Ollendick, 2001), documenting the considerable evidence base of psychological intervention with children.

The origins of the EST movement are numerous and complex, including a confluence of factors both within psychology and from broader trends in health care. Within clinical psychology, a growing disconnect became apparent between the scientific foundations of the field and actual clinical practice. While the literature rigorously documenting the efficacy of specific treatments for a variety of psychological disorders mounted (e.g., Smith, Glass, & Miller, 1980; Weisz, Weiss, Alicke, & Klotz, 1987; Weisz, Weiss, Han, Granger, & Morton, 1995), so too did evidence that these treatments were not used by many clinicians in the field, who instead often showed little familiarity with ESTs and employed treatments with limited research support (Aarons, 2004; Kazdin, Siegel, & Bass, 1990). The so-called "science–practice gap" threatened the legitimacy of clinical psychology as a science-based discipline, and much of the EST movement can be viewed as an attempt to ensure accountability and an empirical foundation for psychological practice.

Although the EST movement garnered significant support within the field, it also generated considerable controversy: Critics noted a number of limitations, such as the narrow focus on research from randomized controlled trials (RCTs) (e.g., Garfield, 1996; Norcross, 2011; Persons & Silberschatz, 1998). The debate regarding ESTs was at times divisive, and the field struggled for years to reach consensus after the idea of ESTs was first introduced. Eventually, common ground was found as the concept of EBP emerged. EBP extended beyond the concept of EST—building on its empirical foundation, while also broadening the ideals for best practice by integrating clinician expertise and experience as well as client-specific contexts to guide practice. In this way, EBP seeks to capture the science *and* practice elements of the field, with an emphasis on the complementary nature of these elements and on the bidirectional relationship between science and practice in applied settings.

Although the progression toward consensus on EBP in the broader field of professional psychology was often contentious, pediatric psychology more readily endorsed the movement, focusing more on *how* to best pursue the EBP principles than on *whether* or not they should be endorsed. Leaders in the Society of Pediatric Psychology (SPP) supported early iterations of ESTs and EBP (e.g., Spirito, 1999a), and the field's commitment to an evidence-based foundation for pediatric psychology practice has not wavered, as evidenced by official society statements, special issues of the *Journal of Pediatric Psychology* (*JPP*) (Cohen et al., 2008; Palermo, 2014a; Spirito, 1999b) and of *Clinical Practice in Pediatric Psychology* (Carter, 2014), and the EBP Resources page developed by the Committee on Science and Practice and maintained on the SPP website (SPP, 2015).

We argue that the ongoing promotion of EBP in pediatric psychology requires attention to three major issues, roughly corresponding to the three components of EBP. First, the field must continue to develop strong research evidence to support treatment and assessment practices in pediatric psychology, and to disseminate the practices with the best research evidence. Second, we must train the next generation of pediatric psychologists to develop essential clinical expertise needed to meet the high standards of EBP. Third, pediatric psychology must continue to address issues of individual context, including how treatments can be best tailored to the patients' cultures, values, and preferences. Our discussion in this chapter provides a brief overview of pediatric psychol-

ogy's progress in each of these critical areas, with an emphasis on developments since the status of the field with regard to EBP was last reviewed (Nelson & Steele, 2009). Finally, recognizing that the implementation of EBP in pediatric psychology requires ongoing efforts to incorporate new evidence within rapidly changing health care and technology contexts, we conclude with a brief discussion of some challenges facing the field in upholding the ideals of EBP in the future.

EVIDENCE BASE IN PEDIATRIC PSYCHOLOGY

Treatment Outcome Research

The empirical foundations of pediatric psychology are substantial and continually growing. RCTs, often considered the "gold standard" of clinical research (Sternberg, 2006), provide much of the most rigorous evidence across both the broader clinical child (e.g., Silverman & Hinshaw, 2008a, 2008b) and pediatric psychology literature (Palermo, 2014a; Spirito, 1999b), indicating that evidence-based treatments (EBTs) are available for a wide range of child and adolescent problems. Furthermore, research on the efficacy of child-focused interventions is proliferating rapidly. In the broader area of clinical child psychology, Chorpita et al. (2011) identified over 140 RCTs conducted with children and adolescents between 2000 and 2009, and Palermo (2014b) recently noted the tremendous growth in RCTs within pediatric psychology.

Despite this progress, important limitations also characterize the current pediatric psychology literature, including suboptimal study quality, small sample sizes, and deficiencies in reporting practices for many studies (Palermo, 2014b). Also, our understanding of the mediators and moderators of treatment outcomes remains limited for many pediatric psychology interventions. Identifying *how* and *for whom* treatments work will be critical in strengthening the evidence base for selection of treatments and tailoring them to unique client contexts (Hinshaw, 2007). In light of notable strengths and limitations, the current state of the evidence base in pediatric psychology is perhaps best characterized as solid and increasing, but with "lots of room to grow" (Palermo, 2014b, p. 759).

Dissemination and Implementation of EBTs

Although a strong evidence base is essential to EBP in pediatric psychology, research findings alone are often insufficient to change clinical practice. In fact, as the EBT literature base grows, practitioners in the field face a critical challenge in keeping abreast of new research developments and selecting the "best" treatments in light of new evidence (Chorpita et al., 2011). In this environment of sometimes overwhelming information volume, efforts to facilitate dissemination of best practices are essential for promoting EBP. Pediatric psychologists have recognized the need to actively advance efficacious treatments "from bench to bedside" (Stark, 2008), and SPP leaders have developed numerous strategies for disseminating information regarding EBTs in clinician-friendly formats. Systematic reviews and meta-analyses help to summarize large and complex treatment literatures, with an aim toward take-away messages to guide practice (Petticrew & Roberts, 2006), and these useful studies are frequently published to provide updates on research in pediatric psychology (e.g., Palermo, 2014a). Furthermore, web-

based resources (e.g., *www.effectivechildtherapy.org*; Society of Clinical Child and Adolescent Psychology, 2015; the Peds CL Practitioner Resource Bank; Thompson & Carter, 2014), as well as workshops and continuing education opportunities at conferences, are critical to efforts to disseminate best practices and encourage implementation of best research evidence in clinical settings.

Evidence-Based Assessment

Although EBP is often viewed within the context of clinical treatment, evidence-based assessment (EBA) is another critical component of EBP and has gained increasing recognition within pediatric psychology in recent years. EBA is essential for the accurate identification of clinical problems and symptoms, appropriate treatment selection, and evaluation of treatment progress and outcomes (Jensen-Doss & Weisz, 2008; Kazak et al., 2010). Paralleling the development of the evidence base for treatments, the state of EBA in pediatric psychology is one of substantial progress but also notable limitations. Reflecting the importance of EBA to pediatric psychology, SPP developed an Assessment Task Force to provide a critical review of the available evidence for measures across a range of pediatric issues, culminating in a special issue of *JPP* on EBA (Cohen et al., 2008). Although numerous evidence-based measures were identified for important constructs within pediatric psychology, so too were critical weaknesses of the current evidence base. In particular, many of the measures used in pediatric psychology were originally developed for healthy children or for those presenting with psychopathology (see Mash & Hunsley, 2005, for a review of EBA in clinical child psychology), and research to validate these measures within specific pediatric health populations is often lacking. Furthermore, not all critical pediatric psychology constructs have well-established measures, highlighting the need for research to develop new measures, establish norms for specific pediatric populations, and determine the utility of measures in informing treatment decisions (Mitchell, Patterson, & Boyd-Franklin, 2011; Youngstrom, 2013). Such research will advance the science of assessment in pediatric psychology, strengthening the field's implementation of EBP principles.

Cost-Effectiveness and Medical Cost-Offset

Changes in health care policy, such as those detailed in the Patient Protection and Affordable Care Act (ACA; Public Law No. 111-148, March 23, 2010), reflect increasing expectations for health care professionals to demonstrate the importance of their role in providing high-quality health care for children and families (Roberts, Canter, & Odar, 2012). EBP is essential to meeting these demands, as pediatric psychology will need to further establish itself as a field grounded in science that provides patient-centered, effective, efficient, and equitable care (Dentzer, 2011; Institute of Medicine [U.S.] Committee on Quality of Health Care in America, 2001; Rozensky & Janicke, 2012). Though often neglected in discussions of the field's evidence base, cost-effectiveness research is a key way for pediatric psychologists to demonstrate the value and emphasize the economic impact of their services (Chiles, Lambert, & Hatch, 1999; Drotar, 2012; Tovian, 2004). As noted by McGrady (2014), pediatric psychologists are well positioned to conduct cost-effectiveness research, and examples of such studies are beginning to emerge. For example, Bandstra, Crist, Napier-Phillips, and Flowerdew (2011) showed

that inclusion of a behavioral intervention for children with feeding disorders significantly decreased the frequency of pediatric visits, thus reducing costs to both families and the broader health care system. Research explicitly addressing cost-effectiveness, cost-offset, and cost–benefit analyses in pediatric psychology remains rare, though, and represents an important area for future research.

TRAINING ISSUES

Training issues have always been critical to the implementation of EBP in professional psychology generally, and pediatric psychology specifically. Training programs at the doctoral, internship, and postdoctoral levels face a daunting task in preparing future pediatric psychologists to practice within an EBP framework, which will require in-depth knowledge of the evidence base of pediatric psychology assessment and treatment approaches, well-developed clinical experience and skill, and the ability to tailor treatment to the unique context of each client. Moreover, the health of the field demands that we train the next generation of researchers, who will continue to build on the current evidence base in developing and validating new treatments and extending existing ones to maximize effectiveness.

The formidable challenge of training the next generation of pediatric psychologists is evident in the recently published "Recommendations for Training in Pediatric Psychology" by the SPP Task Force on Competencies and Best Training Practices in Pediatric Psychology (Palermo et al., 2014). This ambitious and thoughtful report details recommendations for training pediatric psychologists in preparation for careers in research and practice, and is highly relevant to the future of EBP in the field. The recommendations and other training considerations are thoroughly covered by Palermo, Janicke, Beals-Erickson, and Fritz in Chapter 5 of this volume, so we limit our discussion here to highlighting some particularly critical issues related to promoting EBP among future pediatric psychologists.

Research Training

Strong training in research is needed, both to develop future researchers who will continue to build the evidence base in pediatric psychology, and to produce scientifically grounded clinicians who are prepared for research-informed practice. It will be particularly crucial for the future of EBP to train investigators who can conduct clinically relevant research, including intervention studies in applied settings (Bauer, 2007), and can effectively disseminate such research to audiences both within psychology and outside the field (Palermo et al., 2014). A solid foundation in research is also necessary for future clinicians. Within an EBP framework, practitioners must be prepared to read, critically evaluate, and apply relevant research in their work. Furthermore, as the research base grows, clinicians will face the challenge of sorting through increasingly copious literatures and drawing conclusions that they can translate into best practices in clinical settings. Although summaries, updates, and other clinician-friendly dissemination vehicles may facilitate this process, clinicians who have been trained to be informed consumers of science will be essential to the broad implementation of EBP in pediatric psychology.

Clinical Training

Of course, clinical training at the graduate, internship, and postdoctoral levels is essential to facilitating EBP in pediatric psychology. In fact, part of the struggle to implement EBP in the broader field of professional psychology has stemmed from the unfortunate reality that many clinicians already in practice received little or no explicit training in EBP in graduate school, creating an uphill battle to learn EBTs while already "on the job." Supporting the critical role of training, studies by Nelson and colleagues found that the lack of training in EBTs was recognized as a major obstacle to EBP by practitioners (Nelson, Steele, & Mize, 2006), and that formal training in EBTs was a significant predictor of practitioners' self-reported use of these interventions in professional practice (Nelson & Steele, 2007). Therefore, it is critical that training programs explicitly and thoroughly train future pediatric psychologists in the most evidence-based approaches to intervention, assessment, and consultation with pediatric populations. By focusing on training in these core areas of pediatric psychology practice, the field can develop professionals with the specialized clinical expertise that is integral to EBP.

Importantly, current recommendations for EBP training go well beyond simply learning to deliver specific EBT protocols. Instead, clinical training must focus on developing broader case conceptualization skills and the ability to tailor treatments to the unique developmental, family, illness, and cultural context of each individual patient (Palermo et al., 2014). This emphasis is consistent with the idea that EBTs are not "cookbooks" that can be blindly followed; rather, clinical experience and judgment are needed to fully conceptualize each case and deliver well-tailored interventions with skill. Such clinical expertise emerges from a combination of didactic training and significant supervised experience, so these elements are essential in pediatric psychology training. As an example, in our clinical psychology training program at the University of Nebraska–Lincoln, EBP training is woven throughout the curriculum, including basic coursework in evidence-based interviewing and interventions; specialized coursework in clinical child and pediatric psychology; our "clinical comps" model, in which students make case presentations with an EBP focus; and our intervention course, which provides live supervised experience in delivering EBTs (DiLillo & McChargue, 2007). We believe that this kind of comprehensive approach to EBP training is necessary for developing professionals who are both committed to the ideals of EBP and skilled in the process of practicing within an evidence-based framework.

Interprofessionalism

Although pediatric psychology has a long tradition as an interdisciplinary field that values collaboration with a wide range of professionals, the recent emphasis on "interprofessionalism" further highlights the need for training models that go beyond psychology. Interprofessionalism necessitates integrated services in which health care teams work together to provide effective and efficient care for patients (Rozensky & Janicke, 2012). Because this interprofessional model represents a substantial departure from traditional health care practices, which tend to be more fragmented by discipline, training in interprofessional competencies for future psychologists will be essential (Palermo, 2013). Pediatric psychology is well poised to make a successful transition to this team-based health care context, but strong training of the next generation of interprofessionally

competent practitioners will be critical to establishing a central role for psychologists in the integrated health care teams of the future. The explicit emphasis on interprofessional teams in the Affordable Care Act (2010) could accelerate the transition to integrated care, increasing the urgency of training pediatric psychologists who will soon enter a rapidly changing health care environment. Moreover, pediatric psychologists have unique research skills for evaluating the effectiveness and impact of new interprofessional service models; such evaluations will be critical, given the focus on outcomes and efficiency in modern health care.

Assessment of Professional Competencies

In 2009, Nelson and Steele lamented the limited progress at the time in assessment of professional competencies in pediatric psychology. Reflecting on recent years, we see this as an area of important steps forward for the field since the 2009 chapter was written. Building on broader efforts to define core competencies in professional psychology and health services (e.g., Hatcher et al., 2013; Health Service Psychology Educational Collaborative, 2013), the "Recommendations for Training in Pediatric Psychology" report discussed earlier creates a critical foundation for measuring competencies by first carefully and behaviorally defining what is to be measured. Although delineating these competencies is clearly an important development, difficult work remains in determining how to assess competencies in the context of training and beyond (Cohen, 2014). Furthermore, the ongoing assessment of competencies for practitioners already in practice has long been identified as an area of need within professional psychology (Leigh et al., 2007; Roberts, Borden, Christiansen, & Lopez, 2005), but one where progress to date has been more limited.

PATIENT CONTEXT: CHARACTERISTICS, VALUES AND CULTURE

EBP goes beyond employing well-validated treatments with clinical expertise and adds a critical third component: consideration of the unique context of each individual client. This individual context has been most often addressed in terms of ethnic culture, although other individual factors (such as age, gender, socioeconomic status, sexual orientation, religion, and health status) may be relevant in determining the best course of treatment in a particular case (Cohen, 2009). Beyond individual-level factors, the context of the child's family, school, and other relevant systems surrounding the child must be considered. Pediatric psychology has a long history of systems-focused conceptualizations and interventions (see DuPaul, Power, & Shapiro, Chapter 44, this volume; Power, DuPaul, Shapiro, & Kazak, 2003), making the child's context a central consideration for most pediatric psychologists and perhaps facilitating this element of EBP in the field.

Whereas early definitions of ESTs were criticized for lack of attention to cultural context (e.g., Sue, 1999), current formulations of EBP make clear the need to select and adapt treatments in light of each individual's culture (e.g., Bernal, Jiménez-Chafey, & Rodríguez, 2009). Despite this consensus, important questions remain regarding the need for specific cultural adaptations and the best *ways* to tailor treatments. Recent work by Huey, Tilley, Jones, and Smith (2014) identifies some of the most relevant issues in this area, including (1) the effectiveness of psychological treatments with ethnic

minority patients; (2) the relative effectiveness of these treatments for different ethnic groups; and (3) the effectiveness in cultural tailoring for enhancing treatment outcomes. We briefly address these critical questions below and then discuss current recommendations for best practice.

Recent reviews and meta-analyses with children and adolescents have concluded that existing EBTs are in fact effective with ethnic minority youth (Huey & Polo, 2008, 2010). This research further suggests that treatment effects for ethnic minority youth are generally comparable to those found with European American youth (Huey & Polo, 2008), and that ethnic minority status does not moderate treatment effects (Huey & Jones, 2013). Despite these generally encouraging findings, important limitations of the current literature should be noted. In particular, studies comprising the evidence base of treatments with ethnic minority youth make up only a small fraction of the broader treatment literature, and much of this literature focuses on African American and Hispanic children, while other ethnic groups have received significantly less attention (Huey & Polo, 2008, 2010). Recent years have seen a substantial increase in clinical trials focusing on ethnic minority populations (Huey et al., 2014), but much work remains in building a robust evidence base for psychological treatments across cultures.

Although cultural adaptation of EBTs is widely recommended and central to the EBP framework, the evidence for cultural tailoring is mixed. As reviewed by Huey et al. (2014), studies clearly find that culturally tailored EBTs are effective with ethnic minority patients, but conclusions regarding added benefits of tailoring differ across meta-analyses, with some studies finding specific benefits (e.g., Benish, Quintana, & Wampold, 2011; Smith, Rodríguez, & Bernal, 2011) and others finding no effects (Huey & Polo, 2008) with cultural adaptation. It is difficult, however, to draw firm conclusions from this literature because of considerable differences in the degree to which treatments were modified for cultural reasons, leaving many questions about best practices for how to tailor treatments to an individual patient's cultural context. The issue of exactly how to tailor treatments most effectively could be the focus of future pediatric psychology treatment research, particularly given the availability of sophisticated data-analytic techniques for capturing and examining individual variability (see Schurman & Gayes, 2014).

In light of their meta-analytic work, Huey and Polo (2008) suggest two basic recommendations for best practice with ethnic minority youth. First, they unequivocally support the use of EBTs as "first-line" interventions for ethnic minority youth and caution against untested alternative approaches that are likely to be less effective than standard treatments. Second, they recommend making *selective* adaptations to EBTs based on cultural considerations—either by limiting culturally focused elements to those already incorporated into the original protocol, or by tailoring treatments only in ways indicated by specific clients' needs. This approach of starting with the most EBTs and making only strategic modifications while maintaining the core of existing protocols provides guidance for culturally appropriate care within the context of EBP for clinical child and pediatric psychologists alike.

EMERGING ISSUES AND FUTURE CHALLENGES

In addition to the broad issues discussed above, pediatric psychology faces some new challenges as the field continues to pursue the ideals of EBP. Among the issues that

present both opportunities and challenges are the emergence of new treatments and the integration of these treatments into standard pediatric psychology practice. The coming years will undoubtedly produce new approaches that add to the treatment repertoire of the field and have the potential to enhance effectiveness, necessitating that practitioners and training programs keep up with new developments in a dynamic field. Pediatric psychology cannot afford to rest on its laurels, so as new treatments gain empirical support, there must be an ongoing effort to disseminate these innovations to practitioners in the field and to train the next generation in the most updated approaches. Dissemination science (McHugh & Barlow, 2010) must be thoughtfully applied to shorten the gap between validation of new approaches and their widespread adoption in the field, and thus to facilitate continued improvement in the quality of services. Relatedly, pediatric psychology must also adjust to changes in *how* EBTs are delivered to children and families. Recent years have seen innovations in the broader clinical child field, such as modular approaches to delivering EBTs (e.g., Weisz et al., 2012), and such developments will need to be adapted and integrated into pediatric health settings to maximize effectiveness. Similarly, the field will need to be strategic in adjusting to inevitable funding and reimbursement changes while maintaining a core commitment to the pillars of EBP. Finally, changes in technology—in particular, mobile health and telehealth applications—will expand the ways in which pediatric psychologists collect information and deliver interventions, with the potential to enhance effectiveness, lower costs, and increase access to services (Aylward, Cushing, & Nelson, 2014; Ritterband & Palermo, 2009). Technology-facilitated interventions show promise for addressing a wide range of pediatric health issues (Cushing & Steele, 2010), but it will be essential to bolster the evidence base of these interventions (Wu, Steele, Connelly, Palermo, & Ritterband, 2014). Overall, technology holds great promise for facilitating the goals of EBP, but careful consideration is needed regarding how best to harness the emerging capabilities within pediatric psychology.

CONCLUSIONS

Pediatric psychology has made tremendous progress in moving toward the broad implementation of EBP throughout the field. In a relatively short time, the field has made substantial gains in developing the evidence base of pediatric psychology assessment and intervention, specifying clear training needs at varying levels, and working to make pediatric psychology interventions more attentive to individual patients' contexts. Still, much work remains to be done, and formidable challenges face the field in a rapidly changing health care environment. With the solid foundation of EBP as a guiding framework for the field, pediatric psychology is poised to meet these challenges and continue to grow as a discipline that integrates science and practice to provide relevant and impactful care.

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CHAPTER 9

Inpatient Pediatric Consultation–Liaison

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Pediatric consultation–liaison (CL) psychologists are in a unique position to facilitate initiatives to improve patient/family access to care and prevention, as well as to stimulate systems changes that integrate mental and physical health constructs in service design and delivery. The field of pediatric psychology CL encompasses a broad and diverse range of research and clinical activities relating to the provision of psychological services to children whose care is being primarily managed by pediatric clinical disciplines and/or in a pediatric clinical setting. The present chapter is intended to provide a review of recent descriptive and investigative efforts to conceptualize and validate CL practice, and to elucidate the varied roles and interventions that have been designed to address inpatient medical and mental health challenges.

TRADITIONAL MODELS OF CL PRACTICE CONCEPTUALIZATION

In the classic inpatient consultant role, the pediatric psychologist becomes involved in direct patient care via a referral from a physician or subspecialty service, and typically addresses a specific clinical problem or concern. By contrast, in the liaison role, the pediatric psychologist may be employed by or have a portion of time formally dedicated to a specific service, and may be involved in systemic and broader mental health concerns of the service that may directly or indirectly affect the coping and adjustment of individual patients and families. Though the liaison role may involve such practices as attending daily rounds and patient case conferences, systems-level consultation involves addressing more macroscopic concerns that require participation via hospital committees and task forces, as well as out-of-hospital activities that have an impact on policy and practices relating to pediatric patients and their families (Carter, Kronenberger, Scott, & Ernst, 2009).

Hospital CL services can be quite varied in their disciplinary composition, administrative structure, and level of integration into their home department or division. Surveys suggest that the majority of psychologists providing CL services have their primary assignments in departments of pediatrics or psychiatry (Kullgren et al., 2015). Moreover, even within their departmental affiliations, there is considerable structural variability—for example, psychiatrist versus psychologist versus shared service directorship; presence or absence of trainees on the service (medical students, psychiatry residents/fellows, psychology interns/fellows, pediatric residents); and financial support via primarily clinical revenues versus hospital-supported financial base and various combinations. In some cases, this variability can result in service overlap and turf conflicts with colleagues in such parallel disciplines as psychiatry, palliative care, social services, child life, and expressive therapies, which may present challenges to interdisciplinary communication and coordination (Carter, Thompson, & Townsend, 2014).

Increasingly, inpatient CL psychologists are being tasked with serving multiple roles, to varying degrees; it has been proposed that as a result, they are functioning as "pediatric psychological hospitalists" (Carter, Thompson, & Townsend, 2014). In this capacity, the psychologists are responsible for a host of psychosocial issues and factors affecting medically hospitalized children, including but not limited to providing in-hospital evaluation of and intervention in factors that influence patient and family coping and adherence; developing and employing quality improvement programs; collaborating with and educating various health care providers on comprehensive psychosocial patient needs; addressing systemic practices and procedures to ease the stress of patient/family transitions through the health care system and to the community; and translating the research on psychosocial aspects of pediatric illness and hospitalization into improving pediatric hospital care.

THEORY-DRIVEN MODELS

Traditional practice structure-based models, though pragmatically appealing, fail to address and/or integrate key developmental and behavioral health constructs that are crucial to sensitive and effective patient care. Two existing systems-level schemas lend themselves readily to conceptualizing the role and functions of inpatient pediatric CL services. Bronfenbrenner (1979) provides a framework that enhances the appreciation of the many levels and systems in which pediatric patients and their families find themselves, ranging from the individual and family to broader neighborhoods, institutions, and society. This framework leads logically to formulating strategies and interventions that address developmental needs at multiple levels of involvement. Bronfenbrenner's bioecological systems theory (BST) proposes that a child's development takes place within the context of the complex layers (systems) that form his or her environment. This theory posits interactions between and among these layers, such that any change in one layer influences the overall system, and interactions between/among layers also influence the child's outcomes. A CL psychologist works to facilitate the child's adjustment and development by improving functioning and integration at the level of individual systems and across systems.

For health care to be responsive to patients' and families' needs, as well as fiscally sustainable, interventions must be based upon well-assessed determinants of both the

needs and the potential risk profiles of the patients and their families. Kazak (2006) has developed a model of assessment and intervention addressing the health-related stressors faced by families with acutely and chronically ill children. The pediatric psychosocial preventative health model (PPPHM) stratifies preventive and intervention services in response to such factors as family adaptation and coping styles, family dynamics (e.g., distress-provoking vs. resilience-promoting), and targeted support of adaptive functioning, all within the context of broader systems (e.g., school, health care system). The PPPHM includes a family risk model for screening and providing services for all families and children entering the health care system at three levels: universal, targeted, and clinical/treatment. At the universal level, a psychologist may provide all families with education about the inherent stressors associated with chronic illness and its treatment, as well as about service access and availability. At the targeted level, families assessed to be at risk may be provided with more specific education and perhaps short-term intervention centered around anticipated illness demands and transitions. Finally, at the clinical/treatment level, patients and families may be referred to traditional mental health services for comprehensive assessment and intervention.

Figure 9.1 provides an illustration of the potential interface and interactions of the complementary BST and PPPHM. As illustrated in Figure 9.1, in their various roles, pediatric psychologists may be involved in activities that have an impact on each system in BST (concentric circles) and each intervention level in the PPPHM (sections of the triangle). For instance, at the level of the individual system, a psychologist may provide direct clinical services to a specific patient. At the microsystem level, the psychologist may help coordinate implementation of 504 Plan accommodations for school reintegration of a patient or group of patients. Both individual systems and microsystems are commonly involved at every level of treatment in the PPPHM (i.e., clinical/treatment, targeted, and universal); from direct intervention to prevention/education efforts, a child and family are receiving care. Further out from the child, at the exosystem level of BST, a CL psychologist may sit on a panel advising an insurance plan on implementing integrated health care services or may be involved in developing a community in-home peer support system to improve monitoring and adherence for patients with chronic illness. Tasks at this systemic level are aimed less at individual patients and families in crisis, and centered more strongly on providing support and identifying at-risk families (i.e., the targeted and universal levels of the PPPHM). Finally, at the macrosystem level of BST, activities may include conducting research, providing education, and advocating for legislation targeted at altering professional and population attitudes, practices, and policies. For example, a psychologist's activities may be targeted toward such variables as the stigma of mental illness versus the integration of mental health and physical health, with the goal of enhancing physicians' sensitivity to and employment of evidence-based psychological/behavioral health principles and strategies, while also improving population access to psychological services (i.e., the universal level of the PPPHM).

THE FIVE C'S OF CONSULTATION: NEW PERSPECTIVES AND A SIXTH C

With the emerging prominence of systems-based models of CL psychology, the long-standing characterization of five overlapping roles/arenas in which pediatric CL psy-

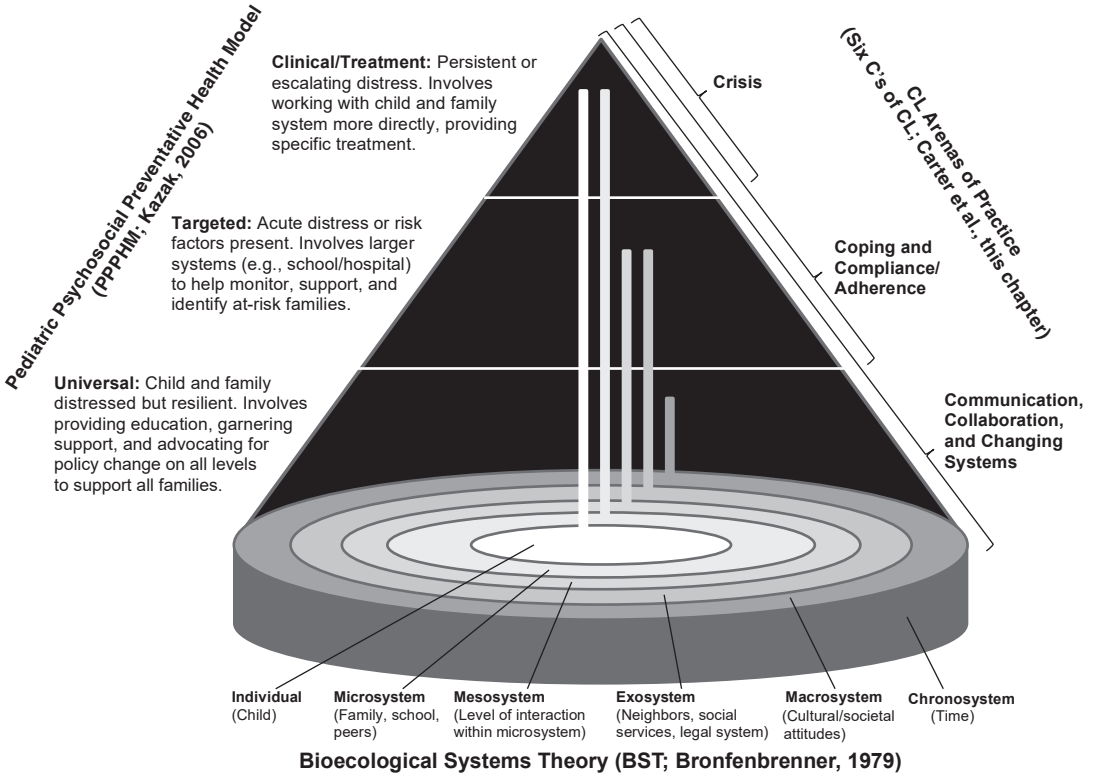

FIGURE 9.1. An illustration of the interface and interactions among the three models discussed in this chapter. The columns projecting from the circles into the triangle represent the levels at which each system in bioecological systems theory (BST) is addressed within the pediatric psychosocial preventative health model (PPPHM). For example, the individual system (child) in BST is targeted at all three treatment/care levels of the PPPHM, while the macrosystem is involved primarily at the universal level. The relationship of the six C's of CL to the other two models is depicted on the right side of the triangle.

chologists function (crisis, coping, compliance/adherence, communication, and collaboration, or the "five C's" of CL; Carter et al., 2009; Carter & von Weiss, 2005) fails to encapsulate the expanding impact of pediatric CL psychology on pediatric health care. It is time for a sixth C. We propose that the sixth C be "changing systems." Though systems change is not a role exclusive to CL practice, pediatric CL psychologists, by virtue of their experiences in complex hospital systems, are uniquely positioned to influence health care policy and planning at various levels. This involves researching, designing, and advocating for health care delivery systems that integrate mental/behavioral and physical health interventions at the population level, while equally emphasizing effective and efficient prevention and targeted interventions with diagnosed health conditions both in and beyond the inpatient environment. Figure 9.1 shows how the six C's of CL relate to the PPPHM and BST.

WORKFLOW AND SETTING FACTORS AFFECTING THE PROVISION OF CL SERVICES

Providers of inpatient CL services face a number of unique programmatic and organizational challenges to their provision of efficient and efficacious treatment for their patients and families, as well as to the liaison relationship with their hospital medical teams. These factors are heavily influenced by institutional characteristics and dynamics, as well as by the ever-changing health care legislation and fiscal environment. Initiatives are needed that promote the creation of effective strategies to reduce the impact of these barriers to the provision of integrated pediatric CL services.

Compared to services in the outpatient setting, CL services face a number of workflow challenges: less predictable frequency and flow of incoming CL referrals (i.e., the "feast or famine" phenomenon); varied types of patients and referral questions; access and scheduling barriers, due to other services in which a patient is being seen; and, finally, unique coding and billing challenges that affect a service's financial sustainability. Setting considerations that may have an impact on the delivery of inpatient psychological services can include the following: hospital expansion of new beds, units, or locations; the need for night, weekend, and holiday coverage; and the ever-decreasing length of inpatient stays (Yu, Wier, & Elixhauser, 2011). Accordingly, CL psychologists must develop specific strategies and tools (e.g., handouts, online resources, referral resources) for providing competent care within all these institutional constraints.

Clinical Volume and Length of Stay

Particular challenges facing psychologists on CL services are the variability and frequently high volume of referrals. Because most consultations are unscheduled, the number of new patients seen by a CL service can vary widely from day to day. Reported annual referrals seen by pediatric CL services range from 150 to 500 or more per year (Piazza-Waggoner, Roddenberry, Yeomans-Maldonado, Noll, & Ernst, 2013; Tunick, Gavin, DeMaso, & Meyer, 2013), with survey data indicating CL services averaging 6.1 (ranging from 1 to 35) new referrals per week (Kullgren et al., 2015). Such variability requires considerable flexibility in scheduling and availability.

Consultations also vary substantially by length of inpatient stay. The general trend has been toward shorter hospital admissions, which places greater pressure on services for rapid evaluation and provision of interventions. Length of stay for hospitalized CL patients ranges from 1 day to over a year, with studies reporting average lengths of stay in the 6- to 7-day range (Kullgren et al., 2015; Piazza-Waggoner et al., 2013; Tunick et al., 2013). It is not unusual for consults to be requested for patients during a 1-day stay or on the day of discharge, calling for immediate evaluation and disposition. One 5-year retrospective study found that 11% of consults were requested on the day of discharge (Piazza-Waggoner et al., 2013). Not surprisingly, attending physicians' satisfaction with CL services is highly related to whether a patient is seen on the day of the request for a consult and whether the consult is managed quickly (Kullgren et al., 2015; Lavakumar et al., 2013). In contrast, physicians tend to expect that a CL psychologist will maintain regular contact with patients hospitalized for extended periods, even over several months or more (Lavakumar et al., 2013; Piazza-Waggoner et al., 2013; Tunick et al., 2013). Due to high levels of referring physicians' satisfaction with CL services (Carter

et al., 2003), and the growing awareness of the psychological needs of hospitalized children, the demand for CL services can quickly exceed the resources of the CL team (Piazza-Waggoner et al., 2013).

Funding and Institutional Support Considerations

An almost universal concern of pediatric CL services, and one of the main factors that may drive CL team composition and function, is the funding and business model of the home institution. These factors are subject to the influence of institutional priorities and changes that directly affect how services are provided and by whom, as well as larger state and national changes that affect both the institution and, ultimately, the CL service.

Several characteristics of CL services can have an impact on adequate income generation from clinical billings: Referrals are often for emergent situations that must be resolved within a tight time frame, necessitating service provision before insurance authorization is received; services are usually provided regardless of insurance coverage; billing is subject to a higher level of denial of claims as compared to traditional psychological services, due to lack of authorization and/or out-of-network status; and reimbursement levels seldom capture the quantity of work provided, which excludes nonbillable indirect activities that are often critical to patient disposition (e.g., team meetings, care coordination, arranging postdischarge services; Bierenbaum, Katsikas, Furr, & Carter, 2013; Drotar, 2012; Kronenberger, 2006; Piazza-Waggoner et al., 2013). Specifically, one survey found that on average, CL psychologists spent only 62% of their time working directly with patients (Kullgren et al., 2015), while a retrospective study documented an average of 28% of clinician time spent in nonreimbursable activity (Bierenbaum et al., 2013). All of these factors combine to make the funding of CL services one of the greatest administrative challenges to pediatric CL practice (Carter & von Weiss, 2005). And although health and behavior (H & B) codes were created to provide a more appropriate and clearer way to document and bill for pediatric CL services, only about one-third of pediatric CL services routinely use H & B codes, compared to about half that use traditional mental health services codes (Kullgren et al., 2015).

As a result of these financial challenges, in almost all cases CL services cannot be supported via traditional collections alone, and the average CL service is less than half supported by clinical collections (Bierenbaum et al., 2013; Kullgren et al., 2015; Kronenberger, 2006; Piazza-Waggoner et al., 2013). In order to account for funding shortfalls, most CL services depend on multiple funding sources (Drotar, 2012; Kullgren et al., 2015; Carter & von Weiss, 2005).

THE PEDIATRIC CL PSYCHOLOGIST: REWARDS, CHALLENGES, AND ROLE STRAINS

Rewards of Being a CL Psychologist

There is a tendency to overemphasize the challenges and stresses associated with pediatric CL work in a hospital inpatient environment. However, a recent survey of CL psychologists (Kullgren et al., 2015) indicated that overall, 82% of respondents felt satisfied

in their roles all or most of the time, while 16% indicated that they sometimes felt satisfied and only 3% rarely found their roles satisfying. Many find that the collaborative and interdisciplinary nature of CL practice offers opportunities for interpersonal and intellectual stimulation (Kullgren et al., 2015; Tunick et al., 2013). This team structure allows for multiple teaching opportunities, mutual consultation, and both social and instrumental support in dealing with role challenges and strains. In addition, this survey found that the majority of respondents (76%) felt equipped to balance the unpredictability and uncertainty of inpatient CL practice always or most of the time, while only 6% rarely felt able to balance these challenges. Finally, 91% of survey responders indicated always or mostly feeling respected by physician colleagues. In their case-controlled study of a CL service, Carter et al. (2003) found that referring pediatricians were highly satisfied with outcomes of pediatric CL service consults by virtue of high levels of goal attainment, and that parents endorsed CL services as very helpful and important in their children's recovery. Thus, despite the numerous challenges and other factors affecting pediatric CL practice, it appears that most CL psychologists are satisfied, respected, and valued by patients, families, and medical colleagues.

Challenges and Role Strains of Being a CL Psychologist

Goal Conflicts with the Referring Service

Role strain can occur as a result of the CL psychologist's duty to provide appropriate, high-quality care to each patient, while also engaging and communicating with a referring service that has its own goals and perspectives. Although in most cases these roles are aligned, at times the perspective or goal of the referring service may conflict with the psychologist's perception of a patient's clinical formulation or intervention needs. For example, the attending service may want to discharge a patient who is medically stable, when the psychologist believes that the patient's behavior or psychological well-being merits delaying discharge until additional interventions or dispositions can be put into place.

Competing Demands from Service and Home Department

CL psychologists may also experience role strain because of divided responsibilities between their "home" department and the hospital. This is particularly relevant to those psychologists practicing in academic medical center settings. One of the more common challenges is defining a role that fits with CL duties while also contributing to the department's overall mission and resources. CL psychologists often have other productivity expectations (e.g., outpatient services, teaching, research) in addition to their CL roles. Balancing these demands is critical for having sufficient time and energy for CL activities, and it requires reasonable productivity demands of the CL service by the home department. In addition, whereas most outpatient clinics close after regular office hours and on holidays (typically diverting patients to emergency services at those times), CL services are frequently held to a medical model of arranging coverage at all times. In some hospitals, after-hours CL coverage is provided by on-call residents, typically in child psychiatry, with attending psychiatrist backup. Survey data suggest that after-hours coverage by attending CL psychologists is less common, with only 21–24%

of CL psychologists reporting providing phone consultation on evenings and weekends, and about 12% providing on-site weekend coverage (Kullgren et al., 2015).

Avoiding Burnout

Though the vast majority of CL psychologists in a recent survey reported overall job satisfaction and adequate resources to perform their jobs, over a third reported struggling with burnout (Kullgren et al., 2015). Research points to a number of personal and institutional factors that may play a role in job burnout for mental health professionals. Studies of professional burnout from a stress and coping perspective (Lazarus & Folkman, 1984) suggest that a sense of inadequacy to meet job demands is a major contributor, along with maladaptive coping strategies (e.g., cynicism and emotional exhaustion) (Thompson, Amatea, & Thompson, 2014). The intensity of the work setting, as represented by the ratio of CL staff to the number of hospital beds, has been found to be correlated with several aspects of job satisfaction (i.e., time for teaching, research, resources, support), highlighting the struggle that many psychologists face when CL staffing is inadequate to meet ongoing demands (Kullgren et al., 2015). Clinicians on successful CL services tend to be characterized as vigorously engaged and dedicated, supportive of team members, and available for mutual consultation; they are provided with instrumental support, engage in camaraderie and humor, provide problem-focused solutions to difficult cases, and are creative/innovative in care delivery (Carter, 2014; Maslach, Schaufeli, & Leiter, 2001).

Promoting Integration with Pediatrics Services

Integrated care models are increasingly valued in care for children with acute and especially chronic medical illnesses (Richardson et al., 2014); this shift favors reimbursement being tied to clinical outcomes, while moving away from procedurally E-based billing. Interdisciplinary care also leads to more desired outcomes in comparison to individually based care (Kolko et al., 2014). Historically, pediatric psychologists within CL services have been at the forefront of advocating for interdisciplinary care for hospitalized children (Carter et al., 2014), demonstrating benefits such as decreased length of stay and improved adherence to care (Ernst et al., 2010). Key to improving outcomes is the integration of pediatric psychology input into the different levels of patient and family care within the medical setting.

Integration into Rounds

Attending bedside/hallway rounds allows the CL psychologist to become more directly integrated into a truly interdisciplinary system in the inpatient setting. This is easiest when the CL psychologist is embedded within a specialist team (e.g., hematology/oncology) as opposed to being in a free-standing service. However, most pediatric CL services are housed within departments of psychiatry, psychology, or behavioral medicine within a pediatrics department, making it difficult to become fully integrated into daily rounds with any one service (Kullgren et al., 2015).

Targeting at-risk patients/families with a high degree of distress can be enhanced by a CL psychologist's being embedded within daily rounds and becoming a part of

daily treatment planning (Kazak, 2006; Rennick & Rashotte, 2009; Ye et al., 2014). The benefits of enhanced coordination of care and communication with patients and caregivers as a unified team have been demonstrated with both acute conditions (e.g., burn care) and chronic illness (e.g., cystic fibrosis; Ernst et al., 2010). Secondary and tertiary prevention of mental health concerns among patients and their families (e.g., decreasing depression in mothers of children hospitalized in the pediatric intensive care unit), are also enhanced when the CL psychologist is embedded in the specialty team (Melnyk et al., 2004).

Integration into Care on the Medical Unit

Interdisciplinary learning, which creates heightened team awareness of psychosocial aspects of patient and family care, may assist medical staff members in more readily identifying emotional and behavioral conditions in their hospitalized patients or parents/caregivers. Increased team contact with CL psychologists can assist medical staffers in setting realistic expectations and becoming more adept at requesting appropriate problem-focused behavioral solutions to patient concerns on the unit, such as desensitization to injections or swallowing medications, identifying warning signs of mental illness, improving adherence to treatment, reducing problematic behavior on the unit, and pain relief (Lavigne, 2013).

TRAINING IN PEDIATRIC CL

Many CL psychologists are involved in the education of psychology trainees, as well as of medical residents and hospital staff. Pediatric CL services are popular and in-demand rotations for graduate students, interns, and postdoctoral fellows, and many CL psychologists maintain active teaching responsibilities (Kullgren et al., 2015; Carter et al., 2003; Piazza-Waggoner et al., 2013). While teaching can be a highly rewarding component of CL work, the significant commitment and effort required can add to the demands on the CL psychologist. However, when well organized, the presence of trainees on a CL service can also increase staffing and potentially enhance the delivery of clinical service. For trainees to be successful on CL, it is critical that they come to the clinical setting with a strong foundation in pediatric psychology, child behavior/development, and clinical child psychology. They must be able to handle new cases with limited time to prepare, flexible in adjusting their schedules to conform to fluctuating service demands, and adaptable in treatment planning for specific patients. Furthermore, strong communication and interpersonal skills in interacting with a variety of providers, health care workers, and families can enable CL trainees to think quickly on their feet in the fast-paced CL setting. The report of the APA Division 54 training task force should be consulted for a comprehensive review of the skills considered essential for the clinical practice of pediatric psychology in general (Palermo et al., 2014), most of which are relevant to CL practice in particular.

Pediatric CL psychologists are also often tasked with providing education and training to medical students, residents, fellows, and other hospital staffers. Frequent topics include the role of psychology in the medical care of patients (e.g., adherence, pain management, coping/adjustment, grief/loss), coaching in how to introduce a consulta-

tion with a family, the biopsychosocial conceptualization of patient symptomatology, general behavioral management strategies, and strategies for improving communication with "difficult" families. This training can be accomplished through rounds and observations of clinical encounters, as well as more formal opportunities such as didactic sessions and workshops. Education about the role of psychology in health care can promote changes in hospital policies and practices that enhance integration of mental health services.

TECHNOLOGICAL INNOVATIONS

Use of Technology to Enhance CL Practice

Time limitations are among the biggest challenges to providing effective inpatient CL services, often within the median number of two patient contacts (Piazza-Waggoner et al., 2013). One potential tool to enhance efficacy under such constraints is the application of new "eHealth" technologies—that is, the employment of electronic technologies that are designed to increase patients' and caregivers' understanding and application of health-related information, and that can serve to supplement and/or replace the roles and functions of clinicians in the delivery of interventions (Cushing & Steele, 2010). Examples include computer-based interventions (e.g., games, websites, CD-ROMs) and interventions involving smartphones or tablets (e.g., applications, texting, digital recording). These technologies can be useful in the inpatient setting to provide direct intervention, to assess and monitor behavior change, and to bridge the gap between inpatient and outpatient care. For example, they can provide treatment continuity to patients in remote areas after hospitalization, in cases where distance to the hospital is a barrier to receiving specialized care (Palermo, 2008).

Technologies Employed in CL Practice

Biofeedback

One of the inpatient interventions most commonly employed by CL psychologists to address anxiety, pain, and coping with stress is some variant of relaxation training (Piazza-Waggoner et al., 2013). Clinical biofeedback can enhance relaxation training by increasing patients' ability to identify the physiological changes associated with their mastering the relaxation response. Newer, more affordable, and more portable equipment employs such devices as interactive video games or apps that convert physiological indices into appealing computer animations, making this technology more appealing to pediatric patients. Devices for monitoring and altering such parameters as heart rate variability, muscle tension, respiration, and temperature, available on both computer and tablet platforms, are commonly employed by psychologists in the inpatient setting, and this technology tends to be well received by patients and practitioners alike (Benore & Banez, 2013; Gallagher, McKenna, & Ibeziako, 2014).

Interactive Patient Care Technology

Interactive patient care (IPC) is the provision of bedside entertainment and education via a patient's in-room TV. One IPC platform, the GetWellNetwork, uses video-based

activities to enhance patient and family education. An example of how psychologists can use this technology is a clinician's posting of important goals (e.g., relaxation skill practice) and events (e.g., times of various activities during the day) on a patient's daily schedule, which is kept on a "digital whiteboard" on the patient's TV. A message function allows the psychologist to post a message remotely on the patient's TV (e.g., "Don't forget to practice your breathing!").

Peer Education Videos

Another eHealth intervention involves providing videos of peer models for demonstrating and reinforcing various coping and adherence strategies. These videos can be accessed from many different modalities both in and out of the hospital, as well as via websites. This flexibility allows patients to access interventions at times when it is convenient for them. Examples of such peer education videos include those on the Coping Club website (*www.copingclub.com*; Ernst, 2011) and Kids4Kids (Kullgren, Kaufman, & Mosley, 2014). Not only do these interventions have potential benefit for the viewers; the youth involved in making the videos often report increased feelings of mastery and satisfaction with helping others when they serve as "experts" in demonstrating coping strategies.

Mobile Devices and Mobile Health Interventions

Mobile health, or mHealth, is a subset of eHealth delivered via mobile technologies (i.e., smartphones, tablets) for the goal of improving health outcomes. Recent data indicate that 37% of American teens have smartphones, and 25% have tablets ("Teens and Technology 2013," 2013); even among children under 8, 75% have some "smart" mobile devices in their homes ("Zero to Eight: Children's Media Use in America," 2013). Mobile devices can be used for implementing specific interventions (e.g., diaphragmatic breathing, relaxation, cognitive-behavioral therapy) and for tracking progress (e.g., goal setting, tracking adherence). Initial feedback on an iPad-based mHealth intervention has been very favorable, with both 83% of CL psychologists and 82% of patients agreeing or strongly agreeing that the intervention was helpful.

Challenges and Recommendations for Using Technology in CL Practice

Considerations in adopting technological tools in pediatric CL activities include the rapid pace of technological innovations, requiring clinician time and expense to stay abreast of new developments; privacy issues, particularly for shared devices requiring data encryption and/or reimaging; equipment reliability concerns; expense to the institution and to patients; ease of use versus need for technical savvy; and accessibility within and beyond the hospital (Rapoff, 2013; Cushing & Steele, 2010).

Before employing eHealth or mHealth interventions, CL psychologists also need to pay attention to the research evidence for these interventions, which ideally should be used in conjunction with other evidence-based face-to-face interventions (Cushing & Steele, 2010). Although a digital device program may have considerable utility with and appeal to tech-savvy youth, a clinician needs to be attentive to scientific evidence supporting its appropriateness for the target patient population, as well as other safety and institutional concerns—for example, infection control when devices are shared between

patients, control over protected health information, and equipment loss prevention (Limke, Peabody, & Kullgren, 2015).

RECOMMENDATIONS FOR RESEARCH AND TEACHING

Research and teaching in the CL setting continue to be challenging, due to the highly diverse and demanding aspects of practice. Over 75% of the respondents to the recent CL practice survey reported rarely or never having enough time for research, and only 29% reported having enough time for teaching "most of the time" (Kullgren et al., 2015). Areas in need of investigation include adapting and validating assessments and evidence-based interventions employed in other clinical child and pediatric psychology populations and settings to the hospital CL setting, with its inherent challenges of shorter stays and competing demands for patient access. Opportunities for research in eHealth and mHealth in pediatric CL practice constitute another area of great promise.

Attendees at any pediatric psychology conference will find a group of dedicated and energetic CL psychologists discussing the satisfaction and challenges experienced in insuring excellence in teaching, service, and research. It is critical that pediatric CL psychology engage in advocacy, program evaluation, dissemination of research, and communication of funding needs to continue the growth and development of the CL field (Kronenberger, 2006).

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CHAPTER 10

Adherence to Pediatric Treatment Regimens

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Effective management of chronic health conditions requires adherence to treatment recommendations. Nonadherence to treatment is a significant behavioral health problem and public health concern, with approximately 50% of children (Rapoff, 2010) and 65–90% of adolescents (Hommel, Davis, & Baldassano, 2009; Logan, Zelikovsky, Labay, & Spergel, 2003) being nonadherent. The ramifications of nonadherence are numerous, including poorer treatment outcomes, drug resistance, poorer health-related quality of life (HRQOL), increased health care utilization, health care costs in excess of $300 billion, and increased morbidity and mortality (DiMatteo, 2004a; McGrady & Hommel, 2013; Rapoff, 2010). This chapter provides an updated discussion of the complexity of treatment adherence in pediatrics—including measurement considerations; theoretical models of adherence; factors that affect adherence at the individual, family, social/contextual, and health care system levels; and evidence-based interventions to improve treatment adherence—with an emphasis on literature published after the preceding (4th) edition of the *Handbook of Pediatric Psychology* was published. We also discuss emerging issues in treatment adherence, including the impact of health care reform in the United States, the economic impact of improving adherence to treatment, and the use of health technologies to manage adherence.

CLASSIFICATION AND MEASUREMENT OF ADHERENCE

Adherence classification is often based on a particular cutoff point/percentage (e.g., a patient is typically considered nonadherent if less than 80% of prescribed medication is consumed). However, this type of classification is particularly problematic because the precise percentage of medication that must be taken to have the desired effect is

not known for many medications, and medications can have differential efficacy across patients due to drug metabolism, pharmacokinetics, dosage timing, and genetic factors. Thus the percentage of medications consumed or treatment completed and the patterns of medication use are more informative.

There are many methods for measuring adherence, depending on the particular treatment of interest. Each offers advantages and disadvantages, and there is no "perfect" measure of adherence, although electronic monitoring approaches are typically considered the "gold standard" of adherence measurement. Table 10.1 describes the various assessment methods; examples and/or calculations; and the primary advantages and disadvantages of each method.

MODELS OF MEDICAL ADHERENCE

Treatment adherence results from the interplay among several factors across multiple contexts. Multivariate models of health behavior contribute to our understanding of adherence to pediatric treatment regimens. This chapter discusses an emerging model of pediatric adherence, but readers are directed to the following resources for a comprehensive description and appraisal of existing models (e.g., the health belief model, social-cognitive theory, the theory of reasoned action/planned behavior, the self and family management framework, and the transtheoretical model; see Grey, Knafl, & McCorkle, 2006; La Greca & Mackey, 2009; and Rapoff, 2010).

The pediatric self-management model (Modi et al., 2012), proposes that self-management behavior is a product of influences and related underlying processes that occur across four domains (i.e., individual, family, health care system, and community). Influences, consisting of modifiable (e.g., distress, parental involvement) and nonmodifiable (e.g., age, socioeconomic status) factors, can either support or hinder pediatric patients and/or families in performing self-management behaviors. Domain-specific influences interact with underlying cognitive (e.g., memory), emotional (e.g., stress management), and social (e.g., shared decision making) processes to impact behavior which in combination, result in the extent to which health advice is followed. This model emphasizes both the modifiable influences and processes associated with self-management behavior as possible targets for intervention; however, it does not illustrate how behavioral processes in one domain may affect other domains, or how the various influences affect outcomes differentially across the four domains.

FACTORS THAT AFFECT ADHERENCE

Research across conditions has demonstrated that many individual, family, community, and health care system factors influence adherence. This section reviews adherence-related factors and the barriers across each domain.

Individual Factors

Nonmodifiable individual influences of adherence include demographic variables such as age, gender, race, socioeconomic status, and cognitive ability. In general, pediatric

TABLE 10.1. Current Assessment Approaches for Treatment Regimen Adherence

Method	Examples/calculation	Advantages	Disadvantages
Objective			
Direct observation	Parent or caregiver watches or records medication consumption	• Accurate • Cost-effective • Verifies consumption • Measures nonadherence frequency	• Feasibility • Intrusive • Inconsistency in raters
Pharmacy record data	Medication possession ratio = # days supplied ÷ # days elapsed	• Verifies medication was filled • Determines how much medication was available during given time frame	• Patients often have multiple pharmacies • Need patient release for each pharmacy • Expensive (e.g., $75 per request) • Mail-order pharmacies can ship same time each month, or two or three via automatic refill • No data on patterns of nonadherence
Pill counts	Adherence percentage = (1) today's date – date prescription filled = # days; (2) # days × # doses prescribed/day = # expected; (3) # filled – # in bottle = # taken; (4) # taken ÷ # expected	• Cost-effective and feasible (particularly if phone assessment is conducted) • Measures presumed consumption and nonadherence frequency	• Can be manipulated positively or negatively via combining and dumping • Organizational issues with medications at home can affect quality of data
Electronic monitoring	Medication Event Monitoring System; Medminder; SimpleMed; Vitality GloCaps; Propeller Health; blood glucose monitors	• Provides good breadth and depth of data • Appealing to tech-savvy patients • Measures presumed consumption and nonadherence frequency • Only assessment tool to measure patterns of adherence	• Expensive • Can be manipulated positively or negatively • Variability in validity and reliability of devices commercially available • Hardware/software can be complex
Biological assays	Drug metabolites (e.g., 6-TGN/6-MMPN); HbA1c; viral load; drug trough levels (e.g., tacrolimus level)	• Blood/urine/saliva concentration of medication • Verifies consumption • May be reimbursed by insurance and integrated into standard care	• Expensive • Subject to pharmacokinetic variation and metabolism • Does not measure adherence patterns or nonadherence frequency • Can be manipulated by recent dosing, depending on medication

(*continued*)

TABLE 10.1. (*continued*)

Method	Examples/calculation	Advantages	Disadvantages
Subjective			
Patient and/or parent report or interview, diet records, or recall	Medical Adherence Measure; Medication Adherence Rating Scale; Morisky Medication Adherence Scale; Medication Adherence Self-Report Inventory; daily diary; structured interview; smartphone apps	• Cost-effective and feasible • Provides patient and/or parent perceptions of adherence behavior • Apps appeal to tech-savvy patients	• Social desirability and recall biases can overestimate adherence • Variable assessment content • May require adherence to recording information in patients for whom adherence is a concern
Provider estimates	Physician/allied health care provider	• Cost-effective and feasible	• Poor reliability and validity • Reactivity

Note. Data from Duncan, Mentrikoski, Wu, and Fredericks (2014); Hommel, Mackner, Denson, and Crandall (2008); and Rapoff (2010).

adherence rates are lower than those for adults (DiMatteo, 2004b), with adherence being lowest during adolescence (Hilliard, Mann, Peugh, & Hood, 2013; Masterson, Wildman, Newberry, & Omlor, 2011; Nichols et al., 2012). Age-related differences are likely the result of a variety of factors, including varying developmental levels (for which age is a proxy), changes in parental responsibility for disease management, and increasing value of peers during adolescence. There is increasing evidence that children and adolescents from minority backgrounds and lower socioeconomic status are less adherent to chronic disease regimens (McQuaid et al., 2012; Naar-King et al., 2013; Nichols et al., 2012). Cognitive processes (e.g., executive functioning, memory) have also demonstrated interference with the ability to manage and successfully execute complex treatment regimens (McNally, Rohan, Pendley, Delamater, & Drotar, 2010; O'Hara & Holmbeck, 2013).

Research has also examined the relationship between adherence and modifiable individual characteristics, such as disease and treatment knowledge, psychological/behavioral difficulties, and health beliefs. Treatment knowledge is often positively correlated with adherence (Carbone, Zebrack, Plegue, Joshi, & Shellhaas, 2013). Some studies have shown, however, that children who are made aware of their HIV status have poorer adherence (Chandwani et al., 2012; Naar-King et al., 2013).

Internalizing symptoms (Herzer & Hood, 2010; King et al., 2014; Park & Nachman, 2010), stressful life events (Helgeson, Escobar, Siminerio, & Becker, 2010), conduct problems/general hyperactivity (Malee et al., 2011), high-risk behavior (Hackworth et al., 2013), and poorer HRQOL (Hilliard et al., 2013) are related to poorer adherence. In contrast, increased anxiety was related to better adherence in pediatric renal and liver transplant populations (Wu, Aylward, & Steele, 2010).

Increased optimism, hope, religious beliefs/practices, involvement in sports, and better coping skills are associated with enhanced adherence and health status (Nichols et al., 2012; Park & Nachman, 2010). In addition, adaptive health beliefs, including general and disease-specific self-efficacy, internal locus of control, and confidence in

the effectiveness of treatments, are associated with better self-management (Hackworth et al., 2013; Helgeson et al., 2010; Sleath et al., 2012). Lower risk taking (Hackworth et al., 2013) and better self-regulation skills (Berg et al., 2014) are also associated with better treatment adherence.

Family Factors

Caregivers and siblings of children with a chronic illness play a critical role in adherence and treatment management. Smaller families and married caregiver status have been related to improved adherence (Carbone et al., 2013; Hilliard et al., 2013). Other family factors influencing adherence include income and insurance coverage status (Modi & Guilfoyle, 2011). Interestingly, more recent immigration has been associated with better adherence (Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010).

Modifiable family influences of adherence include parental involvement in illness management responsibilities, family psychosocial adjustment and functioning, and parenting style (Modi et al., 2012). Greater family involvement and shared treatment responsibility are associated with better adherence for youth with diabetes (Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008; Wysocki et al., 2009), transplants (Simons, McCormick, Mee, & Blount, 2009), sickle cell disease (Alvarez et al., 2009), inflammatory bowel disease (Reed-Knight, Lewis, & Blount, 2011), HIV (Naar-King et al., 2009), and spina bifida (Psihogios & Holmbeck, 2013). Similarly, studies have shown poorer adherence when youth take greater responsibility for management tasks (Hsin et al., 2010; Ingerski, Baldassano, Denson, & Hommel, 2010; Naar-King et al., 2013; Nichols et al., 2012). Ideally, however, a gradual shift in treatment responsibility will occur over the course of a child's development. Finally, findings have been inconsistent regarding the level of paternal involvement for optimal adherence (Dashiff, Morrison, & Rowe, 2008; Wysocki et al., 2009).

Increased parental depression, anxiety, stress, and burden are related to nonadherence (Cunningham, Vesco, Dolan, & Hood, 2011; Eckshtain, Ellis, Kolmodin, & Naar-King, 2010), while better caregiver health and perceived social support can promote adherence (Azzopardi et al., 2014; Monaghan, Hilliard, Cogen, & Streisand, 2011). Poorer family functioning and greater family conflict are related to decreased adherence (Hilliard, Guilfoyle, Dolan, & Hood, 2011; Ingerski et al., 2010; Psihogios & Holmbeck, 2013; Stepansky, Roache, Holmbeck, & Schultz, 2010), whereas greater family cohesion, efficacy, and flexibility are associated with better self-management (Dew et al., 2009; Guilfoyle, Crimmins, & Hood, 2011; Hsin et al., 2010). Poor family communication (particularly in regard to disease management) and adolescent perceptions of poor caregiver–youth relations also contribute to nonadherence (Naar-King et al., 2013). Finally, a permissive parenting style toward normative tasks, less authoritarian style, and increased parental guidance and warmth are related to better adherence (Grabill et al., 2010; Saletsky, Trief, Anderson, Rosenbaum, & Weinstock, 2014).

Community Factors

Relatively little research has examined the role of nonmodifiable or modifiable community factors, such as peer support, social stigma, school-based accommodations, and

availability of social networking, in adherence and self-management. The quality and supportiveness of peer relationships play a role in pediatric self-management; in particular, receiving disease-related support from friends buffers fears related to stigma and self-consciousness, and promotes adherence (Janicke et al., 2009). In contrast, one study demonstrated that 53% of nonadherent instances took place in front of friends (Mulvaney et al., 2013). Given the influential role of peers, and the existing evidence of the relationship between adherence and the community, further research on community factors is warranted.

Health Care System Factors

The relationship between adherence and aspects of the health care system domain remains largely unexplored since the preceding edition of this chapter was published. Given the current emphasis on preventative care, additional research should be conducted to determine the impact of health care system factors on treatment adherence.

Disease and Regimen Factors

Youth with longer disease duration have poorer adherence, and there are significant declines in adherence over the course of treatment (Hilliard et al., 2013). In addition, children with more complex forms of disease (e.g., increased pain crises, continued seizures after 2 years, higher HIV RNA levels) demonstrate poorer adherence (Chandwani et al., 2012; Modi, Rausch, & Glauser, 2014; Usitalo et al., 2014).

Barriers to Treatment Adherence

Although some distinct barriers to adherence exist for specific populations, many of the primary barriers are consistent across illness groups. These include forgetfulness (Blaakman, Cohen, Fagnano, & Halterman, 2014; Chandwani et al., 2012; Gray, Denson, Baldassano, & Hommel, 2012), poor time management (Bregnballe, Schiotz, Boisen, Pressler, & Thastum, 2011), running out of medication (Simons, McCormick, Devine, & Blount, 2010), difficulty with medication routine (Chandwani et al., 2012; Simons et al., 2010), interference with activities, difficulty swallowing medication (Ingerski et al., 2010), taste of the medication (Buchanan et al., 2012), beliefs about medication ineffectiveness or treatment undesirability (Rhee, Belyea, Ciurzynski, & Brasch, 2009), not wanting to be reminded of their illness (MacDonell, Naar-King, Huszti, & Belzer, 2013), and disease frustration (Simons et al., 2010). Importantly, adherence barriers tend to remain consistent over time, emphasizing the importance of early intervention (Lee et al., 2014).

INTERVENTIONS FOR PEDIATRIC TREATMENT ADHERENCE

Over the past decade, a number of interventions have been developed to improve adherence to medical regimens. Although many of the interventions target multiple well-established, modifiable correlates of nonadherence (e.g., knowledge, problem solving), the efficacy of a particular treatment may vary, depending on the assessment method

utilized. In addition, more interventions are being delivered through the internet, and by providers other than psychologists. Although this section provides a summary of recent adherence promotion interventions, we refer readers to several systematic reviews and meta-analyses for additional details regarding their effectiveness (Dean, Walters, & Hall, 2010; Graves, Roberts, Rapoff, & Boyer, 2010; Kahana, Frazier, & Drotar, 2008; Pai & McGrady, 2014).

Educational Interventions

Education interventions focus on providing illness-specific instruction, including the purpose and details of the medical regimen, and are often emphasized at diagnosis and during transitional periods (e.g., adolescence). Overall, there is little empirical support for education only (mean $d = 0.16$), compared to behavioral (mean $d = 0.54$) or combined education and behavioral (mean $d = 0.74$) interventions (Graves et al., 2010; Kahana et al., 2008). Notably, in a recent meta-analysis (Pai & McGrady, 2014), none of the 23 adherence promotion intervention studies were education only, while 83% of the studies included education as an intervention component.

Behavioral Interventions

Behavioral interventions to improve adherence commonly target the antecedents (e.g., forgetting) and/or consequences (e.g., rewards) of following a prescribed medical regimen. When behavioral techniques are combined with education, there is a significant increase in effect size (mean $d = 0.74$; Graves et al., 2010). An example of a successful behavioral intervention utilized electronic observation of medication ingestion, electronic reminders, personalized feedback, and incentives to improve hydroxyurea adherence (Creary, Gladwin, Byrne, Hildesheim, & Krishnamurti, 2014). Behavioral techniques may also be combined with interventions targeting cognitive factors (e.g., illness attitudes, depressive symptoms) related to nonadherence. For example, a web-based intervention using feedback and goal setting to increase positive beliefs about asthma management found improved parent self-efficacy and medication adherence at 6 months posttreatment (Christakis et al., 2012).

Family and Peer Interventions

Interventions that target the family system may be an effective way to improve adherence to pediatric medical regimens. Behavioral family systems therapy for diabetes, which includes problem-solving and communication training, cognitive modification, and functional–structural family therapy, resulted in improved adherence following a tailored treatment (Wysocki et al., 2007). In addition, a family-based group behavioral intervention in pediatric inflammatory bowel disease utilized a combination of empirically supported techniques (education, problem solving, communication) and found significant improvement in medication adherence compared to adolescents in the control group (Hommel et al., 2012). Similarly, findings from a recent randomized clinical trial in pediatric asthma revealed significantly higher adherence and lower family conflict for participants using a teamwork approach to establish shared responsibilities for asthma management (Duncan et al., 2013).

There have been relatively few studies examining the impact of peers on adherence promotion. In a study of adolescents with Type 1 diabetes, an internet-based intervention that included social networking opportunities, in addition to skills training, resulted in significant improvements in self-management behaviors (Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010). However, a recent study of inner-city minority adolescents with persistent asthma showed that peer support, delivered through electronic messages and weekly group sessions, did not affect adherence to inhaled corticosteroids (Mosnaim et al., 2013). Thus more research is needed to understand the potential benefits of peer support of pediatric adherence.

Multicomponent Interventions

Multicomponent interventions are increasingly common and use multiple strategies (e.g., education, behavioral and cognitive techniques) to improve adherence. A previous meta-analysis found moderate effect sizes (mean $d = 0.51$) for multicomponent interventions (Kahana et al., 2008), whereas a more recent evaluation of combined treatment programs revealed small effect sizes (mean $d = 0.20$; Pai & McGrady, 2014). Discrepant findings may be explained, in part, by the difficulty in identifying key intervention components associated with behavior change. For example, a study targeting youth with diabetes found that multisystemic therapy (which included education; behavioral interventions; and family, peer, and school support) resulted in better parent-, but not adolescent-, reported adherence than a telephone support control condition did (Ellis et al., 2012). In a sample of young adults with HIV, a combination of financial incentives for lab results and appointment attendance with motivational interviewing for adherence behavior was associated with improved viral loads at 24 months postintervention (Foster, McDonald, Frize, Ayers, & Fidler, 2014).

Innovative Intervention Delivery

A recent meta-analysis revealed that eHealth interventions that incorporated behavioral methods had larger effect sizes than technology-based interventions that were education only (Cushing & Steele, 2010). For example, a video game designed for adolescents and young adults with cancer resulted in improved medication adherence (Kato, Cole, Bradlyn, & Pollock, 2008). See Wu and Hommel (2014) for more information about technology-based interventions.

Health care providers other than psychologists have also been designated to provide a variety of adherence interventions, given their existing relationships with patients, access to families during routine medical care, and familiarity with the treatment regimen. A meta-analysis by Wu and Pai (2014) showed initial efficacy for interventions delivered by health care providers, particularly immediately following the interventions (mean $d = 0.49$). Several studies of home- and hospital-based interventions delivered by health care providers (e.g., physicians, nurses, trained educators) have been effective in increasing adherence to inhaled corticosteroids among youth with asthma, compared to a control group (Burgess, Sly, & Devadason, 2010; Ducharme et al., 2011). In addition, Britto et al. (2014) showed the implementation of care coordination resulted in a significant increase in patients and family members who were confident in their ability to manage asthma, as well as improved control of asthma symptoms.

EMERGING ISSUES IN TREATMENT ADHERENCE

There are several emerging issues in the area of treatment adherence. First, with the advent of health care reform, proactive and preventive health care will be emphasized throughout the health care system. Organizations are likely to be incentivized for taking better care of their patients (e.g., reducing hospital readmissions, emergency department visits, and costs), and providing self-management support will be a key factor in determining better outcomes. This may also result in a shift of self-management treatment focus from the clinicians' standpoint. Rather than referring patients for intervention when adherence problems become substantial and health outcomes worsen, health care reform offers opportunities to shift the focus toward prevention, early intervention, and integration of self-management support services in standard health care. Demonstrating the cost outcomes associated with improved adherence will be important, as decisions regarding how to spend limited funds will depend not only on what health outcomes are likely to be achieved, but also how much it will cost to achieve them. This can be demonstrated in a number of ways, but cost-effectiveness and cost-offset are likely to emerge as important metrics to justify the expense of providing self-management support (McGrady, 2014; McGrady & Hommel, 2016).

An additional emerging issue concerns the use of technology in research and clinical efforts. With the rapid expansion of wearables and other devices, smartphone apps, internet interventions, electronic medical records, and virtually unlimited technology-based resources to learn about or help manage chronic conditions, the integration of these methods into research and practice is both inevitable and filled with opportunities. Perhaps most critical is the need for adequate vetting of products/resources to determine their utility and quality. There currently exists the technology to self-monitor adherence via smartphone medication tracking apps, record medication consumption via facial recognition and motion sensing technology, and track ingestion via digestible sensors placed on pills that send a signal via physiological changes to a wearable patch. Yet the long-term acceptability to patients, quality of data they generate, and their clinical utility still need to be thoroughly evaluated. It is likely that the plethora of technological resources, combined with a high degree of personalized intervention, can improve end user engagement.

SUMMARY AND CONCLUSIONS

Pediatric treatment adherence is a complex behavioral health issue with significant implications for treatment efficacy, clinical decision making, morbidity and mortality, and health care costs. Measurement of treatment adherence is equally complex; despite the advantages of a multimethod assessment approach, there remains a significant need for evaluation of existing adherence measurement methods that increase validity and reliability.

Several intervention approaches have received empirical support, including behavioral and multicomponent treatment protocols. Due to the multitude of factors that affect treatment adherence, interventions often target many behaviors and train patients in several skills, which can be costly and inefficient. Thus dismantling studies are needed to identify the critical components of efficacious interventions. Treatment outcome stud-

ies will also need to examine the extent to which efficacious interventions produce long-term change in self-management behavior. In addition, changes in our health care climate will require flexibility in who provides interventions and how they are provided. Further evaluation of the method of intervention delivery is needed as well, given that a team approach using allied health care workers (e.g., nurses, social workers, pharmacists, child life) may result in improved patient engagement, efficiency, and treatment adherence. Attention to the impact of adherence interventions on patient outcomes and health care utilization will be important in demonstrating cost-effectiveness. Finally, the issue of disseminating effective interventions is paramount. The time lag from demonstration of efficacy to implementation in practice is too lengthy. Collaboration through care networks, across disciplines, and with the aid of technology should speed the rate of dissemination.

Advances in medical treatment offer new challenges and opportunities for treatment adherence. Some newer biologic therapies, for example, offer less frequent infusion treatments given periodically at the hospital. Yet such advances will not improve adherence for all patients. Related to this, advances in technology that might aid adherence intervention delivery need to be thoroughly tested and thoughtfully integrated into personalized interventions for patients based on their unique treatment needs. Finally, further attention to which intervention components can be used across chronic conditions and how intervention packages can be customized by condition is necessary to capitalize on the efficiency and effectiveness of treatment adherence promotion.

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CHAPTER 11

Chronic and Recurrent Pain

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The experience of pain is common during childhood and adolescence. The term "chronic pain" is applied when pain persists or recurs for 3 months or more, which is generally considered to be beyond the expected time frame for natural healing. Epidemiological studies indicate that 11–40% of children and adolescents experience chronic or recurrent pain (King et al., 2011). A small but significant proportion of these youth (3–8 %) are severely disabled by their pain (Huguet & Miro, 2008). Chronic pain in children can occur within the context of an injury or a chronic health condition (e.g., arthritis, sickle cell disease); however, in many cases no underlying organic disease or injury can be identified, and the pain itself is the problem.

Chronic pain in childhood is an important clinical problem with broad societal impacts. Pediatric chronic pain is among the most costly chronic health conditions in childhood, with an estimated annual economic cost of $19.5 billion (Groenewald, Essner, Wright, Fesinmeyer, & Palermo, 2014). Indeed, children with chronic pain have high rates of health care utilization, including routine medical appointments, emergency room visits, and medication use (Groenewald et al., 2014). Longitudinal studies indicate that children with chronic pain are at risk for pain, psychiatric comorbidities, and pain-related disability in adulthood (Walker, Sherman, Bruehl, Garber, & Smith, 2012). Appropriate treatment of chronic pain in childhood has the potential to reduce pain, disability, and health care costs across the lifespan.

This chapter describes common pediatric chronic pain conditions. We discuss conceptual models of chronic pain in childhood and describe associated biological, psychological, and social factors. We also describe approaches to clinical assessment and treatment. The conclusion of the chapter focuses on future directions in clinical care and research.

COMMON IDIOPATHIC CHRONIC PAIN CONDITIONS IN CHILDREN AND ADOLESCENTS

The most common pain complaints in children and adolescents are "idiopathic," meaning that the cause is unknown. Idiopathic pain conditions include musculoskeletal pain, headache, and abdominal pain (King et al., 2011). The most common musculoskeletal pain locations are lower limb, neck/shoulder, and back pain (King et al., 2011). Headache pain includes episodic or chronic tension-type headache and migraine headache (International Headache Society, 2013). Functional abdominal pain disorders are defined as abdominal pain (with or without other gastrointestinal symptoms) that is not accounted for by an organic disease process in the gastrointestinal tract (Walker et al., 2004).

Neuropathic pain (i.e., "nerve pain") also occurs in childhood and adolescence. This type of pain is usually described as a "burning" or "pins and needles" sensation and can also include hypersensitivity (i.e., lowered pain threshold and greater magnitude pain response), allodynia (i.e., pain caused by a mild stimulus that is usually not painful), and/or spontaneous pain (i.e., pain in the absence of stimulation). One type of neuropathic pain in children is complex regional pain syndrome, type I (CRPS; Stanton-Hicks, 2010). Older terms for CRPS include reflex sympathetic dystrophy and reflex neurovascular dystrophy. CRPS usually involves pain in the distal portion of an arm or leg, and may begin after an injury but persist long after the injury appears to have healed. Symptoms of CRPS include hypersensitivity, allodynia, spontaneous pain, and autonomic dysfunction (e.g., the affected limb may be colder or warmer than the other limb). Secondary muscle weakness and other motor impairments often develop as a result of inactivity and guarding of the limb (Stanton-Hicks, 2010).

Chronic widespread pain in the muscles and tissues of the body can also occur, and is often associated with sleep disturbance and fatigue (Anthony & Schanberg, 2001). In some pediatric settings, these symptoms may be diagnosed as fibromyalgia syndrome; other settings may use the term central sensitization (Woolf, 2011). The diagnosis is based on a history of widespread pain and a positive tender point examination.

CONCEPTUAL MODELS FOR UNDERSTANDING CHRONIC PAIN

A number of models have been put forth to explain pain perception and the development and maintenance of chronic pain. Melzack and Wall (1965) proposed that pain perception depends on a complex "gating" mechanism in the dorsal horn of the spinal cord, through which both sensory and pain fibers relay signals. If the "gate" is open, pain sensations are transmitted to the cortex, where they are recognized as pain. If the "gate" is closed, no signal is sent to the brain, and no pain is perceived. Thus, if an impulse from a sensory fiber (e.g., from rubbing the site of injury) were to reach the "gate" before an impulse from a pain fiber, the connecting neuron could be activated by the sensory fiber and thus be unresponsive to the pain impulse. In other words, the sensory stimulation would close the "gate." Melzack and Wall (1965) also proposed that descending messages from central cognitive mechanisms could open or close the "gate." For example, attentional distraction may temper pain perception, whereas negative affect or catastrophic thinking may increase pain experience. Thus the modulation of pain involves

both ascending and descending pathways that can potentiate or inhibit pain experience. Although the processes involved in pain perception are complex and multifaceted, there is considerable empirical support for the notion that pain modulation involves the integration of bottom-up nociceptive transmission and top-down sensory, affective, cognitive, and attentional processes (Apkarian, Bushnell, & Schweinhardt, 2013).

Conceptual models specific to chronic pain in childhood are grounded in a biopsychosocial framework and highlight interrelations among physical, affective, cognitive, and social factors that influence pain and related disability. For example, Palermo and Chambers (2005) put forth an integrative model of parent and family factors in pediatric chronic pain, which positions the child and his or her pain experience as being nested within broader influences of dyadic processes (e.g., parent–child interactions) and family-level variables (e.g., family cohesion). Several mediating and moderating variables (e.g., child gender, age, emotional symptoms, and coping) are also acknowledged. Palermo (2012) has since expanded upon this model by highlighting additional factors that influence the experience of chronic pain in childhood, including biological factors (e.g., pubertal development, pain modulation), health habits (e.g., sleep), and social factors (e.g., school environment, culture, peer interactions).

Biological Factors

Epidemiological studies indicate that chronic pain is more common among girls than boys (King et al., 2011). Greater prevalence of chronic pain in girls compared to boys has been found in younger (elementary-school-age) children as well as high school students, with greater discrepancies after puberty (Hassan, Muere, & Einstein, 2014). The basis for the increased prevalence of chronic pain in females, however, remains unclear. Some researchers argue that psychosocial factors, rather than differences in peripheral nerve functioning, contribute to observed sex differences (e.g., Blankenburg et al., 2011). There is also some evidence to suggest that ovarian hormones may play a role in chronic pain. For example, changes in hormone levels over the menstrual cycle have been shown to correspond to changes in the severity of reported chronic pain symptoms (Hassan et al., 2014).

Recently, growing attention has been given to the role of pain modulation at the level of the central nervous system. Conditioned pain modulation (CPM) is an experimental methodology in which an individual's perception of a particular pain stimulus (e.g., heat) is reduced when a different pain stimulus (e.g., cold) is applied to another body part at the same time. Although only a few studies of CPM have been conducted with children, emerging evidence suggests that endogenous pain inhibition may be impaired in children who were born prematurely and exposed to numerous invasive medical procedures (Goffaux et al., 2008), and in girls with chronic pain conditions such as irritable bowel syndrome (Williams, Heitkemper, Self, Czyzewski, & Shulman, 2013). These findings indicate that early chronic pain is a disease entity that can affect the entire central nervous system.

Psychological Factors

Children's psychological functioning (e.g., coping, mood, anxiety) can be both a contributing factor to and an outcome of chronic pain. Various coping styles have been

categorized among youth with chronic pain, and these tend to be broad descriptions of avoidance versus approach tendencies (Walker, Baber, Garber, & Smith, 2008). Passive coping strategies, including self-isolation, catastrophizing, and activity avoidance, have been found to be related to higher pain, somatic symptoms, depression, anxiety, and functional disability (Kaminsky, Robertson, & Dewey, 2006). Depressive and anxiety symptoms have been associated with increased pain and disability (Kashikar-Zuck et al., 2013), impairments in school functioning (Kashikar-Zuck et al., 2010), sleep disturbances (Palermo & Kiska, 2005), and poorer health-related quality of life (Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001). Pain-specific anxiety (e.g., fear of pain) and pain catastrophizing (e.g., thoughts of helplessness and inability to cope with pain) have received increasing attention and are associated with greater functional disability (Caes, Fisher, Clinch, Tobias, & Eccleston, 2015; Lynch-Jordan, Kashikar-Zuck, Szabova, & Goldschneider, 2013; Simons & Kaczynski, 2012).

Little is known about the prevalence of psychiatric comorbidities among treatment-seeking youth with chronic pain. In epidemiological studies, chronic pain has been found to be more common among youth with psychiatric disorders (particularly anxiety and depression) than among youth without psychiatric disorders (Egger, Costello, Erkanli, & Angold, 1999). More recent research has focused on long-term trajectories of mental health disorders among youth with chronic pain. For example, youth with functional abdominal pain have been found to be at significantly higher risk of developing anxiety and depressive disorders in adulthood, compared to youth without abdominal pain (Shelby et al., 2013; Walker et al., 2012).

Social Factors

The social context of youth with chronic pain includes parent and family functioning, peer relationships and the school environment, and cultural and socioeconomic factors. Parent and family factors have been studied extensively in pediatric chronic pain, with current conceptual models suggesting a bidirectional relationship between parent/family functioning and child adjustment to chronic pain (e.g., Palermo & Chambers, 2005; Palermo, Valrie, & Karlson, 2014). For example, higher levels of parent distress and greater levels of family dysfunction have been associated with greater pain-related disability in youth (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). Greater parent protective responses (i.e., attention to pain complaints, allowing children to avoid activities due to pain) have also been associated with greater pain-related disability (e.g., Logan, Simons, & Carpino, 2012). In clinical practice, these associations have been characterized as a downward spiral: The child's pain increases parental distress and protective responses, which in turn inadvertently reinforce the child's pain behaviors and perpetuate pain and associated disability (Schechter, 2014).

The experience of chronic pain often makes it difficult for children and adolescents to attend school and maintain friendships. Indeed, children with chronic pain have greater school absenteeism, poorer academic performance, fewer friends, and greater social isolation than youth without chronic pain do (Vervoort, Logan, Goubert, De Clercq, & Hublet, 2014). At the same time, the presence of strong peer relationships has emerged as a protective factor for these youth (Forgeron et al., 2010). Future research examining the mechanisms by which peer relationships influence children's pain and disability is warranted.

Research documenting the role of cultural and socioeconomic variables in pediatric chronic pain is limited. Available data suggest that while socioeconomic status and cultural background do not appear to influence the sensory aspects of pain or pain perception, these factors can have a substantial impact on children's pain expression and the responses of their caregivers (Finley, Kristjansdottir, & Forgeron, 2009). For example, in a recent study examining pain expression in one First Nations community in Canada, results revealed that children in that community tend to express pain with stoicism, which may lead to underestimates of pain intensity (Latimer et al., 2014). More research is needed to understand the impact of race, ethnicity, socioeconomic status, and culture on the experience of chronic pain in childhood.

MODELS OF CARE

Multidisciplinary pediatric pain clinics are considered the standard of care for youth with chronic pain conditions. These clinics are typically located within tertiary care medical centers and generally include physicians, psychologists, nurses, and physical/occupational therapists who work collaboratively to care for their patients. Youth with severe pain-related disability, with certain types of pain conditions (e.g., CRPS), or without access to a specialty pain clinic in their local community may receive treatment in an inpatient or day treatment pain rehabilitation program (see Hechler et al., 2015, for a comprehensive review). Listings of pediatric chronic pain programs in the United States and Canada are available through the American Pain Society (*http://americanpainsociety.org/get-involved/shared-interest-groups/pediatric-adolescent-pain*) and the Canadian Pain Coalition (*http://prc.canadianpaincoalition.ca/en/pediatric_pain_treatment_facilities.html*). Remotely delivered psychological treatments have also been developed for youth who do not have a specialty pain clinic in their community. These include self-guided written materials and relaxation tapes (McGrath et al., 1992), computerized programs on CD-ROMS (Rapoff et al., 2014), and internet interventions (Palermo et al., 2016).

ASSESSMENT

The psychological assessment of youth with chronic pain is conducted via a clinical interview that follows the biopsychosocial model. Domains of assessment include pain characteristics (location, duration, intensity, frequency), comorbid medical conditions, a child's psychological functioning and coping, and social and environmental factors that may be influenced by or may influence the child's pain behaviors. Typically, pediatric psychologists work in tandem with physicians and physical therapists/occupational therapists to assess the child's medical and physical functioning.

The primary means of psychological assessment is a semistructured clinical interview. For an example of a semistructured interview for youth with chronic pain, see Palermo (2012). The clinical interview includes a detailed pain history (i.e., how the pain first started and has progressed over time), pain characteristics (i.e., intensity, frequency, duration, and what the pain feels like), previous treatment, typical pain coping strategies, and multiple domains of daily functioning. The clinical interview can be

supplemented by validated questionnaire measures when available. Relevant domains (with associated validated measures in parentheses) include the following: (1) pain intensity (e.g., numeric rating scales or faces pain scales, von Baeyer, 2006); (2) activity limitations and physical functioning (Functional Disability Inventory, Claar & Walker, 2006; Child Activity Limitations Interview, Palermo, Lewandowski, Long, & Burant, 2008); (3) emotional functioning (e.g., Children's Depression Inventory, Kovacs, 1985; Revised Child Anxiety and Depression Scale, Chorpita, Moffitt, & Gray, 2005); (4) pain-related fear (e.g., Pain Catastrophizing Scale for Children, Crombez et al., 2003); (5) pain coping (e.g., Pediatric Pain Coping Inventory, Varni et al., 1996); (6) school functioning; (7) social functioning; (8) sleep (see Lewandowski, Toliver-Sokol, & Palermo, 2011, for a comprehensive review of available measures to assess sleep in children with medical conditions); (9) parental responses to children's pain (Adult Responses to Children's Symptoms, Van Slyke & Walker, 2006); and (10) general family functioning (e.g., McMaster Family Assessment Device, Miller, Epstein, Bishop, & Keitner, 1985). There are also validated measures that assess the broad impact of chronic pain on children and parents (e.g., Bath Adolescent Pain Questionnaire, Eccleston et al., 2005; Bath Adolescent Pain—Parental Impact Questionnaire, Jordan, Eccleston, McCracken, Connell, & Clinch, 2008).

INTERVENTIONS

Treatment of chronic pain in children is typically multidisciplinary and can include psychological interventions, medication management, physical and occupational therapy, and complementary and alternative medicine approaches. The overarching goal of these interventions is to increase children's physical activity and participation in daily life. A commonly held clinical dictum is that reductions in pain will occur gradually over time as children become more active and resume their daily lives.

Psychological Interventions

Psychological therapies for pediatric chronic pain can include self-regulatory strategies to control pain and enhance bodily awareness (e.g., self-hypnosis, relaxation methods, biofeedback); strategies to change children's maladaptive cognitions about pain; strategies to enhance children's physical activity and general well-being (e.g., activity pacing, sleep hygiene training); operant training for parents to reduce attention to pain behaviors; and cognitive-behavioral therapy (CBT) treatment packages that incorporate many of the preceding techniques. There is also growing interest in acceptance and commitment therapy, which promotes daily functioning by enhancing willingness to experience pain or discomfort in order to live in alignment with personal values and life goals (e.g., Masuda, Cohen, Wicksell, Kemani, & Johnson, 2011). Psychological interventions may be the only treatment that is provided to children, or may be one component of a multidisciplinary approach. For a detailed clinician's guide to delivering CBT to youth with chronic pain, see Palermo (2012). A companion self-help book for parents is also available (Palermo & Law, 2014).

Eccleston and colleagues (2014) conducted the most recent meta-analytic review of published trials of psychological therapies for youth with chronic pain published by the

Cochrane Collaboration. The meta-analysis included 37 randomized controlled trials of psychological interventions for pediatric chronic pain conducted over the past 25 years with 2,111 participating children. Most of these trials evaluated CBT treatment packages. Findings revealed large treatment effects for pain reduction for children with headache and nonheadache pain. Among the few studies that reported on disability and mood outcomes, small treatment effects were found for disability reduction in youth with headache and nonheadache pain, and for anxiety reduction among youth with headache.

Pharmacological Interventions

Prescription and nonprescription medications are often recommended to treat chronic pain in children, and are generally viewed as a temporary means of support as children begin to increase their physical activity and return to their normal daily lives. The most common classes of drugs include antidepressants (e.g., amitriptyline, duloxetine) and anticonvulsants (e.g., gabapentin, pregabalin, topiramate), which are used to treat neuropathic pain conditions as well as chronic daily headache and chronic abdominal pain. Nonsteroidal anti-inflammatory drugs (e.g., ibuprofen, naproxen) may be used to treat pain related to inflammation. Topical agents may be used to treat focal areas of neuropathic pain (e.g., lidocaine patch) or inflammation (e.g., diclofenac gel). Opioid medications (e.g., oxycodone, methadone) are used infrequently and generally only when there is an underlying nociceptive cause for a child's pain problem. Procedural interventions such as Botox injections and lidocaine infusions are also used infrequently. It is important to acknowledge that there are no data regarding the safety or efficacy of most of these medications for the management of chronic pain in childhood; therefore, no guidelines are available regarding their use in clinical practice (Gregoire & Finley, 2013).

Physical and Occupational Therapy Interventions

Physical therapy aims to help a child indirectly or directly alter sensory afferent activity, modify cognitive and emotional responses to painful sensations, and regulate stress responses and regain homeostasis (Tupper, Swiggum, O'Rourke, & Sangster, 2014). Physical therapy interventions typically involve a combination of strength training, stretching, and aerobic exercise, and may also utilize approaches such as systematic desensitization and graded motor therapy. Occupational therapy focuses on helping children to become more independent in activities of daily living, such as grooming, dressing, writing, and doing chores. Data regarding the efficacy of physical and occupational therapy interventions for children with chronic pain are limited. Existing studies typically report outcomes from multidisciplinary programs that include psychological interventions, pharmacological interventions, and physical or occupational therapy (e.g., Logan et al., 2012). Few studies have examined physical or occupational therapy as a sole intervention for youth with chronic pain.

Complementary and Alternative Medicine Approaches

Complementary and alternative medicine (CAM) therapies, such as acupuncture, yoga, and massage, are often prescribed as adjunctive treatments for the management of pedi-

atric chronic pain. There are few randomized controlled trials supporting the efficacy of CAM therapies for the management of pediatric chronic pain (Zeltzer, 2014). There is some evidence for the effectiveness of acupuncture in reducing the frequency and intensity of headaches (Gottschling et al., 2008), and for yoga in reducing symptoms of functional abdominal pain (Brands, Purperhart, & Deckers-Kocken, 2011). As these approaches gain mainstream popularity, research is needed to support their use in pediatric pain management.

FUTURE DIRECTIONS

Chronic pain is an important problem in childhood with the potential to persist into adulthood. Over the past 30 years, there has been tremendous progress in advancing our understanding of this condition and in developing effective treatments. Gaps remain in the classification of chronic pain conditions in childhood, however, and work is underway to develop an evidence-based and multidimensional taxonomy (Fillingim, Dworkin, & Turk, 2014). In addition, many youth with chronic pain do not receive evidence-based pain care, due to barriers such as lack of access, distance from clinics, and lack of trained providers in their local communities. To address these barriers, researchers have developed interventions that can be delivered remotely, such as via CD-ROM (Rapoff et al., 2014) and the internet (Palermo et al., 2016), with preliminary studies indicating that these treatment programs can reduce pain intensity and improve disability in some youth. These low-intensity interventions have the potential to be widely disseminated at relatively low cost, and could play an important role in prevention or early intervention for youth with pain complaints presenting to primary care physicians or other specialty clinics. However, we do not have screening tools available to distinguish between those patients who are most likely to benefit from low-intensity remotely delivered psychological treatment and those who need face-to-face care. There is also little information available to determine which components of multidisciplinary treatment packages will benefit particular patients. Research in this area could help to reduce health-care-related costs for youth with chronic pain by informing allocation of the scarce treatment resources that are available in specialty pediatric pain clinics.

As described above, increasing attention has been given to the role of parental distress in the treatment of youth with chronic pain (Palermo, Valrie, & Karlson, 2014). However, psychological interventions for parents of children with chronic pain are typically brief and limited to pain education and operant training. A meta-analysis of interventions for parents of children with chronic medical conditions found that CBT was not effective at reducing distress among parents of children with chronic pain (Eccleston, Fisher, Law, Bartlett, & Palermo, 2015). Parent-focused interventions such as problem-solving skills training have been shown to reduce distress among caregivers of children with other chronic medical conditions (Law, Fisher, Fales, Noel, & Eccleston, 2014), and may constitute a promising approach for pediatric chronic pain (e.g., Law et al., in press; Palermo et al., 2016). Existing psychological treatments also do not directly target anxiety and depressive symptoms among youth with chronic pain, despite known associations between these factors and greater pain intensity and related disability. Interventions that directly target these known risk factors could potentially enhance outcomes for youth with chronic pain.

In conclusion, chronic and recurrent pain is common in childhood and adolescence

and has the potential to affect health across the lifespan. In recent years, research has attempted to understand the biological, social, and psychological factors that contribute to the development and maintenance of pain and associated disability in youth. We now have rigorous syntheses of evidence suggesting that psychological treatments can improve pain and functioning in these youth. However, little is known about the safety and efficacy of the pharmacological treatments, physical and occupational therapy interventions, and CAM approaches that are widely used in clinical practice. More research is needed to inform the delivery of evidence-based multidisciplinary treatment to youth with chronic pain. Pediatric psychologists can play a leading role in this effort by partnering with our colleagues across disciplines to conduct high-quality clinical trials and develop novel approaches to delivering effective multidisciplinary pain care to these children and their families.

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CHAPTER 12

Management of Pediatric Pain and Distress Due to Medical Procedures

Lindsey L. Cohen, Ronald L. Blount, Jill Chorney, William Zempsky, Nikita Rodrigues, and Laura Cousins

Children undergo routine medical procedures throughout childhood, which are invaluable for optimal health. The World Health Organization (WHO, 2014) recommends that by the sixth year of life, children receive 20–30 vaccinations against 12–20 diseases. Healthy children may also receive finger sticks and venous access as part of regular health care, and children with medical conditions will have any number of additional diagnostic and therapeutic procedures. Although medical procedures are critical, they might be considered a "necessary evil" because of the ancillary pain and distress (e.g., Schechter et al., 2007), which can have long-term negative behavioral and physiological consequences (e.g., Kennedy, Luhmann, & Zempsky, 2008). Given the short- and long-term consequences, WHO has called for increased efforts to develop procedural pain management interventions (Brennan, Carr, & Cousins, 2007).

ASSESSMENT

Accurate assessment is a prerequisite for measuring pain and documenting the effectiveness of interventions (Cohen et al., 2008). The International Association for the Study of Pain (IASP) has defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey & Bogduk, 1994, p. 210). The term "distress" has also been used to describe children's behavioral fear, anxiety, and pain associated with medical procedures.

Children's pain and distress have been quantified via self-reports, observer reports, physiological indices, and observational measures. Several comprehensive reviews of instruments have been published (Cohen et al., 2008, Stinson, Kavanagh, Yamada, Gill,

& Stevens, 2006, von Baeyer & Spagrud, 2006); thus we provide only brief reviews and highlights here.

Two recommended types of self-report instruments are visual analogue scales (VASs) and scales with faces. VASs are typically 100-millimeter lines with behavioral anchors (e.g., "no pain" and "severe pain"). A child marks a point along the line to indicate his or her level of pain. VASs have been extensively researched, are relatively quick and easy to complete, and correlate with other pain measures. However, younger children may find them difficult to understand (Stinson et al., 2006). There are also various scales that include drawings or photos of faces to represent children experiencing pain. One of the most studied of these is the Faces Pain Scale—Revised (FPS-R; Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001), which includes drawings of six gender-nonspecific faces ranging from neutral to high-pain expressions. The FPS-R has good validity; is easy to use; can be completed by 4- to 18-year-olds; and does not contain faces with smiles or tears, which were noted as problematic on other faces scales (Hicks et al., 2001).

Physiological measures potentially indicative of pain include heart and respiratory rate, blood pressure, palmar sweating, and cortisol level, among others (Sweet & McGrath, 1998). Although physiological indicators of pain are intuitively appealing, their validity has generally been less than convincing (Bossart, Fosnocht, & Swanson, 2007; Harrison et al., 2006). Physiology may be influenced by extraneous factors, such as non-pain-related emotional states, movement, and temperature. Monitoring also requires potentially cumbersome and costly instrumentation. Thus physiological indicators are best considered as adjunctive (Sweet & McGrath, 1998).

Observational measures include both global observation scales completed by observers (e.g., VASs) and direct observation scales. VASs may be completed by parents, medical staff members, or other observers, and provide ratings of pain and distress. They have high face validity, correlate with concurrent self-reports, and are easy to complete (von Baeyer & Spagrud, 2006). However, these measures lack detail about the topography and timing of distress behaviors. A number of well-established direct observation measures of procedural pain exist, such as the Observational Scale of Behavioral Distress—Revised (Elliott, Jay, & Woody, 1987) and the Child–Adult Medical Procedure Interaction Scale (Blount et al., 1989). Typical distress behaviors include crying, screaming, pain or fear verbalizations, information seeking, flailing, need for restraint, rigidity, and facial indicators of pain (Blount & Loiselle, 2008). In addition to assessing pain and distress, observational scales allow the quantification of other relevant behaviors (e.g., coping, engagement in an intervention; Chorney, McMurtry, Chambers, & Bakeman, 2015).

TREATMENT

A host of variables influence children's reactions to medical procedures, which suggests that treatments might target any number of avenues. We propose that an ecological perspective (e.g., Bronfenbrenner, 1986) can provide an organizational framework for considering interventions from various foci (see Figure 12.1). Thus treatment may focus predominantly on the pediatric patient, the parents, the health care providers, the medical environment, or culture and society.

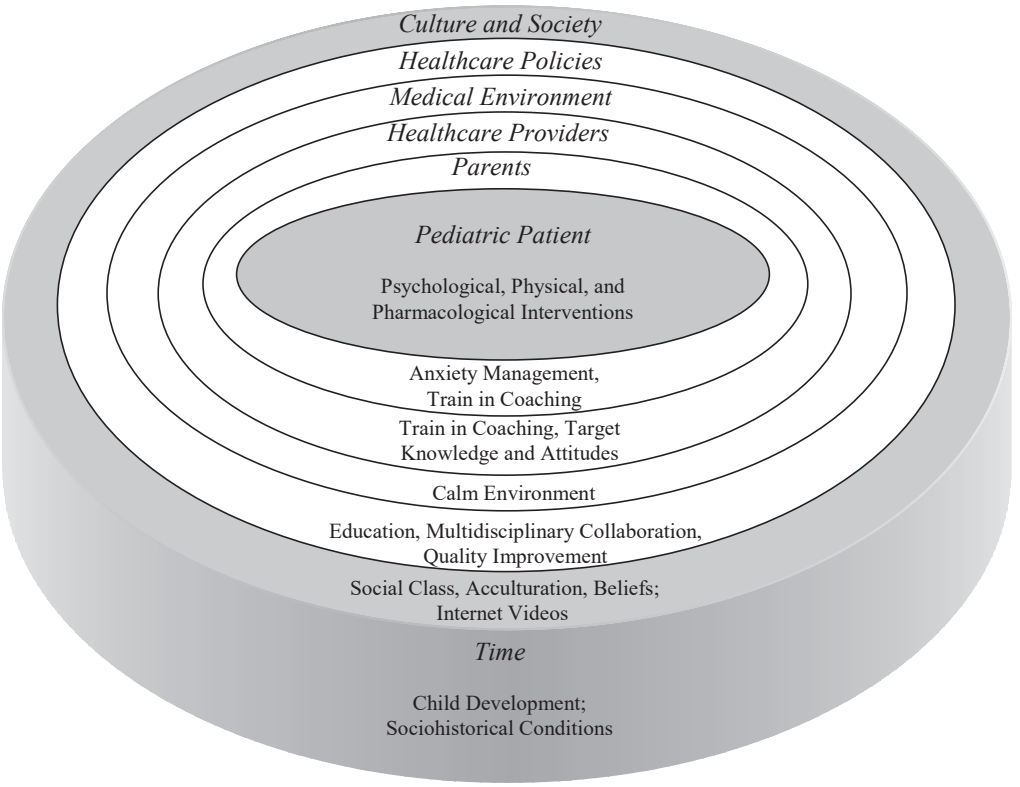

FIGURE 12.1. Management of pediatric procedural pain and distress from an ecological perspective.

The Pediatric Patient

The majority of evidence-based treatments directly target the child. These approaches can be subcategorized as psychological, physical, or pharmacological in nature.

Psychological Interventions

ADVANCE PREPARATION

Preparation programs have been shown to be effective for a range of procedures, including surgery (Kain & Caldwell-Andrews, 2005), venous access (Cohen, 2008), and dental procedures (Melamed, Yurcheson, Fleece, Hutcherson, & Hawes, 1978). Content, format, and timing of information should be considered in providing preparation (Jaaniste, Hayes, & von Baeyer, 2007). Content should be clear, engaging, understandable, and tailored to a child's level of cognitive development (Stanford, Chambers, & Craig, 2005). Prior research also suggests that information should include both (1) what will occur during the procedure (i.e., procedural information) and (2) what the child may perceive or experience (i.e., sensory information) (Tak & van Bon, 2006). Children should be informed about the likelihood of pain during an upcoming procedure; however, the use

of nonemotive language is recommended (Cohen, 2008). Lastly, age-appropriate language should be used, and children should be allowed opportunities to ask questions during and following information provision (Stanford et al., 2005).

Preparatory information may be delivered by means of instructional videos, hospital tours, puppets, medical play, interactive computer programs, modeling, oral or written presentations, or combined formats (Jaaniste et al., 2007). Most importantly, the format, like the content, should be tailored to a child's developmental level and experience in a medical setting (Salmon, 2006). Younger children may benefit more from modeling, while most older children have the ability to process information through oral or written language. Although it is unclear whether procedural-related information is more effectively delivered by health care professionals, well-informed parents, or peers, research suggests that peer modeling is a useful method of delivering preparatory information to children (Jaaniste et al., 2007). Conversely, engaging in medical play with dolls or toys may not be appropriate for communicating information to preschool-age children, as they may have difficulty grasping the symbolic representation of these objects (e.g., Salmon, 2006).

The majority of procedure-related information should be provided in advance of the procedure, with minimal novel information presented immediately prior to or during the procedure (Blount, Piira, & Cohen, 2003). Specific timing is dependent upon the age of the child and the type of medical procedure (i.e., duration of procedure, amount of discomfort, length of hospitalization). Providing information too far in advance may result in the child's forgetting the content or may serve to prolong the period of anticipatory anxiety, whereas preparation too close to the scheduled procedure may exacerbate anticipatory anxiety or distress because it does not give the child sufficient time to process information or develop coping strategies (Eiser, Patterson, & Eiser, 1983; Melamed & Ridley-Johnson, 1988). Generally, given developmental changes in memory and information processing, it is recommended that children older than 6 years of age receive a minimum of 5 days' notice for lengthier or distressing medical procedures; however, children younger than 6 years of age are likely to benefit from fewer than 5 days of notice. Alternatively, for more minor and less distressing medical procedures, children require less notice and may benefit from being informed just prior to the procedures (Jaaniste et al., 2007).

PSYCHOLOGICAL INTERVENTIONS DURING PROCEDURES

The research literature is replete with psychological interventions aimed at lowering pain and distress in children during procedures. These include such techniques as hypnosis, distraction, desensitization, relaxation, imagery, sensory focusing, deep breathing, positive reinforcement of adaptive behaviors, positive self-statements, modeling, and coaching to prompt coping strategies (Chambers, Taddio, Uman, & McMurtry, 2009; Keefe, Salley, & Lefebvre, 1992; Powers, 1999). A number of studies and reviews support the efficacy of psychological interventions for reducing pediatric procedural pain and distress (e.g., Kazak & Kunin-Batson, 2001; Young, 2005). A Cochrane review suggests that the strongest evidence supports hypnosis and distraction for alleviating various types of procedural pain and distress for children 2–18 years of age (Uman et al., 2013).

Although there is variability in the definition of "hypnosis," it is generally purported

to change the perception of pain and distress via relaxation, decreased arousal, imagery, attention, and/or suggestion to encourage an altered state of consciousness (Kuttner, 2012); neuroimaging techniques support this rationale (Wood & Bioy, 2008). Several reviews indicate that hypnosis reduces procedure-related pain and distress (Accardi & Milling, 2009; Birnie et al., 2014; Richardson, Smith, McCall, & Pilkington, 2006). In their Cochrane review, Uman et al. (2013) concluded that hypnosis has the largest effect sizes for reducing pain and distress during needle-related procedures. However, authors have noted methodological limitations (Birnie et al., 2014; Uman et al., 2013). For example, most data have come from the same research group, and the primary outcome variables have only been self-report measures. Furthermore, hypnotizability has been found to be related to the magnitude of treatment benefit (Liossi & Hatira, 2003).

Strong evidence exists for the efficacy of distraction for reducing procedural pain and distress (Birnie et al., 2014; Uman et al., 2013). However, there is variability in response to distraction both within and across studies (Cohen, Cousins, & Martin, 2013). Kleiber and McCarthy (1999) argued that the quality of the distraction might explain discrepancies. Birnie et al. (2014) identified characteristics of distractors that might contribute to efficacy, including interactive versus passive nature (e.g., playing a video game vs. watching a video), adult involvement versus no adult involvement, and high versus low technology (e.g., virtual reality helmets vs. books), and examined these characteristics in relation to child outcomes. Although they found no significant differences among types of distraction in regard to child outcomes, they concluded that further research is needed to help providers determine the best match of treatment and/or characteristics of treatments for individual children, given individual characteristics (e.g., age, previous experience, health care setting, procedure). Selecting a method of distraction that is salient and appealing to the child, is age-appropriate, and can be easily observed should be the goal of utilizing distraction for procedures (Cohen et al., 2013). As with the literature examining hypnosis, reviewers have noted limitations in the studies of distraction. For example, there is a lack of clear evidence to identify whether the type of distraction influences its efficacy across child development and with different procedures (Uman et al., 2013).

PSYCHOLOGICAL INTERVENTIONS AFTER PROCEDURES

As data indicate that children's memories of prior pain experiences predict subsequent pain reporting (Noel, Chambers, McGrath, Klein, & Stewart, 2012), researchers have examined reframing negative memories and highlighting positive aspects immediately following the procedure (Bruck, Ceci, Francoeur, & Barr, 1995; Chen, Zeltzer, Craske, & Katz, 1999). A review suggests that this approach might reduce fears for upcoming medical events (von Baeyer, Marche, Rocha, & Salmon, 2004).

Physical Interventions

Physical interventions have also been used to manage procedural pain. For example, the natural tendency of rubbing the area near the pain site appears to provide pain relief (e.g., Fowler-Kerry, 1992). In a systematic review, Taddio, Ilersich, Ipp, Kikuta, and Shah (2009) found that upright positioning and counterstimulation (i.e., rubbing the area) reduced children's distress behavior (i.e., crying). Physical interventions have been

well studied in infants, particularly skin-to-skin contact between an infant and parent ("kangaroo care"). A recent Cochrane review found favorable effects for skin-to-skin contact in both full-term and premature infants during painful procedures (heel lance, venipuncture, intramuscular injections; Johnston et al., 2014). Efficacy of skin-to-skin care was particularly evident on behavioral indicators of pain (e.g., crying).

Physical interventions have also been combined with other interventions to target pediatric procedural pain and distress. For example, Berberich and Landman (2009) found that an intervention including a plastic device with nubs pressed against the skin, vibration, vapocoolant spray, and distraction was effective for immunization distress. Similarly, Buzzy® is a plastic reusable device that combines vibration with skin cooling via an ice pack and distraction, and data support its effectiveness for intravenous cannulation starts and venipuncture (Canbulat, Ayhan, & Inal, 2014; Whelan, Kunselman, Thomas, Moore, & Tamburro, 2014). These results are promising; however, dismantling studies are necessary to identify the active ingredient (Cohen, 2010).

Pharmacological Interventions

Pharmacological interventions directly target children's procedural pain and distress. As with other types of interventions, the choice of pharmacological interventions should be based on the patient's age and the procedure's invasiveness and duration.

TOPICAL AND LOCAL ANESTHETICS

Topical and local anesthetics are the drugs of choice for simple procedures such as intravenous access, laceration repair, subcutaneous port access, and dermatological procedures (Zempsky, 2008). A local anesthetic, lidocaine injected under the skin, decreases pain from venous access, dermatological procedures, and laceration repair. Lidocaine can be injected with little pain if the technique includes buffering with bicarbonate, warming it before injecting, and injecting slowly with a small-gauge needle (Zempsky, 2008). Topical anesthetics remove sensation from the skin. The most extensively studied of these agents is Eutectic Mixture of Local Anesthetics (EMLA) cream, which is effective for various procedures, including venipuncture and immunization, subcutaneous port access, and lumbar punctures (Uhari, 1993). However, EMLA requires 60 minutes for adequate anesthesia. LMX4 is a liposomal lidocaine cream-based formulation similar to EMLA, and it provides efficacy in approximately 30 minutes.

Vapocoolant sprays such as ethyl chloride and fluoromethane provide transient skin anesthesia, work in about 30 seconds, and are inexpensive. However, the evidence is conflicting regarding their efficacy for injection pain and venous access procedures, and some children find the cold sensation unpleasant (Cohen et al., 2009; Costello, Ramundo, Christopher, & Powell, 2006). Comprehensive reviews have generally concluded that vapocoolants do not have sufficient support in the literature (Hogan, Smart, Shah, & Taddio, 2014; Shah, Taddio, Rieder, & HELPinKIDS Team, 2009). In the emergency department, LET (a combination of lidocaine, epinephrine, and tetracaine) provides anesthesia for laceration repair (Ernst et al., 1995). LET is placed in the laceration by the nursing staff upon a patient's arrival in the emergency department. It provides excellent analgesia and avoids the use of injected lidocaine in lacerations under 3 centimeters long.

PROCEDURAL SEDATION

Various sedation agents are used for procedures that are painful (e.g., fracture reduction), less painful but anxiety-producing (e.g., voiding cystourethrogram), or nonpainful but distressing (e.g., magnetic resonance imaging). Guidelines describe the appropriate monitoring a child should receive during and after procedural sedation (American Academy of Pediatrics, 2006; American College of Emergency Physicians, 2014). Sedation carries risks that include hypoventilation, apnea, airway obstruction, aspiration, laryngospasm, and cardiopulmonary impairment. Common agents are midazolam, nitrous oxide, opiates (e.g., fentanyl, sufentanil, morphine, hydromorphone), propofol, ketamine, and dexmedetomidine. For reviews of procedural sedation agents, see Krauss and Green (2006) or Kost and Roy (2010).

The Parents

Parents or other caregivers take and often accompany their children to receive medical treatments. Parents influence children in multiple ways, and empirical support for the influence of parents is derived from studies of the effects of parents' anxiety, presence during children's medical procedures, and behaviors on children's procedural pain.

Given findings that parents' anxiety is related to children's procedural pain and distress (e.g., Bearden, Feinstein, & Cohen, 2012; Jay, Ozolins, Elliott, & Caldwell, 1983), targeting parents for intervention may be fruitful. A review of studies of the effects of parents' presence versus absence during children's medical treatments yielded equivocal results (Piira, Sugiura, Champion, Donnelly, & Cole, 2005). Rather than focusing on presence per se, many studies have examined specific parent behaviors. In general, studies suggest that some parent behaviors (e.g., criticism, reassurance) are not helpful and may even exacerbate or reinforce child distress, whereas other parent behaviors (e.g., distraction, commands to cope) result in lower child pain and distress. In addition, parents and medical staffers have been found to influence each other's behavior during children's medical treatments (Blount et al., 1989); therefore, changing the behavior of the parents or the staff may further leverage the effects of the broader ecological system to therapeutically influence the children (Cohen, Blount, & Panopoulos, 1997). The approach of targeting parents for intervention in order to provide children patient pain and distress relief has been evaluated across procedures, such as immunizations (e.g., Cohen et al., 2015) and surgery (e.g., Kain, Fortier, Chorney, & Mayes, 2015).

The Health Care Providers

Despite growing recognition of the importance of managing pain, coverage of pain-related topics continues to be relatively limited in training programs for health care providers. Although the majority of medical schools in North America now include some coverage of pain, the amount of time dedicated to this topic is modest (the U.S. median number of hours is 9), and coverage of pediatric pain is especially restricted (Mezei & Murinson, 2011). Training in pain management is similarly limited in nursing programs and programs for other health care professions (MacLaren & Cohen, 2005).

Intervening with the health care providers offers distinct advantages. Providers are

generally available for training for longer periods of time than parents are, and can thus receive more coaching and feedback in skill development. Once trained, providers may improve the outcomes of all patients with whom they interact. Training programs may improve providers' knowledge and attitudes about pain management, but the effect of training on behavior in clinical care has not received sufficient empirical attention (MacLaren & Cohen, 2005). In addition, given research showing the benefits of trained parents' assisting their children during medical procedures, training programs should include education about how providers may facilitate parents' engagement in their children's pain management.

Multimodal programs (including provider-directed education combined with review and feedback, practice reminders, and other support interventions) have also shown efficacy. In one particularly large-scale initiative, Stevens et al. (2009) examined a multimodal knowledge translation intervention aimed at improving pain management practices (including procedural pain management) on inpatient units. The intervention, called Evidence-based Practice for Improving Quality (EPIQ), engaged local providers as champions to lead structured organizational change activities within their own institutions (Stevens et al., 2014). Champions worked with their units to develop specific practice change goals related to pain management, using a range of strategies (e.g., staff education, reminders, tool provision). Results indicated that the units implementing EPIQ had more patients who received analgesia, more regularly used validated pain measures, and had fewer patients who experienced moderate to severe pain during the study.

Clearly, health care providers play a key role in children's pain management. Although there may be time and opportunity to plan for pain management, providers may adopt a "get it over with" approach that does not include pain management (Taddio, Chambers, et al., 2009). For example, providers have reported that topical anesthetics are difficult to accommodate in practice, due to extra costs and time demands (Taddio et al., 2007); however, research indicates that many parents are willing to schedule more time and pay extra for analgesics ($10–25; Taddio, Nulman, Goldbach, Ipp, & Koren, 1994). This issue is complicated by the idea that most psychological, physical, or pharmacological interventions do not completely eliminate pain, and providers may thus discount the approaches altogether (Taddio, Ilersich, et al., 2009). In short, there is work to be done with health care providers in regard to managing pediatric procedural pain and distress.

The Medical Environment

Visiting a children's hospital attests to the fact that the environment is perceived as an important consideration for hospital management. Although great attention and many resources are clearly devoted to the colors, lighting, and décor of children's medical facilities, there is a dearth of research evaluating the impact of the medical environment on the young patients. The American Academy of Pediatrics (2001) Task Force on Pain in Infants, Children, and Adolescents published recommendations for facilitating the comfort of pediatric patients during painful procedures and included details regarding the medical environment. For example, the task force prescribed a quiet and calm environment (e.g., minimizing the beeping of monitors when possible). Studies examining

environmental factors' influence on pain management for premature babies have shown that bright lights and noise may increase infants' procedural distress (Halimaa, 2003). Music following a procedure can reduce patients' pain reports (Good, Anderson, Ahn, Cong, & Stanton-Hicks, 2005). Although there is a paucity of research findings about the medical environment, these variables should be considered in efforts to reduce pediatric procedural distress (e.g., Fanurik et al., 2000).

Health Care Policies

Effective policies help encourage evidence-based practice for pain management. One example of a systematic approach to pain relief is Comfort Central, an institutionwide pain management program that evolved over the past decade at Connecticut Children's Medical Center (Schechter, 2008). This program prioritized children's comfort by establishing administrative authority (i.e., a Pain Steering Committee); modifying the hospital environment and pain management practices throughout all clinics; educating staff, children, and families; fostering multidisciplinary collaboration; and conducting ongoing assessment for quality improvement. Similarly, ChildKind is a global initiative developed by the Special Interest Group on Pain in Childhood of the IASP. This initiative aims to minimize pediatric pain by formally designating health care facilities as "ChildKind Hospitals" if they demonstrate an institutional commitment to providing pediatric pain relief. Furthermore, ChildKind presents evidence-informed policies, protocols, and educational materials on its website (*www.childkindinternational.org*). As scientific information accumulates about best practices, recommendations might be included in policies that mandate pediatric pain relief within and across health care facilities.

Culture and Society

Culture is relevant to the study and treatment of children's procedural distress (Fortier, Anderson, & Kain, 2009; Rollman, 2005); however, limited research has been conducted in this area (Kristjánsdóttir, Unruh, McAlpine, & McGrath, 2012). Adult studies have demonstrated differences in pain across ethnicities (Thomas & Rose, 1991), but research on ethnic differences in children's pain has been minimal (Zatzick & Dimsdale, 1990). The literature emphasizes that individual differences within an ethnic group are greater than group differences between ethnicities (Young, 2005). Furthermore, this work may be confounded by socioeconomic status, access to health care, and resultant experiences. Thus culture may play an important role in children's perceptions and reactions to pain, but potentially important factors such as socioeconomic status, acculturation, specific ethnic grouping, parental attitudes and behaviors, and children's conceptualizations of pain should also be considered (McGrath & McAlpine, 1993). Although we have limited research on the mechanisms and exact effects of cultural factors in children's pain, understanding that pain always occurs in a psychological and social context, and including these factors in assessment, can help improve pain management strategizing (McGrath & McAlpine, 1993).

At a broad societal level, the ubiquity of the internet and social media (e.g., Twitter) provides avenues for widespread dissemination of procedural pain and distress relief recommendations. A review of some online videos suggests that work is needed to deter-

mine whether this approach is effective (Farkas et al., 2015). Clearly, cultural and societal practices influence children's procedural pain and distress experiences, but further research is needed to identify ways in which these factors might be influenced to provide greater pain relief to children.

SUMMARY AND FUTURE DIRECTIONS

The ecological model has been used as a framework for reviewing treatment outcome research in the area of pediatric procedural pain. At the core of the model is the pediatric patient, who is influenced in varying degrees by parents, health care providers, the medical environment, health care policies, and culture and society. There is an assumption in the model that the aspects closest to the child exert the greatest influence on the child; we have found this assumption to be largely supported. Psychological, physical, and pharmacological interventions focused directly on the pediatric patient have received considerable empirical support. The psychologically based interventions are most often delivered within the social context of parents and health care providers. Trained parents or health care providers may assist the child before, during, and after medical procedures; these trained adults might apply these skills during future stressful procedures. However, the potential for generalization of effective coaching by trained parents and medical staff across time, types of medical procedures, and settings has yet to be investigated.

In contrast to the rich literature examining the child and the effects of parents and medical staff, there is much less assessment and intervention research on the effects of the medical environment, health care policies, and culture and society on children's procedural pain. A solid core of explicative research in these areas is needed to guide environmental changes needed to reduce procedural pain. Although environmental manipulations may yield small effects, multiple children may benefit over time. There is a firm foundation of scientific research on pediatric procedural pain, with many pioneering advances having been made over the last several decades. Many of the challenges for future researchers will be to refine the efficacy and application of existing assessment and intervention methods. In addition, maintenance and generalization of procedural pain management skills constitute an emerging area. Lastly, dissemination of effective interventions remains an ongoing goal.

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CHAPTER 13

Pediatric Pharmacology and Psychopharmacology

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Pharmacological interventions for children and adolescents have historically been developed from the literature on adult interventions and adapted to meet the needs of children. However, a colleague and I (Brown & Zygmont, 2009) have underscored that pediatric pharmacology differs markedly from that of adults, including differences in absorption, rates of distribution and metabolism, half-lives, and dosing. Younger children also are apt to experience more unpredictable responses than their older counterparts. In addition, older children and adolescents have the potential to be more active and engaged in their treatment than their younger peers, and are able to provide better information with regard to adverse side effects and the potential benefits of medication. As we have observed (Brown & Zygmont, 2009), adherence to medication regimens is especially influenced by caregivers' attitudes, which invariably influence children's use of medication. Finally, directives from the U.S. Food and Drug Administration (FDA) for assessment and monitoring of safety outcomes have been recently promulgated; in part, these directives have been prepared in response to heightened public awareness of medication safety issues (Brown & Zygmont, 2009).

PEDIATRIC PSYCHOPHARMACOLOGY

A large number of psychotropic agents are used to manage externalizing, internalizing, psychotic, developmental, and tic disorders in children and adolescents. Much of the research on these medications has been conducted as part of the psychopathology literature. However, given the fact that children with chronic medical conditions are more vulnerable to internalizing, externalizing, and neurocognitive conditions, there is value

in understanding their utility in the management of both psychopathology and chronic medical conditions.

Attention-Deficit/Hyperactivity Disorder

The most commonly prescribed psychotropic medications for the treatment of attention-deficit/hyperactivity disorder (ADHD) are the agents known as the stimulants (Zuvekas & Vitiello, 2012). The two groups of stimulants that have been approved by the FDA are methylphenidate-based medications and amphetamine/dextroamphetamine-based agents, both of which are available in both short- and long-acting versions. Adverse side effects of stimulant medication may include decreased appetite, stomachache, insomnia and headache (Barbaresi et al., 2006). Less common side effects include motor tics, headaches, nausea, fatigue irritability, and increases in heart rate and blood pressure (Pliszka & AACAP Work Group on Quality Issues, 2007). Many side effects associated with the stimulants abate after a short period, or may disappear if the dosage or timing of administration is adjusted.

The prescribing of stimulants has increased dramatically over the past three decades (Visser et al., 2014). Explanations for the increase in stimulant medication for the management of ADHD include better identification of the disorder; less stigma than in previous years for medication as a treatment option; a recognition that there are specific subgroups of ADHD; and, finally, the fact that individuals who have no insurance have poor access to mental health services. The available evidence suggests that stimulants are not overprescribed to most children and adolescents in the United States; however, there are certain geographic areas (e.g., western North Carolina) where stimulants are inappropriately prescribed (Angold, Erkanli, Egger, & Costello, 2000).

Preliminary research suggests that approximately 75–85% of children and adolescents respond favorably to the newer, longer-acting stimulant medications (Pliszka & AACAP Work Group on Quality Issues, 2007). Stimulant medications have been demonstrated to improve some of the specific core symptoms associated with ADHD in the short term. In particular, the stimulants are effective in enhancing attention and concentration while also reducing hyperactivity and impulsivity for children with ADHD (Nigg & Barkley, 2014). Research has demonstrated that stimulants decrease disruption in the classroom, increase academic productivity and on-task behavior, and improve teacher ratings of children's behavior (for a review, see Nigg & Barkley, 2014).

There also are major limitations to stimulant treatment. There are individual differences in response to these medications, and not all children will respond to them. And for those children who do demonstrate a positive response, this response rarely equates to "normalization" of their behavior (Nigg & Barkley, 2014). It is noteworthy that the stimulants have limited impact on several domains of functional impairment associated with ADHD, including problems with social behavior and academic achievement, which are frequently the primary reasons why families seek treatment for their children (Nigg & Barkley, 2014). For example, although the stimulants appear to have statistically significant positive effects on social functioning, these effects have not always been clinically significant (Tannock & Brown, 2000). Finally, the stimulants may be contraindicated for some children and adolescents (e.g., in families where there is a member with a substance use disorder).

Preschoolers

The National Institute of Mental Health (NIMH) funded a large-scale multisite clinical trial that systematically studied the safety and efficacy of immediate-release methylphenidate for children 3–5 years of age (Greenhill et al., 2006). A notable limitation of the study was that it only included preschoolers who had moderate to severe dysfunction. Findings revealed that methylphenidate is safe and efficacious in preschool children, although it is recommended that treatment be initiated with lower doses, because preschoolers metabolize stimulants at a slower rate than school-age children do (Greenhill et al., 2006). In addition, preschoolers experience more adverse side effects when treated with high doses of stimulants than school-age children do (Greenhill et al., 2006). It is noteworthy that stimulant medication for preschoolers is recommended as a second-line option: It should only be considered for children with moderate to severe ADHD when behavior therapy has not been effective, and when the symptoms have persisted for at least 9 months (Wolraich et al., 2011).

Comorbidities

Some research has evaluated the effectiveness of stimulant medications for ADHD when children have comorbid diagnoses, including mood disorders and anxiety disorders. The findings from these investigations are mixed; results from several studies suggest that response to stimulant medications is compromised when comorbid conditions exist (Spencer, Wilens, Biederman, Wozniak, & Harding-Crawford, 2000). Alternatively, findings from two large-scale studies did not find an association between anxiety and stimulant response (MTA Cooperative Group, 1999).

Contrary to popular lore, there is no evidence to suggest that stimulant use increases the chance of an individual's developing problems with substance use or dependence. Results from a recent meta-analysis indicated that use of stimulant medication to treat ADHD did not appear to increase or decrease the risk of later developing a substance use disorder (Humphreys, Eng, & Lee, 2013). Nonetheless, because the stimulants have significant abuse potential, adolescents with ADHD should be assessed for substance abuse before stimulants are prescribed.

Nonstimulant Medications

Some nonstimulant medications have been approved by the FDA for the management of ADHD in children and adolescents, including atomoxetine (Strattera), a medication affecting the transmitters of norepinephrine. Another nonstimulant psychotropic therapy in recent use for ADHD is modafinil (Provigil), which is a cognitive enhancement agent primarily used to promote wakefulness. It selectively targets the cerebral cortex and has been prescribed as an off-label treatment for ADHD (Biederman et al., 2005). Clonidine (Catapres, Nexiclon) and guanfacine (Tenex) are alpha-adrenergic agonists that also come in FDA-approved long-acting 24-hour-release versions (Kapvay and Intuniv). Clonidine is most effective in reducing hyperactive and aggressive behaviors, with less improvement demonstrated for problems with focusing or sustaining attention (Ming, Mulvey, Mohanty, & Patel, 2011). Finally, for children with comorbid diagnoses, particularly comorbid internalizing disorders (e.g., anxiety disorders or depression),

other psychotropic medications that target depression, anxiety, or mood lability (e.g., tricyclic antidepressants) may be prescribed.

Multimodal Treatments

A combination of medication with psychotherapeutic interventions (particularly behavioral interventions) for children and their caregivers is considered to be the gold standard in the management of ADHD. Research suggests that multimodal treatment is moderately superior to either pharmacological or nonpharmacological interventions employed alone (Sibley, Kuriyan, Evans, Waxmonsky, & Smith, 2014). The NIMH Multimodal Treatment Study of Children with ADHD (MTA) was the largest and most comprehensive clinical trial of ADHD treatment outcomes to date (MTA Cooperative Group, 1999). In this study, children who received multimodal treatment required lower stimulant doses than those treated with medication alone, and parents reported being most satisfied with the behavioral and combined treatment approaches.

Finally, in a very recent investigation, Helseth et al. (2015) compared the unique and combined effects of evidence-based treatments for ADHD—stimulant medication and behavior modification—on children's rates of reinforcement for deviant peer behavior. Participants included over 200 elementary-school-age children receiving various combinations of behavior modification in a highly structured summer camp program with various doses of methylphenidate. Findings revealed that children with ADHD reinforced the deviant behavior of their peers at a higher rate than control children did in the absence of any intervention. This difference, however, dissipated in the presence of both behavior modification and stimulant drug therapy. Specifically, both low- and high-intensity behavior modification, as well as medium and high doses of stimulant medication, significantly reduced the rate of children's reinforcement for deviant peer behavior in the group with ADHD to levels similar to those in the control group. The authors interpret their data to suggest that evidence-based interventions can substantially decrease the presence of reinforcement for deviant behavior, thereby diminishing potential iatrogenic effects in group-based settings. Moreover, the findings support the notion that peer contagion may be readily managed in group-based treatments for children.

Oppositional Defiant Disorder and Conduct Disorder

A number of psychotropic medications have been employed to manage the aggression and mood disturbances associated with conduct disorder. For example, there is some evidence for the efficacy of the stimulants in managing aggression among children with conduct disorder, with several studies attesting to a moderate effect size in some children with the disorder (for a review, see Brown et al., 2008). The most elaborate of these clinical trials demonstrated a stable effect in children having conduct disorder with and without ADHD (Klein, Abikoff, Ganeles, Seese, & Pollack, 1997).

Controlled and open trials of classical antipsychotic medications such as haloperidol (Campbell, Cohen, & Small, 1982) found significant reductions in aggression and disruptive behavior. However, haloperidol, a neuroleptic agent, has been associated with serious adverse side effects, including significant extrapyramidal symptoms. Extrapyramidal symptoms are drug- induced movement disorders that include acute symptoms of

continuous spasms and muscle contractions (dystonia), motor restlessness (akathisia), rigidity and tremor (Parkinsonian symptoms), and irregular jerky movements (tardive dyskinesia) (Pierre, 2005). Janssen Pharmaceuticals launched several large-scale trials of risperidone in children with disruptive behavior disorders (either conduct disorder or oppositional defiant disorder). Three acute trials (including a total of about 250 children, who were mostly treated over a 6-week interval) found about a 50% reduction in disruptive behavior disorder symptoms, compared with about a 20% reduction of symptoms with placebo (Findling et al., 2004). Three long-term trials followed more than 600 children for 1 year, with continued suppression of disruptive behavior disorder symptoms, but also with infrequent weight gain. Divalproex sodium also has been found effective in ameliorating conduct disorder symptoms; however, only one well-controlled study has been conducted to date (Steiner, Petersen, Saxena, Ford, & Matthews, 2003). Finally, lithium has been demonstrated in some cases to reduce aggressive behaviors among children and adolescents with conduct disorder; some evidence from moderate-sized controlled trials demonstrated that lithium reduced aggressive behaviors in these children and adolescents (Gerardin, Cohen, Mazet, & Flament, 2002).

There is only a minimal literature available on the psychopharmacological treatment of oppositional defiant disorder, except in those cases in which comorbid ADHD is present. The few available studies that do exist suggest some symptom reduction but much more research is needed. The MTA study indicated that children with ADHD and oppositional defiant disorder responded best to medication treatment (i.e., stimulants), with or without the concomitant use of behavioral interventions (Jensen et al., 2001).

All of the medications used to treat aggression and conduct problems are associated with potential adverse side effects. Risperidone, haloperidol, and other neuroleptic medications can be associated with serious extrapyramidal side effects (as described above), as well as headache, nausea, and drowsiness. There is also the potential for neuroleptic malignant syndrome—a serious neurological disorder associated with an adverse reaction to antipsychotic drugs that includes muscle rigidity, fever, and mental status changes (Strawn, Keck, & Caroff, 2007) and can be lethal (for a review, see Brown et al., 2008). Possible side effects of clonidine include sedation, lethargy, and low blood pressure (Connor, 2006). Atomoxetine also can lead to stomachaches, nausea, decreased appetite, and weight loss (Brown et al., 2008).

Very few studies have specifically evaluated the effects of combined psychosocial and medication treatment protocols for children with oppositional defiant disorder or conduct disorder. As noted previously, Helseth et al. (2015) found that the combination of behavior modification and stimulant drug therapy reduced the reinforcement of deviant peer behavior, thereby suggesting that peer contagion can be easily managed in group-based treatments for children. The combination of psychosocial (behavioral) and pharmacological interventions for children with comorbid ADHD and oppositional defiant disorder or conduct disorder leads to moderate to large effect sizes for reductions in ADHD symptoms. Effect sizes for changes in aggression, oppositional behavior, and conduct problems are in the small to moderate range (MTA Cooperative Group, 1999).

Obsessive–Compulsive Disorder

Serotonin reuptake inhibitors and cognitive-behavioral therapy (CBT) are the treatments of choice in the management of obsessive–compulsive disorder (OCD; American

Academy of Child and Adolescent Psychiatry [AACAP], 2012). Two classes of medications have been approved by the FDA for the management of OCD: the selective serotonin reuptake inhibitors (SSRIs) and the tricyclic antidepressants. Clomipramine is the only tricyclic antidepressant that has been demonstrated to be effective for children with OCD (Stewart, Hezel, & Stachon, 2012). Given the demonstrated efficacy of CBT for OCD, coupled with the potential adverse effects of these medications, CBT alone is the preferred treatment modality for children with mild or moderate OCD (AACAP, 2012). For adolescents and caregivers who may be ambivalent regarding the use of medication, CBT also may be the treatment of choice. However, for adolescents with significant comorbid symptoms (including depression, psychotic symptoms or severe ADHD symptoms that may interfere with CBT), medication may be the first-line treatment of choice (Stewart et al., 2012). The combination of CBT and SSRIs has been recommended as the treatment of choice for children with a strong family history of OCD, comorbid tics, or other psychiatric comorbidities that may preclude CBT as the first-line treatment for OCD. Research has generally demonstrated that the use of CBT alone and the use of a serotonin reuptake inhibitor alone are equally superior to placebo in the reduction of OCD symptoms (Pediatric OCD Treatment Study [POTS] Team, 2004).

Major Depressive Disorder

There is a clear consensus that tricyclic antidepressants have no significant pharmacological effect on depression in children (for a review, see Brown et al., 2008). However, in randomized controlled studies of the efficacy of SSRIs, significant differences have been demonstrated on some measures, thereby suggesting potential favorable outcomes for children and adolescents with depressive disorders (for a review, see Brown et al., 2008). Nearly half of the clinician-rated measures favored the SSRIs over placebo, although none of the patient-rated or parent-rated outcomes revealed an improvement with antidepressants. An analysis by the FDA has concluded that few of the randomized controlled clinical trials have demonstrated the newer antidepressants to be more efficacious than placebo on primary outcome measures among children with depression, although several of these trials showed positive and significant effects on secondary outcome measures. Finally, Bridge and colleagues (2007) conducted a review and meta-analysis of randomized placebo-controlled clinical trials assessing the use of SSRIs in children and adolescents with major depressive disorder (MDD), OCD, or non-OCD anxiety disorders (as defined at that time; OCD is no longer classified as an anxiety disorder). An examination of data from 13 clinical trials involving over 2,900 participants indicated that positive effects of these antidepressants were modest for the management of MDD. Thus, as a group, the SSRIs are associated with only small positive effects for children and adolescents with MDD. Consequently, the evidence base in support of antidepressants in children is relatively weak.

Concerns also have been raised about the safety of SSRIs as a treatment option for children and adolescents. The FDA examined the available data and concluded that antidepressant medications were associated with a doubling of the risk for suicidal behavior or suicidal ideation relative to placebo, although the absolute risk was small. Knowledge of side effect profiles is based primarily on studies involving adults. The most common side effects of SSRIs in studies of adult patients with depressive disorders include agita-

tion, sleep disruption, gastrointestinal symptoms, and sexual problems (for a review, see Brown et al., 2008). Moreover, there have been some case reports of growth suppression in children that may be associated with SSRI use (Weintrob, Cohen, Klipper-Aurbach, Zadik, & Dickerman, 2002), warranting caution when the SSRIs are prescribed in pediatric populations. It also should be noted that side effects and medical risks increase when the SSRIs are combined with other psychotropic agents (for a review, see Brown et al., 2008); thus practitioners must be even more cautious about using the SSRIs with chronically ill children and adolescents.

With regard to combined psychosocial and pharmacological treatments, there has been one scientifically rigorous, multisite, randomized controlled clinical trial assessing the efficacy and safety outcomes associated with fluoxetine alone, CBT alone, and CBT in combination with fluoxetine or placebo in depressed adolescents (Treatment of Adolescent Depression Study [TADS] Team, 2004). Findings revealed that the combination treatment was superior to other treatment conditions; that the two medication conditions were superior to CBT alone and to placebo (but also associated with twice as many harm-related adverse side effects); and that CBT had a small protective effect on suicidality. A subsequent analysis suggested that CBT alone had caught up with fluoxetine alone at the 18-week follow-up, and with the combined condition at the 36-week follow-up (Kuehn, 2007). Clearly, MDD in youth represents a difficult and controversial area for the use of psychotropic medications. The conflicting results of outcome studies are well represented for children and adolescents, as is the concern about adverse side effects, including the potential risk of suicidality. Thus, while the antidepressants may be useful in the management of depression in adults, this may not necessarily be the case for children and adolescents, particularly when adverse effects of these psychotropics are considered.

Autism Spectrum Disorder and Intellectual Disability

Despite their ancillary role, psychotropic medications are frequently used in the management of children with autism spectrum disorder (ASD) and intellectual disability. In fact, epidemiological studies indicate that up to one-half of children with ASD receive at least one psychotropic medication during a 1-year period (Aman, Lam, & Van Bourgondien, 2005). The most commonly used psychotropic medications in ASD are antidepressants, antipsychotics, stimulants, and the alpha-adrenergic agonist clonidine. Also used are mood stabilizers, such as lithium and divalproex sodium. It should be noted, however, that the strength of the evidence for the efficacy of these medications is variable, ranging from placebo-controlled clinical trials to open-label case reports.

Stimulants are used to control the symptoms of hyperactivity, impulsiveness, and inattention frequently encountered in children with ASD and intellectual disability. One publicly funded, multisite controlled clinical trial provided evidence that methylphenidate was efficacious in relieving ADHD symptoms in children with ASD, but that its efficacy and tolerability were more variable than in children with ADHD but no developmental disorder (Research Units on Pediatric Psychopharmacology [RUPP] Autism Network, 2005a). Approximately one-half of children with ASD had a positive response to methylphenidate, and about 18% had adverse side effects, some of which were highly disruptive (albeit short-lived).

Antipsychotic medications (antidopaminergic agents marketed for the treatment

of psychosis in adults) are frequently used as off-label agents to treat aggression and severe tantrums in children. Typical antipsychotics have been used for decades to control behavioral problems in children with intellectual disability and ASD. In particular, placebo-controlled studies documented the efficacy of haloperidol in autism (Anderson et al., 1989).

In more recent years, atypical antipsychotics, such as risperidone, have gradually replaced the typical antipsychotic medications. Evidence from a multisite placebo-controlled clinical trial showed that risperidone was efficacious in decreasing severe behavioral disturbances among 5- to 17-year-old children with autism (RUPP Autism Network, 2005b). Approximately two-thirds of the children treated with risperidone improved, compared to 12% on placebo, by the end of the 8-week trial. These data were replicated in a group of children with several types of ASD as defined at that time (autism, pervasive developmental disorder not otherwise specified, or Asperger syndrome), none of whom were selected for extremely disruptive behavior. The beneficial effects of risperidone were sustained through 6 months of treatment, although the behavioral problems recurred after the cessation of medication; these results suggest that risperidone is efficacious for children with ASD, although not curative.

Clonidine and the pharmacologically related guanfacine are alpha-adrenergic agonists that are marketed for the treatment of hypertension in adults, but are frequently also used to manage hyperactivity in children (for a review, see Brown et al., 2008). These drugs are often used in children with ASD to control hyperactivity, aggression, and severe tantrums. Finally, mood stabilizers like lithium and divalproate are also used in children with ASD and intellectual disability for the control of explosive aggression and severe tantrums. Although these medications have demonstrated clear efficacy among adults with bipolar disorders, further data are necessary prior to endorsing their efficacy for ASD and intellectual disability.

With regard to strength of evidence, randomized controlled studies strongly support the efficacy of antipsychotics and stimulants in decreasing symptoms of disruptive behavior in children (ages 5 and older) and adolescents, although the impact of these agents on functioning (including communication and social interactions) is less clear (for a review, see Brown et al., 2008). Furthermore, the medications used in the management of ASD or intellectual disability have specific adverse side effects associated with the pharmacological activities of these agents. It also should be noted that children with ASD and intellectual disability are at increased risk for drug-induced side effects, because the central nervous system (CNS) in these disorders is apt to be more sensitive to pharmacological interventions. Moreover, due to communication and other developmental challenges among these individuals, there is often significant delay or impairment in the recognition of drug toxicities. The antipsychotics are frequently associated with a number of neurological toxicities (e.g., dystonias, dyskinesias, tremors), as noted earlier, and the atypical antipsychotics (e.g., risperidone, olanzapine) are also associated with weight gain. Finally, the atypical antipsychotics also increase the risk of metabolic disturbances, including diabetes and hyperlipidemia.

Bipolar Disorders

Lithium is the best-studied medication for bipolar disorders, with evidence supporting its use (for a review, see Brown et al., 2008). Investigations examining the efficacy of

lithium are not without methodological limitations, however, including small sample sizes and crossover designs that do not allow for adequate drug washout periods. There also is some support for the use of divalproex, clozapine, carbamazepine, olanzapine, ziprasidone, and toprimate as adjuncts to lithium therapy (Brown et al., 2008). There exist some data for the use of risperidone, although no randomized controlled trials are yet available. Finally, there is some preliminary evidence to support the use of SSRIs as beneficial for bipolar disorders, although these agents have also been shown to result in unstable mood.

Adverse side effects associated with psychotropic medication for bipolar disorders are common and range from nuisance-type untoward symptoms to severe toxicities (for a review, see Brown et al., 2008). Some medications such as atypical antipsychotics can induce weight gain, which can result in metabolic disorders including Type 2 diabetes mellitus. There also are some anecdotal reports of adverse cognitive side effects from nearly all psychotropic agents used for mood stabilization; these effects include problems with word retrieval, working memory, and cognitive dulling. Other uncommon, albeit problematic, side effects include hypothyroidism (associated with lithium), abnormal involuntary motor movements and prolactin elevation (associated with antipsychotics), cardiac events (associated with ziprasidone), and hematological and neurological adverse events (associated with clozapine).

Schizophrenia Spectrum Disorders

For both adults and children, traditional neuroleptics and atypical antipsychotic agents are considered first-line agents for the management of psychotic symptoms associated with schizophrenia spectrum disorders (for a review, see Brown et al., 2008). Treatment response for haloperidol, risperidone, and olanzapine is 53%, 74%, and 88%, respectively (Sikich, Hamer, Bashford, Sheitman, & Lieberman, 2004). Generally, more serious side effects occur in pediatric populations than in adults. One large-scale multicenter trial recently completed, Treatment of Early Onset Schizophrenia Spectrum Disorders, included 165 youth from 8 to 19 years of age who were randomly assigned to risperidone, olanzapine, or molindone for 8 weeks, with 2 or more weeks at a predetermined maximal dose (Sikich et al., 2004, 2008). Those with a positive response continued under masked conditions for an additional 44 weeks. Findings did not reveal differences with regard to response rates or magnitude of symptom reduction, although olanzapine and risperidone were associated with significant weight gain. These data call into question the nearly exclusive use of second-generation antipsychotics to treat early-onset schizophrenia and schizoaffective disorder (Sikich et al., 2008).

Many studies of the neuroleptics and antipsychotic agents have included children and adolescents with psychotic symptoms but not necessarily schizophrenia spectrum disorders. The majority of studies have not included children under the age of 13 and have dealt primarily with acute outcomes, with the exception of one 2-year follow-up study of a comprehensive treatment program, which employed a historical control group that had received an undocumented assortment of interventions (Sikich et al., 2008).

As noted throughout this chapter, all currently available medications for schizophrenia spectrum disorders carry the risk of serious side effects and thus require careful monitoring (Brown et al., 2008). Because a serious yet common side effect of atypical antipsychotic agents is weight gain that can result in metabolic disorders including Type

2 diabetes mellitus, the American Diabetes Association, in conjunction with the American Association of Clinical Endocrinologists and the North American Association for the Study of Obesity (2004), has published a monitoring protocol for all individuals receiving atypical antipsychotic medications. Other adverse effects include cognitive difficulties, including cognitive dulling, decreased working memory, and problems with word retrieval; these must be assessed carefully, particularly for school children (Brown et al., 2008).

Anxiety Disorders

Although a number of pharmacological agents have been evaluated for childhood anxiety disorders, the data strongly favor the SSRIs, at least for the management of generalized anxiety disorder, separation anxiety disorder, selective mutism, specific phobia, and social anxiety disorder. Imipramine, one of the first medications evaluated for childhood anxiety, was superior to placebo for children with school avoidance, although not for children with separation anxiety disorder (Klein, Koplewicz, & Kanner, 1992). Because of the risk of cardiotoxicity in overdose and the availability of better-tolerated medications, the use of imipramine has become quite rare (Brown et al., 2008). A multisite placebo-controlled clinical trial sponsored by the NIMH found fluvoxamine (an SSRI) to be highly efficacious and well tolerated among youth from 6 to 17 years of age (RUPP Anxiety Study Group, 2002). Subsequent moderator analyses found that lower parent-reported child depression scores at baseline were associated with a more marked advantage of fluvoxamine over placebo (RUPP Anxiety Study Group, 2003). Other, smaller controlled trials support the efficacy of the SSRIs in children with generalized anxiety disorder (for a review, see Brown et al., 2008). Few data are actually available on functioning or the durability of medication effects. Only limited data exist regarding the long-term use of SSRIs for childhood anxiety disorders, although 94% of acute-phase positive responders to fluvoxamine retained their positive response without any dose changes over a 6-month follow-up period (RUPP Anxiety Study Group, 2002).

The available data pertaining to the efficacy and adverse safety profiles of benzodiazepines and tricyclic antidepressants do not support their use in the management of children and adolescents with anxiety disorders (for a review, see Brown & Zygmont, 2009). In contrast, data from controlled SSRI trials have documented moderate to large positive effects for the acute reduction of the primary symptoms of generalized anxiety disorder, separation anxiety disorder, selective mutism, specific phobia, and social anxiety disorder. With regard to adverse effects, SSRIs tend to be relatively well tolerated in children and adolescents with anxiety. Although transient in nature, the most commonly reported SSRI-related side effects include nausea, diarrhea, insomnia, loss of appetite, sedation, tremor, sexual dysfunction, and disinhibition (Leonard, Ale, Freeman, Garcia & Nigg, 2005).

Tourette's and Other Tic Disorders

The most well-studied pharmacological agents for childhood chronic tic disorders include the dopamine receptor blockers (typical neuroleptics) haloperidol and pimozide; the atypical neuroleptics risperidone and ziprasidone; and the alpha-2-adrenergic agonists clonidine and guanfacine. Randomized controlled trials of between-groups or

crossover designs have been published for each of these agents (for a review, see Brown et al., 2008). Although characterized by relatively small sample sizes and brief duration, these studies suggest at least moderate treatment effects of the typical and atypical neuroleptics and guanfacine, with more equivocal support for clonidine. Several other agents, including atomoxetine, a selective noradrenergic reuptake inhibitor; mecamylamine, a nicotinergic receptor antagonist; and botulinum toxin are being used with some frequency for childhood chronic tic disorders, despite limited empirical support and concerns about safety (Zinner, 2004). The long-term efficacy and safety of psychopharmacological treatments for childhood chronic tic disorders are underresearched.

The strongest evidence for the efficacy in tic suppression has been obtained for the dopamine-blocking agents haloperidol and risperidone (Gilbert, 2006). Both of these agents have shown benefit in at least two controlled trials. Unfortunately, as noted throughout this chapter, these agents also are associated with adverse event profiles serious enough to limit their utility as first-line interventions. Among the alpha-2-adrenergic agonists, the strength of evidence favors guanfacine over clonidine. Both clonidine and atomoxetine have demonstrated modest benefits in children and adolescents with comorbid tic disorder and ADHD. However, methodological limitations related to sample recruitment and attrition rates raise concerns about the generalizability of the findings (Gilbert, 2006). With the possible exception of ziprasidone, which demonstrated efficacy in one controlled trial, other treatments for tic suppression have limited research support.

Again, neuroleptic use is associated with a range of serious side effects, including sedation, cognitive dulling, weight gain, extrapyramidal symptoms, electrocardiographic findings, akathesia, depression, and anxiety (for a review, see Brown et al., 2008). The atypical neuroleptics risperidone and ziprasidone are thought to be associated with reduced risk of extrapyramidal symptoms and tardive dyskinesia, but risperidone is associated with significant weight gain. The adverse side effects of long-term treatment with neuroleptic drugs have been well documented.

Diversity and Multicultural Issues

Clinical trials involving psychotropic medications for children have largely focused on interventions delivered to white males from middle- to upper-middle-class families. This is true for much of the research literature on psychopathology, where females, racial/ethnic minorities, and children from low socioeconomic backgrounds are significantly underrepresented in clinical trials involving psychotropic medications, particularly for the externalizing disorders. Single-parent status, low socioeconomic status, and lower parental education are associated with poorer compliance with medication and parent training, and thereby with less favorable outcomes. In addition, there is evidence to suggest that racial/ethnic minority children are less likely to receive certain pharmacotherapies such as stimulant drug treatment than their white counterparts are. One recent study has suggested that willingness to use interventions was not associated with children's race, gender, or socioeconomic status (Bussing, Koro-Ljungberg, Noguchi, Mayerson, & Garvan, 2012).

Very little research has been conducted about differential metabolism of medications in children by gender, race, or ethnicity. One exception is a prospective investigation conducted by Campbell et al. (1997) on neuroleptic-related dyskinesias in children

with autism. Findings revealed that dyskinesias were higher among girls than boys, thereby suggesting gender as a risk factor for specific adverse effects associated with psychotropic agents. In the adult literature, differential metabolism of various psychotropics has been demonstrated by race and ethnicity: African Americans experience greater toxicities associated with lithium carbonate, and different rates of metabolism for antidepressant agents have been found for Asian Americans relative to other ethnic groups (for a review, see Brown & Zygmont, 2009). Clearly, there are potential moderating effects of gender, race, and ethnicity on both psychosocial and pharmacological interventions for various disorders. This underscores the need for further research in this area as we strive to develop culturally competent treatments.

PHARMACOTHERAPIES FOR CHRONIC HEALTH CONDITIONS

I now turn to those chronic pediatric illnesses for which various pharmacotherapies are employed, many of which exert cognitive or behavioral toxicities that frequently affect learning in the classroom setting and social functioning among peers. For each of these disorders, I review recent literature demonstrating the efficacy of some psychotropic agents for toxicities associated with treatment or neurological impairments resulting from the disease itself. This review includes cancer, sickle cell disease, HIV/AIDS, and seizure disorders.

Cancer

Childhood cancers are chronic conditions that affect development across a number of domains, including cognitive functioning. Pathophysiology and adverse effects resulting from standard treatment modalities may have negative effects on higher-order cognitive skills and academic achievement, thereby compromising daily functioning (including school and play activities) and overall quality of life. The therapies most commonly employed to treat cancer (chemotherapy, radiation therapy), particularly when these therapies are employed as prophylaxis to the CNS (e.g., children with leukemia), may result in adverse long-term CNS-related toxicities, commonly referred to as "neurocognitive late effects." These effects may manifest themselves months or years after completion of cancer treatment and are generally believed to progress and persist for years. Neurocognitive late effects resulting from radiation therapy or chemotherapy may include declines in overall intellectual functioning; deficits in memory, attention/concentration, executive function, and processing speed; delays in academic achievement or diminished school performance relative to healthy peers; impaired nonverbal intelligence and reasoning; delayed arithmetic achievement; and impairments in visual–motor integration, visual-perceptual ability, sequencing, verbal fluency, perceptual localization, and nondominant hand motor skills (for a review, see Daly & Brown, 2015).

Several randomized clinical trials have examined the efficacy of methylphenidate in ameliorating the neurocognitive late effects of cancer treatment in children (Thompson et al., 2001). These controlled clinical trials have provided data to suggest improvements in sustained attention, and the one study comparing moderate and low doses of methylphenidate did not find greater improvements with a moderate dose compared to a low dose of methylphenidate. Few adverse effects were found as a result of the methylpheni-

date therapy, although the long-term efficacy of the medication was not examined under double-blind conditions. Nonetheless, these studies are important, as they underscore the efficacy of stimulant medication in enhancing attentional problems among children with cancer who suffer from cognitive late effects associated with chemotherapy or radiation therapy.

Sickle Cell Disease

Sickle cell disease is a hemoglobinopathy that is frequently characterized by vascular infarcts or "silent strokes" within the CNS in general or the brain more specifically. In severe cases, children may actually experience overt strokes. As results of these silent or overt strokes, children may sustain impairments in attention and executive functioning, as well as other neurocognitive impairments. Of interest is that the structural CNS impairments associated with sickle cell disease are similar to those of children and adolescents with ADHD, including abnormalities in the regions of the frontal lobes (Brown, Davis, Lambert, Hsu, & Eckman, 2000) and the basal ganglia (Pegelow et al., 2002). Thus it stands to reason that children with sickle cell disease may demonstrate the same therapeutic benefits from stimulant drug therapy as their peers with ADHD.

Daly et al. (2012) addressed this question by evaluating specifically whether methylphenidate was effective in enhancing cognitive performance and attention for children with sickle cell disease and cerebrovascular complications who also evidenced attentional problems. Two multisite double-blind clinical trials were conducted: a laboratory trial of the short-term efficacy of methylphenidate, and a 3-week home–school crossover trial evaluating the drug's efficacy. Children and adolescents ranged in age from 7 to 16 years. Assessments in the laboratory trial included measures of sustained attention, reaction time, executive functions, and verbal memory. Assessments in the 3-week trial included parent and teacher ratings of attention. In the acute laboratory study, memory and inhibitory control were positively affected by the use of methylphenidate. Parent and teacher reports from the home–school trial revealed further that moderate-dose methylphenidate produced superior improvement in attention, relative to the placebo dose and a low dose of methylphenidate.

From these data, it would appear that methylphenidate has a positive impact on memory and inhibitory control among children with sickle cell disease, and that higher doses of methylphenidate enhance parent and teacher ratings of attention. The investigators concluded that the stimulants may provide an effective intervention for some children with sickle cell disease and cerebrovascular complications who demonstrate attention problems. No serious adverse effects were associated with methylphenidate in either the acute or 3-week controlled trial.

HIV and AIDS

It is estimated that 30–40% of individuals with HIV suffer from depression, but psychopharmacology studies to date have focused on adults (Ferrando, 2009). The National Institutes of Health Adolescent Medicine Trials Network for HIV/AIDS Intervention (*www.nichd.nih.gov/research/supported/Pages/atn.aspx*) is completing the first feasibility study of combined CBT and medical management of depression in youth with HIV. The results will have implications not only for the mental health of these youth, but

also for the health of the public, as sexual risk behaviors associated with transmission are more likely in the context of depression (Khan et al., 2009). Clearly, more research is necessary to determine safe and effective psychopharmacotherapies for youth with chronic medical conditions, and studies of adherence to such medications in the context of chronic illness management will be critical to ensure treatment efficacy.

Seizure Disorders

The anticonvulsants are typically used to manage seizure disorders, as well as to manage behavioral disturbances associated with bipolar disorders and intermittent explosive disorder. The most commonly prescribed anticonvulsant medication is phenytoin (Dilantin), which is a first-generation anticonvulsant (Elbe, Bezchlibnyk-Butler, Virani, & Procyshyn, 2015). Carbamazepine (Tegretol), divalproex (Depakote), valproic acid (Depkene, Stavzor), and valproate sodium (Depacon) are second-generation anticonvulsants that are also frequently prescribed (Elbe et al., 2015). Finally, the third-generation anticonvulsants include gabapentin (Neurontin), lamotrigine (Lamictal), levetiracetam (Keppra), oxcabazepine (Trileptal), and topiramate (Topamax) (Elbe et al., 2015). The use of these agents is frequently tailored to the specific type of seizure. There are a number of adverse side effects associated with the anticonvulsants, including gastrointestinal complaints, tremors, ataxia, changes in appetite/weight gain, and menstrual disturbances (Elbe et al., 2015). These adverse effects typically can be minimized with lower doses and gradual titration of doses until appropriate blood levels are obtained. Important adverse effects associated with many anticonvulsants include lethargy, sedation, and behavior changes; these may result in cognitive effects, including psychomotor slowing and decreases in attention and memory. Thus careful monitoring of school performance upon initiation of any anticonvulsant is imperative. It also should be noted that the cognitive adverse effects typically can be minimized with slow dosage increases.

CONCLUSIONS AND RECOMMENDATIONS

Pediatric psychologists bring much expertise to clinical and research settings pertaining to the use of psychotropic medications among children and adolescents, and particularly those youth with chronic health conditions. These psychologists have considerable knowledge regarding developmental issues, as well as attitudes of caregivers, teachers, and youth themselves about medications. And they have particular expertise pertaining to the assessment of the safety and efficacy of various psychotropic agents used for children and adolescents. Because of pediatric psychologists' special expertise in assessment, measurement, and research, they are able to contribute significantly to interdisciplinary teams and facilitate collaborative studies at multiple levels. Because the use of psychotropic medications for children and adolescents far exceeds the data that are currently available, much research needs to be conducted over the next several years to shed light on the safety and efficacy of various psychotropic agents and their combination with other medications and psychosocial treatments used to manage chronic illness in the pediatric setting. Moreover, research is urgently needed on the roles of gender, race, and ethnicity as mediating factors in the impact of psychotropic medications on children's behavior and learning.

In particular, advances in genomics have significant implications for the well-being of children and adolescents whose conditions are being managed with various psychotropic agents. In the future, it is likely that genomic information may be used to make important decisions based on safety and efficacy with regard to the use of various psychotropic agents for children and adolescents; this information may be obtained through genetic mapping and familial responses to specific medications. Pediatric psychologists will lend important expertise to this program of research, given their broad knowledge of children's development and the environmental and genetic influences of various pharmacotherapies at different critical periods of development. Their skills in assessment will facilitate controlled randomized clinical trials on the effects of various psychotropic agents on children's cognition, socialization, and behavior among peers. It is also hoped that there will be additional studies examining the combination of pharmacotherapy and psychosocial treatments in special populations, including children with schizophrenia, children with ASD, and preschool children. Such studies will provide important research and employment opportunities for pediatric psychologists in the years to come. It is predicted that the next decade will see emerging and important research in how psychotropic medications may improve child health and well-being in youth with chronic diseases, and ultimately enhance the quality of life for these children and adolescents and their families.

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CHAPTER 14

Pediatric Medical Traumatic Stress

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Pediatric illnesses and injuries, and their medical treatments, can be experienced as traumatic events by patients and family members. Pediatric medical traumatic stress (PMTS) is defined as "a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences" (National Child Traumatic Stress Network, 2003). Although it includes acute stress disorder (ASD) and posttraumatic stress disorder (PTSD), PMTS is broader and generally measured not by diagnosis but by a cluster of posttraumatic stress symptoms (PTSS)—particularly arousal, reexperiencing, and avoidance—linked to medical events. Many children and families experience PMTS, but rates of psychopathology are low. Many initially distressed children and families are resilient and adapt effectively with the aid of short-term, supportive interventions. However, PMTS contributes to poor physical health outcomes, including increased risk of reinjury (Johnston & Martin-Herz, 2010), deficits in health-related quality of life (Colville & Pierce, 2013), and poorer school and physical functioning (O'Connor et al., 2012). These findings point to potential adverse effects of PMTS on daily functioning and suggest that psychosocial interventions be matched to level of family need. Research related to PMTS has grown significantly—supporting recent updates to the integrative trajectory model of medical traumatic stress, documenting PMTS across pediatric conditions, examining longitudinal patterns of and risk factors for PMTS, and evaluating PMTS assessment and preventive interventions (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009).

INTEGRATIVE TRAJECTORY MODEL OF PMTS

The integrative trajectory model of PMTS (see Figure 14.1; Kazak et al., 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016) is a conceptual frame-

work that promotes a competency-based and family-centered approach to PMTS. The model integrates the pediatric illness and injury literatures, and outlines three phases of medical events across pediatric populations: peritrauma; acute medical care; and ongoing care or discharge from care. The timing and duration of each phase vary, depending on the nature and course of the medical event, as well as the possibility of recurrent, cyclical, or subsequent episodes of medical events. The model highlights the role of subjective appraisals of potentially traumatic medical events and potential trajectories of PMTS. Consistent with a growing literature and a competency-based approach, the four trajectories of PMTS include the "resilient" (the majority of families experience minimal PMTS) and "recovery" (a smaller proportion of families experience higher initial levels of PMTS that decline over time) pathways, as well as the "chronic" (consistently elevated PMTS) and "escalating" (increasing level of PMTS) trajectories, which represent a minority of families. This model also emphasizes a family-centered approach to understanding PMTS, as children with illness and/or injury and their family members may experience medical events as traumatic and

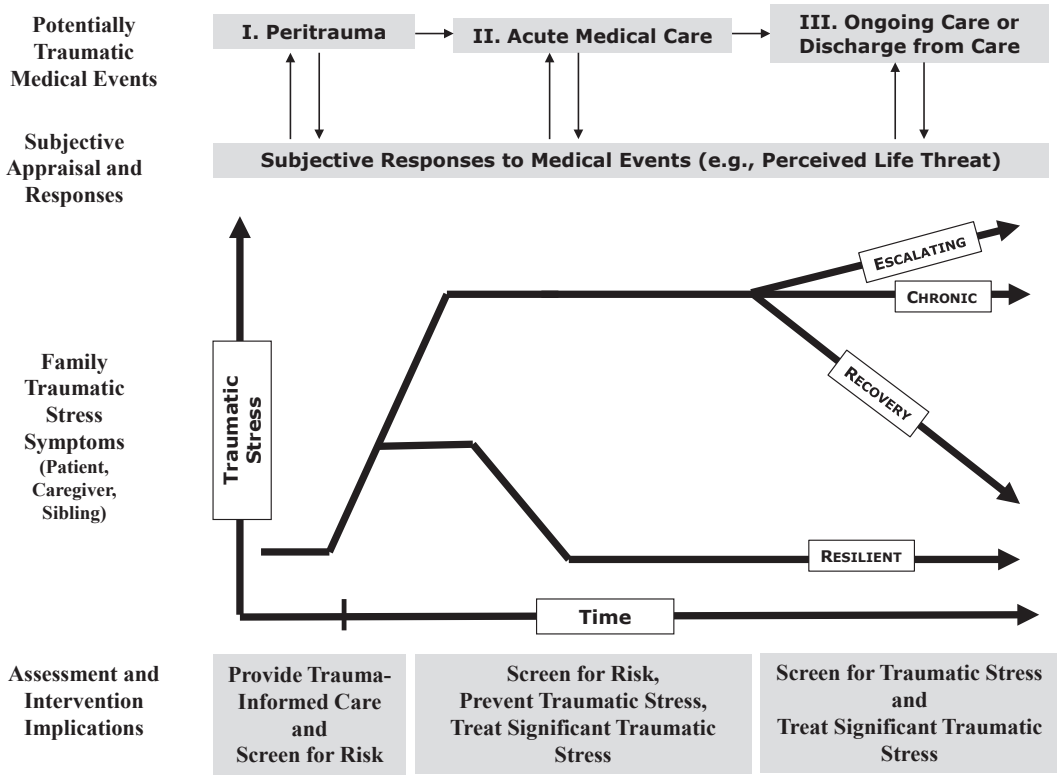

FIGURE 14.1. Integrative trajectory model of pediatric medical traumatic stress (PMTS). A schematic of the model includes medical phases and psychological responses to pediatric injury and illness, as well as important risk factor and indicated psychosocial assessment and intervention practices. From Price et al. (2016). Copyright © 2016 Oxford University Press. Reprinted by permission.

exhibit PMTS. Developmental and additional contextual factors that affect PMTS are embedded within the model and its assumptions as well. The integrative trajectory model delineates implications for assessment and intervention of PMTS, specifically suggesting frequent screening and early intervention, given the variability in PMTS among families across time.

PMTS ACROSS PEDIATRIC POPULATIONS

Pediatric cancer and injury provide the most evidence regarding course, risk factors, and assessment and intervention strategies for PMTS. However, the evidence base for PMTS in other pediatric conditions (e.g., Type 1 diabetes, transplant, intensive care, cardiology) is growing. This expanding research literature indicates that the distress experienced by children and families affected by pediatric illness and injury can be understood in the context of PTSS.

The prevalence of PMTS across pediatric populations is variable (Table 14.1), and the most evidence of longitudinal patterns comes from the injury literature. In general, PMTS is even more prevalent in parents than in patients (children). PMTS in burn populations and intensive care settings for parents and children is quite evident. Multiple factors contribute to variability in the prevalence rates of PMTS, including assessment methods (e.g., interview vs. questionnaire; PTSD vs. PTSS) and use of parent proxy reports compared to child self-reports. Results from a meta-analysis indicated that rates of PTSD among parents of children with chronic illnesses were roughly 23%, with mothers exhibiting higher rates of PTSD than fathers (i.e., 20% vs. 12%; Cabizuca et al., 2009). Findings from another meta-analysis suggested PTSD prevalence rates of about 12% and 20% among youth with illness and injury, respectively, and partial PTSD prevalence of roughly 38% and 25% across illness and injury, respectively (Kahana, Feeny, Youngstrom, & Drotar, 2006). As noted above, PMTS is not limited to diagnostic entities of ASD or PTSD; many studies assess clinically significant levels of PTSS instead of, or in addition to, diagnostic ASD or PTSD. Thus the prevalence of PMTS is likely to be higher than some meta-analyses and systematic reviews that focus on only diagnostic categories indicate.

Few studies have directly compared child and parent PTSS across conditions. Although there were no differences in PTSS rates among children with human immunodeficiency virus (HIV), sickle cell disease (SCD), or transplant (Ingerski, Shaw, Gray, & Janicke, 2010), children with new diagnoses of cancer and unintentional injury reported significantly higher rates of PTSS than did children newly diagnosed with diabetes (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). Parents of youth requiring solid organ or bone marrow transplants reported more PTSS than did parents of youth diagnosed with HIV or SCD (Ingerski et al., 2010). Parents with children newly diagnosed with cancer endorsed higher rates of PTSD than did parents of youth newly diagnosed with diabetes and those with accidental injury (Landolt et al., 2012). This preliminary evidence of potential differences in PMTS across pediatric conditions and between parents and children calls for additional research into reasons for this variability. For example, variation in associated experiences (i.e., need for surgery, extended hospitalization) and in the children's or families' perceptions of life threat may contribute to variation in prevalence of PMTS.

TABLE 14.1. Prevalence (in Percent) of PMTS in Pediatric Illness and Injury

	Time since injury or diagnosis of illness					
	2 days to 6 weeks		2 to 9 months		≥ 10 months	
Population	Child	Parent	Child	Parent	Child	Parent
Cancer		40–83[a]		18–33[b]		7–27[c]
Cancer survival	NA	NA			8–75[d]	20–22[e]
Type 1 diabetes	5–67[f]	5–24[g]		10– 42[h]		7–20[i]
Cardiac disorders		13–34[j]		10– 22[k]		
Intensive care			14–36[l]	9–30[m]		
Injury	2–42[n]	10–23[o]	1–38[p]	5–15[q]	10–19[r]	2–6[s]
Motor vehicle accidents	2–38[t]	5–62[u]	15–25[v]			0–13[w]
Burns	25–31[x]	25–50[y]		5–47[z]		6–18[aa]
Orthopedic injury					7–33[ab]	
Traumatic brain injury			4–16[ac]			

Note. Ranges of prevalence for PTSD, ASD, PTSS, and/or acute stress symptoms are from empirical studies published from 2005 to 2014, and rounding was applied to percentages. Inclusion criteria were $N > 50$ and ≥2 independent studies published during this time. NA, not available.

[a]Landolt et al. (2012), Patino-Fernandez et al. (2008). [b]Tremolada et al. (2013). [c]Stoppelbein and Greening (2007), Tremolada et al. (2013). [d]Alderfer et al. (2009), Rourke et al. (2007). [e]Ozono et al. (2007). [f]Cline et al. (2011). [g]Cline et al. (2011), Landolt et al. (2012). [h]Landolt, Vollrath, Laimbacher, et al. (2005). [i]Landolt, Vollrath, Laimbacher, et al. (2005), Stoppelbein and Greening (2007). [j]Helfricht et al. (2008), Landolt et al. (2011). [k]Helfricht et al. (2008). [l]Bronner et al. (2008). [m]Bronner et al. (2008, 2010). [n]Kassam-Adams et al. (2006), Zatzick et al. (2006). [o]Kassam-Adams et al. (2006), Martin-Herz et al. (2012). [p]De Young et al. (2007), Scheeringa et al. (2006). [q]Le Brocque et al. (2010b), Martin-Herz et al. (2012). [r]Le Brocque et al. (2010a), Zatzick et al. (2006). [s]Landolt et al. (2012), Martin-Herz et al. (2012). [t]Pervanidou, Kolaitis, Charitaki, Margeli, et al. (2007), Winston et al. (2005). [u]Landolt, Vollrath, Timm, et al. (2005), Winston et al. (2005). [v]Pervanidou, Kolaitis, Charitaki, Lazaropoulou, et al. (2007), Schäfer et al. (2006). [w]Landolt, Vollrath, Timm, et al. (2005). [x]De Young et al. (2012), Saxe et al. (2005). [y]Bakker et al. (2012), De Young et al. (2014). [z]De Young et al. (2014), Hall et al. (2006). [aa]Bakker et al. (2013). [ab]Hajek et al. (2010), Wallace et al. (2013). [ac]Iselin et al. (2010), Kenardy et al. (2012).

LONGITUDINAL PATTERNS OF PMTS

Research examining longitudinal patterns of PMTS can help to delineate typical and atypical responses to pediatric injury or illness. Studies examining 6- to 16-year-olds postinjury, and preschool children with minor unintentional burn injuries and their parents, have indicated four distinct trajectories: resilient (minimal PTSS following injury), recovery (initial PTSD or elevated PTSS remitting within 1–3 months), chronic (consistently elevated PTSS or PTSD for 6–24 months postinjury), and delayed-onset (new-onset PTSD diagnosis 6 months postinjury) (Le Brocque, Henrikz, & Kenardy, 2010a). Similar trajectories of psychosocial functioning following a potentially traumatic event (PTE) are common across types of trauma. Longitudinal studies of children newly diagnosed with an acute or chronic illness and their parents follow a similar pattern, although no trajectory analyses have been used to examine these patterns in illness populations. The majority of parents of children admitted to intensive care did not endorse subclinical or clinical levels of PTSD; a smaller proportion of parents reported initially elevated subclinical PTSD that declined over time; and parents in the smallest

group were at risk for chronic clinical levels of PTSD (Bronner et al., 2010). Indeed, some children and parents continue to exhibit PMTS for years following a potentially traumatic medical event.

RISK FACTORS FOR PMTS

Across pediatric illness and injury, risk factors for PMTS include subjective perception of life threat related to the medical event, preexisting psychological difficulties, previous PTEs, and parental PMTS. Although objective measures of injury and/or illness severity do not consistently predict PMTS, recent studies suggest that subjective factors may moderate this relation among children and families adjusting to pediatric conditions. A meta-analysis of predictors of PTSD severity suggested that appraisals of trauma severity and life threat had a large effect size in pediatric injury samples, and a small to moderate effect size in chronic illness samples (Kahana et al., 2006). More recent studies continue to confirm a key role for perceived life threat in the prediction of parent and child PMTS. Objective factors such as length of hospital stay, poor metabolic control (in diabetes), and medical sequelae and relapse (in cancer) also predict PMTS for both pediatric illness and injury groups (Brosbe, Hoefling, & Faust, 2011; Landolt et al., 2012; Landolt, Vollrath, Laimbacher, Gnehm, & Sennhauser, 2005; Ozono et al., 2007). However, child and parent subjective interpretation of morbidity and mortality more strongly and consistently predict PMTS than do the objective measurements of injury or illness severity (Kassam-Adams, Marsac, Hildenbrand, & Winston, 2013).

Preexisting psychological difficulties and previous PTEs confer risk for PTSS across pediatric injury and illness. A systematic review of pediatric unintentional injury (Brosbe et al., 2011) and studies of PTSS trajectories after injury support this association. A meta-analysis found that preinjury psychopathology was one of the strongest predictors of PTSS among injured youth (Cox, Kenardy, & Hendrikz, 2010). Trait anxiety in mothers of children with cancer increased risk for PTSS following diagnosis (Patino-Fernandez et al., 2008).

A growing evidence base suggests that parental PTSS increases risk for child PTSS and maintenance of child PTSS (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Nugent, Ostrowski, Christopher, & Delahanty, 2007). For example, parent PTSS predicted youth PTSS among those who experienced unintentional injury (Brosbe et al., 2011); in youth diagnosed with diabetes, cancer, or injury, initial high rates of PTSS in parents were related to poorer recovery from PTSS in the children over time, but not vice versa (Landolt et al., 2012). A meta-analysis that included many pediatric illness and injury studies found a significant relation between child and parental (especially maternal) PTSS (Morris, Gabert-Quillen, & Delahanty, 2012). In sum, parents' and children's PTSS patterns are highly related and call for a family-centered approach to assessment and treatment of PMTS.

A small literature has examined potential moderators of risk for PMTS and biological risk factors. Although the relation between objective measures of injury severity and later PTSS is usually weak, it may be complicated by parental subjective interpretation of the event. Among a sample of children who experienced burn injuries, the relation between mothers' feelings of guilt and parental PTSS was moderated by the permanency of the children's scarring (Bakker, Van Loey, Van Son, & Van der Heijden, 2010).

Genetic risk, maternal cortisol levels at time of pediatric cancer diagnosis, and heart rate immediately following injury may also contribute to the development of PTSD or predict later PTSS (Amstadter et al., 2011; Olsson, Kenardy, DeYoung, & Spence, 2008; Stoppelbein, Greening, & Fite, 2010).

ASSESSMENT AND TREATMENT OF PMTS

Given the significant variability in children's and parents' responses to pediatric illness and injury, early and ongoing screening and assessment for PMTS are needed to determine the appropriate level of psychosocial support. Screening tools designed to assess risk for PMTS following injury have received the most research attention to date. For example, the Child Trauma Screening Questionnaire (CTSQ; Kenardy, Spence, & Macleod, 2006) demonstrated good sensitivity and specificity in predicting child PTSD symptoms and impairment 6 months postinjury, and this improved when CTSQ scores were combined with triage heart rate (Olsson et al., 2008). There is evidence that screening may be feasible and acceptable to medical staff in an emergency department setting (Ward-Begnoche et al., 2006).

To minimize the risk of PMTS among children and families with pediatric illness or injury, medical staff and psychosocial providers can use trauma-informed care practices to modify the subjective experience of a medically related PTE (e.g., hospital admission process, medical procedures, disclosure of a new diagnosis), so that it is less likely to be perceived as more life-threatening or severe than the medical situation suggests. This approach to patient care (see *www.healthcaretoolbox.org*) also emphasizes assisting families in accessing appropriate emotional and social supports, and provides assessment and intervention materials for a target audience of health care providers. The D-E-F framework described at *www.healthcaretoolbox.org* ("Reduce distress—Ask about fears and worries," "Emotional support—Who and what does the patient need now?", and "Remember the family—Gauge family stressors and resources") guides trauma-informed assessment and intervention at the point of care, with evidence-informed materials in English and Spanish.

The goal of preventive interventions is to reduce or prevent PMTS among children and family members who are at elevated risk or are exhibiting some early symptoms. A meta-analysis of early psychological interventions for youth following a single trauma (not limited to medical trauma, but involving many medical trauma samples, especially pediatric injury) found preliminary support for such interventions (Kramer & Landolt, 2011). Although significant variability in study methods precluded definitive conclusions, this meta-analysis suggested that psychoeducation, promotion of coping skills, and a stepped approach to identifying those at elevated risk may contribute to efficacy (Kramer & Landolt, 2011). Since this meta-analysis was conducted, additional randomized clinical trials (RCTs) have provided mixed evidence for early intervention following pediatric injury (Kassam-Adams, Garcia-Espana, Marsac, & Kohser, 2011; Kramer & Landolt, 2014), and preliminary support for early interventions for mothers of preterm infants (Shaw et al., 2014).

There are a number of preventive interventions with at least preliminary data supporting their effectiveness. For example, the Surviving Cancer Competently Intervention Program—Newly Diagnosed (SCCIP-ND), a three-session manualized intervention for parents/caregivers of children newly diagnosed with cancer, has preliminary data

supportive of reducing PMTS (Kazak et al., 2005). In an RCT (in which nearly one-quarter of youth had experienced a motor vehicle accident), youth who participated in a parent–child four-session intervention, the Child and Family Traumatic Stress Intervention (CFTSI), within 30 days of a single traumatic experience exhibited fewer partial and full PTSD diagnoses 3 months posttrauma, compared to those who received a supportive comparison intervention (Berkowitz, Stover, & Marans, 2011). Recent RCTs of web-based interventions focused on psychoeducation yielded mixed evidence of efficacy (Marsac et al., 2013; Cox et al., 2010). Early psychopharmacological interventions (propranolol, sertraline) represent a new area of research that has yet to provide consistent evidence (Nugent et al., 2007; Stoddard et al., 2011).

Although a large literature demonstrates the efficacy of trauma-focused cognitive behavioral therapy (TF-CBT) as a treatment for child PTSD, there are fewer studies evaluating treatments specifically designed for PMTS. A pilot study of a web-based cognitive-behavioral intervention for long-term survivors of pediatric cancer yielded some evidence of associated decreases in PTSS and other emotional difficulties (Seitz et al., 2014). Another empirically evaluated intervention for medical trauma is the Surviving Cancer Competently Intervention Program, tested in an RCT of 150 families (SCCIP; Kazak et al., 2004). This program integrates cognitive-behavioral and family therapy approaches to address PTSS in adolescent childhood cancer survivors and their parents and siblings.

CLINICAL IMPLICATIONS AND FUTURE DIRECTIONS

Many children and families experience distress following pediatric illness or injury, but cope effectively by using a variety of resources. A smaller proportion of children and parents demonstrate elevated or clinical levels of PTSS that persist and negatively affect health outcome and quality of life. Recent research on PMTS prevalence, longitudinal patterns, and risk factors inform clinical practice and indicate a significant need for standardized screening for risk of PMTS in medical settings, both at the time of a new diagnosis of pediatric illness or injury and throughout medical treatment and recovery processes. Health care providers should attend particularly to the subjective experiences of children and families rather than to objective indicators of injury or illness severity, as well as to preexisting history of PTEs and/or psychological difficulties. Empirically supported screening tools and indicated preventive interventions exist. However, recent studies indicate minimal access to mental health providers focused on PMTS in pediatric trauma centers, as well as limited understanding of PMTS among emergency department medical providers (Zatzick, Jurkovich, Wang, & Rivara, 2011; Ziegler, Greenwald, DeGuzman, & Simon, 2005). Future research on practical implementation of standardized screening and trauma-informed care within clinical settings is needed.

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CHAPTER 15

Palliative Care, End of Life, and Bereavement

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Nearly 45,000 U.S. children under age 20 die each year, leaving behind three times as many grieving parents and siblings (Hamilton, Hoyert, Martin, Strobino, & Guyer, 2013). Over half of these deaths occur in the first year of life, with the top five causes being congenital anomalies, prematurity, sudden infant death syndrome, complications of pregnancy, and unintentional injury. Unintentional injury and homicide are the primary causes of death for children 1–19 years old, accounting for 47%, while cancer is the leading cause of disease-related death at 9%. Although death in childhood is often unexpected, over half a million children are estimated to have life-threatening conditions (Arias, MacDorman, Strobino, & Guyer, 2003).

In many situations, "palliative care," "end-of-life care," or "hospice" may be helpful. Palliative care is described by the World Health Organization (2015) as comprehensive care that improves quality of life and reduces suffering for individuals with a life-threatening condition and their families. This is achieved through early identification, prevention, and treatment of physical, psychosocial, and spiritual distress. National guidelines endorsed by the American Academy of Pediatrics recommend the integration of palliative care at diagnosis to complement curative therapies (National Consensus Project for Quality Palliative Care, 2013). Ideally, palliation increases as curative therapies become less effective, facilitating the transition to end-of-life care. End-of-life care involves management of a fatal condition and preparation of the family in the final months of life (Field & Behrman, 2003). These services are often provided through hospice, a facility or specialized program for families of individuals who are usually within the last 6 months of a life-limiting condition (von Gunten, Ferris, Portenoy, & Glajchen, 2001).

Pediatric psychologists work with families of children with many different life-threatening conditions, as noted in other chapters of this volume. They facilitate com-

munication between health care providers and families, aid coping and adjustment, assist in decision making and advance care planning, provide staff support and education, conduct research to inform practice, and participate in advocacy and policy making. Continuity of care is ideal, but flexibility is often required in practice. Depending on institutional resources, the provision of care may occur as part of an interdisciplinary team that has long-term contact with families, or in a consultative format to provide crisis intervention or grief counseling.

In this chapter, we provide an overview of the current state of research and clinical practice in pediatric palliative, end-of-life, and bereavement care. Attention is paid to the characteristics of pediatric death in the context of increasing medical advances, barriers to palliative care, communication issues, and the psychosocial impact on parents and siblings. Evidence supporting interventions are highlighted, along with recommendations for practice and future research.

CARE OF INFANTS AND CHILDREN AT THE END OF LIFE

Death in the first year of life presents unique challenges for families and the health care providers who work with them. When an infant is hospitalized soon after birth for a life-threatening condition, the baby is often separated from the mother, who is still physically recovering. Interpreting and managing the infant's symptoms can be especially difficult, and many treatments can contribute to additional suffering while offering only limited benefit. However, medical interventions that may compromise current quality of life may be favored if there is a reasonable chance that future quality of life could be improved. Most infant deaths occur within hours or days of birth (Feudtner et al., 2001), but lengthy stays in the neonatal intensive care unit are not unusual. Over 90% of infant deaths occur in the hospital, often after withdrawal of life-sustaining therapy (Fontana, Farrell, Gauvin, Lacroix, & Janvier, 2013; Leuthner, Boldt, & Kirby, 2004), but this can vary considerably across sites (Verhagen et al., 2010).

For older children, most research has focused on deaths among children with cancer. About half of these children die in the hospital, and about half of those deaths occur in the intensive care unit (ICU) (Bradshaw, Hinds, Lensing, Gattuso, & Razzouk, 2005; Klopfenstein, Hutchison, Clark, Young, & Ruymann, 2001). While two-thirds of these children have "do not resuscitate" (DNR) orders, these are usually written in the last month of life, with nearly half in the last week. Similarly, of children who die in the hospital of other conditions, most die in the ICU, and about half have DNR orders (Carter et al., 2004; Drake, Frost, & Collins, 2003). However, rates of palliative care referrals and DNR orders may be lower for certain populations, such as children with acquired immune deficiency syndrome (Lyon et al., 2008).

Children with life-limiting conditions have an average of 11 symptoms in the last week of life (Drake et al., 2003; Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2006; Wolfe, Grier, et al., 2000). Fatigue and pain are the most frequent and bothersome symptoms, occurring in nearly all children at the end of life (Drake et al., 2003; Pritchard et al., 2008; Theunissen et al., 2007). Other common symptoms are respiratory problems, nausea/vomiting, drowsiness, and poor appetite (Hongo et al., 2003; Jalmsell et al., 2006; Wolfe, Grier, et al., 2000), as well as sadness, anxiety, and irritability (Hongo et al., 2003). Although it may be unrealistic to achieve complete symptom control for

children near the end of life, there is ample evidence of poor quality of life in multiple domains (Huang et al., 2010; Tomlinson, Hinds, Bartels, Hendershot, & Sung, 2011).

"Quality of death" is a concept related to but distinct from quality of life; it is based on multidimensional, subjective, culturally based, and dynamic factors over the disease course (Hales, Zimmermann, & Rodin, 2011). Definitions often include death that is free from suffering, allowing families to prepare, honor wishes, and say goodbye. The extent to which the death is congruent with the wishes of the deceased is a common benchmark, but goals of care may differ among health care providers or parents (Hales et al., 2011; Hendrickson & McCorkle, 2008). For example, many adults may wish for a quick and painless death for themselves, while parents may prioritize having more time in lieu of a symptom-free death for their children (Hales et al., 2011; Hendrickson & McCorkle, 2008). Thus a "good death" should be the standard of care, but it is a difficult concept to operationalize and remains an unrealized goal for many children (Hales et al., 2011).

THE ROLE OF PALLIATIVE CARE

Because the death of a child is out of the natural order of events, it is often preceded by prolonged efforts to save the child. Family members and health care providers may avoid discussions about palliative care due to personal discomfort, difficulties acknowledging the death, time constraints, language barriers, and efforts to protect the child from distress (Davies et al., 2008). Other challenges to providing high-quality palliative care include ethical/legal concerns and financial barriers, as well as the availability and dosing of FDA-approved palliative medications for children. Furthermore, community-based palliative care or hospice organizations care largely for adults, who have vastly different illnesses and trajectories from those seen in childhood. All of these factors can hinder the transition of care to the home or hospice for seriously ill children.

A growing body of research indicates that timely and appropriate referrals to palliative care can lead to better outcomes for children and families. For example, one study found improvements in parents' perceptions of the children's symptoms and quality of life, communication, and access to care after referral (Vollenbroich et al., 2012). Health care providers also reported better family support, communication, and cooperation. Other work has shown that children who receive palliative care spend fewer days in the hospital, receive fewer invasive interventions, and are less likely to die in the ICU (Keeley, Keenan, Sheetz, & Bratton, 2013).

COMMUNICATION AND DECISION MAKING

Ongoing communication between families and medical staff is a key component of care at the end of life. However, parents may have overly optimistic beliefs about their children's prognosis and may not feel fully informed of their children's future (Kaye & Mack, 2013; Meyer, Burns, Griffith, & Truog, 2002; Miller et al., 2012; Wolfe, Klar, et al., 2000). Physicians' anxiety and reluctance to prognosticate, convey bad news, and diminish hope can play a role (Meyer et al., 2002). Parents have reported dissatisfaction with their children's care and medical communication at the end of life (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Meyer et al., 2002). In one study, over half

of parents felt they had little or no control in their children's final days, and nearly 25% reported in retrospect that they would have made different decisions (Meyer et al., 2002). Interestingly, physicians' discussions of prognosis may not necessarily diminish hope in parents, even when the chance of cure is low (Mack et al., 2007). Furthermore, parents' hope for cure is not related to long-term grief or symptoms of depression (van der Geest et al., 2015).

It is widely accepted that school-age children should be informed of their illness and treatment, but health care providers and parents still struggle with how to talk to children and include them in decision making. Parents tend to provide more information to older children, but this information is typically focused on treatment and procedural details rather than disease severity (Eiser & Havermans, 1992). In one study, about one-third of bereaved parents talked about death with their children who had cancer, but of parents who did not talk with their children, 27% regretted it (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004).

Children want to be included in communication and decision making (Coyne & Gallagher, 2011). Young children may have difficulty making treatment decisions, but a quarter of children and two-thirds of adolescents want to be involved (Ellis & Leventhal, 1993). Children fear being alone at the end of life, and some may feel isolated if they are aware of their impending death and are unable to talk about it (Hilden, Watterson, & Chrastek, 2000; Theunissen et al., 2007). Nearly all school-age children with cancer want to be told if they are dying (Ellis & Leventhal, 1993), but they also have difficulty talking to parents about death (Theunissen et al., 2007).

Psychologists play a key role in communication with the medical team and family. This can include assessing a family's values and beliefs about death, helping the parents talk about death with the ill child and siblings, giving the child time to ask questions and express him- or herself in developmentally appropriate ways (e.g., journals, artwork), allowing the family members to share feelings for one another, and preparing them to say goodbye. Consensus building and assessing family preferences for end-of-life care, such as life-sustaining treatment, mechanical support, code status, and place of death, is important. Some children may want to leave gifts or belongings to loved ones, participate in funeral planning, or make other requests (Foster et al., 2009).

Advance care planning should consider the cultural, spiritual, and moral values of the child and family (Kirkwood, 2005), as well as ethical and legal guidelines. Recently, unique tools (e.g., Five Wishes, Voicing My Choices™) and family-centered interventions have shown promise in aiding these difficult discussions with adolescents (Lyon, Jacobs, Briggs, Cheng, & Wang, 2013; Wiener et al., 2012; Zahed, Pao, & Wiener, 2015). For patients over age 18, it is important to discuss a living will and durable power of attorney. Advance care plans should be documented in writing and may require periodic revision, depending on changes in the child's status and reevaluation of the family's needs and preferences. While difficult, these discussions have potential to promote healing, provide closure, and minimize uncertainty or regrets after the death.

IMPACT ON PARENTS

Little research has focused on the well-being of parents near the end of a child's life. Caring for a seriously ill child can have negative effects on parental quality of life,

mood, sleep, and fatigue (Klassen et al., 2008; Theunissen et al., 2007). Fear of the child's death and physical symptoms are frequent concerns for parents (Theunissen et al., 2007). About half of parents of children with advanced cancer were found to have high rates of distress (Rosenberg et al., 2013). These outcomes may be worse for parents of children with poorer health status, more intense treatment, less time since diagnosis, and more financial hardship (Klassen et al., 2008; Rosenberg et al., 2013). In fact, parents of children who had a "difficult death" or unrelieved pain, anxiety, trouble breathing, or sleep disruption reported more internalizing symptoms, more severe grief, and worse quality of life up to 9 years later (Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2010; Kreicbergs et al., 2005; van der Geest et al., 2014).

Compared to other types of loss, parental grief is more severe, and parents (particularly mothers) may be at greater risk for complicated or prolonged grief reactions (Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008; Lichtenthal et al., 2015). A child's death is perceived as a series of hopes and dreams that are lost, and grief can intensify at significant times (e.g., holidays, graduation days)—a concept known as "regrief." A systematic review of parents bereaved by cancer indicates risk for depression, anxiety, prolonged grief, and poor quality of life (Rosenberg, Baker, Syrjala, & Wolfe, 2012). Bereaved families also undergo significant changes, with less family cohesion and increased parental and marital strain (Martinson, McClowry, Davies, & Kuhlenkamp, 1994; West, Sandler, Pillow, Baca, & Gersten, 1991). Bereaved parents have reported less marital satisfaction and sexual intimacy, more frequent thoughts of separation, and higher divorce rates than nonbereaved parents (Gottlieb, Lang, & Amsel, 1996; Lang & Gottlieb, 1993). However, some parents also recognize personal growth and positive outcomes, such as greater compassion and closer relationships after a child's death (Gilmer et al., 2012).

IMPACT ON SIBLINGS

Siblings of a child with a chronic illness may be at risk for multiple difficulties, such as internalizing problems, both before the death and afterward (Vermaes, van Susante, & van Bakel, 2012). They may experience diminished contact with the ill child and parents, as well as additional demands to assume caregiving and other adult roles in the home (Gaab, Owens, & MacLeod, 2014; von Essen & Enskar, 2003). They may struggle to maintain a normal routine and view the illness as a loss of their family's way of life (Labay & Walco, 2004; Williams, Williams, & Williams, 2014). Exposure to parental distress and family disruption can also significantly increase risk for psychosocial difficulties in siblings (Drotar, 1997; Long et al., 2014).

Research is limited, but bereaved siblings may have lower social competence and more internalizing and externalizing problems relative to assessment norms or to controls (McCown & Davies, 1995; Rosenberg et al., 2015). Self-concept can decline after the death (Eilegard, Steineck, Nyberg, & Kreicbergs, 2013), and bereaved siblings who are younger or male can also exhibit difficulties in peer relationships relative to classmates (Gerhardt et al., 2012). Adjustment improves with time, but grief symptoms can resurface as siblings reflect back on the loss as they mature (Sveen, Eilegard, Steineck, & Kreicbergs, 2014). Positive outcomes and growth, such as having a better outlook on life and being kinder, have also been reported (Foster et al., 2012).

GRIEF INTERVENTIONS

Research suggests that bereaved individuals underutilize services, and that support groups may be viewed as stigmatizing or unhelpful (Cherlin et al., 2007; Lichtenthal et al., 2015). Currently, there is a relative lack of empirically based interventions for families of children near the end of life or for the staff members who work with them. Several meta-analyses of grief interventions have reached different conclusions regarding efficacy (Currier, Holland, & Neimeyer, 2007; Jordan & Neimeyer, 2003; Larson & Hoyt, 2007; Rosner, Kruse, & Hagl, 2010). The largest effects are found in studies of cognitive-behavioral approaches and in studies that screen for parents and siblings with elevated levels of distress. Challenges remain regarding whom to target, as well as the content, structure, and timing of interventions. Only 30–40% of bereaved parents seek formal services (Lichtenthal et al., 2015). Many families are reluctant to return to the hospital after a child's death, but bereavement services may be limited in the community. Some families find support groups, books, web-based resources, or formal therapy helpful, while others prefer to work through their grief alone. For staff members, stress management, maintenance of professional boundaries, peer support, and debriefings may be useful. However, grief is an intensely personal experience, and what benefits one person may not benefit another. Thus recommendations based on current meta-analyses suggest that services focus on those bereaved individuals with the highest symptoms.

SUMMARY AND FUTURE DIRECTIONS

Pediatric psychologists can make significant contributions to the care of families of children with life-limiting conditions. Children experience significant symptom burden at the end of life, and family members are at elevated risk for difficulties, particularly during the first 2 years after a child's death. Although attention to pediatric palliative care has increased steadily over the past decade, we have more to learn. There is a growing consensus with respect to best clinical practices, but advances in staff education, training, and policy are still needed. The development of standardized measures and controlled, prospective research are important to identify factors related to risk and resilience among family members. Children cannot always provide self-reports near the end of life, but their perspectives should be included whenever possible. Lastly, funding of clinical care and research presents ongoing challenges. Thus, with continued efforts, pediatric psychologists can play an important role in improving care and reducing morbidity in children and families affected by life-limiting conditions.

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CHAPTER 16

eHealth Applications in Pediatric Psychology

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Most pediatric psychologists are likely to have some familiarity with eHealth technologies. However, "eHealth" is defined in a variety of ways in the existing literature, leading to difficulty in gaining conceptual or definitional clarity regarding eHealth, mHealth, telehealth, or telemedicine. (Consistent with terminology adopted by the Centers for Medicare and Medicaid Services, hereafter "telehealth" is used in lieu of "telemedicine.") At the broadest level, Palermo and Wilson (2009) provide an apt definition that encompasses eHealth, mHealth, and telehealth: "the application of interactive and communication technologies to improve or enable health and health care in children, adolescents, and families" (p. 227). This definition highlights that digital technology can be used for two-way communication or for information delivery, and that it can be thought of as either beginning a new clinical progression or accelerating one already underway. Also inherent in this definition is that digital technologies can be used for both assessment and intervention purposes. That is, a protocol that simply uses digital technology to collect data from a patient can be thought of as an application of eHealth/mHealth/telehealth, even if it lacks an intervention component.

The first dividing line that is generally agreed upon by thought leaders in these areas is between eHealth/mHealth on the one hand and telehealth on the other. eHealth and mHealth involve the use of digital technologies to perform a function that is not being performed by a researcher or clinician. That is, the technology is playing an active role in intervention or assessment. The role of technology can be data collection, intervention, or even the application of a sophisticated algorithm to leverage, personalize, and tailor an ongoing intervention to an individual. On the other hand, telehealth is the application of digital technology (e.g., telephone or videoconferencing) to connect two parties who then perform the same roles as if they were in a room together. In this way, the technology is merely serving to connect two or more people; it does not perform an

active assessment or intervention function itself. For instance, a provider and a patient who use a videoconferencing service to meet weekly for cognitive-behavioral therapy for chronic pain are engaged in a telehealth relationship. However, if the provider were to ask the patient to enter daily pain diary data on the computer to supplement the telehealth work, this data entry would be both telehealth and eHealth. If the patient were then to enter data on his or her smartphone, the relationship would have crossed into the final distinction between eHealth and mHealth.

For most purposes, it is useful to think of mHealth as a special case of eHealth. The technology still plays a primary role (acting independently without additional contact with a provider) or a secondary role (as an adjunct to a relationship with a provider). However, the technology is carried with, worn on, or housed inside the patient. Examples include a smartphone, a wearable device (e.g., an activity band or smartwatch), or implanted/ingested equipment (e.g., swallowed sensors that are capable of detecting medication levels). In the case of mHealth, the final distinction is between active and passive technologies. Active technologies require some input from the user (e.g., an ecological momentary assessment survey), whereas passive technologies gather data from, or even intervene independently of, the patient (e.g., a wearable device that vibrates and encourages a user to move after the user has been sitting too long).

UNIQUE OPPORTUNITIES TO INCREASE DOSE AND REACH

Common problems in pediatric psychology could be more effectively managed by using digital technologies to extend the dose and reach of typical clinical care. "Dose" refers to the amount of intervention that is provided to a given patient. For example, in a study of patients recruited from the regular flow in a pediatric gastroenterology clinic, 82% completed all of the required modules for an evidence-based pediatric encopresis treatment program delivered over the internet (Ritterband et al., 2008). Similar results are possible using telehealth methods, with one recent report of an intervention for inflammatory bowel disease achieving 100% attendance at treatment sessions (Hommel, Hente, Herzer, Ingerski, & Denson, 2013). This high rate of completion is one of the proposed advantages of digital interventions. Because these interventions remove the barriers that accompany attending a clinic (often located in a tertiary care center, in the case of pediatric psychology), patients are freer to receive evidence-based therapies in locations and at times that are convenient for them, and they may thus receive higher doses of treatment.

In addition to dose, digitally mediated intervention programs have the benefit of allowing a patient and a provider separated by distance to engage in a therapeutic relationship. Improved "reach" is therefore a potential benefit of both eHealth/mHealth and telehealth interventions. For example, a telehealth program designed to treat pediatric obesity was recently delivered to rural children and families, and yielded outcomes similar to those of a standard-of-care condition (Davis, Sampilo, Gallagher, Landrum, & Malone, 2013). Similarly, added precision in the diagnosis of pediatric obesity has been observed when telehealth consultations take place between a pediatric obesity expert and a rural health care provider (Shaikh, Cole, Marcin, & Nesbitt, 2008). Although perceived loss of personal connection or technical malfunctions are concerns in telehealth, the majority of parents and providers receiving consultation report high levels of

satisfaction with the service they receive, and technical issues do not appear to be major barriers for well-resourced programs (Davis et al., 2013; Van Allen, Davis, & Lassen, 2011).

DELIVERING EVIDENCE-BASED SERVICES THROUGH A DIGITAL MEDIUM

There is some tension in the digital health sphere between scientists who prioritize evidence-based digital products and technologists who appear to be adept at developing and disseminating attractive and engaging tools that may ultimately have limited correspondence to findings in the empirical literature. To date, the philosophy guiding much of the eHealth/mHealth development in the academic realm has been to "port" empirically supported treatments validated in a face-to-face context to a digital medium (Ritterband, Andersson, Christensen, Carlbring, & Cuijpers, 2006). Fortunately, this approach has been well received by patients and their parents (Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009; Ritterband et al., 2008), has clear practical guidelines for intervention development (Ritterband et al., 2003), and has yielded efficacious products (Cushing & Steele, 2010). Unfortunately, only a very few evidence-based eHealth programs are now available for providers and consumers to use, and well-validated programs sometimes lack the polish and features of commercial efforts, due to the lag time from grant funding to dissemination (Riley, Glasgow, Etheredge, & Abernethy, 2013).

On the other hand, while many consumer products are available in the digital health realm, there is often a mismatch between these products and expert recommendations or the empirical literature. For example, review studies comparing mHealth apps to expert recommendations for pediatric obesity (Schoffman, Turner-McGrievy, Jones, & Wilcox, 2013), evidence-informed practices from the U.S. Food and Drug Administration and the National Institutes of Health (Breton, Fuemmeler, & Abroms, 2011), and systematic reviews of the pediatric physical activity and dietary interventions literatures (Brannon & Cushing, 2015) have concluded that there is poor correspondence between apps developed for commercial purposes and a variety of criteria advanced by the academic community.

Taken together, the two paragraphs above highlight that the respective approaches to digital health taken by academics and technologists in isolation each leave a great deal to be desired. It is becoming an accepted part of the academic zeitgeist that reviewing well-established treatments, developing a manualized protocol, securing funding, performing qualitative interviews, pilot testing, and validating the protocol through a randomized controlled trial will produce an outcome that closely mirrors the face-to-face models and outcomes (e.g., Palermo et al., 2009; Ritterband et al., 2008). However, this approach has drawn some criticism for being slow to meet the needs of a rapidly changing marketplace (see Riley et al., 2013). Within the pediatric psychology literature, it has been proposed that some of the needs for rapid program development may be met in part by using systematic review and meta-analysis to identify and communicate opportunities to technology and business stakeholders (Brannon & Cushing, 2015). It is likely that both approaches will be useful to different populations. For example, in the case of a clearly identified clinical population where well-established face-to-face treatments are available (e.g., chronic pain), porting an evidence-based treatment to a

digital medium can improve the treatment's dose and reach over those of traditional approaches (e.g., Palermo et al., 2009). When the target population is more heterogeneous, and there is rapid momentum toward dissemination of non-evidence-based technologies in the interest of capturing market share, it may be more useful to conduct a literature review and attempt partnerships with industry to bring the best available (if not fully validated) evidence to the marketplace.

ASSESSMENT APPROACHES

Digital technologies have broad applicability to assessment in pediatric psychology. The merits of such approaches are easy to grasp; as one example, it is advantageous to have a record of pill-taking behavior each time a patient is prescribed to take a dose (electronic monitoring of medication adherence has been well reviewed; see Ingerski, Hente, Modi, & Hommel, 2011). In addition, many dependent variables of interest to pediatric psychologists (e.g., pain, functional impairment, quality of life, health behavior) are powerfully influenced by affective, physiological, and contextual variables that act on the dependent variables on the order of seconds, minutes, or hours. Without digital technologies, the field largely relies on assessments that span weeks or months and may miss a great deal of variability. Below, several types of digital assessment methodologies are reviewed.

Ecological Momentary Assessment

"Ecological momentary assessment" (EMA) refers to repeated assessments of a patient's behavior that are triggered by an event. In an eHealth context, communication can occur via text messaging, a smartphone app, or repeated web-based surveys. Triggering events can be set times of day or clinically relevant phenomena such as pain experiences (i.e., time-based vs. event-based assessment). EMA has been used to shed light on the relationship between affect and physical feeling states and physical activity in children (Dunton, Atienza, Castro, & King, 2009); to examine the links among sleep, caffeine consumption, and affect (Whalen et al., 2008); to study peer relationships in diabetes (Helgeson, Lopez, & Kamarck, 2009); and to evaluate asthma symptoms in adolescents (Mulvaney et al., 2013). EMA methods have also been used extensively to study health behavior. Studies have used EMA to examine diet and physical activity following bariatric surgery (Ratcliff, Zeller, Inge, Hrovat, & Modi, 2014), sedentary behavior (Gorely, Marshall, Biddle, & Cameron, 2007), and smoking triggers (Piasecki, Trela, Hedeker, & Mermelstein, 2014). As the field continues to progress, the next step will be to use EMA data to inform intervention in as close to real time as possible.

Accelerometers

Wearable accelerometers provide a reliable and valid method of measuring both sleep and physical activity in children and adolescents. Through validation against oxygen consumption and polysomnography, research-grade accelerometers have established themselves as acceptable proxies for energy expenditure and sleep by having high criterion validity (Meltzer, Montgomery-Downs, Insana, & Walsh, 2012; Trost, Loprinzi,

Moore, & Pfeiffer, 2011). Whereas many research-grade accelerometers are available, direct-to-consumer products have little to no published validation testing, and the studies that appear in the literature suggest that device makers may overstate their accuracy (Montgomery-Downs, Insana, & Bond, 2012).

Physiological Monitoring Systems

Ambulatory monitoring systems have the potential to measure physiological variables in children and adolescents outside lab settings. By making physiological assessment ambulatory, these systems may make it possible to understand moment-to-moment relationships between physiology and subjective, behavioral, and social states. In one example, a group of children with autism spectrum disorder (ASD) were compared against a group with ASD and a comorbid anxiety diagnosis. Using real-time physiological monitoring, the investigators were able to determine that the group with comorbid anxiety demonstrated a blunted heart rate response to a psychosocial stressor, and that lower heart rate was associated with higher anxiety symptoms (Hollocks, Howlin, Papadopoulos, Khondoker, & Simonoff, 2014). While this study took place in the context of a laboratory, it is possible to deploy the equipment used in a free-living environment, potentially adding an exciting physiological dimension to data gathered in pediatric psychology research.

TREATMENT APPROACHES

The field of pediatric psychology has developed some consensus through the initial work of Palermo and Wilson (2009), and a later modification by Cushing and Steele (2010), that eHealth interventions can be defined as "applications of technology that seek to either improve a client's [patient's] understanding of health information or use technology as a surrogate for the clinician in treatment delivery" (Cushing & Steele, 2010, p. 937). In general, it appears that eHealth interventions are effective strategies for managing a range of problems encountered in pediatric psychology, provided that the interventions use behavioral strategies for modifying health behavior (Cushing & Steele, 2010). In the discussion below, intervention programs using the internet, text messaging, virtual reality, and emerging mHealth approaches are highlighted.

The Internet

The internet is a powerful tool for delivering intervention content. Websites themselves can be static or dynamic and interactive. Importantly, there appears to be some consensus that internet interventions go beyond static websites and are tailored to individuals; moreover, the majority are self-guided and based on interventions that have demonstrated efficacy in a face-to-face context (Ritterband et al., 2006). Examples of presenting problems in pediatric psychology for which effective internet interventions have been developed include encopresis (Ritterband et al., 2008), chronic pain (Palermo et al., 2009), obesity (Williamson et al., 2005), smoking (Buller et al., 2008), haemophilia (Breakey et al., 2014), functional gastrointestinal disorders (Bonnert et al., 2014), and insomnia (de Bruin, Oort, Bögels, & Meijer, 2014).

Text Messaging

While other applications of mHealth interventions (i.e., apps designed for smartphones) have promise, the most common mHealth intervention to date is simple communication via text messaging. In fact, the average adolescent uses text messaging and is comfortable with a high volume of texts (e.g., 30 per day at the median; Lenhart, 2015). Within the field of pediatric psychology, text-messaging interventions have resulted in a greater number of blood glucose logs relative to email reminders in patients with Type 1 diabetes (Hanauer, Wentzell, Laffel, & Laffel, 2009), and greater retention relative to paper records in a self-monitoring intervention designed to track health behaviors (i.e., physical activity, screen time, and consumption of sugar-sweetened beverages; Shapiro et al., 2008).

Also of importance, text messaging appears to be an important strategy for increasing intervention dose when the primary mechanism of delivery is another eHealth technology. One study reported that six messages delivered over a 9-month period increased children's use of a smoking prevention website by approximately 4.5 times (Cremers et al., 2014). Indeed, in areas where intervention dose is critical (such as pediatric obesity), parents report a desire to receive two to three weekly text messages that offer advice, provide support on how to manage weight without risking body image problems, and coalesce around a weekly theme (Sharifi et al., 2013).

An emerging line of work is beginning to shed light on the kind of text messages that pediatric patients prefer. In one study, investigators found that adolescents in an obesity program preferred casual messages (i.e., ones using emoticons and abbreviations) that triggered thoughts about their long-term goals and included practical tips for achieving success (Smith, Kerr, Fenner, & Straker, 2014). In the same study, adolescents reported that normative feedback was not a motivator, and that reminders of not completing health behaviors could be shame-inducing rather than motivating.

Virtual Reality

Virtual reality is an immersive digital media technology that can simulate a sensory experience in an imagined world. Virtual reality has been used as a training method for injury prevention, such as fire safety (Padgett, Strickland, & Coles, 2006) and traffic safety (Schwebel, Gaines, & Severson, 2008). In addition, virtual reality is commonly used to manage pediatric pain during wound care following burn injuries (Hoffman et al., 2014) and to manage procedure-related pain (Gershon, Zimand, Pickering, Rothbaum, & Hodges, 2004). Recently, the modality has been extended as a longer-term therapeutic intervention for chronic headache (Shiri et al., 2013). However, this study was a single-arm trial that also included biofeedback, making the independent effect of the virtual reality component difficult to discern.

Emerging mHealth Approaches

One notable example of the potential in mHealth is an app developed to manage Type 1 diabetes (Cafazzo, Casselman, Hamming, Katzman, & Palmert, 2012). Before validating the intervention, the team spent time conducting ethnographic interviews to facilitate a user-centered design process. As a result, the intervention involved wireless

communication with a glucometer, gamification of the intervention content, and social media integration. For example, if blood glucose was uncontrolled for 3 days in a given context (e.g., before breakfast), the app would detect the trend and prompt the user to make a judgment about what had been causing the trend and how to bring about a change. This intervention highlights what is possible with mHealth, in that it included a smartphone, sensor, EMA, and user-centered design.

ETHICAL AND PROFESSIONAL ISSUES

The digital nature of communication in the eHealth/mHealth and telehealth areas presents a number of new ethical and regulatory challenges for pediatric psychologists. Competency in telepsychology should be the guiding principle that guides the ethical pediatric psychologist. "Telepsychology" is the term that the American Psychological Association (APA) has chosen to cover all digital applications of psychology (APA, 2013). The APA has been expansive in its definition of telepsychology: "Telecommunication technologies include but are not limited to telephone, mobile devices, interactive videoconferencing, email, chat, text, and Internet (e.g., self-help websites, blogs, and social media)" (p. 792). The information transmitted by these means can include images, audio content, and many other types of data. Therefore, even psychologists who do so little as engage in phone calls with their patients should be familiar with the telepsychology guidelines. Because a full discussion of the ethical issues inherent in eHealth is beyond the scope of this chapter, the interested reader is referred to a recent *Journal of Pediatric Psychology* commentary for a helpful section on ethical issues (Wu, Steele, Connelly, Palermo, & Ritterband, 2014).

CLINICAL USE

eHealth technologies have many uses in clinical care (Aylward, Cushing, & Nelson, 2014). One example is how an ever-present smartphone can be used to facilitate goal attainment in an intervention context. We (Cushing, Jensen, & Steele, 2011) used a commercially available smartphone app to help improve self-monitoring compliance in the context of a pediatric weight management intervention. Self-monitoring is a critical driver of outcome in pediatric weight management (Cushing, Borner, & Steele, 2014), and having patients move from a paper-and-pencil system to a mHealth medium appeared to have a causal impact on self-monitoring compliance. Clinicians interested in learning more about intervention development are encouraged to review Cushing, Walters, and Hoffman (2014) for a clinically valid method of intervention development.

CONCLUSION

eHealth applications in pediatric psychology hold a great deal of potential for providing and perhaps even increasing the effectiveness of established interventions. Moreover, before the invention and development of some emerging technologies, there were fundamental questions about how children and adolescents interact with their families, are

affected by their care teams, experience their illnesses, and make choices about their health behavior that it was impossible to answer. With careful theory development and testing, eHealth holds the potential for dramatically accelerating care and discovery in pediatric psychology.

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CHAPTER 17

Genetics and Genetic Testing

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The field of medical genetics has grown tremendously over the past decade, particularly since the completion of sequencing the human genome in 2003 (Feero, Guttmacher, & Collins, 2010). Genes are building blocks within our life code and provide the instructions needed for the creation of proteins within the body. Health conditions or diseases that have at least some heritability can involve changes (mutations) in a single gene or, more typically, involve multiple genes. Of special relevance to clinical practice and research in pediatric psychology are the identification of genes involved in common chronic pediatric health conditions, and the use of genetic tests to determine disease risks and diagnoses (Tarini, Tercyak, & Wilfond, 2011). When paired with patient education and counseling, genetic test results offer personalized risk information, which can be linked with interventions to prevent, delay, or treat disease. A vast amount of research on the uptake and outcomes of genetic counseling and testing for disease risk has included adults. With the exception of newborn screening, the majority of pediatric genetic testing in the United States has been used within the diagnostic context, rather than for predictive or preventive purposes (see Table 17.1). Pediatric genetic testing has its roots in prenatal screening for conditions such as Down syndrome. Prenatal testing and counseling provides information to adults so that they can make decisions related to their fetuses' health (Rappaport, 2008; Rimoin & Hirschhorn, 2004). The goal of this chapter is to review current concepts and key findings relevant to the application of genetic testing to children's health in the postnatal period.

GENES AND ENVIRONMENT AS CONTRIBUTORS TO CHILDREN'S HEALTH

Most contemporary frameworks in epidemiology that seek to understand children's health and illness adopt a biopsychosocial perspective. Doing so acknowledges that both genes and the environment, including social and behavioral factors and hazard-

TABLE 17.1. Types of Genetic Testing Relevant to Pediatric Populations

Type of test	Description
Molecular diagnostic	Used when illness symptoms are already present. Results indicate whether a child has a positive diagnosis for the illness, such as fragile X syndrome or Duchenne muscular dystrophy.
Carrier	Used most often when there are no illness symptoms but a child is at heightened risk (e.g., due to family history). Results indicate whether the child carries a particular genetic code for the illness, such as sickle cell disease.
Predictive	Used to determine whether a child is at risk for developing an illness (during childhood or later in life). Currently, not utilized for children unless preventive measures that mitigate risk exist, or in certain clinical situations such as Huntington disease.
Newborn screening	Used to determine whether a newborn infant should receive additional testing for an illness or may benefit from illness preventive measures. Newborn screening programs are often population-based and implemented statewide, such as newborn screening for phenylketonuria.
Metabolic biomarkers	Used to detect or measure molecules or patterns that are related to a disease state or biological process, such as islet autoantibodies for Type 1 diabetes risk.

ous exposures, contribute to children's and adult's health outcomes—individually and in combination with each other (Baye, Abebe, & Wilke, 2011; Oberlander, 2012). The environmental factors influencing children's short- and long-term health outcomes begin to act even prior to birth, within the prenatal environment; this action is also referred to as "fetal programming" and is described in the "developmental origins of health and disease" hypothesis (Hanson & Gluckman, 2011). For example, researchers have examined the impact of smoking and drinking during pregnancy, and of prenatal exposure to medications, on children's health (Swanson, Entringer, Buss, & Wadhwa, 2009; Viteri et al., 2015). One of the largest studies convened that used the biopsychosocial framework was the National Children's Study (NCS) (Guttmacher, Hirschfeld, & Collins, 2013). The NCS planned to follow a large cohort of children from birth onward to identify the variety of biological, environmental, and psychosocial factors affecting children's health and other outcomes. Although the NCS was recently discontinued, many investigators are continuing to examine the impact of genetic, environmental, and behavioral factors on children's health outcomes (Katzmarzyk et al., 2014; Nugent, Goldberg, & Uddin, 2016).

While a thorough review of gene–environment interaction is outside the scope of this chapter, another concept relevant to this interaction framework is "epigenetics." Epigenetics involves the study of how social and environmental factors influence gene expression independent of gene sequence (Zhang & Meaney, 2010). Though prior work relied on animal models, more recent work has begun to examine these issues in humans for mental health outcomes, substance use, and obesity (Lester, Marsit, Conradt, Bromer, & Padbury, 2012; Manco & Dallapiccola, 2012), with attention to the importance of the early childhood caregiving environment (Letourneau, Giesbrecht, Bernier, & Joschko, 2014).

Epigenetics is a rapidly growing area of research, including in pediatrics. As the field of epigenetics matures, pediatric psychologists can be involved in efforts to trans-

late epigenetic findings into practice. These efforts will have legal implications (e.g., regulation of toxins acting through epigenetic mechanisms to affect child health) and ethical implications (e.g., privacy, confidentiality) (Rothstein, Cai, & Marchant, 2009). One example of a current effort to apply understanding of the genetic contributors to health into practice is universal newborn screening. There has been increased interest in applying new technology (i.e., next-generation sequencing) to universal newborn screening so that babies' entire genomes can be sequenced. One of the benefits of using this method in newborn screening is that family members could, very early in a child's life, receive additional information on health problems for which the child is at risk, and could thus engage in relevant risk-reducing and screening behaviors. However, there are a number of pertinent ethical issues, including the question of which parties should have access to the genomic results and the potential for genomic results to lead to difficulties in gaining access to health care, obtaining insurance, or obtaining employment (Roberts, Dolinoy, & Tarini, 2014).

GENETIC TESTING IN DISEASE PREVENTION AND CONTROL

Genetic testing thus has the potential to be a powerful complement to disease prevention efforts; however, it is not without ethical controversy (see "Ethical and Social Considerations," below). For some genetically based health conditions, there are known health behaviors that reduce the likelihood of disease onset/severity or allow for earlier disease detection (e.g., familial melanoma) (Green, Williams, Logan, & Strutton, 2011; Yagerman & Marghoob, 2013). Communication about a child's genetic risk for a health condition could be integrated with behavioral interventions aimed at promoting adherence to preventive health behaviors, thereby improving health outcomes. This approach to integrating risk communication with behavioral intervention is consistent with the movement toward personalized approaches to health care and prevention, to improve diagnostic accuracy and tailor preventive recommendations and treatments so that they are most effective for individuals with specific risk factors (Schleidgen, Klingler, Bertram, Rogowski, & Marckmann, 2013). There is a need for empirical behavioral research on the most effective ways of communicating genetic risk to children and their families, and of doing so within the context of health promotion interventions (Hay et al., 2007; Tercyak & Tyc, 2006).

GENETIC TESTING AND DELIVERY OF RISK INFORMATION

The process of genetic testing typically involves multiple steps: (1) pretest education counseling with the patient and/or parent, provided by a genetic counselor, medical geneticist, or physician; (2) provision of a DNA sample (commonly from saliva or blood); (3) waiting for test results (ranging from days to months, depending on the type of testing); (4) posttest genetic counseling, in which test results are interpreted and discussed with the patient and/or family; (5) engagement in necessary medical follow-up; (6) family communication to potentially at-risk relatives; and (7) potential testing of those family members. A growing literature documents the impact of pediatric genetic testing on both parents and children, as well as the impact of adult's testing on their untested

children. A number of outcomes associated with pediatric genetic testing have been examined, including the psychological consequences of receiving genetic test results, changes to perceptions of disease risk, health behavior changes, and family communication about disease risk, prevention, and control (see next sections).

OUTCOMES OF GENETIC TESTING

Psychological Outcomes

Children's and parents' experiences and outcomes surrounding genetic testing are heterogeneous. Some studies indicate that genetic testing can be associated with increased psychosocial adversity, while others do not (Wade, Wilfond, & McBride, 2010). Genetic testing in children could harm children's psychosocial well-being by changing their self-perceptions, decreasing sense of control, and altering interactions with family members (e.g., about health behaviors) (Ross et al., 2013). On the other hand, genetic testing could provide relief from uncertainty and could lead to increased social support and empowerment (Duncan et al., 2008). A recent systematic review of empirical studies on the impact of pediatric genetic testing on children concluded that on average, children (ages 8–18 years) do not experience significant psychological distress or negative social consequences following testing (Wade et al., 2010).

One example of heterogeneous outcomes is provided by research on testing for familial adenomatous polyposis (FAP; an inherited form of colorectal cancer that can occur early in life). Codori, Petersen, Boyd, Brandt, and Giardiello (1996) found that although some children had increased distress after FAP testing, children overall did not exhibit clinically significant levels of psychological distress (i.e., depression and anxiety symptoms, behavior problems). At longer-term follow-up, some children reported clinical levels of anxiety (Codori et al., 2003). Another study of children who received FAP testing revealed a trend, such that children receiving positive results had higher anxiety and depression symptoms than children receiving negative test results (Michie, Bobrow, & Marteau, 2001).

In newborn screening, psychological outcomes research has focused on parents. A number of large-scale studies are focusing on newborn screening and examining gene–environment contributors to the onset of Type 1 diabetes (Aas, Tambs, Kise, Magnus, & Ronningen, 2010; Barker et al., 2004; TEDDY Study Group, 2007). Studies have begun to examine the impact on parents of Type 1 diabetes newborn screening (Johnson, 2011; Kerruish, 2011). Some findings indicate that mothers experience clinically significant levels of distress after testing (Aas et al., 2010; Kerruish et al., 2007). Mothers with babies at high risk reported worrying and thinking about test results more than comparison mothers (Kerruish et al., 2007), and anxiety symptoms increased in mothers who received positive test results (Hummel, Ziegler, & Roth, 2004).

Pediatric psychologists can play a major role in leading future studies on psychological outcomes after pediatric genetic testing, using larger samples and rigorous study designs (Wade et al., 2010). Future studies could examine the extent to which children's psychological outcomes are affected by testing versus the medical follow-up required for children who receive positive results (e.g., regular colonoscopies for children with positive FAP test results), so that interventions can be appropriately targeted (Douma, Aaronson, Vasen, & Bleiker, 2008).

Risk Perceptions

A key goal of genetic counseling is to communicate effectively with patients and their families about risks for a given health condition or conditions. "Risk" is a difficult concept to convey, and accurate assessment of risk perception is challenging (McBride, Koehly, Sanderson, & Kaphingst, 2010; Weinstein, 1999). In the pediatric literature, studies have examined the extent to which parents recall risk information after receiving genetic test results and counseling about their children's health. This work has been done most extensively in newborn screening for risk for Type 1 diabetes. In The Environmental Determinants of Diabetes in the Young (TEDDY), an international Type 1 diabetes newborn screening study, 39% of mothers underestimated their children's risk for Type 1 diabetes in their first year of study participation (Johnson et al., 2011). Over time, individuals became less accurate in recalling their children's risk, and maternal anxiety and depressive symptoms were linked with accuracy of risk recall (Hood, Johnson, Baughcum, She, & Schatz, 2006). As pediatric genetic testing becomes more common, pediatric psychologists will have the unique expertise needed to implement high-quality studies of risk perceptions, the role of numeracy (ability to understand numerical information) in risk perceptions, and genetic health literacy.

Behavior Change

One of the more potent and clinically appealing extensions of genetic testing is to understand whether (and, if so, how) risk feedback promotes health behavior change and preventive health maintenance. For children who received genetic testing for Type 1 diabetes at birth, 43–67% of mothers reported implementing diabetes-preventive behaviors (Smith et al., 2014). These included changes to children's diet, monitoring of blood glucose, and frequency of contact with health care providers (Kerruish, 2011; Smith et al., 2014). A number of maternal characteristics were related to behavior changes, including more accurate perceptions of their children's risk for developing diabetes, maternal anxiety, and high levels of information seeking (Smith et al., 2014). These findings were obtained despite the fact that many children identified as being at increased risk for a health condition may not go on to develop symptoms of the disease until later in life, if at all. If taken to an extreme, efforts to stave off disease onset could become a preoccupation and source of maladaptive coping (Baum, Friedman, & Zakowski, 1997). Psychological monitoring as part of a clinical research trial is important, including the need to anticipate and communicate with children about their own disease risk management, and to use developmentally appropriate content and strategies (Tercyak, Swartling, Mays, Johnson, & Ludvigsson, 2013). Pediatric psychologists can conduct descriptive studies of behavioral, psychological, and family communication after pediatric genetic testing, to lay the foundation for the design of informed interventions to improve outcomes after testing and to achieve better understanding of the mechanisms that underlie these outcomes.

Family Communication and Attitudes

Genetic testing is often provided to individuals, but naturally raises issues about an individual's family members, who share genetic material and thus are potentially at genetic

risk themselves. Research has considered how individuals disclose genetic test results to family members and the impact on the family system. Within pediatric psychology, studies have examined mothers' disclosure of their breast cancer genetic risk results (e.g., *BRCA1/2* mutation testing) to their children. More than half of mothers (63%) in one sample reported disclosing *BRCA1/2* genetic test results to children, particularly if the children were at least 13 years old (Tercyak, Mays, et al., 2013). Mothers were more likely to disclose if they received negative or otherwise uninformative test results and if they perceived there to be more benefits to disclosure (e.g., decreasing their children's worry) than risks (e.g., increasing their children's worry) (Tercyak, Mays, et al., 2013). The contents of disclosure discussions ranged from advice about a daughter's decision to seek testing, to the importance of healthy lifestyles and health care, to reassurance, to reaffirming the daughter's "right to know" (Patenaude, DeMarco, et al., 2013). Important areas for continued work include understanding parental decision-making processes in regard to disclosure; anticipating and supporting families with strategies for communicating risk under different circumstances (e.g., children's anxiety, family stress, "teachable moments"); clarifying children's understanding of risk and correcting misconceptions; and understanding children's decision-making processes for seeking testing for themselves in the future (Patenaude, DeMarco, et al., 2013).

A significant body of literature has examined parent's attitudes about genetic testing in children for treatable and untreatable childhood health conditions. One study examined this issue in a sample of Dutch adults who were currently parents or planned to become parents in the future (Plass, van El, Pieters, & Cornel, 2010). Approximately 75% of respondents were in favor of genetic testing, including testing for untreatable childhood health conditions such as Duchenne muscular dystrophy. Participants endorsed that knowledge of their child's genetic test result for untreatable disorders would prevent an overly long diagnostic period. In contrast, a study of parents in the United States using hypothetical disease scenarios revealed that one-third of the sample reported interest in genetic testing for their children, including for a disease that had no treatment (Tarini, Singer, Clark, & Davis, 2009). Future studies could examine the potential role that cultural factors have in affecting attitudes towards pediatric genetic testing.

Other studies have examined parents' attitudes about genetic testing for their children for health conditions where certain preventive behaviors would mitigate children's disease risk. Parents generally report that they are interested in genetic testing in these circumstances (Levine et al., 2010; Taber, Aspinwall, Kohlmann, Dow, & Leachman, 2010). Parents support genetic testing for children in these cases because the results will enable early detection of the health conditions and better medical management and health, relief from anxiety or uncertainty, and the children's improved awareness of risk for the conditions. Reasons why parents do not support genetic testing for children under these circumstances include concerns about employment or insurance discrimination related to the results, concerns about the children's ability to understand the test results or cope emotionally with the results, the costs of the testing itself, and parents' wanting children to be able to choose whether they undergo genetic testing (Levine et al., 2010; Taber et al., 2010).

In a series of studies by Tercyak and colleagues about parents' interest in multiplex genetic susceptibility testing for common pediatric health conditions, parents viewed the benefits of pediatric testing to outweigh its risks and were moderately interested

in pediatric testing (Tercyak et al., 2011). Moreover, parents who undergo such testing themselves tend to be more willing to test their children if the parents hold positive attitudes toward pediatric genetic testing and intend to change the children's health behaviors (Madeo, Tercyak, Tarini, & McBride, 2014).

Researchers have begun to explore how parents make decisions related to genetic testing for their children, when such tests are available. As one example, Alderfer et al. (2015) examined parents' decision-making approaches related to *TP53* testing for their children. Parents used approaches ranging from "automatic decisions" (in which parents perceived clear benefits to testing and had few second thoughts about whether to pursue testing) to "considered decisions" (which involved considering the pros and cons of testing) to "deliberated decisions" (which required the most thought and time devoted to analyzing pros and cons of testing). In addition, research has begun to examine young adults' preferences for predictive genetic testing, such as testing for hereditary breast/ovarian cancer. Patenaude, Tung, et al. (2013) collected behavioral data from young adult women (18–24 years) whose mothers had received *BRCA1/2* testing, including data on the potential impact on their own plans for having children if they were to receive positive test results. Given recent calls to expand breast cancer genetic testing to the wider population (King, Levy-Lahad, & Lahad, 2014), this will probably continue to be a growing area of research.

CONDITIONS TO BE EXAMINED IN FUTURE RESEARCH

Genetic testing among or affecting children will continue to expand as basic science discoveries in genetics and advances in genetic testing proliferate. Asthma, obesity, coronary heart disease, and substance abuse are all examples where there have been advances in identifying genetic contributions to illness (Belsky & Sears, 2014; Faith, Carnell, & Kral, 2013; Manco & Dallapiccola, 2012; McAdams et al., 2013; Wadsworth & Sandford, 2013). Additional opportunities for research and clinical collaboration will arise from conditions where pediatric genetic testing is increasingly common or desired by patients themselves. Newborn screening for cystic fibrosis has been integrated into standard medical care in many locations (Castellani et al., 2010; Ciske, Haavisto, Laxova, Rock, & Farrell, 2001). Moreover, new pediatric genetic testing opportunities may come from testing currently available to adults. Patients and families may also advocate for genetic testing for particular conditions.

ETHICAL AND SOCIAL CONSIDERATIONS

There has been considerable debate about the ethics of pediatric genetic testing in clinical practice and research, which ties into the larger debate on the potential implications of genetic testing for employment and health care, the accessibility of testing, and individuals' comprehension of test results (Lea, Kaphingst, Bowen, Lipkus, & Hadley, 2011; May, Zusevics, & Strong, 2013; Roberts et al., 2014). Professional organizations have provided guidelines on appropriate use of genetic testing in pediatric populations. For example, guidelines have been jointly issued by the American Academy of Pediatrics and the American College of Medical Genetics and Genomics (Ross et al., 2013). Of

relevance to the topics in this chapter, these guidelines recommend that (1) newborn screening should be available to all families, but that parents can decline testing for their babies; and (2) pediatric predictive genetic testing is permissible for adult-onset health conditions when there is a clear health or psychosocial benefit of early knowledge about risk.

Advances in molecular diagnostics (e.g., next-generation sequencing techniques) have led to new tests, including whole-exome sequencing (WES) (Bick & Dimmock, 2011). WES is the simultaneous analysis of a large number of genes, which could be involved in health conditions across the lifespan. Children who receive WES are typically symptomatic, and thus WES is pursued to facilitate diagnosis and treatment planning. WES is offered in some pediatric settings either clinically or through research protocols (Baylor College of Medicine, Medical Genetics Laboratories, 2014; Cincinnati Children's Hospital Medical Center, Division of Human Genetics Diagnostic Laboratories, n.d.; National Institutes of Health, National Human Genome Research Institute, 2014); however, ethical issues have been raised. WES can yield a large number of findings. Some of these findings are difficult to interpret, given that discoveries about genetic contributors to health are ongoing; in addition, incidental findings may concern adult-onset health conditions that have no known preventive behaviors or that are unrelated to the original clinical question (Abdul-Karim et al., 2013; Lantos, Artman, & Kingsmore, 2011). As a result, institutions have designed guidelines concerning which pediatric patients will be offered WES, and what results will be returned and how (Lantos et al., 2011). For example, one institution's policy states that incidental findings will not typically be provided to families if the findings are unrelated to the diagnosis or health condition that precipitated testing (Lantos et al., 2011).

FUTURE DIRECTIONS AND THE ROLE OF THE PEDIATRIC PSYCHOLOGIST

It is important for pediatric psychologists to identify their roles as both clinicians and researchers in this area. As clinicians, pediatric psychologists are aware of children's developmental capacities and families' needs for information and psychosocial referral services. Pediatric psychologists are well suited to partner with genetic counselors, medical geneticists, and other health care providers to deliver genetic risk information to children and families in developmentally appropriate and family-centered ways (Patenaude, Guttmacher, & Collins, 2002), and to help family members implement recommended preventive behaviors. Psychologists could provide anticipatory guidance to parents on issues that may arise after genetic test reporting, such as how and whether to communicate test results to other family members, how to respond to children's questions related to the test results, and how to minimize parental modeling of anxiety related to the children's genetic risk. Psychologists may also normalize parental concerns about the children's current and future health, and emphasize both the resilience of children in coping with medical adversity and the benefits of receiving genetic test results.

Pediatric psychologists should continue to lead and collaborate on research in pediatric genetic testing, including research that helps to translate clinical genetics into public health practices for disease prevention and control. Such translational research could include efforts to integrate genetic testing into developmentally appropriate interventions to improve adherence to risk-reducing behaviors, and to promote the accessibility

of genetic testing to traditionally underserved populations. Future studies would benefit from examining the uptake and outcomes of pediatric genetic testing for common disease risk (Tercyak et al., 2011). These studies could include high-quality prospective and longitudinal studies that incorporate mixed methods (Wade et al., 2010). In our field, we are well positioned to collaborate with multidisciplinary teams to track the psychological and behavioral outcomes associated with pediatric genetic testing, and to contribute to epigenetic research on the combination of biological, environmental, and behavioral factors contributing to children's health outcomes. Future generations of scientist-practitioners may benefit from receiving specialized doctoral or postdoctoral training in areas relevant to pediatric genetic testing (e.g., public health and/or genetics) (Patenaude, 2003, 2010).

Pediatric genetic testing has the potential to yield major impacts on children's long-term physical health and psychosocial outcomes. This is particularly true as new advances in genetic testing, including multiplex panel testing, whole-genome sequencing, and direct-to-consumer approaches to testing become increasingly popular (Hiraki, Rinella, Schnabel, Oratz, & Ostrer, 2014; Patenaude, 2011). Pediatric psychologists can play major roles in ensuring that children and their families receive optimal clinical services centered around genetic testing, and in conducting cutting-edge research that pushes this growing field forward. Pediatric psychologists have highly applicable expertise in socioecological factors influencing child psychosocial and health outcomes that could augment gene–environment and epigenetic studies; use of family systems approaches to understand how families communicate about genetic test results and manage recommended health behaviors; and methods of tracking changes in children's understanding of and coping with their genetic risk over their lifespan. In summary, pediatric psychologists are uniquely suited to understand the impact of pediatric genetic testing, and to facilitate the ethical and appropriate use of genetic testing to promote child psychosocial and physical health outcomes.

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PART III

MEDICAL, DEVELOPMENTAL, BEHAVIORAL, AND COGNITIVE-AFFECTIVE CONDITIONS

CHAPTER 18

Pediatric Asthma

Elizabeth L. McQuaid and David A. Fedele

Asthma is the most common chronic illness facing children in the United States. Currently, an estimated 7.0 million of U.S. children are diagnosed with asthma (Akinbami et al., 2012). Despite the availability of effective treatments, both the direct costs (e.g., medical expenditures) and the indirect costs (e.g., lost productivity) of asthma continue to increase and place substantial burdens on patients, families, and health care systems (Bahadori et al., 2009). Pediatric psychologists are uniquely positioned to help patients and their families manage asthma through educational and behavioral interventions, and are well suited to investigate the interplay between psychological factors and disease course.

DEFINITION AND SCOPE OF THE PROBLEM

Asthma is a chronic inflammatory disorder of the airways that involves intermittent, recurring, and variable periods of airway obstruction (National Asthma Education and Prevention Program [NAEPP], 2007). Asthma pathophysiology involves chronic inflammation, airway hyperresponsiveness, bronchoconstriction, airway swelling, and mucus production. Two core processes are chronic underlying inflammation, and active exacerbations involving bronchoconstriction. Asthma symptoms occur as a result of airway hyperresponsiveness to triggers, including airborne irritants (e.g., cigarette smoke), seasonal changes, and respiratory infections, as well as allergens that may elicit symptoms among individuals with sensitivity (e.g., animal dander). Triggers vary among individuals, and sensitivity can change over time, necessitating individualized treatment and ongoing communication with health care providers.

Asthma Prevalence and Morbidity

Approximately 9.5% of youth are diagnosed with asthma (Akinbami, Moorman, et al., 2012). Asthma is more prevalent among African Americans/blacks (11.2%) than

among non-Hispanic whites (7.7%). Among Hispanics, the overall prevalence is 6.5%; however, this figure masks important subgroup differences. Puerto Ricans are disproportionately affected (16.1%), relative to Hispanics of Mexican descent (5.4%; Moorman et al., 2007). Genetic factors appear to play an important role in asthma onset and outcomes. Estimates of asthma heritability are moderate to high (36–79%; March, Sleiman, & Hakonarson, 2013; Vercelli, 2008). Initial research also suggests modest to moderate heritability in disease features such as response to bronchodilators (29%) and overall airway responsiveness (51.1%; McGeachie et al., 2013).

Asthma prevalence increased rapidly over the last three decades of the 20th century, but then increased at a slower rate from 2001 to 2010 (Moorman et al., 2012). Greater exposure to indoor allergens, due to youth's spending more time inside, may play a role in increased prevalence (Platts-Mills, Blumenthal, Perzanowski, & Woodfolk, 2000). These effects are thought to be particularly pronounced among urban families with poor housing conditions (Akinbami, Moorman, Garbe, & Sondik, 2009). Others have proposed a "hygiene hypothesis," whereby frequent antibiotic use and decreased exposure to infections early in life may alter the immune responses and lead to an increased likelihood of asthma onset (Mattes & Karmaus, 1999). Indeed, the timing of exposure to allergens and infections appears to matter; very early exposures may be protective, whereas later, persistent exposures may increase allergic sensitization and contribute to the development of asthma and other atopic diseases (e.g., Lynch et al., 2014).

Asthma can be controlled by effective medication management and avoidance of triggers; however, exacerbations can still occur. Asthma exacerbations are more prevalent among children, females, and African Americans/blacks. Among Hispanics, Puerto Ricans have more frequent exacerbations relative to Hispanics of Mexican descent (Moorman et al., 2012). Asthma mortality is rare but highest among adults 65 and older (5.8 per 10,000), and lowest among children under 17 (0.3 per 10,000; Moorman et al., 2012). Asthma deaths have been linked to certain risk factors, including black race, frequent emergency department (ED) visits, medication nonadherence, and poor self-management skills (e.g., difficulties in perceiving symptom severity) (NAEPP, 2007).

Basic Medical Approach

The NAEPP (2007) guidelines outline a stepwise approach to managing asthma according to illness severity and level of asthma control. The report highlights four key care components: regular symptom monitoring, self-management education, control of environmental triggers, and a systematic approach to medication management (NAEPP, 2007). Depending on the severity and course of the condition, childhood asthma may be medically managed by a primary care pediatrician or may necessitate the involvement of a specialty provider.

Practice guidelines recommend responding in a timely manner to acute exacerbations, preventing disease progression by trigger avoidance, and using long-term control medications to reduce airway inflammation. A central feature involves a written asthma "action plan," which includes information about medications and dosing as well as instruction regarding health care utilization (e.g., a bronchodilator medication timeline when experiencing symptoms; Zemek, Bhogal, & Ducharme, 2008). Collaboration and clear communication between parent and physician also appears instrumental in asthma outcomes (Riekert et al., 2003).

The pharmacological management of asthma is comprised of two classes of medications: quick-relief/rescue and long-term control medications. Quick-relief medications (e.g., albuterol) are used to provide rapid relief of bronchoconstriction, which is found in all forms of asthma; such medications are intended for use on an as-needed basis. For patients with intermittent asthma, a quick-relief medication, such as a short-acting beta-2 agonist (e.g., albuterol) may be the only form of treatment. Systemic corticosteroids (e.g., prednisone) are also considered quick-relief medications, but are generally used to reverse exacerbations when other medications have been ineffective.

Patients with persistent forms of asthma generally require both quick-relief and long-term-control medications. Long-term control medications include inhaled corticosteroids (e.g., budesonide, fluticasone propionate), and alternative preventive medications such as cromolyn sodium and leukotriene modifiers. Combinations of medications (e.g., fluticasone propionate and salmeterol) offer a dual delivery of inhaled corticosteroid along with a bronchodilator in a single therapeutic dose. Omalizumab, an anti-immunoglobulin E (IgE) antibody that is delivered once or twice monthly subcutaneously, is another treatment for persistent allergic asthma (Hendeles, Khan, Shuster, Chesrown, & Abu-Hasan, 2015). Dosage counters now appear on some medications; these can be used to prompt refills and monitor medication usage (Conner & Buck, 2013).

Measurement of Asthma Status

The presentation of asthma can vary widely over the illness course (Calhoun, Sutton, Emmett, & Dorinsky, 2003). The NAEPP (2007) guidelines classify asthma severity as intermittent, mild persistent, moderate persistent, or severe persistent, based on clinical history, symptom profile, medication use, and spirometry. Indicators of disease status encompass a few broad categories, including measures of asthma control, lung function measures, biological markers, and health care utilization measures. In 2012, the National Heart, Lung, and Blood Institute issued a series of recommendations regarding standardized measures of asthma (see Busse, Morgan, Taggart, & Togias, 2012, for full overview and references). Measures of asthma control assess the frequency of daytime and nocturnal symptoms and the extent of reliance on quick-relief medications over a short time window. These are usually parent report and/or child report measures (see Cloutier et al., 2012, for examples of validated instruments). Lung function measures involve the use of spirometry to evaluate the volume and flow of air movement through the lungs. Forced expiratory volume in the first second (FEV_1), forced vital capacity (FVC), and FEV_1/FVC ratio are recognized as core outcome measures of lung capacity and flow (Tepper et al., 2012). Lung flow is known to be highly variable, however, and outcomes should be measured over time (Tepper et al., 2012). Currently the only biological marker identified as a "core measure" is multiallergen testing to determine allergic status (Szefler et al., 2012). Other measures, such as exhaled nitric oxide, a marker of airway inflammation (Smith, Cowan, Brassett, Herbison, & Taylor, 2005), and airway resistance by forced oscillation (Ritz et al., 2002), are considered as supplemental measures (Szefler et al., 2012) and are not typically used in clinical care. Health care utilization measures, such as claims data indicating use of emergency services, provide information regarding asthma acuity but may also reflect local health care system resources or family response patterns (Akinbami, Sullivan, et al., 2012).

PSYCHOLOGICAL ASPECTS

Emotions and Asthma Course

Some individuals with asthma (approximately 15–30%) identify stress and emotions as triggers for asthma episodes (Isenberg, Lehrer, & Hochron, 1992; Wright, Rodriguez, & Cohen, 1998). Early research documented that some children with asthma react with bronchoconstriction when subjected to stressful experiences (e.g., McQuaid et al., 2000; Miller & Wood, 1994). Stress and inflammation are seen as important underlying factors influencing asthma course (Chen et al., 2011; Wright, Cohen, & Cohen, 2005), and stress is often conceptualized as a mediator of asthma outcomes (Rand et al., 2012). Stress exposure is thought to play a role in the onset and exacerbation of asthma through alterations in neuroendocrine, immunological, and autonomic nervous systems, in the context of perinatal and genetic factors (Wright et al., 2005). An exciting line of research suggests that early life stresses can effect changes in gene expression (epigenetic changes), such as DNA methylation. One recent study found associations between DNA methylation and increased odds of asthma among Puerto Rican children (Chen et al., 2013). Models that investigate the reciprocal influences among physiological processes, psychological vulnerability, and life circumstances in explaining the relationships between emotions and asthma are useful for guiding future research and informing innovative intervention programs.

Behavioral Adjustment

Children with asthma demonstrate more internalizing behavior problems than the normative population (e.g., Klinnert, McQuaid, McCormick, Adinoff, & Bryant, 2000) or comparative samples of healthy controls (e.g., Bruzzese, Fisher, Lemp, & Warner, 2009). Youth with asthma are also more likely to experience externalizing behavior problems compared to their peers (McQuaid, Kopel, & Nassau, 2001). Both internalizing and externalizing behavioral difficulties in youth are more evident with increasing asthma severity (Goodwin et al., 2013; McQuaid et al., 2001). These relationships are likely to be bidirectional and reciprocal (Kaugars, Klinnert, & Bender, 2004). Psychological distress in youth is associated with poorly controlled asthma and nonadherence (e.g., Bender, 2006; Bender & Zhang, 2008). Clinically significant behavior problems are linked to increased asthma symptoms and reduced functional status in youth with asthma (Weil et al., 1999). Moreover, youth with asthma and a comorbid anxiety or depressive disorder are more likely to report increased asthma symptoms and burden than those without a psychiatric comorbidity (Richardson et al., 2006). Caregiver mental health is also linked to asthma management (Barlow & Ellard, 2006). Youth whose caregivers have clinically significant distress are more likely to be hospitalized (Weil et al., 1999), and maternal depressive symptoms are associated with youth asthma management difficulties (Bartlett et al., 2004), illustrating the importance of identifying comorbid psychiatric and behavioral issues.

Developmental and Family Implications

A chronic illness such as asthma has the potential to affect the achievement of age appropriate developmental tasks, such as individuation from parents, the establishment

of peer relationships, and the formation of a positive self-image. Effective pediatric asthma management requires a range of skills, including recognizing and monitoring symptoms, avoiding asthma triggers, communicating with health care providers, and taking medications as prescribed. Youth's participation in management varies by age, developmental maturity, and attitude toward the illness, and is influenced by family members and family dynamics (Fiese & Everhart, 2006; Kaugars et al., 2004). Optimally, caregivers can involve children in the disease management process in a developmentally appropriate fashion by providing direct guidance, then supervising task performance, and eventually allowing children to perform the skills independently (Brown, Avery, Mobley, Boccuti, & Golbach, 1996). Youth asthma management responsibility increases with age, as caregivers expect their children to be more independent in disease management (McQuaid, Kopel, Klein, & Fritz, 2003). Asthma management difficulties can emerge in early adolescence as youth begin taking more control of their treatment regimens. Early adolescents endorse inadequate levels of medication use, inconsistent symptom monitoring and response behaviors, and trigger avoidance (Bruzzese et al., 2012; Clark et al., 2010). Disease management difficulties continue into adolescence, including low adherence to daily medications (e.g., <50% of prescribed doses), difficulty monitoring and responding to symptoms, and challenges with avoiding asthma triggers (Drotar & Bonner, 2009).

Reasons for disease management difficulties in adolescents with asthma are likely to be multifaceted and to involve demographic, family-level, parental, and personal factors (Canino, McQuaid, & Rand, 2009). The treatment regimen for persistent asthma can be complex, making self-management arduous for adolescents (Drotar & Bonner, 2009). In addition, families often face challenges in distributing responsibilities for asthma management tasks between caregivers and youth. Specifications of developmental expectations for children's self-management of illness, and identification of children at particular risk because of psychological or developmental factors, are key roles for pediatric psychologists (Jandasek & Fedele, 2014).

ROLES OF PEDIATRIC PSYCHOLOGISTS

Pediatric psychologists can function as educational resources, help facilitate behavior change in asthma management, and provide valuable consultation to health care providers. Several roles for pediatric psychologists in facilitating asthma management are emphasized: (1) recommendations for providing patient, family, health care provider, and school-based education; and (2) recommendations for implementing psychosocial intervention techniques to address comorbidities and promote effective management.

Patient and Family Education

Several types of asthma knowledge deficits, including inaccurate beliefs about the type and use of medications, poor understanding of the course of asthma, and incorrect beliefs concerning asthma management, have been reported (Clark et al., 1998; Zimmerman, Bonner, Evans, & Mellins, 1999). Youth with asthma may also have difficulty identifying and responding to symptoms, using medications appropriately, and communicating with caregivers and their medical team members (Guevara, Wolf, Grum, &

Clark, 2003). Participation in educational programs emphasizing self-management for youth with asthma are linked to improved lung function, fewer missed school days, and lower rates of health care utilization (Ahmad & Grimes, 2011; Coffman, Cabana, & Yelin, 2009; Guevara et al., 2003). Programs incorporating a focus on behavior change, rather than providing information only, are more likely to be successful (Gibson et al., 2002; Graves, Roberts, Rapoff, & Boyer, 2010).

Health Care Provider Education

Physician training programs have been developed to improve health care providers' knowledge of asthma treatment guidelines and to enhance their skills in provider–patient interactions (Clark et al., 1998). One example, the Physician Asthma Care Education program, utilizes a structured, interactive curriculum for physician training. Results of a controlled trial indicated many positive outcomes, including increased likelihood of patients' receiving long-term control medication prescriptions (Clark et al., 1998). This program has also improved asthma outcomes in patients from low-income backgrounds (Brown, Bratton, Cabana, Kaciroti, & Clark, 2004). Offering health care providers cultural competence training may also improve outcomes. One study found that parents who attended practice sites with policies to promote cultural competence were less likely to underuse long-term control medications (Lieu et al., 2004). Pediatric psychologists may also partner with medical providers to incorporate health behavior change interventions in the clinical setting (Spaulding, Devine, Duncan, Wilson, & Hogan, 2012), and may train medical providers to deliver adherence promotion interventions during routine medical care visits for asthma (Rohan et al., 2013).

School-Based Education

School-based asthma education programs are successful in improving asthma management skills and reducing asthma-related morbidity (see Bruzzese, Evans, & Kattan, 2009, for a review). Historically, these programs have focused on teaching individual self-management skills in a group format. Results include improvements in asthma knowledge, higher self-efficacy about asthma management, and reduced morbidity (e.g., fewer missed school days due to asthma; Evans et al., 1987; Spencer, Atav, Johnston, & Harrigan, 2000). In recent years, school-based programs have expanded to include a combination of caregivers, school personnel, and/or peers (Bruzzese, Unikel, Gallagher, Evans, & Colland, 2008; Bruzzese, Unikel, Shrout, & Klein, 2011; DePue et al., 2007). School personnel, including nurses, teachers, and other staff members, should continue to be targeted to improve asthma knowledge and management (Bruzzese et al., 2008).

Psychosocial Interventions to Address Comorbidities and Promote Effective Management

Psychosocial interventions for asthma include problem-solving techniques, motivational interviewing, and adherence monitoring (Borrelli, Riekert, Weinstein, & Rathier, 2007). These interventions may be offered singly or in combination and should be tailored to a family's cultural background to facilitate effectiveness. Interventions may be delivered in an inpatient pediatric setting through consultation–liaison work; during

routine medical visits as part of a multidisciplinary asthma team (e.g., pulmonary physicians, psychologists, social workers); on an outpatient basis; and through technological avenues (e.g., text-messaging reminders).

Problem-solving skills interventions have been successful in improving quality of life, reducing health care utilization, and improving asthma symptoms (Pulgaron, Salamon, Patterson, & Barakat, 2010; Seid et al., 2012; Walders et al., 2006). Motivational interviewing interventions constitute a patient-centered approach that shows promise in increasing motivation for asthma management and medication adherence among youth (Borrelli et al., 2007; Riekert, Borrelli, Bilderback, & Rand, 2011). Suboptimal levels of adherence have been targeted through interventions that include objective monitoring of medication use plus feedback and support (e.g., problem solving; Rohan et al., 2013; Spaulding et al., 2012). These interventions can be effective in improving adherence to long-term control medications; however, sustaining treatment gains has proven difficult (Otsuki et al., 2009).

Interventions that focus on empowering families to manage their children's illness have also gained increasing recognition (Canino et al., 2008; Warman, Silver, & Wood, 2006). These family-based interventions can involve encouraging developmentally appropriate distribution of management tasks among family members, promoting a balance between child self-management and parental involvement or supervision, and enhancing asthma awareness among family members. Interventions that consider adolescent autonomy and focus on helpful family support for youth management appear promising and have been effective in improving medication adherence and decreasing functional impairment (Duncan et al., 2013).

Health disparities in asthma are well documented and multidetermined among ethnic minority and disadvantaged families (see Canino et al., 2009, for a review). Health disparities may stem from limited access and suboptimal medical care, increased environmental exposures, and families' health beliefs, among several other factors. The prevalence of health disparities has encouraged the development and dissemination of culturally tailored asthma management programs for specific high-risk populations, with some success (Weiss, 2007). For example, one web-based, culturally tailored educational program targeting African American urban high school students resulted in decreased asthma symptoms and fewer missed school days (Joseph et al., 2007). A family-based program targeted toward Puerto Rican families of children with asthma also demonstrated symptom reduction for participating children (Canino et al., 2008). Given the well-documented disparities in asthma outcomes (Akinbami, Moorman, et al., 2012), such programs represent an important priority for future research.

Technological interventions constitute an increasingly common treatment modality for youth with asthma (Mosnaim, Powell, & Rathkopf, 2012; Nickels & Dimov, 2012; Seid et al., 2012). These interventions are interactive, capitalize on a growing technology format, can be readily disseminated, and facilitate communication with multiple users. Web-based tools have been developed to deliver educational interventions to patients and caregivers and to facilitate communication with a patient's health care team (see Mosnaim et al., 2012, for a review). These interventions have been successful in increasing asthma management and knowledge, improving quality of life, and decreasing health care use (Guendelman, Meade, Benson, Chen, & Samuels, 2002; Jan et al., 2007; Krishna et al., 2003), and can be accessed at home or in the school (Joseph et al., 2007). Mobile phone interventions also appear promising. For example, a multi-

component intervention that included motivational interviewing, problem-solving skills training, and adolescent-generated reminders and encouraging text messages for asthma management reduced asthma symptoms and improved quality of life (Seid et al., 2012). Technological interventions have been less successful in improving medication adherence (Gustafson et al., 2012; Mosnaim, Cohen, Rhoads, Rittner, & Powell, 2008), suggesting that barriers to consistent use may be complex.

CONCLUSION

The very high prevalence of asthma means that most children will have a few peers with asthma in their classrooms. Over the past two decades, there have been coordinated efforts at national and local levels to diagnose and manage asthma more effectively. Guidelines from national organizations provide recommendations for accurate diagnosis and effective management of the disease (Global Initiative for Asthma, 2008; NAEPP, 2007). Implementation of these recommendations, however, remains a difficult task for health care professionals and families. Many families still perceive asthma as episodic and respond only to observable symptoms, rather than recognizing asthma's chronic course and attempting to prevent future episodes (Callery, Milnes, Verduyn, & Couriel, 2003). Misconceptions about the necessity, nature, and function of asthma medications also persist (Conn, Halterman, Lynch, & Cabana, 2007). Adherence to the medications that are regularly prescribed for children with persistent asthma remains poor, with estimates of adherence rates hovering around 50%, and even lower for children from minority backgrounds (McQuaid et al., 2012; Rohan et al., 2010). In order to accomplish reductions in asthma morbidity and improvements in management, research and clinical advances are necessary, and health care policy considerations are relevant.

Research Directions

Research addressing the complex interactions among stress and emotions, immune function, and asthma exacerbations may lead to new approaches to asthma control. Further work is needed to explain the gap between physicians' recommendations for asthma management and families' actual implementation of management practices. Research frameworks that incorporate multiple components of the socioecological model and identify individual and systems factors supporting adaptive asthma management will serve to inform the development of future interventions. As an example, an intervention that employed multisystemic therapy to target the individual, family, community, and health care system domains demonstrated notable improvements in youth medication adherence and lung function (Naar-King et al., 2014).

Clinical Directions

Psychologists and other mental health professionals can play many roles in working with families of children with asthma and through collaborating with health care providers. Specifically, psychologists can help physicians identify family barriers to adherence and construct management plans that take family circumstances and strengths into account. Individual and family interventions can be critical in preventing psychosocial factors

from decreasing treatment adherence or exacerbating symptoms. Psychologists can also participate in the programming and implementation of educational interventions, with an emphasis on developmental and family approaches. The interventions provided by mental health professionals can help to "bridge the gap" between health care providers and patients to assist families in understanding asthma, and to support them in following their management plan.

Policy Implications

Because of the high prevalence and risks of asthma, along with its disproportionate impact on ethnic minorities, low-income families, and inner-city communities, asthma treatment represents an important public health priority. Through mobilizing communities and health care systems to recognize the complexities of asthma management, psychologists can serve as influential advocates for patients and families. Examples include the many asthma coalitions that have been formed on local levels with mental health representation to promote access to effective asthma care for patients and families.

Multidisciplinary approaches to clinical care are particularly useful for children with severe asthma and in cases where psychosocial barriers impede care. Psychologists are encouraged to evaluate the effectiveness of collaborative care approaches to asthma, in order to document improvements in clinical outcome and cost-offset associated with interdisciplinary asthma management (see McGrady & Hommel, 2016, for a review of this approach). These data are instrumental in securing payment for pediatric psychology services and in promoting the value-added benefit of collaborative care models.

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CHAPTER 19

Advances and Emerging Issues in Cystic Fibrosis

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Cystic fibrosis (CF) is a progressive, genetic illness caused by mutations in the CF transmembrane conductance regulator (*CFTR*) gene (Cutting & Zeitlin, 2012). Although it is the most common life-shortening genetic disorder among European American populations, it is found in all races and ethnicities. There are approximately 30,000 people living with CF in the United States and 70,000 worldwide. Advances in the development of treatments have extended survival to a median of 41 years for an infant born with CF today (Cystic Fibrosis Foundation [CFF], 2013). This is an increase in lifespan of 10 years since 2002. Furthermore, for the first time, half of the CF population consists of adults over the age of 18 (Jain & Goss, 2014). This has important implications for the need to assist adolescents with CF in making the transfer to adult care and the transition to adult roles, particularly in disease self-management (Modi, Quittner, & Boyle, 2010). Improvements in diagnosis and treatment have also contributed to increased lifespan. Since 2010, all 50 states have established newborn screening programs, and more than 61% of children diagnosed with CF in 2012 were identified by abnormal results on newborn screens (CFF, 2013). This has led to the immediate introduction of pancreatic enzymes for infants who need them (87%; CFF, 2013), facilitating weight gain and growth. New genetic correctors and potentiators have also been approved by the U.S. Food and Drug Administration (FDA), in an effort to correct the underlying genetic defect.

CF is caused by having two mutations of the *CFTR* gene, which leads to the malfunction or absence of the CFTR protein. This results in accumulation of thick mucus that obstructs the airways of the lungs and other organ systems. It also results in bronchiectasis, which is defined as "progressive dilation of the airways, as a result of

inflammation, infection, and subsequent repair" (Dodd, Lavelle, Fabre, & Brady, 2015, p. 194). In addition, the mutation causes *in utero* blockage of the pancreas, preventing release of enzymes to aid digestion. This leads to malabsorption of fats, proteins, and fat-soluble vitamins. This protein defect also affects the liver, gallbladder, intestines, and reproductive system. Approximately 30% of patients have sinus disease, 20% develop CF-related diabetes, 15% bone disease, and 10% liver disease (CFF, 2013), and further, 98% of males are sterile (Sueblinvong & Whittaker, 2007). Chronic inflammation and infection, particularly in the lungs, constitute the leading cause of morbidity and early mortality (Ratjen et al., 2015).

A number of palliative treatments (e.g., inhaled antibiotics, airway clearance) have been developed to address common symptoms. Also, very recently, the first gene-modifying drugs have been approved for those with the *G551D* mutation (CFF, 2013; 4% of the population) and more recently the *F508 del* mutation. These new medications are the first to target the underlying CFTR defect, at an annual cost of $265,000 to $373,000 per year. The daily treatment regimen is both complex and time-consuming, taking between 2 and 4 hours per day (Sawicki et al., 2013). The typical routine includes nebulized medications (e.g., bronchodialators, mucolytics to loosen secretions, acute and chronic inhaled antibiotics), airway clearance (e.g., vest, acapella), oral medications (e.g., low-dose azithromycin, vitamins), and enzymes with each meal and snack. Frequent lung infections are common, and patients are often colonized with multiresistant bacteria, such as *Pseudomonas aeruginosa*. Antibiotics (oral, nebulized, or intravenous) are used both preventively and during acute exacerbations. For those with pancreatic insufficiency, a higher-calorie diet is required (110–200% of the recommended daily allowance), as well as consumption of enzymes with all meals and snacks.

The aim of this chapter is to review the key challenges of living successfully with CF for both affected individuals and their families. First, we address the challenges of adhering to this complex treatment regimen throughout the lifespan, followed by a discussion of transition of responsibility and transfer to adult care. Next, the prevalence and consequences of psychological distress in patients and caregivers are presented, including new international guidelines for annual screening of depression and anxiety. Finally, issues arising from medical advances and longer lifespan are addressed, including diversity among patients and the psychosocial consequence of new infection control guidelines.

ADHERENCE TO PRESCRIBED TREATMENTS

Medication adherence is generally poor across individuals with chronic diseases (Graves, Roberts, Rapoff, & Boyer, 2010); however, as described above, the daily regimen for CF is one of the most challenging. It takes several hours each day, requires a high degree of knowledge and skill to perform correctly, and in many cases requires disclosure of the disease (e.g., taking enzymes at meals with others; Modi, Quittner, et al., 2010; Quittner, Zhang, et al., 2014). Poor adherence is directly related to pulmonary exacerbations (Eakin, Bilderback, Boyle, Mogayzel, & Riekert, 2011), need for intravenous antibiotics, poor weight gain and growth, and gastrointestinal symptoms (e.g., constipation, abdominal pain). A recent national study using pharmacy refill records indicated that adherence to all pulmonary medications was, on average, 50% or less (Quittner,

Zhang, et al., 2014), and there was a negative association between age and adherence (see Figure 19.1).

Infants and Toddlers

Computed tomography scans have shown that infants with CF already have bronchiectasis in the lungs soon after birth (Stick et al., 2009), and over time they are colonized with bacterial pathogens, leading to inflammation of the airways. Thus it is important to begin respiratory treatments soon after diagnosis, in addition to calorie boosting and enzyme replacement therapy. Nutrition is key during this period, because there is a strong relationship between weight-for-age at 4 years and improved survival at age 18 (Yen, Quinton, & Borowitz, 2013). Soon after diagnosis, parents must learn about CF and its management, establish relationships with their CF care team, and grieve for the loss of a "healthy" child. Parents often feel guilty about the genetic transmission of the disease and report elevations in depression and anxiety (Wong & Heriot, 2007).

A child's behavior can also have a negative impact on adherence. As children grow older, they often begin to refuse treatments. Oppositional behaviors, difficulty swal-

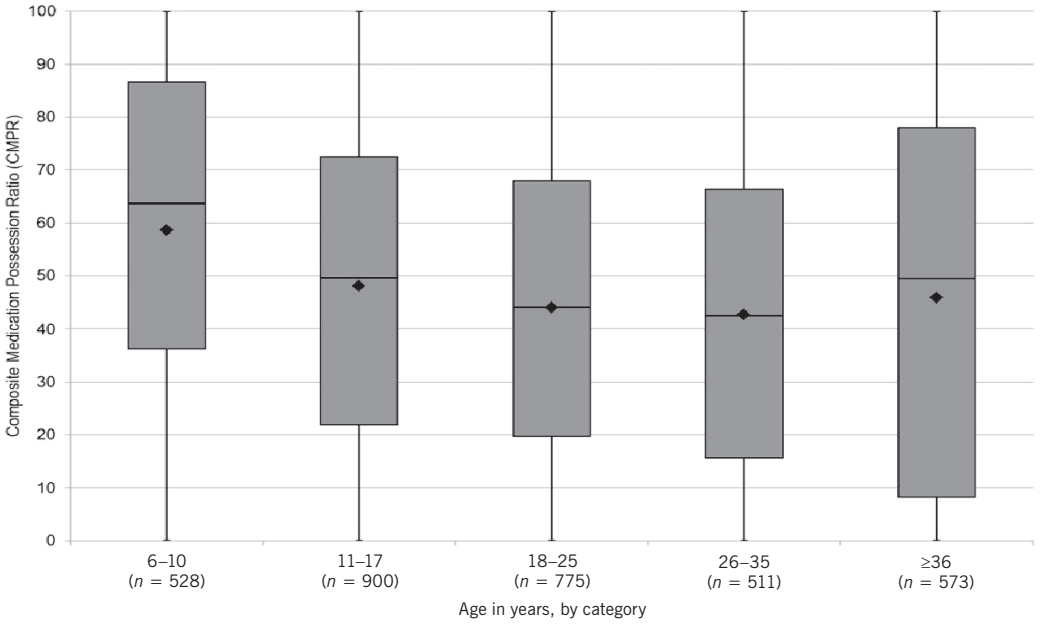

FIGURE 19.1. Composite medication possession ratios (CMPRs) by age category. A CMPR is the average of individuals' medication possession ratios. The bottom, midline, and top of each box represent the lower quartile, median, and upper quartile, respectively. The endpoints of the vertical lines represent the minimum and maximum values. From "Pulmonary medication adherence and health-care use in cystic fibrosis" by A. L. Quittner, J. Zhang, M. Marynchenko, P. A. Chopra, J. Signorovitch, Y. Yushkina, and K. A. Riekert, 2014, *Chest, 137*(3), 642–650. Copyright © 2014 American College of Chest Physicians. Reproduced with permission.

lowing pills, and time management are key barriers to adherence (Modi & Quittner, 2006). For example, it can be difficult to get an infant or toddler to sit still and wear a nebulization face mask for 20 minutes twice a day. Parents are encouraged to provide distractions, such as watching cartoons or playing with special toys during treatment sessions. Modeling appropriate treatment behavior, such as having a parent also wear a face mask during nebulized treatments, can likewise be beneficial for the child (Cary, Soultan, & Anbar, 2014). Behavioral interventions have been successful in teaching parents how to manage oppositional behaviors at mealtimes and help young children learn to swallow pills (Marciel, Quittner, Modi, & Cruz, 2008; Stark et al., 2009).

School-Age Children

Different challenges emerge for school-age children. Parents report oppositional behaviors, and difficulties with time management, whereas children report difficulty swallowing pills and the bad taste of the medicines they inhale (Modi & Quittner, 2006). In addition, significant gaps in knowledge of disease management have been identified in both parents and children, with parents answering 68% of the questions correctly and children only 55% (Modi & Quittner, 2006; Quittner et al., 2010). Overall, children under 12 years had higher rates of adherence than children over 12 to using Medication Event Monitoring System SmartCaps, which record each bottle opening, to evaluate adherence to enzymes (Barker & Quittner, 2016). This decrease in adherence with age is probably due to reduced parental supervision, which has been shown to influence adherence for both school-age and adolescent children with CF (Modi, Marciel, Slater, Drotar, & Quittner, 2008).

There is a great deal of emphasis on calorie boosting and weight gain during this period, which often results in high levels of parental stress (Filigno et al., 2012) and of resistance on the part of children. Several studies have shown that parent–child interactions during mealtimes can become dysfunctional, with parents nagging, coaxing, and even spoon-feeding their children in an effort to help the children make their calorie goals (Stark et al., 2009). A recent behavioral intervention, "Be In Charge!," improved adherence to dietary recommendations and caloric intake in children ages 4–12 years; this intervention included the use of differential reinforcement (e.g., ignoring inappropriate behaviors, praising on-target behaviors), goal setting, and rewards (Janicke, Mitchell, Quittner, Piazza-Waggoner, & Stark, 2008).

Adolescents

Several studies suggest that adherence decreases significantly in adolescence (Quittner, Zhang, et al., 2014), partly due to greater independence, less parental supervision, and the emergence of psychological distress (Modi et al., 2008; Quittner, Zhang, et al., 2014; Smith, Modi, Quittner, & Wood, 2010). Teens with CF may experience delays in puberty, increased rates of hospitalization for infections, and overall declines in health (Johannesson, Gottlieb, & Hjelte, 1997; Yen et al., 2013). Barriers to adherence in adolescents reflect these normative changes and are reported by approximately 60% of adolescents (George et al., 2010). In adolescents, key barriers include time management, competing social activities, discomfort with taking medications in public, and elevated perceptions of treatment burden. Rates of adherence are approximately 50%

in this age group (Quittner, Zhang, et al., 2014) and relatively stable (Modi, Cassedy, et al., 2010).

Challenges with body image also emerge, with girls seeking to maintain "thin" bodies and boys wanting to grow bigger and stronger. Because of increased resting energy expenditures and digestive problems, adolescents may be underweight and shorter than their peers (Sinaasappel et al., 2002). Despite this, many females desire a thin body image and may titrate their enzymes to lose weight or consume fewer calories. Females also report more internalized passivity and "giving up" with regard to self-care (Patterson, Will, Berge, & Milla, 2008), and are more likely to limit physical activity, than boys.

Embarrassment and desire for social acceptance also function as barriers to adherence (Dziuban, Saab-Abazeed, Chaudhry, Streetman, & Nasr, 2010; Modi, Quittner, & Boyle, 2010; Patterson et al., 2008). Adolescents report decreased adherence to medications and high-fat food consumption, as well as embarrassment about coughing—all of which are visible to peers (Patterson et al., 2008). Airway clearance, a time-consuming and isolating treatment, is frequently "skipped" and is perceived by teens as the most acceptable treatment to miss (Dziuban et al., 2010; Modi, Cassedy, et al., 2010). Family functioning is also associated with adherence: More positive relationships (both observed and self-reported) are associated with better adherence, particularly to airway clearance (DeLambo, Ievers-Landis, Drotar, & Quittner, 2004). Parent–child psychosocial strains, such as fighting, nagging, and overprotecting, have been associated with worse adherence in adolescents, especially among females (Patterson et al., 2008).

Emerging Adulthood

In 1986, approximately 29.2% of individuals with CF were 18 years or older; however, in 2013 this proportion rose to nearly half (CFF, 2013). Given this increase in lifespan, adherence in adulthood is an important target for intervention. Overall, adherence in adults is 50% or less, and approximately 20% of adults do not complete regular airway clearance (Quittner, Zhang, et al., 2014). Transition of treatment responsibility from parents to adolescents, and transfer to adult care, are the major challenges of this period.

Adults with CF have reported that planning for the future and performing adult roles (e.g., going away to college, getting a job) can facilitate better adherence, along with a shift toward peer support (George et al., 2010; Modi et al., 2010). Barriers to adherence center on this increasing independence and desire to engage in "normal" adult activities (e.g., moving away from home, traveling). The treatment regimen is viewed as highly burdensome; in response, many adults report a desire to "rebel" against their disease, or to take planned "holidays" from their regimen (George et al., 2010).

TRANSITION TO SELF-MANAGEMENT

The term "transition" refers to a gradual process of shifting CF management from the parent to the child, whereas "transfer" simply refers to the event of switching from pediatric to adult care (Tuchman, Schwartz, Sawicki, & Britto, 2010). Although the transfer process may occur between the ages of 18 and 20, transition of responsibility should begin in the school-age period (Madan, Alpern, & Quittner, 2014).

Transition of Responsibility

Adolescents with CF gradually take on responsibility for their care; however, this transition is not a linear process. Adolescents who are supervised when completing treatments are more adherent (Modi et al., 2008). One study showed that by age 15, adolescents were taking responsibility for the majority of their treatments; however, their adherence was quite low. As a result, by the time adolescents reach ages 16–17, parents may become reinvolved to ensure that treatments are getting done.

During this transition, studies have identified specific parent and friend behaviors that are helpful in increasing adolescent self-management. Helpful behaviors by parents include reminders, assistance in preparing treatments, monitoring and rewarding treatment completion, and assistance in navigating the health care system; helpful behaviors by friends include phone calls and visits, flexibility in scheduling activities, and distractions from the illness (Barker, Driscoll, Modi, Light, & Quittner, 2012). In contrast, adolescents have reported that nagging, arguments about treatments, and controlling behaviors are not helpful.

Guidelines for transition of responsibility have been outlined in several recent articles. Williams, Mukhopadhyay, Dowell, and Coyle (2007) have suggested that parents make the transition from "complete director" to "noninvolvement," while individuals with CF make the transition from "overwhelming recipient" to "independent administrator." Madan et al. (2014) recommend that this process take place through successive approximations to the goal of independence—starting with minor tasks (such as turning the equipment on) at age 6, progressing to preparing treatments at age 10, and moving on to completing them independently (including the "cleanup phase") by age 16. This process must happen for each type of treatment, because the skills required are quite different. Collaborative decision making has also been used to facilitate transition, with parents modeling decision making at first with the health care team, followed by greater participation and decision making by the teen. At some centers, the adolescent meets with the providers alone, followed by a joint session, which includes the parent. Qualitative studies have shown that even after patients gain independence in self-management, parents return to take on additional treatment responsibilities during exacerbations or hospitalizations (Williams et al., 2007).

Transfer of Care

Guidelines for transfer of care suggest that a timeline for transfer be created when an adolescent is 14 years of age (Madan et al., 2014). However, as of 2008, fewer than 50% of pediatric CF centers routinely provided families with timelines or written information about the transfer process (Tuchman et al., 2010). Although transfer programs exist in about 18% of CF centers, these programs often lack structure or clear goals. Three transfer programs have reported on their feasibility and acceptability. The first, in Australia, is a two-phase program that includes encouraging clinic attendance, promoting self-management skills, and assessment of general health and psychosocial issues in the preparation phase. The active phase adds an orientation to the adult service and scheduling of an initial appointment with the adult team (Craig, Towns, & Bibby, 2007). A second transfer program, ON TRAC in Canada, includes developing clinical pathways for transfer (e.g., educational workshops, skill building, disease and health care sys-

tem awareness), collaboration with the adult clinic, and measurement of readiness for transfer (Gravelle, Paone, Davidson, & Chilvers, 2015). A third transfer program, CF R.I.S.E. in the United States (Baker, Riekert, Sawicki, & Eakin, 2015), includes assessments of knowledge, self-management, and achievement of intermediate goals toward transfer. This "toolkit" provides practitioners with measures to identify gaps in knowledge and skills that require remediation to prepare for transfer. These three models take different approaches to transfer, but at this time there are no outcome data on any of them.

One issue that has been largely neglected is the provision of education on sexual health and fertility. Two of the programs described above recommend that practitioners discuss these issues with their adolescent patients (Baker et al., 2015; Gravelle et al., 2015). Education on sexually transmitted infections (STIs) and long-term fertility should be provided. One study found that females with CF wanted more information about reproductive health and felt their level of knowledge was inadequate (Gage, 2012). Specifically, they did not understand the extent of their reduced fertility or the potential impact of pregnancy and delivery on their health. Males reported that they "heard" about their infertility later than they would have liked, and those who were informed later were more likely to find this information upsetting (Sawyer, Ferrant, Cerritelli, & Wilson, 2005). Specifically, young men would have preferred to have a semen analysis performed prior to age 18. It is also critical to distinguish between the risk of contracting an STI and the ability to conceive children. Although males with CF are likely to have reduced fertility, they are equally likely to acquire an STI.

For males with CF, infertility (98%) is due to congenital bilateral absence of the vas deferens, which does not limit sperm production, but blocks sperm in the ejaculate (McArdle, 2011). Assistive reproductive techniques (e.g., sperm extraction) have advanced rapidly over the past 10 years and can be used to enable men with CF to have children. Females with CF also have fertility challenges because of delays in growth; these delays can lead to abnormal ovulatory cycles and thicker cervical mucus, which impedes the penetration of sperm. A growing number of women with CF are having children, and recent evidence from a national longitudinal study on their health outcomes indicated that although they reported more symptoms and pulmonary exacerbations, there was no immediate negative impact of pregnancy on their health status (Schechter et al., 2013).

PSYCHOLOGICAL DISTRESS

A great deal of evidence, including meta-analyses and systematic reviews, indicates that children, adolescents, and adults with chronic conditions are at higher risk for depression and anxiety than community samples (Fauman et al., 2011). In addition, psychological distress has been consistently associated with worse health outcomes (Hilliard, Eakin, Borrelli, Green, & Riekert, 2015). Caregivers of children with chronic conditions have also reported higher levels of depression and anxiety than parents of healthy children (Bessier et al., 2011). In single-center studies, elevated symptoms of depression and anxiety have also been found in children and adults with CF in the United States and Europe (Smith et al., 2010) and among caregiving parents (Bessier et al., 2011).

Recently, a large international screening study (The International Depression/

Anxiety Epidemiological Study, or TIDES) was conducted in nine countries to assess symptoms of depression and anxiety in patients with CF ages 12 years through adulthood, and caregiving parents of children with CF ages birth to 17 years (Quittner, Goldbeck, et al., 2014). We measured these symptoms in 6,088 patients and 4,102 parent caregivers at 154 CF centers in the United States and Europe. Elevated symptoms of depression were found in 10% of adolescents, 19% of adults, 37% of mothers, and 31% of fathers. Elevations in anxiety were found in 22% of adolescents, 32% of adults, 48% of mothers, and 36% of fathers. Overall, elevations were two to three times higher than in community samples (see Figure 19.2). Comorbidity of anxiety and depression were also observed, with respondents reporting elevated anxiety much more likely to report symptoms of depression as well (odds ratios: adolescents = 14.97, adults = 13.64, mothers = 15.52, fathers = 9.20). We evaluated the concordance of these symptoms in 1,122 parent–teen dyads. Adolescents whose parents reported either depression or anxiety were also more likely to report elevations in these symptoms (odds ratios = 2.22–2.32).

EMERGING ISSUES

Measures of Health-Related Quality of Life

"Patient-reported outcomes" (PROs) are the large umbrella under which measures of health-related quality of life (HRQoL) fall. The U.S. FDA (2009) has issued guidance permitting the use of PROs as primary or secondary endpoints in clinical trials of new medications. It strongly encourages disease-specific measures, which are developed by using qualitative input from patients and key stakeholders. A PRO is defined as any measure of health status that is directly elicited from the patient and assesses how he or she "survives, functions or feels" in relation to a health condition.

In CF, the widely used Cystic Fibrosis Questionnaire—Revised (CFQ-R; Quittner, Sawicki, et al., 2012) is the "gold standard" for measuring HRQoL. It has demonstrated excellent psychometric properties (Quittner, Sawicki, et al., 2012; Quittner, Buu, Messer, Modi, & Watrous, 2005), and there are developmentally appropriate versions for school-age children, adolescents/adults, and parents of younger children (Quittner, Sawicki, et al., 2012). The CFQ-R has been used to measure (1) improvements in respiratory symptoms, which led to FDA approval of aztreonam lysine for inhalation (Retsch-Bogart et al., 2009); (2) outcomes following lung transplantation (Quittner, Barker, Blackwell, Romero, & Woo, 2009); (3) differences in HRQoL by socioeconomic status and race/ethnicity (Sawicki et al., 2011, 2013); and (4) associations between psychological distress and HRQoL (Riekert, Bartlett, Boyle, Krishnan, & Rand, 2007).

We have recently developed a pictorial, preschool version of the CFQ-R for children ages 3–6 years with CF. This new instrument is important, given the focus in CF on early and aggressive treatment in young children to prevent damage to the lungs (Rosenfeld et al., 2012). As new medications are developed and tested in this young population, the central challenge has been identifying relevant endpoints for trials, since pulmonary function tests cannot be performed until age 6. The Preschool CFQ-R provides an opportunity for both parents and preschoolers to report on changes in symptoms and other aspects of disease management (Alpern et al., 2015). This preschool version utilizes a forced-choice paradigm: first asking young children to point at two pictures that represent the extreme ends of the rating scale, and then having them make

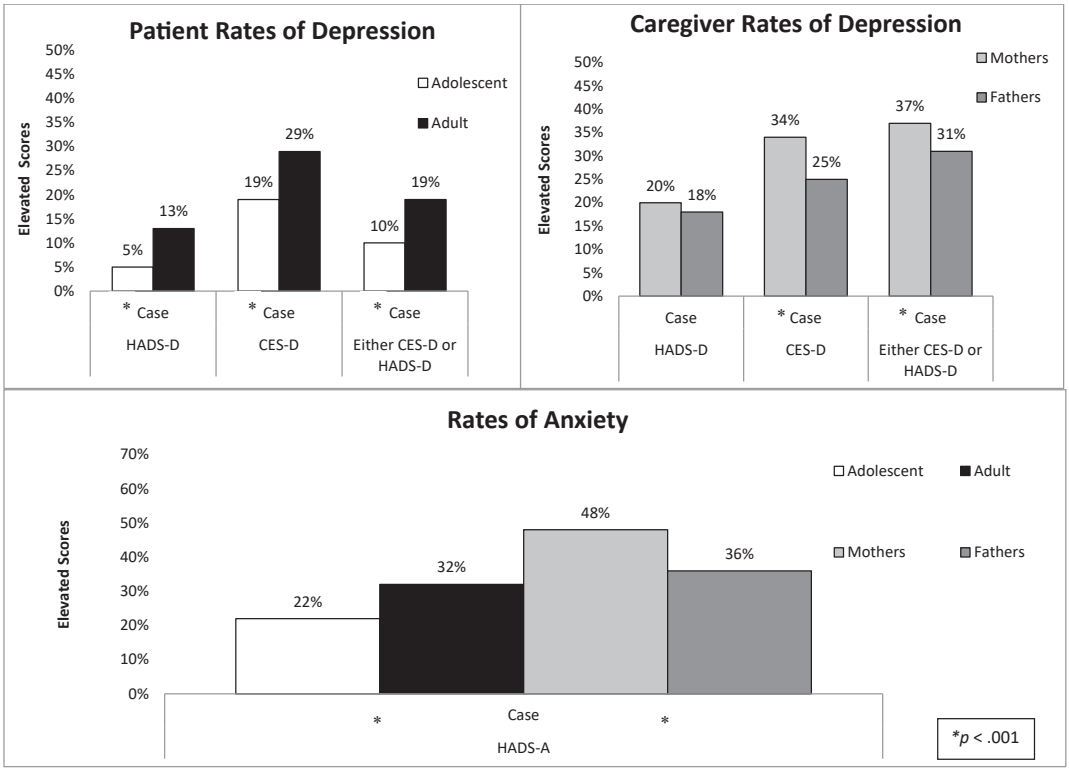

FIGURE 19.2. Rates of depression and anxiety reported by respondents in TIDES. CES-D, Center for Epidemiologic Studies Depression Scale; HADS-D, Hospital Anxiety and Depression Scale—Depression; HADS-A, Hospital Anxiety and Depression Scale—Anxiety. From "Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: Results of The International Depression Epidemiological Study (TIDES) across nine countries" by A. L. Quittner, L. Goldbeck, J. Abbott, A. J. Duff, P. Lambrecht, A. Solé, . . . D. Barker, 2014, *Thorax,* 69(12), 1090–1097. Copyright © 2014 BMJ Publishing Group, Ltd. Reproduced with permission.

a second choice between the two closest ratings. Good reliability and validity have been reported (Cruz et al., 2009). Importantly, the Preschool CFQ-R gives young children the opportunity to report on their respiratory and digestive symptoms and other domains of functioning that are affected by CF. As pediatric psychologists, we should advocate for the use of PROs whenever possible, but especially in evaluation of new medications and decisions about lung transplantation. PROs give patients and parents a "voice" in these key areas.

Impact of Genetic Screening

CF has been largely been considered a "European American" disease, but new research shows that view to be inaccurate. The World Health Organization (WHO, 2004) has reported that in the last two decades, the rates of diagnosis have been increasing in Latin

America and the Middle East, as well as among those who have immigrated to Western Europe from the Indian subcontinent. CF has also been diagnosed in South Africa in people of pure African descent. The incidence of CF in Latin American populations ranges from 1 in 3,900 to 1 in 8,500, depending on ethnic origin. In some countries, such as India and Egypt, the specific gene mutations for CF have not been determined; this lack of knowledge hampers diagnosis and treatment (WHO, 2004).

Minority Status

The number of Hispanic individuals in the United States diagnosed with CF has steadily increased, rising from 4.1% in 1992 to 7.7 % in 2012 (CFF, 2013). Comparisons of U.S. Hispanic and non-Hispanic patients with CF have found the following for Hispanic patients: (1) earlier acquisition of *Pseudomonas aeruginosa,* (2) worse nutritional status, (3) lower mean lung function, (4) more complications (e.g., liver disease, diabetes), and (5) worse HRQoL (Quittner et al., 2010). Hispanic patients also had a lower median family income by zip code, were more likely to have public insurance, and had lower levels of maternal education.

Infection Control Guidelines

The CFF has published updated infection control guidelines to manage the risk of transmission of multiresistant bacteria (e.g., *Pseudomonas aeruginosa, Burkholderia cepacia*) between patients (Saiman et al., 2013). The updated guidelines now require complete patient segregation within clinics, and patients are told that they should not be in contact with anyone who has CF. Every clinic staff member is also required to wear a fluid-resistant gown and latex gloves when speaking to or caring for each patient, adding a mask and eye protection if a patient is suspected of having a pathogen transmissible through droplets in the air (e.g., sneezing, coughing). Notably, CF is the *only* chronic disease that requires complete patient segregation, with significant psychosocial consequences (e.g., social isolation).

FUTURE DIRECTIONS

Interestingly, the field of CF treatment has become a cutting-edge model for how to develop better treatments and disease management strategies in chronic illness more generally. Led by the CFF, major initiatives related to mental health and adherence are being disseminated. Thus the two key future directions for research in CF are also relevant for other chronic conditions, such as diabetes, sickle cell disease, and hemophilia: (1) incorporating mental health into the routine care of children and adolescents with chronic illnesses through annual screening and treatment of depression and anxiety; and (2) utilizing evidence-based interventions to improve adherence in the specialty clinic setting.

First, TIDES and other studies have demonstrated that children and adolescents with chronic illnesses and their parents are at increased risk for symptoms of depression and anxiety. Despite a number of prestigious national organizations in pediatrics recommending annual screening of all adolescents beginning at age 12, this recommen-

dation has not been implemented in either primary care or specialty clinics for children and adolescents with chronic illnesses (U.S. Preventive Task Force, 2009).

Recently published international guidelines on mental health in CF (Quittner et al., 2016) have advocated annual screening of depression and anxiety, so that these symptoms can be addressed systematically. Depression in particular has been shown to decrease adherence to prescribed treatments, and thus it affects both health outcomes and quality of life (Hilliard et al., 2015). In response to these guidelines, in 2016, the CFF funded Mental Health Coordinators in 84 CF centers, the majority of whom are psychologists. The CFF recently put out a call to fund an additional 55 centers. Implementation of these guidelines will necessitate training health care providers to identify the key symptoms of depression and anxiety, implement basic education and preventive efforts, and utilize evidence-based treatments to address them. This clearly represents a fundamental change in the management of chronic illnesses that has wide applicability across diseases, with psychologists likely to take a leading role in these efforts.

Second, adherence is a central challenge in the management of all chronic conditions and accumulating evidence suggests that problem-solving interventions, delivered in specialty clinics as part of routine care, are effective in improving adherence (DeLambo et al., 2004). These interventions should be developed with input from patients, parents, and providers, and be rated as acceptable and useful by all stakeholders. They also need to be feasible for use in busy clinics, which have constraints on time and space. The IMPACT model, described in detail elsewhere (Quittner, Alpern, & Blackwell, 2012), included remediation of gaps in knowledge and skills, as well as a brief (10-minute) problem-solving session to address adherence barriers. This intervention was effective in improving both lung function and body mass index in adolescents at 18 CF centers (Quittner, Kimberg, Marciel, Zhang, & Riekert, 2011). It is clear that psychologists will play key roles in both of these future research and clinical initiatives.

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CHAPTER 20

The Psychological Context of Diabetes Mellitus in Youth

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This chapter surveys key research findings in three domains of adaptation of youths and families to diabetes: (1) the central role of the family in diabetes management; (2) the ways in which diabetes management affects, and is affected by, stress, coping, and psychological adjustment in youth; and (3) the broader social context in which diabetes management occurs.

The two primary forms of diabetes mellitus (American Diabetes Association, 2015) involve impaired glucose metabolism via either absolute insulin deficiency (Type 1; T1D) or insulin resistance which may lead to relative deficiency (Type 2; T2D). Published psychological research mostly concerns T1D and, to a lesser extent, T2D, so this chapter focuses on that research. Treatment of T1D includes several daily insulin injections or use of an insulin pump, daily self-monitoring of blood glucose (SMBG), regulation of carbohydrate intake, regular exercise, and minimizing hyperglycemia or hypoglycemia (American Diabetes Association, 2015). The hemoglobin A_{1C} (HbA_{1C}) test estimates mean blood glucose over the prior 3 months, and is done at follow-up visits. Patients with T2D involving insulin resistance may be treated with daily oral medications that enhance insulin sensitivity. Patients with T2D involving insulin deficiency take two or more daily insulin injections with a regimen like that for T1D. T1D and T2D both raise long-term risks of heart, kidney, eye, and nerve disease, but maintaining near-normal HbA_{1C} reduces these risks greatly (Diabetes Control and Complications Trial Research Group, 1994; United Kingdom Prospective Diabetes Study [UKPDS] Group, 1998). Current diabetes care targets an HbA_{1C} level of 7.5% (American Diabetes Association, 2015) through use of insulin pumps or multiple daily insulin injections, frequent SMBG, and family education in correcting glycemic fluctuations. These complex demands affect, and are affected by, psychological variables. Guided by Modi et al.'s (2012) conceptual framework, we review key studies that have explored individual, family, care system, and community influences on successful coping with pediatric diabetes.

FAMILY DIABETES MANAGEMENT

Parental Involvement in Diabetes Care

In pediatric diabetes, the "patient" is effectively the family; T1D management depends heavily on family communication (Wiebe et al., 2005), family problem solving (Wysocki, Iannotti, et al., 2008), and parental supportive involvement (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Ellis et al., 2007; Wiebe et al., 2005; Wysocki et al., 1996). Although research has historically emphasized the important role of mothers, more recent research suggests that shared involvement of mothers and fathers leads to better outcomes (see Hilliard et al., 2014).

Managing diabetes in the family requires a delicate balance of fostering the adolescent's growing independence with maintaining control of the diabetes care. Longitudinal studies suggest that when parents give up responsibility too early, adolescents have poorer adherence and deteriorating glycemic control (e.g., Wu et al., 2014). Studies suggest that transfer of responsibility should be balanced with the youth's developmental stage, incorporating factors such as age, pubertal status (Palmer et al., 2004), diabetes knowledge (Holmes et al., 2006), and self-efficacy (Wiebe et al., 2014). Collaborative parental involvement and support for increasing autonomy have been associated with the best medical and psychological outcomes (Wu et al., 2014). Positive dimensions of family functioning, such as providing social support, predict favorable adaptation to diabetes. Higher levels of family cohesion, parental acceptance, and family warmth have been associated with better adherence, glycemic control, and quality of life; higher levels of family conflict predict less adequate diabetes management and glycemic control (Drotar et al., 2013).

Diabetes Knowledge and Skills

Knowledge of the fundamentals of diabetes physiology and management increases with the child's age (Heidgerken et al., 2007). Youth with T1D and their caregivers are prone to technical errors (e.g., miscalculating carbohydrates or insulin doses) (e.g., Schmidt, Klover, Arfken, Delamater, & Hobson, 1992; Weissberg-Benchell et al., 1995), so T1D knowledge and skills should be refreshed regularly. Parental knowledge may have more impact on care for younger children, while adolescents' knowledge and skills may become more important as parental involvement decreases (Wysocki, Iannotti, et al., 2008).

Knowledge may be necessary but insufficient for effective T1D management (Heidgerken et al., 2007), as HbA_{1C} is also influenced by adherence, adequacy of the regimen, family communication, diabetes problem-solving skills, and relationships with health care providers. As diabetes subject matter grows, measures of diabetes knowledge become obsolete quickly. Most traditional diabetes knowledge tests measure recognition, recall, and comprehension rather than higher cognitive skills. However, Heidgerken et al. (2007) have reported the psychometric validation of the multiple-choice Diabetes Awareness and Reasoning Test, which is perhaps the most psychometrically sound measure of T1D knowledge for use in pediatrics. Wysocki, Iannotti, et al. (2008) introduced the Diabetes Problem-Solving Interview to assess youth's and caregivers' problem solving for prevention or correction of glycemic fluctuations. HbA_{1C} was significantly worse among youth whose caregivers' results on this measure indicated weaker skills, but

youth's scores did not predict HbA_{1C}. Enhancing caregivers' diabetes problem-solving skills and promoting youth's use of acquired skills could improve outcomes.

Diabetes Self-Management and Treatment Adherence

Treatment adherence is a key variable affecting youth's metabolic status. Achieving targeted HbA_{1C} may forestall long-term complications (Diabetes Control and Complications Trial Research Group, 1994). Strict adherence to the T1D regimen is very difficult, and only a minority of patients and families achieve it consistently (Johnson, Silverstein, Rosenbloom, Carter, & Cunningham, 1986). Adherence measures include parent or youth report questionnaires (e.g., La Greca, Swales, Klemp, & Madigan, 1988), daily diaries, or structured interviews (Johnson et al., 1986; Wysocki, Buckloh, Antal, Lochrie, & Taylor, 2012). Electronic measures of adherence include retrieval of memory-stored SMBG data, insulin pump data, or accelerometers to measure physical activity. Like diabetes knowledge tests, adherence measures must evolve as T1D care changes.

INTERVENTIONS TARGETING FAMILY DIABETES MANAGEMENT

A recent meta-analysis (Hood, Peterson, Rohan, & Drotar, 2010) concluded that multicomponent interventions, such as those described below, are most likely to affect $HbA_{1C.}$

Parent Training in Behavior Management

Delamater et al. (1990) randomly assigned youth newly diagnosed with T1D to conventional therapy, supportive counseling, or self-management training (a diabetes-specific behavioral parent training intervention). Self-management training yielded significantly lower HbA_{1C} than conventional therapy over a 2-year follow-up.

Interventions Targeting Family Communication and Problem Solving

Robin and Foster's (1989) behavioral family systems therapy (BFST) has been tested with adolescents with T1D. The first trial improved family communication and conflict resolution (Wysocki et al., 1999, 2000), but not adherence or HbA_{1C}. In a second trial, a revised BFST intervention yielded durable gains in directly observed family communication (Wysocki, Harris, et al., 2008) and in treatment adherence and HbA_{1C} (Wysocki et al., 2007). Multisystemic therapy (MST), an intensive, problem-focused therapy that engages the family, school, health care, and peer systems affecting T1D care, has improved adherence (Ellis et al., 2005, 2012) and health care utilization (Ellis et al., 2008). The BFST and MST trials suggest that intensive family interventions can yield moderately durable benefits.

Clinic-Integrated Interventions

Others have evaluated clinic-integrated interventions to promote healthy parent–youth teamwork for diabetes care (Anderson, Brackett, Ho, & Laffel, 1999; Laffel et al., 2003; Laffel, Brackett, Ho, & Anderson, 1998; Svoren, Butler, Levine, Anderson, &

Laffel, 2003). This series of studies has shown modest benefits of these approaches. More recently, Nansel, Iannotti, and Liu (2012) reported that a low-intensity clinic-integrated intervention yielded lower HbA_{1C} for 12- to 14-year-olds, but not for 9- to 11-year-olds; there were no treatment effects on adherence for either group.

eHealth and the Diabetes Online Community

Research has also evaluated the impact of eHealth interventions on T1D adherence. Herbert, Owen, Pascarella, and Streisand (2013) conducted a systematic review of text messaging interventions for youth with T1D and concluded that such interventions are feasible and engaging, but their longer-term impact on self-care and glycemic control is unknown. Several trials of varied eHealth interventions for T1D management are in progress.

Use of social media for social support, advocacy, and maintaining current diabetes knowledge is increasing in patients and parents of patients with T1D, but there are limited studies confirming the benefits of the so-called "diabetes online community." Many social network sites and blogs are available, targeting varied audiences, but empirical studies of the benefits of this community are needed.

Interventions for Youth with T2D

There are few intervention trials for youth with T2D. The Treatment Options for Type 2 Diabetes in Adolescents and Youth (TODAY) trial compared three T2D regimens (metformin, metformin + rosiglitazone, and metformin + an intensive lifestyle therapy intervention). After 6 months, metformin + intensive lifestyle therapy had superior effects on HbA_{1C} compared with metformin alone, but the metformin + rosigliatzone combination was superior to either of those regimens (TODAY Study Group, 2012). Another retrospective study examined adolescents with poorly controlled T2D who were admitted to the hospital for treatment with a ketogenic very-low-calorie diet (Willi, Martin, Datko, & Brant, 2004). HbA_{1C} dropped 1.4 points after 60 days (end of diet), and there was a 12% reduction in body mass index (BMI) at 6 months. These changes were significantly greater than those of controls.

Other lifestyle interventions to reduce T2D and cardiovascular risk in youth have shown promise (Van Buren & Tibbs, 2014). Lifestyle interventions, when combined with metformin, have shown positive effects for children with prediabetes, including decreases in BMI and body fat, and improvements in insulin sensitivity (e.g., Garnett et al., 2014). In a multifaceted school-based intervention with inner-city youth at high risk for T2D, the addition of coping skills training was found to have a positive effect on key markers of metabolic risk (Grey et al., 2009).

STRESS, COPING, AND PSYCHOLOGICAL ADJUSTMENT

Stress and Coping

Psychological stress can affect youth's ability to take care of T1D by affecting metabolic control and adherence. Diabetes-related stress has been found to mediate the relationship between HbA_{1C} and psychological adjustment (Malik & Koot, 2009). Moreover, cer-

tain coping styles may be related to poorer T1D outcomes, such as avoidance coping or neglecting self-care (Grey, Lipman, Cameron, & Thurber, 1997). Coping strategies such as problem solving, acceptance, and distraction are related to better self-management and adjustment, with self-management mediating the association of coping with metabolic control (Jaser et al., 2012).

Psychological Adjustment

Youth with T1D, especially younger children, may not differ from same-age peers in the general population in psychological adjustment (e.g., Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007; Lawrence et al., 2006); however, others report that T1D increases the risk of psychological problems in adolescents, including depression (e.g., Hood et al., 2006; Kovacs, Goldston, Obrosky, & Bonar, 1997), anxiety (Kovacs et al., 1997), and eating disorders (e.g., Jones, Lawson, Daneman, Olmsted, & Rodin, 2000). One review concluded that having T1D at least doubles the prevalence of depression among youth (Grey, Davidson, Boland, & Tamborlane, 2001). This elevated risk is of significant concern, as psychological problems such as depression have been correlated with poorer glycemic control in youth with T1D (Hassan, Loar, Anderson, & Heptulla, 2006), and psychological adjustment in adolescents has been linked to glycemic control in early adulthood (e.g., Bryden et al., 2001). A recent review and meta-analysis found moderate associations between depression and poor treatment adherence as reported by children and adolescents with diabetes (Kongkaew, Jampachaisri, Chaturongkul, & Scholfield, 2014).

Adolescents with T2D are also at increased risk for psychological adjustment problems—especially problems associated with excess weight, including poor self-esteem and body image, depression, anxiety, and behavioral problems (e.g., McGavock, Dart, & Wicklow, 2015). Youth older than 10 years with T2D may have a much higher risk of moderate to severe depression than youth with T1D (Lawrence et al., 2006). The TODAY study, however, found that 14.8% of youth reported clinically significant depressive symptoms—a rate similar to that for adolescents without T2D (Anderson et al., 2011). Older girls reported more depressive symptoms than younger girls or boys (Anderson et al., 2011).

Disordered eating and weight control behaviors are special concerns because of both the immediate and long-term impact of these behaviors on glycemic control. In T1D, the rates of eating disorders in preadolescent and adolescent girls are higher than in girls without diabetes (e.g., Jones et al., 2000; Young et al., 2012). These behaviors may include insulin omission, strict dieting, excessive exercise, laxative use, self-induced vomiting, and binge eating (e.g., Jones et al., 2000), and are more prevalent in girls than boys (e.g., Bryden et al., 1999). Eating disorders and disordered eating behavior are associated with higher HbA_{1C} and earlier onset of complications (e.g., Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997; Young et al., 2012).

Youth with T2D also are likely to be at increased risk for disordered eating and weight control behaviors. In a study of weight loss practices among adolescents with diabetes, 9.3% of females and 2% of males with T2D reported skipping insulin does for weight loss (Lawrence et al., 2008). In the TODAY study of adolescents with T2D, 6% had clinical and 20% had subclinical levels of binge eating (TODAY Study Group, 2011). Justice (2004) found that adolescents with T2D and higher BMI reported greater

body dissatisfaction, and that disordered eating had a significant impact on adherence to the daily regimen.

Interventions Targeting Stress, Coping, and Psychological Adjustment in T1D

Several studies have evaluated individual psychological interventions targeting coping and stress management, treatment adherence, and mood and behavioral problems in youth with T1D. See Winkley, Landau, Eisler, and Ismail (2006) for a meta-analysis of these studies.

Stress Management/Coping Skills Interventions

Coping skills training focused on increasing mastery by replacing ineffective coping skills with more constructive behaviors has yielded positive effects for youth with T1D (e.g., Grey, Boland, Davidson, Li, & Tamborlane, 2000). These studies showed lasting benefits (1 year) on HbA_{1C} and quality of life. For example, Grey et al. (2000) found that adolescents who received coping skills training achieved lower HbA_{1C}, better diabetes self-efficacy, better coping, and less negative impact of T1D on quality of life. Whittemore and colleagues (2012) conducted a multisite trial of an internet coping skills training intervention and an internet educational intervention with youth entering adolescence. Both interventions improved quality of life over time, with completion of both programs being better than completion of only one (Grey et al., 2013; Jaser et al., 2014).

Cognitive-Behavioral Therapy and Self-Monitoring Interventions

Cognitive-behavioral interventions typically target the identification and modification of negative cognitions to improve problem solving and coping. A multicomponent intervention (Mendez & Belendez, 1997) targeted stress management, social skills, glucose discrimination, problem solving, and self-monitoring with adolescents with T1D and their parents. This intervention improved adolescents' blood glucose monitoring adherence, diabetes knowledge, and social skills, but did not improve HbA_{1C}. A cognitive-behavioral intervention incorporating problem solving and cognitive restructuring reduced anxiety, anger, and diabetes-related stress in four of six youth (Hains, Davies, Parton, & Silverman, 2001). Five of six youth improved at least one self-care behavior (Silverman, Hains, Davies, & Parton, 2003). Cook, Herold, Edidin, and Briars (2002) reported that a 6-week problem-solving diabetes education program resulted in improved HbA_{1C}, more frequent SMBG, and better problem-solving skills.

Self-monitoring of diabetes self-management behaviors increases treatment adherence in youth with T1D (e.g., Kumar, Wentzell, Mikkelsen, Pentland, & Laffel, 2004). Current technology permits innovative SMBG methods. For example, Kumar et al. (2004) tested the use of an integrated wireless handheld modem and diabetes data management software and a wireless-enabled blood glucose monitor, using an integrated motivational game in which participants guessed blood glucose based on prior readings. The Game Group transmitted significantly more blood glucose results, experienced less hyperglycemia, and increased diabetes knowledge over the 4-week trial, compared to the control group.

Motivational Interviewing

Motivational interviewing (MI) is a flexible, client-centered, directive approach to enhancing motivation for change (Miller & Rollnick, 2013), which can be used to enhance adolescents' motivation to make changes in diabetes treatment adherence. MI components include awareness building, generating alternatives, problem solving, making choices, goal setting, and avoidance of confrontation (Channon et al., 2007). MI has produced small but significant effect sizes across a range of child health behaviors, including T1D-related behaviors (Gayes & Steele, 2014). Motivational interviewing has been added to cognitive-behavioral therapy and family-based contingency management (systematic reinforcement of desired behaviors) to improve blood glucose monitoring and HbA_{1C} in adolescents with T1D (Stanger et al., 2013).

SOCIAL CONTEXT OF DIABETES

Management of diabetes requires adherence to multiple daily tasks not only in the home, but in the school and community as well. Thus the supportive involvement of friends, teachers, and health care professionals, in addition to family members, is integral to successful diabetes management.

Peer Involvement in Diabetes Care

Studies have evaluated links between peer relations and T1D outcomes (see Palladino & Helgeson, 2012, for a review). There is more evidence that social conflict is harmful than that social support is helpful (Palladino & Helgeson, 2012). In one longitudinal study, friend conflict predicted a decline in psychological well-being and deterioration in HbA_{1C} over 1 year (Helgeson et al., 2007). Perceptions of peer reactions also play a role in diabetes management, as adolescents indicate that adherence is more difficult in social and peer contexts (Berlin et al., 2006), particularly when they anticipate negative reactions from peers (Hains et al., 2007). Adolescents with T1D may have more difficulty with social acceptance (Helgeson et al., 2007), and thus more vulnerability to social pressures that conflict with adequate diabetes self-care. Several peer interventions have been evaluated and show promise for increasing diabetes knowledge and peer support, but randomized controlled trials are necessary (Greco, Pendley, McDonell, & Reeves, 2001; Pendley et al., 2002).

Diabetes Care in Community Settings

School

The American Diabetes Association (2015) guidelines on management of diabetes in school recommend that students with T1D and T2D receive accommodations under applicable laws (i.e., Section 504 plans or individualized education programs). Research suggests that certain accommodations may be amenable to intervention, such as training school personnel in diabetes care, teaching classmates about diabetes, assigning each child with diabetes a "diabetes buddy," and allowing youth to have flexibility to perform self-care behaviors in the classroom (Siminerio & Koerbel, 2000; Wagner, Heapy,

James, & Abbott, 2006). Hains et al. (2009) found that students with T1D who expect negative attributions about teachers' reactions to T1D self-management are likely to demonstrate poorer adherence and more stress while in school.

Health Care Settings

Recent research has examined children's socialization as health care consumers and their achievement of autonomous relationships with health care providers. Every child with T1D must be prepared to face a lifetime of interactions with health professionals, and to cultivate partnerships founded on trust and communication. Effective transition of children from pediatric to adult medical services requires a multidimensional and multisystemic approach (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Reflecting a focus on patient-centered communication and shared medical decision making, Croom et al. (2011) found that adolescents who rated their diabetes providers as valuing their perspectives had better treatment adherence and glycemic control and better parental relations.

SUMMARY

We have surveyed three lines of diabetes research: family management of diabetes; stress, coping, and psychological adjustment; and the social context of diabetes. This review has revealed an impressive array of well-validated and carefully conceived measures of diabetes-specific psychological processes, as well as multiple randomized controlled trials of appropriate interventions. Recommendations for optimal psychological care for patients with diabetes have been developed to guide the translation of this research into routine pediatric diabetes care (Delamater, de Wit, McDarby, Malik, & Acerini, 2014), and centers have started to implement comprehensive and integrated programs of psychological assessment and intervention (Kichler, Harris, & Weissberg-Benchell, 2015). Future research and clinical endeavors must consider the broader social, cultural, and ethnic contexts of children and adolescents with diabetes.

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CHAPTER 21

Sickle Cell Disease

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Sickle cell disease (SCD) includes a spectrum of inherited abnormalities in hemoglobin (Hb), the protein that carries oxygen in the red blood cells (Ballas, 1998). In the United States, it is estimated that 90,000–100,000 people are living with SCD (Hassell, 2010). The disease occurs in 1 of every 500 African American births and 1 of every 1,000–1,400 Hispanic American births (National Heart, Lung, and Blood Institute [NHLBI], 2009). Like youth with other chronic illnesses, children and adolescents with SCD are at risk for problems in emotional, social, physical, and school functioning. This chapter briefly describes the medical aspects of SCD, including clinical manifestations and approaches to treatment. Research on psychosocial functioning of youth with SCD is then reviewed, along with the literature on making the transition to adult health care. This chapter concludes with recommendations for future research and practice within the context of a medical home model.

MEDICAL ASPECTS

Genetics and Biology

Sickle Cell Trait

Individuals with sickle cell trait have one gene for normal beta globin gene and one gene for sickle beta globin. The presence of this one sickle gene has historically provided protection from death from malaria, but does not itself cause a disease state or lower life expectancy (Tsaras, Owusu-Ansah, Owusa Boateng, & Amoateng-Adjepong, 2009). The sickle cell gene is found mostly among people with ancestors from areas of the world where malaria is endemic, such as sub-Saharan Africa, the southern Mediterranean, and Latin America. In the United States, sickle cell trait is found in 1 in 12 African

Americans and 1 in 40 Hispanics (NHLBI, 2009). Exercise-induced sudden death is a rare complication that has recently affected college sports, with the resulting requirement that all players must be tested for sickle cell trait or sign a waiver; this requirement has been controversial (Thompson, 2013).

Sickle Cell Disease

All parents of children with SCD carry the trait, and the passage of this trait is what results in the disease in their children. There is a 1:4 chance for each pregnancy that both parents will pass on the abnormal gene, resulting in a child with two copies of the sickle cell gene. This state is SCD, and unlike sickle cell trait, the disease leads to a serious chronic illness with many potential complications and shortened lifespan (Ballas, 1998). The most common and severe form of the disease occurs when an individual inherits two sickle genes (HbSS). Milder but still serious forms of the disease occur when an individual inherits one sickle cell gene and another type of abnormal hemoglobin gene, such as the gene for hemoglobin C (HbSC) or HbS beta + thalassemia.

Clinical Manifestations

Disease Severity

The effects of SCD are highly variable from one patient to another. The subtype of SCD is the most important indicator of disease severity (Van den Tweel, van der Lee, Heijboer, Peters, & Fijnvandraat, 2010), with patients with sickle cell anemia (HbSS or HbS beta 0 thalassemia) having more severe disease and shortened lifespan compared to patients with HbSC or HbS beta + thalassemia (NHLBI, 2014). Published average lifespans are still in the 40s for HbSS disease and the 60s for HbSC disease. Other factors affecting disease severity include comorbid conditions, such as asthma, and adherence to therapies. Utilization rates have also been used as indicators of disease severity, but illness perceptions need to be considered: Logan, Radcliffe, and Smith-Whitley (2002) found that perceived illness-related stress by parents and adolescents with SCD predicted routine clinic and urgent service use (e.g., emergency room visits).

Anemia

One of the hallmarks of SCD is anemia, or low hemoglobin levels (Ballas, 1998). Sickle red blood cells last 10–20 days (compared to normal red blood cells, which last 120 days), and this leads to anemia. As the red blood cells travel through the body to deliver oxygen, they become irreversibly sickled, increasing rate of death and severity of anemia, and leading to pain and organ damage. Symptoms of anemia include easy fatigue and exercise intolerance.

Pain

The second hallmark of SCD is sickle cell pain, or vaso-occlusive crisis (VOC). VOC varies among and within patients in terms of location, severity, frequency, intensity, and quality, but is categorized as acute (blockage in blood flow), chronic (damage from

repeated restricted blood flow to tissues), or neuropathic (tissue damage from blockage in blood vessels of nerves) (Ballas, Gupta, & Adams-Graves, 2012; Franck, Treadwell, Jacob, & Vichinsky, 2002). Children and adolescents report pain on 7–30% of days, with an average duration of 2.5 days and an average pain rating of 5 on a 10-point scale (Dampier, Ely, Brodecki, & O'Neal, 2002). Different pain trajectories may be evident according to frequency, age of onset (infancy, childhood), and age at peak pain frequency, as well as disease type (Dampier et al., 2014). Pain can be spontaneous, but is often precipitated by cold, dehydration, emotional stress, or physical illness (Ballas, 1998). Over 90% of pain episodes are treated at home (Smith & Scherer, 2010), but it remains the leading reason for hospital admissions (Ballas et al., 2012). Higher initial number of body sites with pain and higher pain intensity scores have been associated with longer length of hospital stay (Fosdal, 2015).

The NHLBI (2014) sickle cell guidelines give recommendations for the evaluation and treatment of VOC. Strong evidence supports rapid treatment with around-the-clock administration of oral or intravenous opioids, and, to a lesser degree, the addition of nonsteroidal anti-inflammatory medications for acute sickle cell pain. There is no evidence to support the use of short-acting opioid medications in chronic pain, which may be associated with bone damage from repeated episodes of sickling (avascular necrosis), may be neuropathic pain from frequent pain episodes, or may be less specific in nature. Acute pain should also be treated with oral or intravenous hydration, application of heat, and distraction. There is significant bias against patients with SCD in the medical community as "pain medication seekers," though addiction to pain medication is actually lower in this group than in the overall community (Solomon, 2008).

Infectious Complications

Reduced or absent splenic function places patients with SCD at high risk for rapid death from bacterial infections. The NHLBI (2014) guidelines recommend immediate care for all patients with SCD for any temperature greater than 101°F, due to this risk for death. Penicillin prophylaxis from birth to 5 years of age has greatly lowered the risk of death in early childhood. However, medication adherence rates were less than 50% in one study (Walsh et al., 2014) and only 55% for adhering to fever recommendations in another study (Schultz et al., 2015).

Pulmonary and Cardiac Complications

Children with SCD have a 20–50% risk of asthma, and those with asthma have twice as much risk for death as patients with SCD without asthma have (Knight-Madden, Barton-Gooden, Weaver, Reid, & Greenough, 2013). Pulmonary hypertension is a complication of young adults that confers a 2-year mortality rate greater than 50% (Ataga et al., 2006). It is suspected when patients have shortness of breath at rest and inability to exercise.

Renal Disease

Patients with SCD are likely to have hyposthenuria, or the inability to concentrate urine, which results in frequent urination and often nocturnal enuresis. Kidney disease pro-

gresses to end-stage renal failure in 16–18% of patients with SCD (Nath & Hebbel, 2015).

Stroke and Central Nervous System Complications

Stroke is one of the most feared complications of SCD, previously affecting nearly 10% of children (Frempong, 1991). Strokes in children are typically ischemic strokes of the middle cerebral arteries, presenting as one-sided weakness, aphasia, seizures, or altered consciousness. Children who have a stroke have more than a 50% chance of recurrent stroke unless they begin lifelong monthly blood transfusions (Ware et al., 2011). Primary stroke prevention is now the standard of care, with all children with sickle cell anemia screened by ultrasound annually from 2 to 16 years of age. An additional 35% of children with sickle cell anemia have silent infarcts—strokes found by magnetic resonance imaging that do not have overt physical signs (DeBaun et al., 2014).

Growth and Development

Children with sickle cell anemia often experience delayed growth and puberty—on average, 2 years later than other children (Rhodes et al., 2009). Women with SCD are able to have children of their own, but require high-risk obstetric care (Yu, Stasiowska, Stephens, Awogbade, & Davies, 2009). Men with SCD have normal fertility, but are at risk for impotence from priapism, an unwanted painful erection (Olujohungbe et al., 2011).

Treatment Options

Children with SCD are now expected to live into adulthood, so the goals of treatment have turned from survival to health. The NHLBI (2014) guidelines include health maintenance, management of acute complications, and management of chronic complications, although they note the paucity of randomized clinical trials in SCD.

Hydroxyurea

Hydroxyurea (HU) is the only medication approved by the U.S. Food and Drug Administration for use in SCD. Research has documented decreased pain and acute chest syndrome, and increased hemoglobin levels and survival rates, with the use of HU (Steinberg et al., 2010). Studies have further shown that the medication is safe and effective in children as young as 9 months of age (Wang et al., 2011). Despite HU's known efficacy and safety, adherence remains problematic (Walsh et al., 2014); problems with swallowing capsules, forgetting, and not wanting to take the medication are potential targets for intervention (Creary, Gladwin, Byrne, Hildesheim, & Krishnamurti, 2014).

Chronic Transfusion Therapy

Transfusion therapy is recommended for all patients with SCD who have had a stroke or are at risk of stroke, but not for pain episodes. The benefits of transfusion must be weighed against the risks of iron overload. Each transfusion of red blood cells contains

iron that the body is unable to get rid of on its own, eventually damaging the liver, heart, pancreas, pituitary, and gonads. Without chelation therapy with daily oral medication or subcutaneous infusions overnight, transfused patients die of heart failure from iron overload. Adherence to chelation has been abysmal due to side effects, but newer formulations are now available that may promote daily use (Walsh et al., 2014).

Stem Cell Transplant

The only cure currently available to patients with sickle cell anemia is stem cell transplant. The major impediments to stem cell transplant are the low availability of matched donors, and the risks of complications from transplant, including a small but real risk of death (Locatelli & Pagliara, 2012). It is hoped that newer regimens will decrease toxicity and other risks of transplant without losing efficacy. The ultimate hope for cure may lie in gene therapy, now in the early phases of clinical trials (Chandrakasan & Malik, 2014).

Adherence

A review of medication adherence in pediatric patients with SCD found overall adherece rates between 48 and 89% (Walsh et al., 2014). Adherence has been higher for more concrete recommendations, such as follow-up clinic appointments, and lower for vague recommendations, such as maintaining hydration (Barakat, Lutz, Smith-Whitley, & Ohene-Frempong, 2005). Forgetting, time constraints/competing activities, running out of medication, and health status have been identified as barriers to adherence, with adherence being more adversely affected by multiple barriers (Crosby et al., 2009; Witherspoon & Drotar, 2006). Few interventions have been developed to address these barriers, but the advent of eHealth and mHealth may offer feasible and effective approaches to promoting adherence—for instance, through the use of an Avatar (Crosby et al., 2012; Modi, Crosby, Hines, Drotoar, & Mitchell, 2012) or a mobile device (Creary et al., 2014).

PSYCHOSOCIAL ASPECTS

Children and adolescents with SCD are at risk for psychosocial distress within emotional and social domains of functioning. The literature has consistently shown greater risk in these youth for internalizing behaviors (i.e., depression, anxiety) and, to a lesser extent, externalizing behaviors (e.g., attention-deficit/hyperactivity, oppositional defiance) (Anie, 2005; Benton, Boyd, Ifeagwu, Feldtmose, & Smith-Whitley, 2011). Issues raised within studies have included the lack of attention to ethnicity, socioeconomic status, and racial discrimination in research on psychosocial outcomes (Trepacz, Vannatta, Gerhardt, Ramey, & Noll, 2004), as well as the potential overlap among symptoms of SCD and psychiatric conditions (e.g., disrupted sleep, fatigue) (Benton, Ifeagwu, & Smith-Whitley, 2007). A relationship has, in fact, been found between greater rates of painful crises and higher levels of depression and state anxiety in youth with SCD (Unal, Toros, Kutuk, & Uyaniker, 2011). In addition, higher hospital admission rates and length of stays for pain crises have been obtained for toddlers/preschoolers with

behavior problems (Bakri, Ismail, Elsedfy, Amr, & Ibrahim, 2014) and children/adolescents with mental health diagnoses (Myrvik, Burks, Hoffmann, Dasgupta, & Panepinto, 2013). Children's functional disability also has been predicted by their parents' response to their pain, especially in children with more depression and anxiety (Peterson & Palermo, 2004).

Health-Related Quality of Life

Over the past 10 years, the evaluation of the psychosocial functioning of youth with SCD has focused more on the multidimensional construct of "quality of life" than on individual psychological areas of dysfunction. Patient characteristics (age, gender, mental health status), family demographics (parental education, socioeconomic status), and disease severity (disease-related complications, comorbid conditions, treatments, utilization rates) have been examined in relation to health-related quality of life (HRQoL). Female gender has been associated with poorer self-reported physical HRQoL (e.g., Jackson, Lemanek, Clough-Paabo, & Rhodes, 2014; Palermo, Schwartz, Drotar, & McGowan, 2002). Older children and adolescents have increased odds of poorer psychosocial HRQoL, according to parent reports but not child reports (e.g., Panepinto, O'Mahar, DeBaun, Loberiza, & Scott, 2005). Improvement over time in self-reported physical and psychosocial HRQoL has, in fact, been found for both adolescents and young adults with SCD (Jackson et al., 2014). Psychological symptoms or neurobehavioral comorbidities have been associated with poorer parent-reported psychosocial HRQoL among youth (Panepinto et al., 2005) and self-reported psychosocial HRQoL among adolescents and young adults with SCD (Jackson et al., 2014). More severe disease (i.e., pain frequency and intensity) and greater health care utilization have been related to worse physical HRQoL of children and adolescents, according to parents (e.g., Dampier et al., 2010; Palermo, Riley, & Mitchell, 2008). Both barriers to treatment adherence (Fisak, Belkin, von Lehe, & Bansal, 2011) and actual adherence (Barakat et al., 2005) have been associated with poorer HRQoL. Barakat and colleagues have suggested that better adherence may have a negative impact on HRQoL, due to possible interference with physical and social activities. Conflicting results on HRQoL have been found regarding socioeconomic status when measured by parental education or work status (Palermo et al., 2002; Panepinto et al., 2005). When controlling for family income, patient age, and number of comorbid conditions, Panepinto, Pajewski, Forester, Sabnis, and Hoffman (2009) revealed impaired parent-reported and child-reported physical HRQoL. In addition, Palermo et al. (2008) identified individual/family socioeconomic distress as a significant predictor of children's physical and psychosocial HRQoL, and neighborhood socioeconomic distress as an independent predictor of physical HRQoL.

Pain Management

The variability of pain expression in all individuals with SCD is due to physical, psychological, social, cultural, and spiritual factors (Ballas et al., 2012). To address this variability, research has focused on coping as a fluid process of managing stress related to SCD and to life events (Hildenbrand, Barakat, Alderfer, & Marsac, 2015; Mitchell et al., 2007). Children and their parents have been shown to use both adaptive approach-oriented (e.g., social support, relaxation) and avoidant-oriented (e.g., distraction) coping

and coping assistance strategies, respectively. Such active coping strategies have been consistently associated with decreases in negative thinking, increases in active health management, fewer school absences, and more involvement in daily activities on pain days. Greater use of coping strategies by youth have also been related to decreased parent involvement in disease management tasks (Oliver-Carpenter, Barach, Crosby, Valenzuela, & Mitchell, 2015), which may promote independence in making the transition to adult health care.

A few interventions for management of SCD have been developed since the review of psychosocial interventions for pain and adherence by Chen, Cole, and Kato (2004), but further empirical support is needed. Extending an earlier study using smartphone technology (McClellan et al., 2009), Schatz et al. (2015) implemented one session of cognitive-behavioral training, including psychoeducation about pain and coping and demonstration of distraction, deep breathing, and guided imagery, along with a home-based practice within a randomized clinical trial. Results showed increased use of active coping strategies and reduced next-day pain intensity when these strategies were used, but no change in negative thinking or functional activity, in youth with SCD. Two quasi-experimental studies showed that one session of training in guided imagery (Dobson & Byrne, 2014) or biofeedback-assisted relaxation training (Myrvik, Campbell, & Butcher, 2012) with home daily practice was effective in reducing pain frequency, pain intensity during pain episodes, and functional disability. Cognitive-behavioral techniques were evaluated by Barakat, Schwartz, Salamon, and Radciffe (2010) within a family-based intervention that incorporated home-based and community-based culturally sensitive material for adolescents with SCD. Small to medium effects on health-related and psychosocial variables were obtained, but only when the intervention and the attention control groups were combined.

Cognitive Functioning

Neuropsychological research on children with SCD has most often included some combination of comparison groups: children who have experienced a documented neurological infarct, silent infarct, or no infarct, and healthy controls. In general, studies have revealed inverse relations between the degree of neurological injury and cognitive functioning (Berkelhammer et al., 2007). Findings have documented deficits in IQ, executive functioning, memory, language, visual–motor abilities, and academic achievement. A meta-analysis of 18 studies indicated an overall significant but small effect size in the magnitude of difference in full-scale IQ between children with SCD and healthy controls, with larger effect sizes as children grew older (Schatz, Finke, Kellett, & Kramer, 2002). Greater lesion volume and experience of silent infarct have both indicated increased cognitive impairment (Schatz et al., 2002; King et al., 2014). However, lower IQ scores have been found in children without any neurological injury, compared to healthy controls (Steen et al., 2005).

Deficits in attention and executive functioning have been well documented as generally related to the existence and severity of neurological injury (Schatz et al., 2002). When compared to children with SCD with no history of injury, children with SCD with documented stroke or silent infarct have demonstrated greater impairments in sustained attention (Brown et al., 2000), although children without any neurological injury have also demonstrated these deficits (Schatz, Brown, Pascual, Hsu, & DeBaun, 2001).

Lesion location has been implicated in executive functioning deficits (including working memory deficiencies) and in spatial skill deficits (Wang et al., 2001). Deficits in syntactical skills, working memory, and cognitive flexibility have been associated with actual cerebral blood flow as measured by transcranial Doppler velocities (Sanchez, Schatz, & Roberts, 2010).

Research has described academic difficulties as additional areas of potential challenge. Young children with SCD have demonstrated fewer school readiness skills, compared to healthy controls (Steen et al., 2002). Deficits in reading and math have been documented, though inconsistent, when children with and without infarct are compared (Berkelhammer et al., 2007). Children with SCD, particularly those with silent infarct, experience grade retention or special education services more often than healthy controls do (Schatz et al., 2001; King et al., 2014). Disease and management variables may also have indirect effects on academic concerns, including the impact of school absences due to hospitalizations, medical appointments, or pain (Schatz, Finke, & Roberts, 2004).

Transition

SCD is now considered a lifelong condition rather than a childhood disease, due to increased life expectancy rates (Quinn, Rogers, McCavit, & Buchanan, 2010). Adequate transition from pediatric care to appropriate adult-based medical care is warranted, in that young adults have a higher risk for death following transition (Quinn et al., 2010). Transition should be a dynamic process rather than a one-time event (Treadwell, Telfair, Gibson, Johnson, & Osunkwo, 2011). Studies have found that concerns of adolescents, caregivers, and siblings include lack of transition information, fears about leaving pediatric care providers, and worry about adult care providers' abilities to understand and treat the patients' needs (Porter, Graff, Lopez, & Hankins, 2014; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004).

"Transition readiness" is part of the dynamic process, including assessments of a patient's thoughts about transition, anticipated difficulties, knowledge of medical history, and identification of a new provider (McPherson, Thaniel, & Minniti, 2009; van Staa, Jedeloo, van Meeteren, & Latour, 2011). These studies have found overall low readiness scores and lower scores on specific areas, such as knowledge and interest in transition. Higher disease severity has been associated with lower interest in transition and higher anticipated transition difficulty. However, Anie and Telfair (2005) found that more physical symptoms predicted greater self-efficacy, which may suggest higher efficacious disease self-management. Although age has been associated with responsibility for care (Anie & Telfair, 2005), older age at onset of the transition process has been identified as a risk factor for unsuccessful transition (Andemariam et al., 2014).

Systemic issues also have an impact on transition, including limited access to appropriate providers, insurance issues, and communication between pediatric and adult care providers (Treadwell et al., 2011). Identifying an adult provider has been a challenging aspect of transition, probably due in part to the limited availability of adult hematologists (Sobota, Neufeld, Sprinz, & Heeney, 2011). Patients and providers alike express a need for education, including more collaboration between pediatric and adult care settings, knowledge about long-term effects of SCD, and discussion regarding responsibilities of self-management (van Staa et al., 2011). Although 89% of SCD care providers

recognized the need for a systematic transition process, only 67% reported engaging in any type of transition activity (Telfair et al., 2004).

SCD centers are expanding transition programs to include transition schedules, multidisciplinary teams, multimedia materials, and readiness assessment (Montalembert & Guitton, 2013). The American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians (2011) recommend that transition should include an introduction, modification of transition plans to accommodate for each patient's individual differences, plan revisions, and readiness checklists. Interventions should be based on a theoretical framework (e.g., developmental-ecological), and program success should be assessed (Griffin et al., 2013), though only about 54% of SCD centers formally evaluate their programs (Sobota et al., 2011).

FUTURE DIRECTIONS

The focus of future research and clinical care for children and adolescents with SCD and their families should be on integrating medical and mental health care services. Previous recommendations are still applicable following this review of the literature: use of qualitative and quantitative assessment methods to assess adaptation (Hildenbrand et al., 2015) over time (Jackson et al., 2014); screening of emotional, behavioral, and social functioning (Unal et al., 2011); screening of developmental status and neurocognitive/academic functioning, along with early intervention services and educational programs to address developmental and academic needs (Glass et al., 2013); family-focused interventions directed toward disease management and using culturally sensitive materials (Barakat et al., 2010); and effective transition readiness programs for adolescents and young adults (Griffin et al., 2013). The role of medical and psychosocial variables as predisposing, precipitating, or perpetuating factors will also need to be determined within this multilevel system of research and care (Bakri et al., 2014; Benton et al., 2007).

In addition, the issue of health care disparities in ethnic minority populations and those living in poverty will need to be addressed, as it directly affects the physical and psychosocial functioning of children with SCD. Data indicate that families of children with SCD experience difficulties accessing health care services (e.g., getting appointments and medications), due to such factors as insurance/managed care coverage and authorization policies (e.g., Boulet, Yanni, Creary, & Olney, 2010; Newacheck, McManus, Fox, Hung, & Halfon, 2000). Studies also show that the household income of many children with SCD is below the federal poverty level, which also affects access to and use of health care (Boulet et al., 2010). Efforts by the Centers for Medicare and Medicaid Services to reduce hospital readmissions for certain diagnoses, such as SCD, may have a further impact on care, due to the high 30-day readmission rates (over 30%) found for pediatric and adult patients (Stone, 2015).

A patient-centered medical home (PCMH), with a focus on continuous, comprehensive, family-centered, coordinated, and culturally effective care, may offer a framework in which to place these recommendations (American Academy of Pediatrics, Section on Hematology/Oncology, Committee on Genetics, 2002). A PCMH may be based within a multidisciplinary SCD clinic in collaboration with a primary care pediatrician, or within a primary care pediatric practice where referrals are made to SCD specialists. Family and patient education (including genetic education and counseling), health

maintenance, acute illness care, and psychosocial care would be key components of the PCMH. Such factors as the expertise of the primary care pediatrician, availability of a multidisciplinary SCD team, family choice, and complexity of SCD will determine which setting is best for individual patients and their families. In addition to overall difficulties in accessing a PCMH for children with SCD, one study identified the coordination of care as a particularly challenging component (Raphael, Rattler, Kowalkowski, Mueller, & Giordano, 2013). Within such a PCMH, the role of social networks will need to be examined as it relates to disease and health care management, with specific attention to relationships between medical providers and extended family members (Vaughn et al., 2011). Ensuring comprehensive standards of care that include empirically supported psychosocial services for children and adolescents with SCD and their families will be essential as health care policies and practices evolve within the current and future health care system.

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CHAPTER 22

Pediatric Cancer

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Approximately 1 in every 285 individuals in the United States will be diagnosed with cancer before the age of 20, resulting in over 15,000 new cases per year (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Cancer in children varies widely in terms of histology, location, required treatment, expected late effects, and overall prognosis. Acute lymphoblastic leukemia (ALL) is the most common malignancy in children (26%), and brain tumors are the most common solid tumors (21%). Hodgkin and non-Hodgkin lymphoma are the most common (21%) diagnoses during adolescence, followed by thyroid (11%), brain (10%), and testicular (8%) tumors. Survival at 5 years postdiagnosis is now achieved for over 80% of youth with cancer, and approximately 1 in every 530 young adults in United States is a cancer survivor. This contrasts sharply with the view of pediatric cancer as a fatal illness 30 or more years ago; however, cancer remains the leading cause of death by disease for children, and successful treatment completion is not a guarantee that life returns to "normal." Improved prognosis has been achieved with aggressive protocols that can create considerable symptom burden and family disruption during treatment, as well as medical and behavioral late effects that may affect development and reduce quality of life. Late recurrences or secondary cancers remain significant threats and are growing causes of death for long-term survivors during adulthood. Nonetheless, there is increasing recognition that substantial numbers of affected children and their families demonstrate great resilience.

MODELS AND STANDARDS OF PSYCHOSOCIAL CARE

Biopsychosocial (Armstrong, 2006), family ecological (Alderfer & Kazak, 2006), and lifespan developmental (Gerhardt, Tuinman, & Vannatta, 2015) models strongly inform

the clinical efforts and research of psychologists within pediatric oncology. Practice models vary widely among treatment centers, but psychologists often serve as consultants to, or integrated members of, multidisciplinary oncology teams. Involvement may be triggered at diagnosis as part of routine care, or may be solicited when members of the health care team identify behavioral or emotional concerns involving a child or family (Selove, Kroll, Coppes, & Cheng, 2012). Efforts to facilitate appropriate care and allocate limited psychosocial resources have led to an emphasis on early psychosocial screening of families, in order to identify child, family, and socioecological risk factors (Kazak, Schneider, Didonato, & Pai, 2015). The benefits of titrated care have been increasingly documented (e.g., Barrera et al., 2014; Kazak et al., 2011). Psychologists provide services to improve emotional and behavioral outcomes for patients, parents, and siblings; to reduce the physical symptoms associated with cancer care; and to facilitate communication and the delivery of medical intervention. International pediatric oncology and psycho-oncology organizations have advocated that psychosocial services are an essential component of efforts to provide treatment and reduce suffering for all children with cancer. Unfortunately, few if any of those calls were accompanied by detailed recommendations for the services that should be required across the continuum of cancer care (Wiener, Viola, Koretski, Perper, & Patenaude, 2015). Comprehensive standards for training, multidisciplinary collaboration, psychosocial and neurocognitive assessment, and intervention with individuals and families were published by panels of experts in a special issue of *Pediatric Blood and Cancer* in December, 2015 (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015).

PHASES OF CANCER CARE

Distinct phases in the course of the cancer experience create different stressors for families and opportunities for psychologists to assess, intervene, and collaborate with multidisciplinary teams. The initial weeks after diagnosis are a chaotic time for families, as they struggle to understand and share complex medical information and make rapid decisions regarding treatment and clinical trial participation. The intensity, duration, and setting (i.e., hospital, outpatient clinic, family home) of active treatment vary markedly by diagnosis, with variations in protocols triggered by a child's age and gender, as well as by a growing number of genetic markers. Traditionally, treatment involves induction, consolidation, and maintenance of cancer remission; however, treatment for different diagnoses can range from a single surgical resection to years of multimodal therapy combining oral, intravenous, or intrathecal chemotherapy, surgery, radiation, stem cell transplant, and/or novel immunotherapies (American Cancer Society, 2015). Children and parents cite both common and distinct concerns during treatment. Children may experience barriers to participation in normative roles and activities as their greatest sources of stress during treatment, while parents report managing the physical side effects of treatment and managing emotional reactions as areas of concern (Rodriguez et al., 2012).

The eventual transition off active treatment can involve a mixture of celebration and worry about whether treatment will be a long-term success. Primary caregivers in particular may experience fears about "what comes next" and wariness about losing the structured support of a trusted group of multidisciplinary providers (Wakefield

et al., 2010). There may be pressure (if it has not already been experienced) to resume "normative" roles at work for parents, in school and with friends for survivors, and to reestablish family roles and routines. Uncertainty about disease recurrence, secondary malignancy, or the emergence of late effects is expected at this time. Those concerns may continue into the survivorship period, when care continues to involve ongoing surveillance for new or recurrent cancer, as well as evaluation or treatment of medical late effects. This phase is a common point of contact with families by behavioral researchers, but is a less intensive period of clinical assessment and intervention. "Long-term survivorship" refers to children's reaching the 5-year anniversary of their cancer diagnosis without signs of active or progressive disease. Depending on the age of diagnosis, this period may be long before or within adulthood, but there is an expectation that medical care and surveillance will be lifelong and tailored to each individual's cancer-specific risks (Eshelman-Kent et al., 2011).

Finally, a subset of children will not respond fully to cancer treatment or will develop other life-threatening complications. Treatment decisions and communication challenges in the context of advanced cancer can resemble diagnosis, but now involves consideration of whether to shift goals to emphasize palliative versus tumor-directed care.

Diagnosis and Initiation of Treatment: Communication and Decision Making

The diagnosis of a child's cancer involves considerable distress, invasive or painful diagnostic procedures, and an avalanche of information. Although communication is important throughout all phases of cancer care, it is particularly critical when families must make initial decisions about treatment and clinical trial participation. Parents can find it difficult to assess a child's prognosis accurately, whether this difficulty is due to communication gaps with medical providers, conflicting information from different sources, or active efforts to maintain optimism and hope (Mack, Wolfe, Grier, Cleary, & Weeks, 2006; Miller et al., 2012). They may not understand key elements of clinical trials, such as random assignment to conditions or the fact that they even have a choice about whether to participate in research (Kodish et al., 2004). Written summaries, staged consent discussions, and multidisciplinary participation in informational meetings have been suggested by patients and parents as useful ways to guide their decision making and acquisition of complex information (Baker et al., 2013).

Although the National Cancer Institute recommends open and honest communication with children about their diagnosis and treatment, little research informs how this can best be accomplished by parents and medical care providers. Parents often need to translate difficult and complex information to their child as well as other family members. Although involvement of children in decision making is ideal, child presence when parents are seeking information may alter this process considerably (Olechnowicz, Eder, Simon, Zyzanski, & Kodish, 2002; Whitney et al., 2006). Pediatric psychologists can help parents construct developmentally appropriate explanations and address difficult questions that arise, while providing support to children and parents during complicated conversations. Although parents often fear that delivering accurate information to a child will cause the child anxiety, the opposite is generally true; indeed, open communication reduces uncertainty and provides a sense of control (Grootenhuis & Last, 2006).

Active Treatment: Managing New Roles and Routines, Symptom Burden, and Emotional Distress

Pediatric cancer affects entire families, and lengthy, intensive treatment inevitably creates shifts in family routines to meet competing demands and caregiver responsibilities. Parents often divide roles and responsibilities, with one assuming primary responsibility for managing the affected child's medical care and the other overseeing financial and household needs, including the care of siblings (Long & Marsland, 2011). A growing body of research is addressing the often overlooked impact of cancer on siblings, including their informational needs, risk for adverse outcomes, and possible benefit from psychosocial intervention (Alderfer et al., 2010). Nonetheless, few consistent perceived deficits in family functioning have been found, particularly after the first year of treatment (Van Schoors, Caes, Verhofstadt, Goubert, & Alderfer, 2015). Mothers, but not fathers, of children with cancer have reported elevations in family conflict (Pai et al., 2007); this difference is believed to result from the division in family responsibilities at the hospital and home (Long & Marsland, 2011). A common myth has been that the strain of caring for a child with cancer erodes the quality of the relationship between parents; however, marital/couple satisfaction does not appear to be systematically different from that of other parents (Pai et al., 2007). Furthermore, divorce rates or changes in parental cohabitation status are similar to those in the general population (Grant et al., 2012).

The burden of physical symptoms associated with cancer treatment is well recognized, and children commonly experience anticipatory or reactive nausea and vomiting, pain, and procedural distress. Parents rate a child's pain, fatigue, lack of appetite, and emotional distress as major concerns during treatment (Heden, Poder, von Essen, & Ljungman, 2013; Rodriguez et al., 2012). Behavioral approaches to symptom management are well validated and recommended as part of standard services for children undergoing cancer treatment; however, implementation remains inconsistent (Duff, Gaskell, Jacobs, & Houghton, 2012; Redd, Montgomery, & DuHamel, 2001). Behavioral relaxation strategies (e.g., diaphragmatic deep breathing, guided imagery, progressive muscle relaxation, and biofeedback) can address pain, nausea, or tension associated with anxiety. Distraction is commonly taught to children as a method for diverting attention from pain and distress related to invasive procedures, and parents are often trained to engage their children in these approaches (see Law, Noel, Nagel, & Dahlquist, Chapter 11, and Cohen et al., Chapter 12, this volume). Emerging areas of research on symptom management center around the role parents play in amplifying or dampening a child's distress through their own emotional and behavioral responses during procedures and over time (Caes et al., 2014; Cline et al., 2006; Harper et al., 2013).

Side effects of medical treatments (e.g., nausea, pain, fatigue, alterations in appearance) may be one reason why there are poor rates of adherence to prescribed treatment in pediatric oncology. Poor adherence to oral medications (e.g., maintenance doses of chemotherapy for leukemia) increases the likelihood of disease recurrence and death (Lilleyman & Lennard, 1996). It has been estimated that adolescents with cancer may take less than half of their prescribed oral chemotherapy (Butow et al., 2010); such estimates have led to recommendations for routine, objective assessments of adherence, as well as development of more effective interventions (McGrady, Williams, Davies, &

Pai, 2014). Families often struggle to find a balance between encouraging their child's independence and ensuring delivery of treatment (Landier et al., 2011). As in other illness populations, positive family relationships and open communication are predictive of better adherence (Butow et al., 2010). Interventions to promote treatment adherence (see Hommel, Ramsey, Loiselle Rich, & Ryan, Chapter 10, this volume) are frequently implemented by psychologists working within pediatric oncology centers, although probably less systematically than desired. Later in the cancer trajectory, adherence concerns center around engagement in recommended follow-up care (Landier, Wallace, & Hudson, 2006) and recommended health promotion practices (Zhang et al., 2015).

During the course of cancer treatment, concerns may arise regarding distress or shifts in a child's mood, often with observations of changes in appetite and sleep, fatigue, and irritability. Differential diagnosis can be challenging, as illness and treatment factors (e.g., oral corticosteroids) can cause acute or chronic changes in affect or behavioral state (Drozdowicz & Bostwick, 2014). Overall, elevations in internalizing symptoms for children with cancer are significant but modest (Pinquart & Shen, 2011), and there is little evidence of persistent distress, particularly after the early stages of treatment (Patenaude & Kupst, 2005). Dispositional and coping models have been the focus of significant research, but these studies have had somewhat different aims and conclusions. Efforts to explain high rates of resilience in children with cancer have linked a repressive adaptive style with lower than average levels of depressive and posttraumatic stress symptoms (Phipps, 2007). Alternatively, the use of engagement coping to manage cancer-related stress, particularly secondary control coping strategies, is predictive of lower internalizing symptoms during treatment that overall appear to exceed normative levels but may not reach clinical cutoffs (Compas et al., 2014).

Caregivers of children with cancer demonstrate statistically significant elevations in general distress and posttraumatic stress symptoms, compared to instrument norms and parents of healthy children (Pai et al., 2007). These small to medium effects are stronger for mothers than fathers. Longitudinal studies report elevations in parental distress primarily at the time of a child's cancer diagnosis and early treatment (Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006), although elevated distress may continue for a subset of parents (Vrijmoet-Wiersma et al., 2008). Investigation of coping by parents suggests that they draw upon a range of approach strategies (Greening & Stoppelbein, 2007) both to manage cancer-related stressors (i.e., primary control coping), and to redefine those stressors and manage their subsequent impact (i.e., secondary control coping) (Compas et al., 2015). Interestingly, secondary control coping may result in positive benefits for partners as well as individuals themselves.

Models of traumatic stress (see Kazak, Price, & Kassam-Adams, Chapter 14, this volume) have greatly influenced conceptualization of child and parental outcomes across the course of care for pediatric cancer, leading to an emphasis on levels of acute and posttraumatic stress symptoms in children with cancer and their family members. Rates of formally diagnosed posttraumatic stress disorder (PTSD) are low within this population; however, elevations in posttraumatic stress symptoms (PTSS) have been consistently reported, particularly for parents of children during treatment and survivorship (Brown, Madan-Swain, & Lambert, 2003; Dunn et al., 2012; Kazak et al., 2004). Contradictory findings have also emerged, including reports that levels of PTSS do not exceed those found in families of typically developing children or may actually

decline to below average during long-term survivorship (Howard Sharp, Rowe, Russell, Long, & Phipps, 2015; Phipps et al., 2015).

Efforts to resolve these discrepancies have focused on methodological factors (e.g., study inclusion criteria) and methods for assessing PTSS in cancer and control samples (e.g., asking questions that focus individuals' attention on the "trauma" associated with their cancer care) (Phipps et al., 2015; Werba & Kazak, 2009). Particularly productive has been research identifying individual differences that may account for variability in PTSS above and beyond objective characteristics of the cancer experience, such as differences in temperament and trait anxiety in children or parents (Harper et al., 2014; Howard Sharp, Rowe, et al., 2015). There is growing evidence that prior experiences place certain individuals at greater risk for PTSS—for example, parents who have a history of prior traumatic life events (Boman, Kjallander, Eksborg, & Becker, 2013) or are experiencing the relapse of their child's cancer (Jurbergs, Long, Ticona, & Phipps, 2009). This is consistent with theory and work with other populations (Werba & Kazak, 2009), where there is evidence that PTSS risk in children is reduced in the context of caregiver support and overall connectivity to others (Howard Sharp, Willard, et al., 2015). Finally, posttraumatic growth has been a rising area of interest in pediatric oncology; researchers are increasingly recognizing the potential for psychological and interpersonal benefits that accompany or follow cancer treatment (Barakat, Alderfer, & Kazak, 2006; Phipps et al., 2014, 2015).

Given evidence that the experience of pediatric cancer can be highly stressful, and that at least a subset of parents, siblings, and possibly patients experience heightened distress or decreased quality of life, there are ongoing efforts to develop and validate interventions based on cognitive-behavioral and family systems models. Consistent with systems theories, addressing parental stress has been identified as key to facilitating not only parental adjustment, but the adjustment of the ill child and siblings as well. These interventions have focused primarily on teaching parents problem solving, improving family communication, and accessing social support (Kazak et al., 1999; Marsland et al., 2013; Mullins et al., 2012; Sahler et al., 2013). The results of these programs have been variable, with inconsistent or small effects. Control conditions in these studies are typically "treatment as usual" or standard psychosocial care (e.g., access to multidisciplinary psychosocial services). This may suggest that families benefit from these routine services or that only a subset of at-risk families would benefit from more targeted intervention. Finally, as in the rest of pediatric psychology (see Cushing, Chapter 16, this volume), there are emerging efforts to use technology to make interventions more appealing and increase the feasibility of delivering interventions to families who may have logistical barriers to participating in traditional in-person protocols or are weary of time spent at the medical center (Sahler et al., 2013; Wakefield et al., 2015).

Treatment Completion and Survivorship: Transitions and Development

New stresses are associated with the completion of cancer treatment and the early stages of survivorship. Children and families are focused during this time on reestablishing "normal" life and resuming or prioritizing roles that may have been substantially altered during active treatment. The focus of medical care becomes ongoing assessment and treatment for emerging medical late effects, as well as cancer recurrence or secondary malignancy. Late effects involve physical and functional impairments that may emerge,

persist, and even intensify a year or more after therapy ends, depending upon an individual's primary disease and specific treatments (Meck, Leary, & Sills, 2006). Large cohort studies such as the Childhood Cancer Survivorship Study (*https://ccss.stjude.org*) have identified the relative risks of different medical and behavioral late effects in survivor subpopulations, as well as patterns of health behaviors and service utilization. The impact and meaning of different late effects may vary at different developmental periods or transitions (Gerhardt et al., 2015). Despite the availability of comprehensive and personalized risk information (Children's Oncology Group, 2014), complex informational needs regarding late effects are likely to be present at treatment completion (Wakefield, Butow, Fleming, Daniel, & Cohn, 2012), and adult survivors identify unmet informational needs as a major concern (Keegan et al., 2012).

Neurocognitive late effects that result from treatment directed to the central nervous system (CNS)—either for primary brain tumors or for malignancies that can disseminate to the CNS—can include specific deficits in attention, memory, processing speed, and visual–motor integration, as well as broader indicators of diminished global cognitive abilities and academic performance (Campbell et al., 2007; Robinson et al., 2010). Although these deficits can begin to manifest themselves during active treatment, they are often conceptualized as late effects that emerge or worsen a year or more after treatment completion. Cranial radiation, younger age at treatment, time since treatment, and female gender are recognized as risk factors, and clinical trials have actively sought to reduce or eliminate radiation from treatment protocols, particularly for younger children, with mixed results (Castellino, Ullrich, Whelen, & Lange, 2014). Although some research has addressed the role of contextual factors (e.g., socioeconomic disadvantage, quality of the home environment, parent–child interactions) that may increase vulnerability to neurocognitive late effects and associated academic or psychosocial sequelae, this is an area that warrants greater attention (Ach et al., 2013; Patel et al., 2016).

Clinical management of survivors with neurocognitive risk should involve serial assessment of global and specific deficits, as well as functional impact on academic competence and performance (Nathan et al., 2007). Pediatric psychologists and neuropsychologists should not only perform testing, but facilitate parental understanding of results and implementation of recommendations for individualized educational plans. Although school reentry or integration services are recommended to begin while children are undergoing active treatment, ongoing involvement can educate school personnel regarding neurocognitive late effects, support parental advocacy for appropriate services, and encourage survivors' reinvestment in school (Castellino et al., 2014). Rigorous clinical trials have shown only limited success in improving neurocognitive outcomes in survivors via behavioral and pharmacological approaches (Butler et al., 2008; Conklin et al., 2010; Hardy, Willard, Allen, & Bonner, 2013).

Management of neurocognitive late effects should involve ongoing evaluation of additional emotional and behavioral comorbidity. Although childhood cancer survivors are not generally at risk for social maladjustment, survivors of brain tumors and children who receive CNS-directed cancer treatment are at risk for social isolation, victimization, and poor peer acceptance (Salley et al., 2014; Vannatta, Gerhardt, Wells, & Noll, 2007). Social difficulties may be more common than emotional maladjustment for school-age survivors (Schulte & Barrera, 2010); however, adult survivors of brain tumors are at risk for depression, anxiety, suicidal ideation, and severe psychopathology (Shah et al., 2015). Deficits in education, employment, independence, and development

of intimate adult attachments are also identified for long-term survivors of pediatric brain tumors (Gurney et al., 2009; Zeltzer et al., 2009).

There has been steadily increasing interest in efforts to establish clinical models for behavioral health promotion for pediatric cancer survivors (Nathan et al., 2009). Specific health risk behaviors—such as use of tobacco, alcohol, and illegal substances; unsafe sexual practices; and sun exposure without sunscreen—may be equally or only slightly less prevalent in survivors than in the general population (Clarke & Eiser, 2007). This is concerning, given the physical vulnerabilities associated with prior cancer treatment. Poor nutrition (Owens, Hanson, McArthur, & Mikhailov, 2013) and suboptimal levels of physical activity have also raised concern as contributing factors to health challenges such as obesity (Zhang et al., 2014) and poor bone density (Mays et al., 2011). Future work is expected in this growing area of emphasis, with a focus on maintaining or establishing healthy lifestyle behaviors during treatment and early survivorship, as well as among older adolescents and young adults.

As with other chronic conditions originating in childhood, there has been mounting efforts to help pediatric cancer survivors navigate the transfer from pediatric to adult health care providers, although there have been different opinions and limited data about how to meet this growing public health challenge (Heirs et al., 2013). Many long-term survivors remain in pediatric care beyond the age of majority or discontinue recommended care altogether (Casillas et al., 2015). Survivorship clinics tailored to the needs of long-term survivors exist, but may not be available to most and have not yet demonstrated superiority to other models (Ford, Chou, & Sklar, 2013). Theoretical and applied models for the preparation of cancer survivors to assume responsibility for their health care and achieve a planned transfer of their medical care to appropriate settings are contributing to this discussion (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011).

Advanced Cancer and End-of-Life Care: Choices and Dilemmas

Despite remarkable improvements in survival, a subset of children with advanced cancer have a high likelihood of dying from their disease or from treatment-related conditions. Aggressive tumor-directed treatment is likely to continue until very close to the time of death (Fowler et al., 2006), and treatment choices may include experimental therapies that pose new ethical dilemmas and communication challenges (Crites & Kodish, 2013). Documentation of the symptom burden experienced by patients at the end of life promotes consideration of models for better symptom management (Wolfe et al., 2015) and for overcoming barriers to comprehensive palliative care (Weaver et al., 2016). Tools for providing adolescents and young adults with the opportunity to participate in advance care planning are also available and undergoing evaluation (Zadeh, Pao, & Wiener, 2015). Advanced communication training and relationships established with families during earlier stages of cancer care can place psychologists in a strong position to work with medical teams to offer these choices to patients and their families. Continuity of psychosocial care is rare across phases of care involving active treatment, palliative or hospice care, and bereavement. Furthermore, there are significant gaps in our knowledge of what interventions are needed or would be effective. Psychologists need to play an active role in research and program development to establish new, empirically informed models of multidisciplinary care that can meet the needs of these vulnerable children and families.

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CHAPTER 23

Pediatric Traumatic Brain Injury and Spinal Cord Injury

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This chapter provides an overview of the medical, cognitive, and psychosocial consequences of traumatic brain injury (TBI) and spinal cord injury (SCI). These central nervous system (CNS) conditions share the characteristics of a sudden, traumatic onset of a life-altering condition in a previously healthy child or adolescent, and an uncertain (and often extended) course of recovery. However, they differ with respect to their relative effects on cognitive-behavioral versus physical functioning, as well as their attendant caregiving demands. In addition, although TBI affects children of all ages, with peaks in early childhood and adolescence, SCI primarily affects teenagers. This chapter focuses on the assessment and treatment issues associated with these conditions, as well as promising approaches for intervention.

TRAUMATIC BRAIN INJURY

Epidemiology

TBI is a brain insult acquired as the result of an external mechanical force. TBI constitutes a subset of acquired brain injury, but does not include acquired insults from nontraumatic causes, such as anoxia, infections, or tumors. It is the most common cause of death and long-term disability for children under 15 years of age, with nearly half a million children in this age range suffering a TBI every year (Faul, Xu, Wald, & Coronado, 2010). About 90% of pediatric TBI is considered mild (Glasgow Coma Scale [GCS] scores in the 13–15 range, typically without neuroimaging evidence of brain injury). Falls are the leading causes of TBI, with rates highest among children ages 0–4

years and older adults (Faul et al., 2010). Child abuse as a cause of TBI is most common among infants (about 20%). Among children ages 0–2 years, boys are more likely than girls, and nonEuropean American children are more likely than European American children, to incur inflicted TBI. The rates of TBI related to motor vehicle traffic accidents and assault are highest among adolescents. Overall, males are 1.5 times more likely than females to sustain TBI.

Neuropathology and Pathophysiology

The pathophysiology of TBI is usually discussed in terms of "primary" and "secondary" effects. Primary effects are related to the trauma itself, such as skull fractures, contusions, and hemorrhages. Primary injuries most commonly occur as results of the biochemical forces of acceleration–deceleration. Rotational movement can produce focal contusions (bruises), as well as diffuse axonal injury. Focal injury is most common in the frontal and anterior temporal areas, whereas shear strain injury occurs most commonly at the white–gray matter boundaries. Secondary effects occur subsequent to the trauma and include brain swelling, cerebral edema, elevated intracranial pressure, hypoxia, mass lesions, and seizures. Brain damage has been linked to a number of changes in cerebral metabolism that affect the developing brain over an extended period of time, such as excessive production of free radicals and excessive production of excitatory amino acids (Beers, Berger, & Adelson, 2007).

Outcomes

Medical Complications

Possible acute medical complications of TBI include seizures, hydrocephalus, and intracranial infections arising from penetrating injuries (National Institute of Neurological Disorders and Stroke [NINDS], 2015). Pain, particularly headache, is a common acute and long-term consequence of TBI. Acute postconcussive symptoms may include dizziness, vertigo, and sleep difficulties. Children may also experience coordination difficulties and unsteady gait. Other senses, such as vision, hearing, and taste, may be affected, resulting in difficulty recognizing or processing what is being seen, ringing or rushing sounds in the ears (tinnitus), and odd tastes or smells (NINDS, 2015). TBI can also result in endocrine changes, including the early onset of puberty and growth hormone deficiencies (Kaulfers et al., 2010).

Neurobehavioral and Psychosocial Consequences

Moderate to severe TBI in children is typically associated with significant cognitive morbidity and can contribute to short- and long-term deficits in many domains (Babikian & Asarnow, 2009). These include orientation to person, place, and time; intellectual functioning; academic skills; language skills; nonverbal skills; attention, memory, and other executive functions (EFs); and adaptive behavioral competence (e.g., Anderson, Brown, Newitt, & Hoile, 2011; Muscara, Catroppa, & Anderson, 2008). Children with TBI often display characteristics similar to those of children with attention-deficit/hyperactivity disorder (ADHD) or learning disorders, such as concentration problems,

memory deficits, and uneven academic performance. Most important from the perspective of assessment and intervention is that cognitive consequences for a given child can be highly variable, with deficits in some domains or settings and intact abilities in others (Ylvisaker & Feeney, 2007). Although cognitive deficits show improvement over time, there is also evidence that some problems may not emerge or become evident until higher-level skills are required (Anderson et al., 2006). Children with TBI are sometimes described as "growing into" their deficits, making it important to follow children with more severe injuries over time.

Deficits in EFs, discourse, and language pragmatics are common consequences of pediatric TBI that adversely affect both academic and social functioning (e.g., Chapman et al., 2006). Deficits in these skills may not be apparent on traditional intelligence or achievement testing, but may contribute to classroom failure following TBI. Similarly, children with TBI may have difficulties abstracting meaning from both written and spoken language, despite normal performance on tests of language abilities (Chapman et al., 2006). This discrepancy between capacity as assessed in structured testing situations and performance in everyday settings presents challenges for assessment and treatment planning (Chesire, Canto, & Buckley, 2011). Classroom or community observations may provide a valuable complement to traditional office-based assessments.

Behavioral changes represent the most persistent consequences of TBI in children (McKinlay, Grace, Horwood, Fergusson, & MacFarlane, 2009). Research suggests that approximately half of children with TBI develop novel psychiatric disorders in the initial months after injury (Max et al., 2012). These new psychiatric disorders cut across diagnoses and often involve personality changes marked by increased impulsivity and affective lability. Anxiety symptoms are also common (Karver et al., 2012). Recent research also identified specific problems with social information-processing skills and social competence, including fewer friendships (e.g., Muscara, Catroppa, Eren, & Anderson, 2009).

It is often difficult to estimate the effects of TBI on a child's behavior, because children with behavior or learning problems are more likely to sustain traumatic injuries (Goldstrohm & Arffa, 2005). Children with preinjury behavior problems may also be more likely to develop diagnosable disorders after their injuries. Behavioral problems often fail to resolve, despite some recovery of cognitive functions. In general, postinjury behavior is not strongly related to children's cognitive skills (e.g., Yeates, Taylor, Walz, Stancin, & Wade, 2010). More severe injuries, less advantaged family environments, and younger age at injury are predictive of poorer outcomes (Anderson et al., 2006). However, research on predictors of behavioral recovery is complex, and clinicians should be aware that there is substantial variation in outcome at the individual level.

Family Burden and Distress

TBI creates stress for parents and families that may persist for many years following severe injuries (Aitken et al., 2009; Stancin, Wade, Walz, Yeates, & Taylor, 2010). TBI is linked to elevated psychological symptoms and clinical distress among family members (Stancin et al., 2010). However, many families adapt successfully to the increased demands of the injury. Factors such as socioeconomic status, ethnicity, family resources and stresses, and initial response to the injury appear to moderate the injury's impact

on caregivers, placing some families at greater risk for long-term difficulties (Hart et al., 2007; Yeates et al., 2010). Careful assessment of family resources and stresses should facilitate identification of families who may benefit from more intensive intervention. Although most studies have focused on mothers, limited evidence suggests that mothers and fathers may respond to TBI differently, with fathers relying on denial more commonly as a coping strategy and reporting higher levels of distress (Wade et al., 2010). Differences in how mothers and fathers respond may exacerbate strains between parents and contribute to family burden (Bendikas, Wade, Cassedy, Taylor, & Yeates, 2011).

Assessment

TBI severity is usually assessed by the GCS (mentioned above), a 15-point scale that incorporates specific assessment of eye-opening, motor, and verbal response. Scores of 13–15 are indicative of mild injury; scores of 9–12 represent moderate injury; and scores of 3–8 reflect severe injury (Teasdale & Jennett, 1974). Other indicators of severity, such as duration of impaired unconsciousness, length of posttraumatic amnesia, and neuroimaging findings, can be helpful in understanding neurobehavioral outcomes. Advanced imaging techniques (e.g., diffusion tensor imaging) appear to be particularly sensitive to diffuse axonal injury and can be used to characterize the initial injury, underlying mechanisms, and injury evolution. Analysis of neuronal biomarkers found in blood has also shown promise in improving diagnosis (Papa et al., 2013).

Although pediatric psychologists are most often involved in cases of moderate to severe TBI, they are increasingly called upon to support recovery from the persistent symptoms arising from mild TBI, often referred to as "postconcussive syndrome." Most individuals will recover fully within the first few weeks after mild TBI; however, a minority will develop persistent symptoms (Barlow et al., 2010). Factors such as age, injury severity, history of prior head injuries, preinjury attention and internalizing behavior problems, female gender, and a variety of psychosocial factors appear to contribute to symptom maintenance; however, research findings have been mixed (Broshek, De Marco, & Freeman, 2015). Recent guidelines in an Institute of Medicine and National Research Council (2014) report on sports-related concussions in youth provide more comprehensive discussion of this topic.

For moderate to severe TBI, a comprehensive neuropsychological evaluation is often warranted to elucidate neurobehavioral deficits and assist with reentry into the school and community. Office-based assessments should be integrated with parent and teacher reports and direct observation to provide an ecologically valid assessment of strengths and weaknesses (Ylvisaker et al., 2007). Assessments of family adjustment are also recommended, because posttraumatic stress symptoms and poor family adaptation may complicate recovery.

Intervention

Recent review articles outline existing interventions for pediatric TBI (Brown, Whittingham, Boyd, & Sofronoff, 2013; Pangilinan, Giacoletti-Argento, Shellhaas, Hurvitz, & Hornyak, 2010). Treatment approaches can be divided into psychoeducation/information; cognitive remediation; behavioral approaches; family-centered treatments/

positive behavioral supports; orthotics; and medication. The nature of an intervention depends to some extent on the target problem (e.g., memory vs. anger).

Cognitive remediation approaches include strategies for improving attention, memory, and other EFs (Limond & Leeke, 2005). Although evidence is limited, recent research (Galbiati et al., 2009; Van't Hooft et al., 2007) suggests that a structured approach to retraining specific elements of attention and memory, coupled with metacognitive strategy training, may contribute to improved neuropsychological and adaptive functioning. Use of compensatory strategies and devices, such as pagers, personal digital assistants, and talking watches, may also help address ongoing difficulties with memory, planning, and organization skills in older children (DePompei et al., 2008).

In response to the limitations of traditional behavioral treatment paradigms, Ylvisaker, Jacobs, and Feeney (2003) developed an intervention model incorporating positive behavioral supports and antecedent behavior control to improve on-task behaviors/task completion and to reduce aggressive and disruptive behaviors. Their approach engages a child's parents and/or teachers in identifying and addressing environmental antecedents to problem behaviors, and in providing appropriate supports and scaffolding to the child to ensure successful task completion. Although limited to multiple, well-designed single-case studies, the growing evidence base for positive behavioral supports suggests that they can provide an effective approach for addressing behavioral issues in the school and home (Ylvisaker et al., 2007).

Family problem solving (FPS), a hybrid approach integrating TBI education with training in self-regulation, problem solving, communication skills, and positive behavioral supports, has been evaluated in three small studies and one larger randomized clinical trial (RCT) to date (e.g., Wade et al., 2015). FPS involves collaborative problem solving among child, family, and therapist to address family-identified concerns and has been shown to reduce executive dysfunction, externalizing behaviors, and parental distress (Wade et al., 2012, 2015). The utility of training in positive parenting skills in reducing behavior problems following TBI and other forms of acquired brain injury has also been documented in recent RCTs (e.g., Antonini et al., 2014; Brown, Whittingham, Boyd, McKinlay, & Sofronoff, 2014).

Because TBI results in secondary psychiatric disorders, most notably ADHD (Levin et al., 2007), treatments developed for these other conditions may also be successfully used to treat similar symptoms following TBI (Pangilinan et al., 2010). For example, several small RCTs suggest that psychostimulant medications used in the treatment of ADHD may be effective in reducing attention problems after pediatric TBI (Backeljauw & Kurowski, 2014).

With respect to mild TBI, recent research indicates that a brief period of rest followed by a graded return to activities is likely to be better than prolonged rest (Thomas, Apps, Hoffmann, McCrea, & Hammeke, 2015). Aerobic training programs and other types of physical therapy interventions may be beneficial for individuals with prolonged symptoms after mild TBI (Schneider et al., 2014). Both the cognitive and behavioral consequences of pediatric TBI appear to be responsive to cognitive-behavioral interventions, and interventions that integrate training in metacognitive strategy use (including problem solving) may be particularly effective for adolescents. To date, there is a paucity of information on the combined use of cognitive-behavioral interventions with medications and other treatments commonly used for TBI in children.

School Reentry and Intervention

School reentry after TBI can be challenging for both the student and the school, as confusion, concentration/memory difficulties, and fatigue are typically greatest during the initial weeks following the injury. Recent guidelines and consensus statements discuss the importance of pacing return to school activities after injury (Halstead et al., 2013). Variability in abilities can prove particularly challenging for teachers, who may misattribute uneven performance to low motivation or behavioral difficulties. Pediatric psychologists can play an important role in educating classroom personnel as well as peers (Halstead et al., 2013). The positive behavioral supports described previously, as well as self-monitoring strategies, have been used successfully in classroom settings to reduce behavior problems and increase work completion (Feeney & Ylvisaker, 2006, 2008). Because cognitive deficits may emerge with increasing academic or organizational demands, psychologists can also facilitate transitions from one academic setting to another (Chesire et al., 2011).

SPINAL CORD INJURY

Epidemiology

SCI is less common than TBI, but is life-changing for the injured child and his or her family. SCI in individuals younger than 15 years of age comprises <4% of the annual incidence of SCI (National Spinal Cord Injury Statistical Center [NSCISC], 2013). As reported by Vitale, Goss, Matsumoto, and Roye (2006), males are more than twice as likely as females to sustain SCI, especially during adolescence. African American children have a higher rate of SCI than other ethnic and racial groups, followed by Native Americans, Hispanics, and Asians. Motor vehicle crashes (56%) are the most common causes of SCI in youth, followed by falls (14%), gunshot wounds (9%), and sports injuries (8%); however, the etiology varies with age. Of those who were injured in a motor vehicle crash, the majority did not wear seat belts (68%) and/or were intoxicated with alcohol or drugs (30%) (Vitale et al., 2006).

TBI commonly accompanies SCI in those with cervical injuries sustained in motor vehicle crashes (57%) (Brown, Brunn, & Garcia, 2001). Although a GCS score of 3 has been noted as a negative predictor for survival following SCI (40% mortality rate), 99% of patients who have a GCS score of 4 or greater survive (Vitale et al., 2006). Thus there will be an increasing number of adults with childhood-onset SCI. A pediatric psychologist can play a valuable role in helping the child and family to understand and address long-term psychosocial implications and the complex interdisciplinary medical management needs.

Neuropathology and Pathophysiology

SCI pathophysiology can be divided into primary and secondary effects. In traumatic SCI, the primary effects begin when fractured or dislocated vertebrae bruise or tear spinal cord tissue, causing bleeding and damage to axons and cell membranes (NINDS, 2013). However, SCI may also result from other insults to the spinal cord, such as neo-

plasm or transverse myelitis (Galvin, Scheinberg, & New, 2013). Due to swelling, the spinal cord enlarges within the spinal canal, cutting off blood flow and oxygen to spinal cord tissue. Secondary biochemical effects and cellular processes, including changes in blood flow, release of neurotransmitters, initiation of inflammatory immune response, and release of free radicals, further contribute to spinal cord damage and neuronal death.

SCI affects neurological input and output beneath the level of the lesion, and is associated with varying degrees of loss of sensation and motor function. The American Spinal Injury Association has developed an Impairment Scale to classify the extent of remaining motor and sensory functioning. Injuries are classified as "complete" or "incomplete," depending on whether any sensation, motor function, or anal contraction/sensation is preserved below the level of the injury (American Spinal Injury Association, 2013; NINDS, 2013).

Outcomes

Medical Complications

SCI contributes to a range of medical complications, including breathing dysfunction, pneumonias, circulatory problems, spasticity, autonomic dysreflexia, pressure ulcers, deep vein thrombosis, pulmonary embolisms, pain, bowel and bladder dysfunction, depression, and sexual dysfunction. One-third of individuals with SCIs will experience at least one hospitalization in the course of a year due to these medical complications. Life expectancy is decreased in those living with SCI, with the most common causes of death being pneumonia and septicemia (NSCISC, 2013). With high cervical SCI, diaphragm control is lost, and a child will require a mechanical ventilator for respiratory management. Even in children with slightly lower levels of injury (i.e., low cervical and upper thoracic), accessory respiratory muscles and abdominal muscles are affected, leading to altered breathing mechanics. Altered breathing mechanics lead in turn to frequent pneumonias and respiratory infections, as well as other medical problems (NINDS, 2013). Individuals with higher thoracic injuries (T6 level or above) may also experience autonomic dysreflexia, a life-threatening medical complication arising from an imbalance between the CNS and the peripheral nervous system. Autonomic dysreflexia results in elevated blood pressure, heart rate alterations, headaches, anxiety, and profuse sweating and flushing above the level of injury (McGinnis et al., 2004).

SCI often leads to the development of bladder and bowel dysfunction, commonly referred to as "neurogenic bladder and bowel" (NINDS, 2013). To manage these complications, most individuals are required to perform intermittent catheterizations to empty the bladder, avoid urinary tract infections, and prevent incontinence. They also often follow a bowel program with stool softeners and suppositories to prevent chronic constipation, impaction, and fecal incontinence. Urinary and fecal incontinence can be a source of embarrassment for older children and adolescents, and its successful management necessitates considerable adherence.

In addition to respiratory, bowel, and bladder concerns, SCI can lead to muscle spasticity that may cause pain or physical discomfort. Pressure ulcers are frequent due to decreased mobility and impaired sensation. In addition, long-term effects of decreased

activity may occur, such as osteoporosis, high cholesterol, and obesity (NINDS, 2013). Given the chronic (and in some cases life-threatening) medical complications associated with pediatric SCI, it is particularly important to follow a child and family over the long term.

Psychosocial and Behavioral Consequences

The acute emotional impact of SCI can be profound, resulting in feelings of shock, anger, denial, anxiety, grief, and depression, especially among adolescents. Psychologists may be called in during inpatient rehabilitation to assess depressive symptoms and potential suicidal ideation, and to address denial and nonadherence with rehabilitative recommendations. Because SCI is most frequently caused by vehicular crashes and violence, posttraumatic stress disorder (PTSD) is common, affecting 25% or more of pediatric survivors (Boyer, Knolls, Kafkalas, Tollen, & Swartz, 2000). Survivors of SCI are at elevated risk for anxiety and depression, with girls and older adolescents at greatest risk (Klaas, Kelly, Anderson, & Vogel, 2014). Quality of life is also impaired relative to that in normative samples, with child and parent mental health symptoms contributing to poorer overall quality of life (Garma, Kelly, Daharsh, & Vogel, 2011). Adult survivors of pediatric SCI experience elevated rates of alcohol or drug misuse, depression, and anxiety that are linked to medical complications (January, Zebracki, Chlan, & Vogel, 2014). When compared to the general population, individuals injured during childhood have equivalent educational attainment, but lower levels of community participation, employment, income, independent living, and marriage (Anderson, Krajci, & Vogel, 2002).

Various demographic, medical, and behavioral characteristics have been identified as predictors of positive medical and psychosocial outcomes, including younger onset of injury, longer time since injury, higher educational level, greater functional independence, fewer medical complications, and higher levels of participation in everyday activities (Anderson, Vogel, Chlan, & Betz, 2008; Kelly, Klass, Garma, Russell, & Vogel, 2012). Family functioning is predictive of functional independence, with children from higher-functioning families achieving greater functional independence (Boyer, Hitelman, Knolls, & Kafkalas, 2003).

Family Burden and Distress

Given the demands for medical and physical care and the risks of medical complications associated with SCI, caregivers experience elevated levels of anxiety, as well as depressive symptoms and clinical depression (Dreer, Elliot, Shewchuk, Berry, & Rivara, 2007). Because parental and child psychological adjustment are closely linked (Boyer et al., 2000), facilitating parent/family functioning may also improve child adaptation.

Approaches to Community Reentry and Intervention

Since community reintegration, advanced education, and functional independence have been associated with higher life satisfaction and better quality of life (Kelly & Vogel, 2013), proactive psychological interventions can focus on increasing community participation. It is also essential to discuss adulthood transition early in the course of adjust-

ment to pediatric SCI, with the goals of increasing functional independence and mobility, as well as social interaction and community integration skills. Children with SCI need to be provided with the necessary tools for decision making, including community integration and participation at every developmental stage. Specialized camps, adaptive sports, school activities, sleepovers, and exercise programs may facilitate successful integration (Alexander & Matthews, 2010).

Behavioral and Cognitive-Behavioral Approaches

Although empirical evidence is lacking, standard cognitive-behavioral treatments for depression and PTSD should also be effective in reducing these symptoms after pediatric SCI. In addition, standard behavioral approaches may be used to address adherence to treatment regimens (Gorski, Slifer, Townsend, Kelly-Suttka, & Amari, 2005). Established pain management protocols may be adapted to address discomfort arising from spasticity.

Family-Centered Approaches

Family-centered treatments may be helpful in reducing caregiver burden and improving family functioning. Family therapy may also be useful in addressing parental overprotectiveness, and help parents facilitate exposure to normative experiences (such as chores and volunteer or part-time jobs) in older children and adolescents. Moreover, as patients develop necessary cognitive and physical skills, psychologists can help them assume the responsibility for self-care and prevention of medical complications.

Developmental Transitions

Sexuality, relationships, and marriage pose significant concerns for survivors of childhood SCI and may not be adequately addressed by medical care providers. However, research suggests that being able to have meaningful relationships is essential to greater life satisfaction (Anderson et al., 2002). Hence psychological treatment for adolescents and young adults may also focus on such matters as sexual functioning, birth control methods and fertility, and employment.

CONCLUSIONS AND FUTURE DIRECTIONS

TBI and SCI are both caused by traumatic, and in some cases violent, events in previously healthy children. Considerable adaptation is required on the part of the injured individuals and their families. TBI and SCI also contribute to acute and longer-term child and caregiver distress, depression, and PTSD. For both injuries, social-environmental characteristics such as family functioning and resources can have as significant an influence on long-term adaptation as injury severity or level. Accordingly, clinicians treating both TBI and SCI must understand recovery in the broader contexts of family, school, and community. Successful psychological intervention is likely to involve coordination with other medical and rehabilitation professionals. However, TBI, unlike SCI, may have profound effects on subsequent learning, EFs, behavioral organization, and

self-awareness (Trahan, Pepin, & Hopps, 2006), which consequently pose more significant challenges in many respects for parents, teachers, and clinicians.

Considerable research remains to be done to establish evidence-based treatments for children with TBI and SCI. However, a growing literature highlights several promising approaches for treating behavioral and family issues following TBI. For SCI that is not comorbid with TBI, established treatments for the target diagnosis or symptom (e.g., cognitive-behavioral treatment for PTSD or depression) are likely to be appropriate. However, psychologists assessing and treating children who have sustained both TBI and SCI must take into account neuropsychological deficits arising from the TBI when developing and implementing treatment plans. Effective treatment also requires an awareness of the developmental context of the injury.

The future holds the potential for substantial changes in the evaluation and treatment of both these types of injuries. Improvements in neuroimaging may allow clinicians to more precisely identify and target neural changes arising from TBI. Identification of genes (e.g., apolipoprotein E4) associated with neurological vulnerability may enable clinicians to identify children at greatest risk for long-term consequences (see Kurowski, Martin, & Wade, 2012). Research on the use of functional electrical stimulation to trigger movements in limbs that have lost sensory and motor input may allow individuals to regain motor function after SCI. Although use of these devices is currently limited, bioengineering research should contribute to advances in the ease of implantation and ability to stimulate natural-looking movements. Pediatric psychologists can play an important role in helping individuals with TBI or SCI and their families understand the implications and limitations of technological advances, while supporting adaptation and growth. As research on outcomes of pediatric TBI and SCI continues, and as more evidence-based interventions are developed to improve child and family outcomes, pediatric psychologists will have more information and interventions to offer injured children and their families.

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CHAPTER 24

Spina Bifida

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Spina bifida (SB) is a relatively common congenital birth defect that has a pervasive impact on the physical, neurocognitive, psychological, and social functioning of affected individuals and their families. Given the characteristics of this condition as well as the complexities of medical adherence in this population, pediatric psychologists are uniquely qualified to provide assessment and intervention services to these individuals.

SYMPTOMS, DIAGNOSIS, AND SCOPE

During the early stages of normative embryonic development, the neural tube closes and ultimately forms the brain and spinal cord. When this closure fails, a neural tube defect (such as SB) can develop, with the majority of abnormalities involving the lower portions of the spinal cord (sacral and lumbar areas).

Diagnosis

SB can be diagnosed with advanced prenatal ultrasound or maternal serum alpha-fetoprotein (Copp et al., 2015). Postnatally, a diagnosis can be made by using X-ray, magnetic resonance imaging, or computed tomography. There are four types of SB, varying in severity (Copp et al., 2015):

1. Occulta, the mildest form, is often referred to as "hidden" SB; there is no open lesion, and generally there are no symptoms or associated disabilities.
2. Closed neural tube defects (e.g., lipomeningocele) occur when the spinal cord has a malformation of fat, bone, or meninges; in most cases there are no symp-

toms, although some individuals may experience loss of motor function and bladder and bowel dysfunction.

3. In meningocele, the spinal fluid and meninges protrude through the abnormal vertebral opening; however, the spinal cord remains intact.
4. Myelomeningocele is the most severe form of SB. The spinal cord is exposed and causes moderate to severe disability, including partial to complete paralysis as well as bladder, bowel, and sexual dysfunction.

Most studies of SB have been conducted with samples that are largely or exclusively made up of individuals with myelomeningocele. Thus, unless stated otherwise, this subpopulation is the focus of this chapter.

Epidemiology

Across all types, SB occurs in approximately 3 of every 10,000 live births. Incidence, however, differs among ethnic/racial groups and geographically. Hispanics have the highest rate (4.2 per 10,000 live births), followed by non-Hispanic European Americans (3.2 per 10,000), and African Americans (2.6 per 10,000; Boulet et al., 2008). The mortality rate among youth with SB is roughly 1% per year from ages 5 to 30, with the rate being highest among those with the highest lesion levels (Bowman, McLone, Grant, Tomita, & Ito, 2001; Oakeshott, Hunt, Poulton, & Reid, 2010). Lifetime direct costs for a child with SB are estimated at $600,000, with slightly over one-third for medical costs and the remainder for indirect costs, including special education, assistive technology, caregiver support, and loss of future earnings (Copp et al., 2015).

Causation and Prevention

Despite advances in the medical management of SB, knowledge of the underlying mechanisms causing this neural tube defect remains incomplete. Genetic factors are believed to be primary components of causation; however, few genes involved in SB have been identified (Copp et al., 2015). There are also several nongenetic factors linked with SB; of these, inadequate maternal folic acid consumption is the most well-established risk factor.

Clinical Presentation

The severity of disability in SB is linked with the level of lesion on the spinal cord, with higher levels causing more impairment. In some cases, there is a tethering of the spinal cord (i.e., tissue attachments that stretch the spinal cord and limit its movement) during growth. Common manifestations of myelomeningocele include motor and sensory neurological deficits below the level of the lesion (e.g., paralysis); neurogenic bladder (e.g., incontinence, urinary tract infections) and bowel (e.g., incontinence, constipation); spasticity; orthopedic conditions (e.g., contractures, hip dislocation, and scoliosis); and pressure ulcers. SB is also often associated with hydrocephalus (excessive accumulation of cerebrospinal fluid in the ventricles of the brain, which is treated with a shunt—a drainage tube surgically placed in the brain) and with the Chiari II malformation (struc-

tural defects in the cerebellum, accompanied by symptoms such as apnea or swallowing difficulties in infants and by headache, scoliosis, and balance/coordination issues in children and adults).

Individuals with SB also frequently exhibit hearing and visual impairments; coordination disorder; difficulties with visual–spatial processing; reductions in finger dexterity and hand function; and seizures. They experience cognitive and academic difficulties as well, including executive dysfunction; attention problems (focusing and shifting); and difficulties with reading, pragmatic language, language comprehension, and math (Copp et al., 2015).

PSYCHOLOGICAL ASPECTS OF SPINA BIFIDA: INDIVIDUAL AND FAMILY FUNCTIONING

The psychological adjustment of individuals with SB is likely to be determined by the interacting influences of multiple biological, neuropsychological, social, and contextual factors (see Figure 24.1).

Psychosocial Adjustment

Youth with SB are at risk for exhibiting higher levels of depressive symptoms and lower levels of self-concept than comparison children (Holmbeck et al., 2003). Children with SB also exhibit social difficulties (i.e., they tend to be socially immature and passive, have fewer friends, and date less during adolescence; e.g., Holmbeck et al., 2003), and these difficulties are maintained over time (Holmbeck, DeLucia, et al., 2010). Youth with SB tend to be more dependent on adults for guidance and are less likely to express their own viewpoints during observed family interactions (Holmbeck et al., 2003).

Youth with SB have reduced health-related quality of life (HRQOL) as compared to both healthy samples and samples of youth with other chronic health conditions; these differences tend to be stable across age groups, gender, geographical location, and time (Murray et al., 2015; Sawin & Bellin, 2010). Some measures of condition severity are associated with HRQOL, including presence of hydrocephalus and lack of mobility (Cope et al., 2013; Dicianno, Gaines, Collins, & Lee, 2009). Other robust predictors of HRQOL include socioeconomic status (SES), pain levels, and parenting stress (Bellin et al., 2013).

Family Functioning

Research on families of youth with SB (Holmbeck, Greenley, Coakley, Greco, & Hagstrom, 2006) supports a resilience–disruption view of family functioning (Costigan, Floyd, Harter, & McClintock, 1997), whereby the presence of a child with SB disrupts normative family functioning, but many families exhibit considerable resilience. Families of youth with SB from lower-SES backgrounds are particularly at risk for lower levels of family cohesion, supporting a cumulative-risk view of such families (Holmbeck, Coakley, Hommeyer, Shapera, & Westhoven, 2002).

With respect to the functioning of parents, a meta-analysis of 15 studies (Vermaes, Janssens, Bosman, & Gerris, 2005) found medium to large negative effects for the

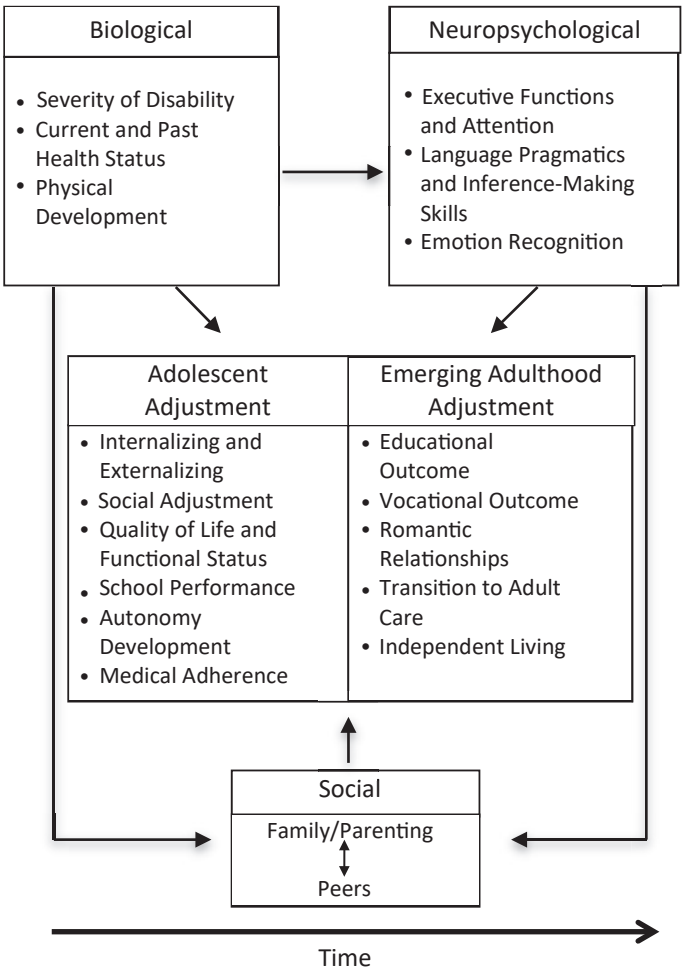

FIGURE 24.1. Bioneuropsychosocial model of psychological adjustment in adolescents and emerging adults with spina bifida. From "Psychosocial and family functioning in spina bifida" by G. N. Holmbeck and K. A. Devine, 2010, *Developmental Disabilities Research Reviews, 16*(1), 40–46. Copyright © 2010 by John Wiley and Sons. Reprinted with permission.

impact of SB on mothers' and fathers' psychological adjustment, with somewhat larger effect sizes for mothers (d = 0.73) than for fathers (d = 0.54), as well as negative effects on parental stress and quality of parenting (Holmbeck, Johnson, et al., 2002; Vermaes, Gerris, & Janssens, 2007). Such parents feel less satisfied and competent as parents, feel more isolated, are less adaptable to change, and hold less optimistic views about the future than comparison parents (Holmbeck et al., 1997). Parents who are single, older, socially isolated, and/or from an ethnic minority group or a low-SES background are particularly at risk for such outcomes (Holmbeck, Coakley, et al., 2002). Siblings of children with SB are better adjusted when their families have more positive attitudes

toward SB, greater family satisfaction, and lower levels of sibling conflict (Bellin, Bentley, & Sawin, 2009).

Young Adult Outcomes

The quality of health for individuals with myelomeningocele tends to decline from adolescence to young adulthood, presumably due to difficulties in navigating the transition to adult health care (Holmbeck, Bauman, Essner, Kelly, & Zebracki, 2010; Liptak, Kennedy, & Dosa, 2010). Given these difficulties and the continued role of parents as caregivers for their adult children with SB, many young adults with SB continue to receive medical care from pediatric specialists. Regarding psychosocial adjustment, emerging adults with SB, like their younger counterparts, are at risk for depressive symptoms and anxiety (Bellin et al., 2010; Dicianno et al., 2009), but are less likely than their typically developing age-mates to engage in risky behaviors (e.g., alcohol use, multiple sexual partners; Murray et al., 2014). Regarding educational and vocational outcomes, emerging adults with SB are less likely to go to college (41–56% vs. 66% of typically developing youth; Bowman et al., 2001; Cope et al., 2013; Zukerman, Devine, & Holmbeck, 2011) and have lower rates of employment (e.g., 36–48%; Cope et al., 2013; Liptak et al., 2010; Zukerman et al., 2011) than those found in typically developing youth (e.g., roughly 75%; Cope et al., 2013; Liptak et al., 2010; Zukerman et al., 2011) and in youth with other chronic conditions (68%–78%; Liptak et al., 2010).

With respect to relationship quality, 43–77% of young adults with SB live with their parents (Bowman et al., 2001; Cope et al., 2013). Over half (52–68%) have had a romantic relationship (Cope et al., 2013), although this rate is lower than in typically developing young adults (Zukerman et al., 2011). Parents of youth with SB are less likely to discuss issues of sexuality with their offspring (Sawin, Buran, Brei, & Fastenau, 2002). With respect to community participation and social integration, participation in leisure and recreational activities tends to be low, with over 50% participating in no such activities (Boudos & Mukherjee, 2008).

More generally, the best predictors of successful navigation of young adult milestones appear to be condition-related (i.e., hydrocephalus, lesion level, and mobility status; Cope et al., 2013); neuropsychological (e.g., executive functioning; Zukerman et al., 2011); personality-based (e.g., intrinsic motivation; Zukerman et al., 2011); familial (e.g., SES, parental intrusiveness; Zukerman et al., 2011); logistical (e.g., transportation, accessibility; Barf et al., 2009); and financial (e.g., lack of health insurance). Other predictors include lack of job training and vocational rehabilitation services, employment discrimination, and stigmas related to physical appearance (Dicianno et al., 2008, 2009).

MANAGEMENT OF SB AND THE ROLE OF THE PEDIATRIC PSYCHOLOGIST

Individuals with SB require lifelong, extensive, and active treatment from an interdisciplinary team that focuses on the following: bladder and bowel management, mobility, skin care and other self-care activities, health care maintenance, psychological well-being, educational and vocational counseling, social services, recreation and leisure activities, and prevention and management of complications. Interestingly, research on

adults with SB has indicated that up to one-half of hospitalizations are due to potentially preventable conditions, such as urinary tract infections and pressure ulcers (Mahmood, Dicianno, & Bellin, 2011).

The ultimate goal in treating youth with SB is for them to experience satisfying and productive lives as independently functioning and healthy adults in society (Zebracki, Zaccariello, Zelko, & Holmbeck, 2010). Providing anticipatory guidance to parents and caregivers, such as long-term implications of living with a disability, is crucial as these youth move through various developmental stages. SB clinics often include teams of specialized physicians, nurses, pediatric neurosurgeons, urologists, orthopedic surgeons, physical therapists, occupational and recreational therapists, nutritionists, pediatric psychologists, and social workers. Pediatric psychologists can take on a variety of roles within such an interdisciplinary team. Along with social workers, pediatric psychologists can provide support to family members, as well as psychosocial services addressing mental health problems (e.g., depressive symptoms, medical adherence difficulties). Given the array of cognitive, emotional, psychosocial, and learning impairments seen in SB, regular comprehensive neuropsychological, psychosocial, psychoeducational, and speech–language evaluations are strongly recommended to monitor declines and to provide recommendations for intervention and treatment (Deaton & Castaldi, 2011). Psychologists can also engage in interventions aimed at improving HRQOL, coping, and participation, and can employ behavioral strategies with the goals of improving medical adherence (particularly for catheterization, bowel programs, and skin checks), enhancing general living skills, and/or encouraging independence in the management of medical care.

EVIDENCE-BASED ASSESSMENTS AND INTERVENTIONS

In contrast to the extensive literature on evidence-based interventions for other chronic physical conditions (e.g. Type 1 diabetes), there is a lack of such interventions for families of young people with SB (Holmbeck et al., 2006). More generally, with only two exceptions (Betz, Smith, & Macias, 2010; Stubberud, Langenbahn, Levine, Stanghelle, & Schanke, 2015), no randomized clinical trials (RCTs) have been reported for this population across all of the psychosocial domains listed in Figure 24.1.

For example, in one of the two RCTs conducted with individuals with SB, goal management training was employed to address executive functioning impairments in this population (Stubberud et al., 2015). Findings revealed that the intervention produced significant improvements in executive functioning, self-reported depressive and anxiety symptoms, HRQOL, and coping skills. Other preliminary work points to the need for more RCTs. A manualized summer camp-based intervention was developed to target independence and social skills among children, adolescents, and young adults with SB (Holbein et al., 2013; O'Mahar, Holmbeck, Jandasek, & Zukerman, 2010). Preliminary research on this intervention found that statistically significant gains occurred in individualized goals and in the independent management of SB-related responsibilities.

In the area of assessment, most investigators have relied on generic measures or have adapted illness-specific measures developed for other populations. For example, O'Hara and Holmbeck (2013) assessed medical adherence with the Spina Bifida Self-Management Profile, an adaptation of the Self-Management Profile that was originally

developed for youth with Type 1 diabetes (Wysocki & Gavin, 2006). Also, Kaugars et al. (2011) and Holbein, Zebracki, and Holmbeck (2014) provided validation data for an observational coding system to be applied to observed family and peer interactions, respectively; this system was an adaptation of a coding system developed by Smetana, Yau, Restrepo, and Braeges (1991). On the other hand, some measures have been developed specifically for this population (e.g., the Kennedy Krieger Independence Scales—Spina Bifida Version; Jacobson et al., 2013).

ISSUES OF DIVERSITY

As is the case for other pediatric health conditions, research is needed on how the presence of SB may affect individuals and families differently, depending on the presence of various diversity characteristics (e.g., race, ethnicity, language, age, gender, sexual orientation, religion, geographic location, SES, education, family structure, disability status, physical appearance). The few studies that have examined racial/ethnic differences among individuals with SB have found differences in health-related and psychosocial outcomes (Chowanadisai et al., 2013; Devine, Holbein, Psihogios, Amaro, & Holmbeck, 2012; Swartwout, Garnaat, Myszka, Fletcher, & Dennis, 2009). Other diversity characteristics that are important to consider include cultural and religious/spiritual beliefs. Because a family's culture—the beliefs, values, meanings, and actions that shape the lives of an identified group of people—has an impact on all aspects of family life, it is important to understand how the meaning of and response to SB may vary, depending on culture-based normative beliefs (Ripat & Woodgate, 2011).

EMERGING AREAS AND RECOMMENDATIONS FOR FUTURE CLINICAL WORK AND RESEARCH

Clinical Recommendations

Clinics can enhance comprehensive care by adopting a model for identifying families in need of treatment for psychosocial difficulties. For example, Kazak (2006) has presented a pediatric psychosocial preventative health model (PPPHM), based on a social-ecological framework. (See also Carter et al., Chapter 9, this volume.) According to this model, all families receive a brief assessment to determine what level of services they need—universal, targeted, or clinical/treatment. Importantly, risk factors can change, and families can move among these three risk status groups over time.

Recommendations for Future Research

The literature on family and psychosocial functioning in individuals with SB will benefit from theory-driven advances that include the following features: (1) a developmental emphasis; (2) a focus on both illness-specific and general family processes; (3) models examining mediational processes; and (4) models taking into account family-related variables (e.g., autonomy-promoting parenting) that serve as potential buffers for associations between risk factors (e.g., neurological status) and negative outcomes (e.g., academic failure). It is also recommended that research be programmatic and longitudinal.

Predictor and outcome variables all need to be assessed over time, particularly during key developmental periods or transition points (e.g., early childhood, transition to elementary school, early adolescent transition, transition to early adulthood).

In conclusion, using theoretical models such as the bioneuropsychosocial model (see Figure 24.1) to inform future research studies will help move the field toward a better understanding of the various factors that influence child psychosocial adjustment and family functioning in youth with SB. Moreover, the field would do well to identify areas of resilience, and factors associated with resilience, in youth with SB and their families.

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CHAPTER 25

Epilepsy

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Pediatric epilepsy is a largely neglected area in pediatric psychology (Wagner, Modi, & Smith, 2011). While it is one of the most common pediatric neurological disorders, psychological services for children with epilepsy (CWE) have primarily focused on neuropsychological testing and identification of deficits. The high rates of neurodevelopmental and psychological comorbidities, including anxiety, depression, behavioral, learning, and developmental disorders (Russ, Larson, & Halfon, 2012), as well as difficulties adjusting to and managing epilepsy, make pediatric psychologists critical members of the health care team—but few such psychologists are involved in epilepsy care. This chapter reviews (1) epilepsy symptoms, diagnosis, and prevalence; (2) neurodevelopmental and behavioral comorbidities, including evidence-based assessment and treatment; (3) assessment and treatment of epilepsy medication side effects; (4) health-related quality of life in epilepsy; (5) transition and emerging adulthood; (6) adherence and self-management; (7) the role of a pediatric psychologist in epilepsy; and (8) diversity issues related to epilepsy.

ILLNESS SYMPTOMS, DIAGNOSIS, AND SCOPE

Epilepsy affects 1% of youth and carries a $9.6 billion annual direct economic burden, with additional significant indirect costs (Yoon, Frick, Carr, & Austin, 2009). Epilepsy has been defined by the International League Against Epilepsy (ILAE) as characteristic of any of the following events: (1) at least two unproved seizures more than 24 hours apart, (2) one unprovoked seizure with a high probability of recurrence over the next 10 years, and (3) diagnosis of an electroclinical syndrome upon evaluation (Fisher

et al., 2014). Approximately one-third of all epilepsies have no known cause (Berg et al., 2010). The current ILAE classifications for epilepsy etiology are currently being modified (Berg et al., 2010) and thus are not presented here. However, typical etiology terminology includes "idiopathic" (i.e., no underlying cause other than heredity), "symptomatic" (i.e., an acquired or genetic cause indicative of underlying disease), and "cryptogenic" (symptoms with an unknown cause) (Commission on Classification and Terminology of the International League Against Epilepsy, 1989). The most visible sign of epilepsy is a seizure, which results from abnormal brain discharges that abruptly and temporarily alter cerebral function.

Seizures can be localized (i.e., focal), generalized (i.e., absence, myoclonic, tonic–clonic), status epilepticus, and unknown (neonatal seizures, infantile spasms). Focal seizures originate in one area of the brain, and generalized seizures cross hemispheres. Focal seizures can secondarily generalize. Status epilepticus occurs when a person has a prolonged generalized tonic–clonic seizure or at least two back-to-back seizures without full recovery. An extensive overview of epilepsy classifications and seizure types has been recently published (Smith, Wagner, & Edwards, 2015a).

Antiepileptic drugs (AEDs) are the first-line treatments for epilepsy, but they can result in numerous side effects, such as increased irritability, low frustration tolerance, aggression, mood lability, somnolence, and slowing of cognitive processes (Glauser, 2004). These side effects are highly burdensome and may affect psychological functioning (e.g., they may result in depression) and quality of life (Modi, Ingerski, Rausch, & Glauser, 2011). The prognosis of pediatric epilepsy varies greatly and is related to age of onset, presence of neurodevelopmental and behavioral disorders, and response to treatment (Berg, Zelko, Levy, & Testa, 2012; Selassie et al., 2014).

One-third of CWE have medically refractory epilepsy (i.e., failure to respond to two or three AEDs; Geerts et al., 2010). Once refractory epilepsy has been established, evaluation for surgery (e.g., partial or full lobe resection, lesionectomy, corpus callosotomy) is usually indicated. If surgery is not a viable option, two other efficacious treatments are available: neurostimulative implantation devices (e.g., vagus nerve implants) and high-fat, low-carbohydrate, adequate protein diets (ketogenic diet, modified Atkins diet; Smith, Wagner, & Edwards, 2015b). Some childhood epilepsies can remit in childhood or change during puberty. Girls can show an increase in seizures with menses onset, suggesting that biological changes during puberty influence seizure activity (Crawford & Lee, 1999).

COMORBID NEURODEVELOPMENTAL AND BEHAVIORAL DISORDERS: PREVALENCE, ASSESSMENT, AND TREATMENT

Up to 60% of CWE meet criterion for a psychological disorder, yet two-thirds do not receive treatment (Ott et al., 2003). The most common psychological comorbidities include neurodevelopmental disorders (e.g., attention-deficit/hyperactivity disorder [ADHD], learning disorders, cognitive disorders), externalizing disorders (e.g., oppositional defiant disorder [ODD], conduct disorder), and internalizing disorders (e.g., anxiety, depression; Russ et al., 2012; Wagner, Wilson, Smith, Malek, & Selassie, 2015). Early detection and intervention of these disorders are critical to optimize epilepsy management. ADHD is now classified as a neurodevelopmental disorder, but it is included

here in the section on behavioral disorders because it better aligns with those assessment and treatment recommendations.

Neurodevelopmental Disorders

Epilepsies identified during infancy are often devastating and linked to refractory seizures and intellectual delay. Babies with infantile spasms (i.e., West syndrome) typically experience developmental stagnation or regression, which can persist despite seizure control (Djuric, Kravljanac, Tadic, Mrljes-Popovic, & Appleton, 2014). CWE in the first 2 years of life are at high risk for intellectual disability (ID; up to 40%), which can lead to an increased risk for autism spectrum disorder (ASD; up to 21%; Reilly et al., 2014). The increased risk of ASD comorbid with epilepsy is linked to genetic pathogenesis (Pavone, Striano, Falsaperla, Pavone, & Ruggieri, 2014). In turn, overall prognosis is poor for CWE with early-onset syndromes and comorbidities, particularly if they experience delays in epilepsy referral and diagnosis (Berg, Loddenkemper, & Baca, 2014). Even preschool-age children with uncomplicated epilepsy are at increased risk for neurocognitive, developmental, and social deficits during this critical period of development (Rantanen, Nieminen, & Eriksson, 2010).

Neurodevelopmental disabilities, including ID, ASD, ADHD, and cognitive dysfunction (Wagner et al., 2015), have reported prevalence rates of 36% in CWE ages 6–18. Of the CWE who do not have severe cognitive or academic deficits, many have subtle but diffuse neurocognitive deficits in memory, attention, and processing speed, which make learning much more challenging (Hermann et al., 2006). In a 2-year follow-up study, the presence of behavioral health comorbidities was associated with worse cognitive trajectories, especially executive functions (Hermann et al., 2008). Almost half of CWE have learning disabilities and struggle with academic performance (Russ et al., 2012). Even CWE who have syndromes previously thought to be benign (i.e., childhood absence epilepsy), have significant executive functioning deficits, despite intact neurocognitive functioning and seizure freedom (30%; Masur et al., 2013). Notably, AED side effects can mirror these neurocognitive deficits, and it is imperative that clinicians differentiate AED side effects from deficits associated with epilepsy.

Evidence-Based Assessment

All CWE should have a neuropsychological evaluation at epilepsy diagnosis and across the course of their disease—particularly as significant changes are made to their epilepsy treatment regimens, in periods of rapid brain development, and/or after changes to seizure presentation and frequency (Hermann et al., 2008). If neuropsychological testing is not feasible, executive function screening is critical.

Evidence-Based Treatment

Academic services such as Section 504 plans and individualized education programs (IEPs) are available to CWE who have comorbid neurodevelopmental/learning disorders. Common 504 plan and IEP accommodations include preferential seating; one-on-one instruction; behavioral intervention and monitoring; extended time for tests/homework; classroom scribing; presentation of information in multiple formats (e.g.,

written, oral); and speech, occupational, and physical therapies. For CWE experiencing neurodevelopmental disorders, state-funded early intervention programs provide therapies (e.g., speech, occupational, and behavioral) from birth to 3 years of age.

Behavioral Disorders: Externalizing and Internalizing

CWE and their families often have difficulty adjusting to epilepsy and its associated comorbidities. Soon after diagnosis and often due to fears of seizure activity, many caregivers will make changes to the family environment, including shifting recreation activities from outside to inside the home (Painter, Rausch, & Modi, 2014), restricting activities (Rodenburg et al., 2013), and engaging in cosleeping behaviors (Larson et al., 2012). One systematic review found that families with CWE experienced less parental support, were more overprotective, had higher maternal depression, and had more family dysfunction compared to controls (Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005).

Depressive symptoms are known to overlap with common neurocognitive deficits in CWE and with AED side effects (i.e., fatigue, sleep disturbance; Kanner et al., 2012). Chronic irritability has been indicated as a primary indicator of depression in CWE (Jones et al., 2008). Surveillance studies have reported a prevalence rate of depression in 8% in CWE ages 6–12, and over 20% in CWE ages 13–18 (Wagner et al., 2015). Fourteen percent of CWE endorsed suicidal ideation (Guilfoyle, Monahan, Wesolowski, & Modi, 2015). The lifetime prevalence of an anxiety disorder in children with new-onset epilepsy is 36%, compared to 22% in healthy controls (Jones et al., 2007). The frightening nature and unpredictability of seizures are unique precipitants of anxiety, along with volumetric enlargement of the amygdala and thinner orbital and prefrontal cortices (Jones et al., 2015). Finally, population-based studies have shown that ADHD and ODD are highly comorbid with epilepsy with prevalence rates of 25–40% for ADHD (Jones et al., 2007) and 13–16% for ODD in CWE (Cohen et al., 2013).

Evidence-Based Assessment

Many well-validated assessment tools can be quickly administered and utilized in epilepsy clinics. The "gold standard" measure for pediatric depression is the Children's Depression Inventory—2nd Edition (Kovacs, 2010). To address the potential symptomology overlap between neurocognitive deficits associated with epilepsy (e.g., vegetative symptoms due to AEDs) and depression, the Neurological Disorders Depression Inventory for Epilepsy—Youth is available (Wagner et al., 2016). Routine depression screening is indicated, due to increased risk for suicidal ideation, when even one psychiatric diagnosis is present (Jones, Siddarth, Gurbani, Shields, & Caplan, 2013). The Multidimensional Anxiety Scale for Children—Second Edition (March, 2013) and the Revised Children's Manifest Anxiety Scale—Second Edition (Reynolds & Richmond, 2008) can be used for anxiety screening.

The Vanderbilt ADHD Diagnostic Parent and Teacher Rating Scales (Wolraich et al., 2003) are hallmark measures for ADHD assessment and can track fluctuations in externalizing symptoms (both ADHD and ODD) over time. Of note, pediatric psychologists should exercise caution when using these measures in patients with epilepsy, because inattention and distractibility can be difficult to differentiate from absence sei-

zures and AED side effects (Salpekar & Mishra, 2014). Thus a careful assessment of symptom onset, epilepsy onset, and seizure semiology is critical.

Evidence-Based Treatment

Cognitive-behavioral therapy (CBT) is often the first line of intervention for internalizing disorders and can even be applied to manage AED side effects (e.g., increased irritability). Blocher, Fujikawa, Sung, Jackson, and Jones (2013) tested a CBT intervention targeting social anxiety and self-concept, with significant reductions in anxiety noted. CBT was also tested in a computer-assisted format with similar effects (Blocher, Fujikawa, Sung, Jackson, & Jones, 2013). In recent years, epilepsy-specific interventions have been developed to target emotional and social functioning more broadly and improve coping skills (Carbone, Plegue, Barnes, & Shellhaas, 2014; Wagner, Smith, Ferguson, Van Bakergem, & Hrisko, 2010).

Evidence-based treatments for ADHD include a combination of neurostimulant medication and parent-based behavioral treatment. Neurostimulants are well tolerated and often effective for CWE and comorbid ADHD (Salpekar & Mishra, 2014). Parent-based behavioral treatments for ADHD and ODD can be used when behavioral changes are secondary to AEDs or seizures.

ASSESSMENT AND BEHAVIORAL TREATMENT OF AED SIDE EFFECTS

Pediatric psychologists have a unique opportunity to assist medical colleagues in addressing AED side effects when an AED is offering seizure control and side effects are tolerable, but interfering with daily functioning. Given that AEDs can result in mood and behavioral changes in children, broad-band psychological instruments, such as the Behavior Assessment Scale for Children, Second Edition (BASC-2; Reynolds & Kamphaus, 2004), can be helpful to determine a child's baseline psychological functioning (Guilfoyle, Wagner, Smith, & Modi, 2012) and differentiate between depression and anxiety symptoms. Pediatric psychologists using the BASC-2 with CWE should be aware of possible clinical elevations on the Atypicality scale, given that items ask about having seizures, staring, and falling down. The BASC-2 should ideally be administered at diagnosis prior to AED initiation, so that these baseline data can be used at a later period when children may experience AED side effects. Pediatric psychologists can educate families on the necessity of preventing mood/behavioral triggers, facilitate adherence, teach patients CBT strategies to identify and manage physiological symptoms, and educate parents on positive reinforcement for use of adaptive coping skills. All these approaches can optimize AED tolerability and improve health-related quality of life.

HEALTH-RELATED QUALITY OF LIFE

Health-related quality of life (HRQOL) is an important patient-reported outcome. Beyond seizures and side effects (Modi, Ingerski, Rausch, & Glauser, 2011), studies have demonstrated that parent/family stress, parental worries/fears, perceived stigma (Wu, Follansbee-Junger, Rausch, & Modi, 2014), maternal depression, and number of

AEDs (Ferro, 2014) are significant negative predictors of HRQOL. HRQOL impairments may become more pronounced during adolescence, when typical milestones, including learning to drive, are challenged by the demands of epilepsy management. Driving restrictions in some U.S. states preclude some adolescents with epilepsy from obtaining driver's licenses, or require them to surrender their licenses, until their seizures are well controlled. As adolescents are often away from caregivers (e.g., overnight visits, traveling to extracurricular activities), families face decisions about disclosing the epilepsy diagnosis to peers and thus increasing the potential for stigma (Cheung & Wirrell, 2006). In addition, incontinence or convulsions during a seizure may increase fears surrounding social acceptance, and many adolescents report social isolation and peer and romantic relationship difficulties (Institute of Medicine, 2012).

While there are several well-validated generic HRQOL instruments, including the Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Rode, 1999), epilepsy-specific measures also exist. Specifically, the Quality of Life in Childhood Epilepsy (QOLICE) is a parent proxy report of HRQOL in youth 4–18 years of age (Sabaz et al., 2003), and the Quality of Life in Epilepsy for Adolescents is a self-report HRQOL instrument (Cramer et al., 1999). Although these measures are sensitive to the needs of youth with epilepsy, they are lengthy. A new PedsQL Epilepsy Module is currently being validated in hopes of creating a brief yet epilepsy-specific instrument (Follansbee-Junger et al., 2016).

TRANSITION AND EMERGING ADULTHOOD

Young adulthood is associated with many socially important milestones, including romantic relationships, independent living, attending college, and starting a career. Such milestones, like those of adolescence, may be delayed by intractable seizures. Longitudinal studies demonstrate that adults who were diagnosed with childhood epilepsy are less likely to be well educated, to be employed, or to have a romantic partner than those without epilepsy (Geerts et al., 2010). Furthermore, young adults with epilepsy are less likely to meet these milestones than are youth with other chronic illness conditions (Pinquart, 2014). There are no currently available specific assessment tools or interventions tailored to young adults with epilepsy.

ADHERENCE AND SELF-MANAGEMENT

Factors in Epilepsy Treatment Adherence and Self-Management

Self-management is the "interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition," while adherence represents "the extent to which a person's behavior coincides with medical or health advice" (Modi et al., 2012, p. 3). Management of epilepsy requires taking AEDs, avoiding known seizure triggers (e.g., sleep deprivation, photostimulation), managing stress, and practicing good sleep hygiene. AED nonadherence is a significant problem and has significant negative consequences, including poor short-term (Modi, Wu, Rausch, Peugh, & Glauser, 2014) and long-term (Modi, Rausch, & Glauser, 2014) seizure control. Sixty percent of young CWE (2–12 years) and their families demonstrate some level of AED nonadherence (Modi, Rausch, & Glauser, 2011; Modi, Wu, et al., 2014), which wors-

ens to 79% during adolescence (Carbone, Zebrack, Plegue, Joshi, & Shellhaas, 2013). Predictors of AED nonadherence include lower socioeconomic status, poor epilepsy knowledge, poor family problem solving, poor family communication, and parental fears/concerns (Carbone et al., 2013; Loiselle, Rausch, & Modi, 2015). During adolescence, teenagers often desire to take their AEDs independently and set their own sleep schedules, but these behaviors may trigger seizures and thus need to be monitored by caregivers.

Evidence-Based Assessment and Treatment

Although a multimethod assessment (e.g., electronic monitors, self/parent-report, pharmacy refills) of adherence is ideal, it is generally not feasible in clinical practice. However, ad hoc questions regarding missed doses and adherence barriers can readily be used in clinical settings.

Modi and colleagues (2013, 2016, 2016) have developed and are testing an adherence promotion intervention focused on teaching problem solving and increasing epilepsy knowledge for youth with epilepsy and their families, with notable initial efficacy. In general, caregivers are encouraged to maintain a key role in disease management (Ryan, Arnett, Pai, & Modi, 2014). Caregivers are encouraged to provide continual oversight until self-management/adherence behaviors are part of routine care for CWE, and then to withdraw that support slowly. Technology (e.g., text-messaging reminders, apps) can also aid in adherence, especially for adolescents and their caregivers.

THE ROLE OF THE PEDIATRIC PSYCHOLOGIST

Pediatric epilepsy and its associated psychosocial comorbidities are optimally managed by an interdisciplinary team of health care providers. In recent years, pediatric psychologists have increasingly integrated their unique skill set into pediatric epilepsy interdisciplinary teams by offering behavioral health assessment and interventions. Both outpatient (i.e., referrals, in-clinic services) and inpatient pediatric psychology services can be feasible and viable (Guilfoyle et al., 2012).

For many children with new-onset epilepsy, identification of the most effective AED with no seizures and no side effects is difficult and can often cause stress and fear of future seizures during this adjustment period. Furthermore, AED side effects, school absences, and the onset of learning difficulties can all lead to academic decline. Pediatric psychologists are uniquely trained to facilitate interdisciplinary collaborations, address barriers to medical care (such as medical nonadherence), enhance patient–provider communication, and promote health behaviors. Routine screening by pediatric psychologists can proactively identify psychological difficulties that emerge when epilepsy-related challenges occur (e.g., recurrence of seizures, AED changes, neurocognitive difficulties secondary to AED side effects, AED nonadherence). Pediatric psychologists can also triage patients for additional services (e.g., neuropsychological testing, developmental testing, psychiatry), facilitate school collaborations to enhance academic services, and offer interventions to optimize functioning and adjustment. In addition, medical providers often struggle with the question of whether to discontinue an AED when it causes intolerable mood lability, especially if the AED controls seizures. Medical providers can

potentially optimize AED tolerance by collaborating with a pediatric psychologist, who can teach caregivers more effective behavioral strategies to prevent mood or behavioral escalations and identify high-risk situations that may intensify AED side effects.

DIVERSITY ISSUES

The North American Commission of the ILAE published a systematic review regarding disparities in epilepsy, indicating that mental health care was poorer for CWE if the children were older, had one psychiatric diagnosis, had higher verbal intelligence, were on AED polytherapy, or had a parent with lower education. However, compared to adults, CWE were more likely to see neurologists and use emergency rooms or be admitted to hospitals (Burneo et al., 2009). A significant global health treatment gap in epilepsy has been identified between high- and low-income countries, as well as between rural and urban settings (Meyer, Dua, Ma, Saxena, & Birbeck, 2010). Overall, much work needs to be done to understand the impact of health disparities and stigma on the health and psychosocial outcomes of CWE.

CONCLUSIONS

Given the high rate of psychological comorbidities, the complexity of epilepsy management, and the need for ongoing evidence-based assessment and intervention, pediatric psychologists are well suited to improve care for CWE. Evidence-based assessments that fit the needs of CWE are critical in evaluating for neurodevelopmental and behavioral disorders. Although there is some initial research related to epilepsy-specific assessment of depression and HRQOL, new studies that evaluate assessment tools for other disorders, such as anxiety or behavioral problems, warrant attention. Evidence-based treatments in pediatric epilepsy are understudied, and more evaluation is needed to determine whether general treatments (e.g., parent behavioral training) are efficacious in this population, or whether new treatments need to be developed for CWE. Programs and interventions designed to improve self-management and transition are critical to the long-term outcomes of CWE. Use of technology may be one avenue to engage adolescents and young adults, but this approach has yet to be tested. Overall, pediatric psychology has been underutilized within this field, and pediatric psychologists thus have a unique opportunity to help CWE and their families, as well as the health care teams in which they are cared for.

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CHAPTER 26

Medical and Psychosocial Aspects of Juvenile Idiopathic Arthritis

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Pediatric rheumatic diseases are chronic multisystem disorders that involve acute and chronic tissue inflammation of the musculoskeletal system, blood vessels, and skin. "Juvenile idiopathic arthritis" (JIA) is the most common type of childhood arthritis and a major cause of short- and long-term disability among chronic pediatric diseases (Petty, Laxer, Lindsley, & Wedderburn, 2016). The term "juvenile rheumatoid arthritis" (JRA) is also used here, because the criteria for this diagnosis were the inclusion criteria for many of the studies cited in this chapter. The newer classification schema, JIA, has broader inclusion criteria, including psoriatic arthritis, enthesitis-associated arthritis, and an undifferentiated group. Children with chronic arthritis and their families have to adhere to complex daily medical regimens and cope with the psychosocial impact of living with a chronic disease.

This chapter reviews the medical aspects of JIA, adherence to medical regimens, and psychosocial adjustment in JIA. Clinical and research implications are reviewed at the end of each section.

MEDICAL ASPECTS

As the word "idiopathic" in its name indicates, the etiology of JIA is not known, although variables thought to be important in the pathophysiology of the disease include genetic predisposition, unknown environmental triggers, and immune reactivity. The hallmark of the disease is synovitis (inflammation of the synovial membrane of a joint). There are seven subtypes of JIA; the categorization is made according to the symptomatology that

occurs over the first 6 months of disease (Petty et al., 2016). The five major subtypes constitute the focus here.

As can be seen in Table 26.1, signs/symptoms, manifestations, and treatment approaches vary by subtype. Children with more severe disease (such as systemic-onset JIA) require more complicated treatment regimens, often involving combined drug therapy. Children with systemic-onset JIA are frequently admitted to the hospital to establish a firm diagnosis and begin therapy. Most children will respond to appropriate therapy. These children are at risk for macrophage activation syndrome, which can be life-threatening. The systemic symptoms will generally subside over the first few months of disease, but the joint symptoms persist and often progress. This subtype remains the most difficult group to treat, and up to 25% of children have continually active disease and require additional combination drug therapy.

Medical Treatment

Once the diagnosis is established, most children require regular therapy. The specific therapy used depends on the age of the child and the severity of the arthritis. Nonsteroidal anti-inflammatory drugs (NSAIDs) may be used as initial therapy. Well-established drugs such as naproxen or ibuprofen are used in young children, and longer-acting, once-a-day drugs such as nambutome, piroxicam, or the COX-2 inhibitor celicoxib are often used in older children and adolescents.

Children with pauciarticular disease may respond to NSAIDs, but intra-articular corticosteroids may be needed for unresponsive joints, and occasionally second-line agents or disease-modifying antirheumatic drugs (DMARDs) such as sulfasalazaine or methotrexate are added. In polyarticular disease, DMARDs such as hydroxychloroquine, sulfasalazaine, or methotrexate are used early. Low-dose, short-term corticosteroid therapy may be used as "bridge therapy" to control symptoms during a transitional period, as DMARDs take weeks to months to become fully effective. Biological agents may be added as well. In systemic disease, DMARDs such as methotrexate may be used initially in the disease course, and daily corticosteroids may be required for pericarditis or unresponsive disease. Biological agents to counteract interleukin (IL) and tumor necrosis factor (TNF), including anti-IL-1, anti-IL-6, and anti-TNF agents, are frequently used.

Children with eye involvement are generally treated with corticosteroid eye drops and dilating agents. The activity of the eye disease does not usually fluctuate with that of the joint disease. Every effort is made to avoid long-term corticosteroid therapy in children because of these drugs' toxicity, including growth retardation, iatrogenic Cushing disease, osteoporosis, fractures, obesity, and hypertension.

In addition to drug therapy, children with JIA must be carefully monitored for growth abnormalities, nutrition, vision, and school and social functioning, as well as psychological and emotional health. Therapeutic exercise programs with professional supervision may be needed to maximize joint motion and minimize muscle atrophy. Overall, the disease outcomes have markedly improved over the past two decades, and most children with JIA who have early diagnosis and receive appropriate treatment will have minimal joint deformity and can lead active, normal lives (Petty et al., 2016). An important predictor of favorable outcomes is how well children follow their medical regimens, as discussed below.

TABLE 26.1. Five Major Subtypes of Juvenile Idiopathic Arthritis

Subtype	Percent affected	Signs/symptoms	Other manifestations	Treatment
Systemic-onset	5–10%	Rash, high cyclic fevers, arthritis or arthralgia; severest joint involvement in hands, hips, and neck	Lymphadenopathy (inflammation of lymph nodes), hepatosplenomegaly (enlargement of liver and spleen), pericarditis (inflammation of sac enclosing the heart), serositis (inflammation of serous membrane)	Nonsteroidal anti-inflammatory drugs (NSAIDs), disease-modifying antirheumatic drugs (DMARDs), biological agents; >50% of patients require combined drug therapy
Polyarticular, rheumatoid factor negative (RF–)	30%	>4 joints involved; hands, wrists, hips, knees, ankles, neck, temporomandibular joint (TMJ)	Joint limitation/destruction, eye inflammation (uveitis)	NSAIDs, DMARDs, biological agents; >50% require combined drug therapy
Polyarticular, RF+	10%	>4 joints involved, often severe; hands, wrists, hips, knees, ankles, neck, TMJ	Rheumatoid nodules, uveitis, joint damage	NSAIDs, DMARDs, biological agents; >50% require combined drug therapy
Oligoarticular				
Persistent	40%	<4 joints involved, usually knees, ankles	Leg length discrepancy, uveitis, joint damage; positive antinuclear antibody test a risk factor for disease	NSAIDs, DMARDs
Extended	10%	Develops in >4 joints over next few years		
Enthesitis-related	10%	Involves large, lower-extremity joints and back	Joint damage, acute uveitis, enthesitis (inflammation where tendons or ligaments insert into bone); associated with human leukocyte antigen B27 (a protein found on surface of white blood cells and implicated in arthritis)	NSAIDs, DMARDs, biological agents

Pain in JIA

Chronic or intermittent pain is a primary symptom for many children and adolescents with JIA. Patients often report mild to moderate pain (Gragg et al., 1996; Hagglund, Schopp, Alberts, Cassidy, & Frank, 1995; Thompson, Varni, & Hanson, 1987; Varni et al., 1996). A 2-week electronic pain diary study showed that adolescents with arthritis reported, on average, mild pain intensity, whereas 9.2% reported no pain, and 17.1% reported pain on every diary entry (Stinson et al., 2008). About 60% of children with JIA report joint pain at disease onset, 50% report pain at 1-year follow-up, and 40% continue to report pain 5 years later (Lovell & Walco, 1989). Moreover, adults who as

children were diagnosed with JRA report significantly more pain, fatigue, and disability than gender-matched healthy controls (Peterson, Mason, Nelson, O'Fallon, & Gabriel, 1997). Thus pain is a significant problem for many children with JIA that persists into adulthood and is associated with greater disability. Pain affects multiple areas of their lives, and its effect is not fully explained by disease activity alone. For additional reviews on pain in JIA, readers can refer to our comprehensive chapter on pain in JIA (Rapoff & Lindsley, 2016) and to Law, Noel, Nagel, and Dahlquist (Chapter 11, this volume).

Clinical and Research Implications

Pediatric psychologists who work with patients with JIA need to know the patients' subtypes of JIA, to understand the physical and psychosocial demands on the patients and their families. They also need to know the types of treatments the patients are receiving, to understand issues that might affect adherence. For example, some medications are delivered by injection, and some children may need help in coping with pain from injections. Also, some children require physical and occupational therapies and nutritional interventions, which further complicate adherence and may require more comprehensive interventions to improve or maintain adherence.

ADHERENCE TO MEDICAL REGIMENS

Children with JIA and their parents are usually asked to adhere consistently and over a long period of time to a variety of therapeutic regimens, most notably medications, therapeutic exercises, and splinting of joints. Many of these regimens may have delayed beneficial effects and in the short term may cause unwanted side effects, such as gastrointestinal irritation and pain. The need for consistent adherence over a long period of time, delayed beneficial effects, and negative side effects have all been predictive factors of greater adherence problems in pediatric chronic diseases (Rapoff, 2010).

Adherence Rates to Regimens for JIA

Adherence to NSAIDs varies depending on the measure used, with higher rates (83–95%) by parent or child report or pill counts (April, Feldman, Platt, & Duffy, 2006; Kvien & Reimers, 1983), and lower rates (45–70%) by serum assay or electronic monitoring (Litt & Cuskey, 1981; Litt, Cuskey, & Rosenberg, 1982; Rapoff, Belmont, Lindsley, & Olson, 2005). Adherence rates have been found to be relatively stable over a 1-year period by parent report, with medication adherence rates of 86.1%, 91.7%, 90.4%, 92%, and 88.8%, and therapeutic exercise adherence rates lower at 54.5%, 64.1%, 61.2%, 63%, and 54.3%, respectively, at baseline and at 3-, 6-, 9-, and 12-month follow-ups (Feldman et al., 2007). Adherence rates also vary according to the cut point used to classify patients as adherent or nonadherent. Using the cut point convention of classifying patients as nonadherent if they took <80% of doses (Rapoff, 2010), Brewer, Giannini, Kuzmina, and Alekseev (1986) found nonadherence rates of 11–14% for active and placebo medications, whereas Rapoff et al. (2005) found that 48% of newly diagnosed patients with JIA were nonadherent. There is also consistent evidence that adherence is lower to therapeutic exercise regimens than to medications, by both parent

and patient reports (April et al., 2006; Feldman et al., 2007; Hayford & Ross, 1988; Rapoff, Lindsley, & Christophersen, 1985). Most of the studies on young people with JIA have focused on adherence to NSAIDs and therapeutic exercises. However, one study did report on adherence to methotrexate, a DMARD, and found a nonadherence rate of 18% as reported by parents, defined as missing three or more doses in an 8-week period (Pelajo et al., 2012). A few studies have targeted improvements in adherence to regimens (primarily medications) for JIA.

Adherence Intervention Studies

Early studies used single-subject designs with small samples. Two studies have examined the efficacy of parent-managed token reinforcement programs in altering adherence to regimens for JIA. In both studies, adherence to medications and other regimens (e.g., splint wearing) was greatly improved compared to baseline conditions (Rapoff, Lindsley, & Christophersen, 1984; Rapoff, Purviance, & Lindsley, 1988a). In the Rapoff et al. (1988a) study, improvements were also seen in clinical outcomes (e.g., decrease in the number of actively affected joints). A third study evaluated less complex behavioral strategies (self-monitoring and positive verbal feedback) combined with educational strategies, and improvements in medication adherence were seen for two of the three patients (Rapoff, Purviance, & Lindsley, 1988b).

The success of interventions with limited numbers of patients who were persistently nonadherent led our group to conducted a randomized controlled trial for newly diagnosed patients with JIA that evaluated a clinic-based, nurse-administered educational and behavioral intervention to promote adherence and prevent nonadherence to nonsteroidal medications (Rapoff et al., 2002). Thirty-four participants (mean age = 8.44 years) were randomly assigned to the experimental or (attention placebo) control groups. Patients and parents in the experimental group were given information about adherence improvement strategies (prompting, monitoring, positive reinforcement, and discipline techniques). The control group received only educational information about JIA and its treatments. At a 52-week follow-up, the experimental group showed significantly better overall adherence than the control group (77.7% vs. 56.9%), and, as predicted, the adherence levels significantly dropped over time in the control group but not in the experimental group. There were, however, no significant postintervention group differences on disease activity and functional status measures.

A unique randomized clinical trial focused on preventing osteoporosis in children with JIA (mean age 6 years) by increasing adherence to calcium (Ca) (Stark et al., 2005). Children assigned to the behavioral intervention (BI) group, who received nutritional education and behavior modification, achieved a significantly greater increase in dietary Ca intake than that of children in the enhanced-standard-care (ESC) group, who received education on JIA only. In addition, a finding of clinical significance was that 92% of children in the BI group achieved the treatment goal of 1,500 mg of Ca/day, compared to 17% of children in the ESC group. Collectively, the studies described here suggest that behavioral strategies combined with education may be the most effective way to improve adherence to regimens for JIA, and to prevent deterioration in adherence over time in newly diagnosed patients.

Consistent with recent trends toward developing online or eHealth interventions (Cushing & Steele, 2010), researchers are beginning to adapt traditional face-to-face

interventions into web-based formats, sometime supplemented by cell phone applications. Stinson et al. (2010) developed and evaluated a 12-week internet-based self-management program for adolescents with JIA and found that, relative to a control group, participants in the internet program group showed significantly greater knowledge and lower weekly pain intensity. There were, however, no differences between the groups on quality of life, self-efficacy, adherence, or stress. In fairness, the program's primary focus was not on promoting adherence, but rather on general coping strategies.

Clinical and Research Implications

Clearly, more studies are needed on adherence to therapies for JIA, particularly the DMARDs and biological agents. We also need to develop more practical methods of monitoring adherence. Ideally, electronic monitoring would become a financially viable method if more insurance companies and health care organizations adopted their use and if the costs of the monitors came down. Adherence could be monitored in real time, and the information could be sent electronically to health care providers to identify and help patients remedy adherence barriers (Rapoff, 2010). For now, the development of self-report measures that are reliable and valid is needed. So far, only two measures have been developed and partially validated for patients with JIA: the Parent Adherence Report Questionnaire and the Child Adherence Report Questionnaire, which have shown promising results in clinical settings (De Civita, Dobkin, Ehrmann-Feldman, Karp, & Duffy, 2005; April et al., 2006).

There is also a need for more randomized intervention trials using multiple sites and larger sample sizes. Intervention efforts would benefit greatly from the development of eHealth interventions, which offer several advantages: (1) They can be highly structured, thus enhancing treatment fidelity; (2) they can also be tailored to specific barriers faced by patients and families; (3) patients and families can have access to adherence interventions from their homes; (4) engaging elements (such as audio, animations, brief video clips, and interactivity) can be built into these programs to make them more attractive; and (5) outcome assessments can also be online and monitored in real time (Rapoff, 2014).

PSYCHOSOCIAL ADJUSTMENT

A substantial body of research exists on the psychosocial adjustment and coping of children and adolescents with JIA (for reviews, see Quirk & Young, 1990; Turkel & Pao, 2007). Overall, studies evaluating the psychosocial adjustment of children with JIA report mixed findings regarding coping and psychosocial quality of life for these children. Recent studies have expanded their focus to include the parents and siblings of children with JIA, and these studies also report mixed findings regarding families' ability to cope with JIA.

Social and Emotional Adjustment

A subset of children with JIA are at increased risk for an anxiety or depressive disorder, compared to healthy controls (e.g., Mullick, Nahar, & Haq, 2005). A meta-analysis by

LeBovidge, Lavigne, Donenberg, and Miller (2003) concluded that children with juvenile arthritis displayed an increased overall risk for adjustment problems and internalizing (anxious and depressive) symptoms, but no increased risk for lowered self-concept or externalizing problems. In a 1-year prospective study, Sawyer et al. (2004) found that children with arthritis reported significantly lower quality of life than healthy children. More recent studies also report a variety of psychological concerns, including separation difficulties, behavioral problems, sleep disturbance, and emotional lability in children with JIA (Russo et al., 2012).

In contrast to the studies cited above, several studies suggest little to no emotional or social difference between children with JIA and normative controls (e.g., Noll et al., 2000). Huygen, Kuis, and Sinnema (2000) found similar self-esteem, body image, perceived competence, social support, and psychopathology in children with JIA and healthy peers. Children with JIA did, however, show less ability to participate in sports and less frequent opportunities to play with friends. In a large study by Filocamo et al. (2010), researchers found no difference in psychosocial health reported by 472 children and adolescents with JIA compared to 801 healthy peers. Thus it appears that many children with JIA function as well as their healthy peers emotionally, but that a subset of children with JIA are at increased risk for emotional and social concerns such as anxiety, depressive disorders, and lower overall quality of life.

School Adjustment

High rates of school absenteeism have been reported in recent studies. In one study, 33% of children with JIA reported not being able to attend school, and those who were able to attend school missed 63% of school days, compared to 20% for healthy controls (Bouaddi et al., 2013). Russo et al. (2012) found that 50% of children with JIA experienced prolonged school absence (greater than 6 months) due to their disease, and that 8.3% of children in their sample required a personal assistant at school. Studies support the conclusion that children with more severe JIA are significantly more likely to miss school than children with less severe JIA or healthy peers (Bouaddi et al., 2013; Sturge, Garralda, Boissin, Dore, & Woo, 1997).

Regarding adjustment within the school setting, children with JIA generally report sufficient peer support from friends and romantic partners (Kyngäs, 2004). However, Schanberg, Anthony, Gil, and Maurin (2003) found that 56% of children with JIA reduced their school activities at least once during a 2-month period when they experienced increased pain, stiffness, or fatigue. Females with JIA may also be less likely than their peers to play sports, have a best friend, and spend leisure time with friends during middle and high school (Haverman et al., 2012).

Long-Term Psychosocial Adjustment

Studies of young adults with JIA consistently report impaired physical health compared to normative peers; however, long-term psychosocial outcomes for adults with JIA are less clear (Arkela-Kautiainen et al., 2005; Haverman et al., 2012; Ostile, Johansson, Aasland, Flatö, & Möller, 2010). Several studies report similar educational achievement to that of siblings and peers. For instance, in a long-term follow-up study of 123 young adults with JIA, spousal relationships, educational level, and employment status were

all reported as similar to those of population controls (Arkela-Kautiainen et al., 2005). Flatø et al. (2003) examined a cohort of 268 young adults with JIA and found that these young adult patients had comparable levels of education, social function, and mental health status to those of population controls, but that the patients had higher rates of unemployment (19% vs. 7%). Foster, Marshall, Myers, Dunkley, and Griffiths (2003) similarly found that adults (mean age = 30 years) with JIA had comparable educational attainment to that of local controls, but that unemployment rates for adult patients were threefold higher than those of controls. Therefore, it appears that children with JIA function fairly typically through the age of dependence, but tend to have more functional limitations as they progress through life.

While many studies suggest long-term emotional functioning similar to peers and normative controls (Ding, Hall, Jacobs, & David, 2008; Russo et al., 2012), several studies also report increased rates of anxiety, depression, and psychiatric illness in young adults with JIA (Mullick et al., 2005; Packham, 2004; Packham, Hall, & Pimm, 2002). Packham et al. (2002) conducted a long-term follow-up of 246 adults diagnosed with JIA (mean age = 35.4 years) and found that these adults experienced higher levels of anxiety (31.6%) than the general population did (18%), but levels of depression similar to or lower than (5.2% current, 21.1% past) those of the general population (12% current, 20% past).

Parents and Siblings of Children with JIA

Parental distress, family cohesion, and cognitive appraisals of JIA are important factors in child and family adjustment (Helgeson, Janicki, Lerner, & Barbarin, 2003; Wagner et al., 2003). Families of children with JIA report multiple illness-related stressors, such as school difficulties, fears for the children's future, problems with managing treatment regimens, and financial burdens (Degotardi, Revenson, & Ilowite, 1999). Despite this, the majority of families appear to be fairly well adjusted, reporting high levels of family cohesion/expressiveness and low levels of family conflict. Reid, McGrath, and Lang (2005) examined parent–child interactions among children with juvenile fibromyalgia, children with JIA, and healthy controls during a pain-inducing exercise task. Controlling for pain, they found no significant differences across groups on parent–child interactions. Gerhardt et al. (2003) also observed similar parenting practices in mothers and fathers of children with JIA, compared to mothers and fathers of healthy classmates.

Despite an overall positive picture, increased family burden and increased parental distress have been reported in families of children with JIA. Parents of children newly diagnosed with JIA are almost three times more likely to report lost time from work (Rasu et al., 2014), and parents of children with active arthritis report worse quality of life regarding daily activities, poorer cognitive functioning, and increased emotional distress (Haverman et al., 2014; Manuel, 2001; Waite-Jones & Madill, 2008b). Whereas early studies suggested that siblings of children with JIA were not negatively affected by their siblings' illness (Daniels, Miller, Billings, & Moos, 1986), more recent studies indicate that siblings are at risk from a number of negative psychosocial effects, including emotional distress, forfeited time with peers, and adverse experiences vicariously shared with the ill sibling (Barlow & Ellard, 2006; Waite-Jones & Madill, 2008a).

Thus research indicates that JIA contributes to increased stress for mothers and fathers, and that it has negative impacts on siblings' feelings of well-being.

HEALTH DISPARITIES AND THE ROLE OF ETHNICITY

Although JIA predominantly affects children of European descent, children of Hispanic and African American ethnic minority status who have JIA tend to have increased disease activity and worse psychosocial outcomes compared to their European American counterparts (Pelajo et al., 2012; Ringold et al., 2013), as is the case in other pediatric medical populations. Despite this observed difference in disease severity, an international multisite investigation found that the duration of systemic JIA symptoms was similar for Hispanic and non-Hispanic patients (Shishov et al., 2007). Brunner et al. (2006) found that patients with Medicaid status were more often of nonwhite race, and after the researchers corrected for disease variables and race, children with Medicaid status had significantly higher disability and lower psychosocial quality of life than children with private insurance. Researchers have also observed differences in parental choice of treatment approach, such as Hispanic families' reporting a higher use of complementary and alternative medicine (Zebracki, Holzman, Bitter, Feehan, & Miller, 2007), and differential parental coping between Native American and European American parents of children with juvenile rheumatic diseases (Andrews et al., 2007). Whereas parenting studies in the United States find little difference in parenting style between families of children with JIA and families of healthy controls (Gerhardt et al., 2003; Reid et al., 2005), a study conducted in India with 32 children with JIA and 32 healthy controls found that both mothers and fathers of Indian children with JIA were significantly more demanding, while mothers were also overprotective and pampering with object rewards compared to mothers of Indian healthy controls (Yadav & Yadav, 2013). Thus JIA may variably affect children of different ethnic groups, and parents of different ethnic backgrounds may cope differently in relation to their children with JIA.

Clinical and Research Implications

The bulk of the empirical evidence suggests that children and adolescents with JIA do not appear to be at greater risk of developing clinically significant adjustment problems. However, children who experience more severe disease appear to be at greater risk for adjustment problems and psychosocial concerns. Family cohesion appears to be a protective factor in both child and parent adjustment. More longitudinal studies are needed to assess psychosocial adjustment and coping among children with JIA, coupled with well-timed psychosocial interventions for those deemed to be at risk. Clinical interventions should consider potential ethnic differences in children's and parents' coping and preference for treatment. Pediatric researchers and clinicians increasingly recognize the importance of measuring the impact of JIA across many aspects of a child's life and should continue to include health-related quality of life and psychosocial measures of adjustment, coping, and functional outcomes. Studies on adjustment and coping should also include measures of adaptive or protective factors specific to children and families of children with JIA (Barlow, Shaw, & Wright, 2000, 2001).

SUMMARY AND CONCLUSIONS

JIA is the most common type of childhood arthritis and can cause both short- and long-term disability. The etiology of JIA is not yet known. While pain continues to be a significant problem for many children and adults with JIA, overall disease outcomes have markedly improved in recent years with the use of DMARDs. Adherence to medical regimens is well documented to predict favorable outcomes, with the combination of behavioral strategies and education demonstrating the most efficacy. However, more research is needed to develop improved and novel adherence strategies that prevent deterioration in adherence and maintain function over time in newly diagnosed patients.

The majority of children with JIA function as well as their healthy peers emotionally, socially, and academically, but a subset of children with JIA are at increased risk for short- and long-term psychosocial concerns. Similarly, most parents and siblings display positive adjustment to a child's having JIA; however, families are at risk for increased parental burden and distress, as well as for decreased sibling well-being. Finally, health disparities may exist for children and parents of minority ethnic groups compared to their white counterparts. More work is needed to minimize the functional impact of JIA on children and their families. Randomized multisite trials that utilize novel and innovative eHealth technologies to reach families in their homes and provide education, support, and behavioral interventions are needed.

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CHAPTER 27

Cardiovascular Disease

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Pediatric psychologists are becoming increasingly involved in the care of children with cardiovascular conditions. This chapter provides a brief medical overview, discusses psychological aspects of illness across stages of development, and highlights emerging areas in which pediatric psychologists can play an important role with this patient population.

PEDIATRIC CARDIAC DISORDERS: SCOPE OF ILLNESS

Cardiovascular disease in children encompasses a number of disorders. Congenital heart disease (CHD) involves structural defects in the heart that are formed during fetal development. CHD is the most common birth defect, occurring in approximately 8 out of 1,000 live births and affecting nearly 40,000 infants annually in the United States (Hoffman & Kaplan, 2002). Defects can range from mild (e.g., atrial septal defect), requiring no surgical intervention or medication and only periodic cardiac follow-up, to severe (e.g., hypoplastic left heart syndrome), requiring several palliative open-heart surgeries within the first few years of life, daily medications, close cardiac follow-up, and the need for an eventual heart transplant. Cardiac lesions are grouped by subtype: Acyanotic lesions often involve holes in the walls of the heart chambers, but blood remains fully oxygenated; cyanotic lesions cause obstructed blood flow, resulting in reduced oxygenation of the blood, or cyanosis. The causes of most CHD are unknown, but are thought to be related to both genetic and environmental factors. In fact, some genetic syndromes (e.g., trisomy 21, 22q11.2 deletion syndrome) have high rates of associated structural heart defects. Many forms of CHD can be detected prenatally, allowing parents to be counseled about treatment options—which may include preparation for deliv-

ery at a high-risk birth center and transfer to a facility where neonatal cardiac surgery can be performed, or, in some cases, termination of the pregnancy. Due to advances in surgery and medical technology, most children born with even the most severe forms of CHD are now surviving to adulthood (Bernstein, 2011a).

In contrast to children with CHD, who by definition are born with the condition, other children acquire heart disease, often from bacterial or viral infections that damage the heart. Examples of such conditions include endocarditis, rheumatic heart disease, and cardiomyopathy. In some cases, damage to the heart can be reversed or minimized with medication. In other circumstances, damage to the heart may progress, leading to heart failure and the eventual need for a heart transplant (Bernstein, 2011b).

Another type of cardiac disorder that affects children is arrhythmia, which is characterized by a disturbance in heart rate or rhythm (abnormally fast, slow, or irregular). Arrhythmias can result from complications related to congenital or acquired heart disease, or can be caused by other genetic abnormalities (e.g., long Q-T syndrome). The main risk of any arrhythmia is decreased cardiac output, which can lead to sudden death. In many cases, arrhythmias can be successfully controlled with medication. For children who do not respond to medication or are at high risk for sudden death, treatment options may include transcatheter ablation or an implantable cardioverter–defibrillator (ICD; DeWitt & Abrams, 2015).

Systemic hypertension can also affect children, although it is not common in infants or young children, and is typically associated with another underlying disease process. In older children, hypertension is most commonly associated with obesity (Lande, 2011). Because treatment of obesity is discussed elsewhere in this volume (see McCullough, Ranzenhofer, Evans, & Jelalian, Chapter 32), obesity-related hypertension is not discussed further here.

PSYCHOLOGICAL ASPECTS OF ILLNESS

Most research on the psychological aspects of pediatric cardiovascular disease has been conducted with the CHD population. There has been limited psychological research on children with acquired heart disease or arrhythmias. Therefore, the remainder of this chapter focuses on findings in the CHD population.

Neurodevelopmental Outcomes

Many studies have investigated the impact of CHD on neurodevelopment. While not all children with CHD will have neurodevelopmental problems, children diagnosed with moderate to severe forms of CHD appear to be at increased risk for deficits in the areas of intellectual ability, academic achievement, language skills, visual–motor integration, visual–spatial skills, executive function and attention, social cognition, and fine and gross motor skills (Marino et al., 2012). Although these deficits are often mild, lower than expected functioning across several domains is common, leading researchers to conceptualize a developmental "signature" of "high-prevalence, low-severity" abnormalities for individuals with CHD (Wernovsky, 2006). Despite the fact that some studies investigating the impact of CHD on neurodevelopment have limitations such as small sample sizes or lack of control groups, research has collectively demonstrated that the pattern of deficits in CHD follows a predictable developmental course, as outlined below.

Findings across Development

During infancy, gross motor and oral–motor/feeding delays tend to be most common; however, there are also higher than expected rates of early cognitive, fine motor, and language concerns (Mussatto, Hoffmann, et al., 2014; Sananes et al., 2012). Although limited by lack of a control group, one longitudinal study found that 54% of children with CHD between 6 months and 3 years of age without a diagnosed genetic syndrome demonstrated at least one area of significant delay on standardized developmental testing; 19% of children who scored in the average range on developmental testing during the first year demonstrated at least one area of developmental concern by age 3 years (Mussatto, Hoffmann, et al., 2014).

During preschool, early deficits in motor and language functioning can contribute to difficulties developing more complex visual–motor and language skills. Children who required heart surgery during infancy tend to have intelligence quotients in the low- to mid-average range, with weaknesses in the areas of expressive language, visual–motor integration, motor planning and organization, and oral–motor control compared with population norms (Karsdorp, Everaerd, Kindt, & Mulder, 2007). Children with CHD have also been shown to have higher rates of utilizing early intervention services than the general population (Forbess et al., 2002).

At school age, intelligence appears to remain stable in the low- to mid-average range, but lower than expected scores are often reported in the areas of academic achievement, sensory–motor and fine motor function, visual–spatial skills, language, working memory, sustained attention, social cognition, and executive function (Bellinger et al., 2003; Miatton, DeWolf, Francois, Thiery, & Vingerhoets, 2007). Adolescents with CHD have similar deficits, with elevated rates of special education, tutoring, and grade retention (Bellinger et al., 2011). These findings have implications for adulthood. Although there is significant variability, adults with CHD can have continued difficulties with executive function, problem solving and planning, and adaptive skills, as well as lower educational attainment and employment rates, than the general population (Daliento et al., 2005; Zomer, Vaartjes, Grobbee, & Mulder, 2013).

Risk and Resiliency

Given these neurodevelopmental deficits in children with CHD, considerable research has focused on biological, medical, and environmental risk and resiliency. Biological differences relevant to neurodevelopment have been reported among children with CHD, beginning *in utero*. At birth, infants with CHD have been found to have lower brain volumes and an increased incidence of white matter or hypoxic injuries (Licht et al., 2009). Among subtypes of CHD, cyanotic heart disease increases developmental risk, due to chronic hypoxemia (Marino et al., 2012). Other biological risks include microcephaly and having a suspected or confirmed genetic abnormality, which is true for up to 30% of children with CHD (Marino et al., 2012).

Although studies have examined whether a single aspect of care (e.g., surgery using deep hypothermic circulatory arrest vs. low-flow cardiopulmonary bypass) affects neurodevelopment (Bellinger et al., 2011), the causes of neurodevelopmental deficits appear multifactorial and cumulative (Marino et al., 2012). The following surgical and medical factors appear to increase risk for neurodevelopmental deficits: premature birth, mechanical support (extracorporeal membrane oxygenation [ECMO], ventricular assist

device [VAD]) or heart transplantation, cardiopulmonary resuscitation, perioperative seizures, abnormalities on neuroimaging, and prolonged hospitalization (Marino et al., 2012).

Finally, environmental factors have an impact on risk. As in other chronic illness groups, socioeconomic status (SES) tends to be positively associated with neurodevelopmental test scores (Marino et al., 2012). Other aspects of the environment, such as parenting style, have also been found to predict neurodevelopment (McCusker et al., 2007). Specifically, parental overprotectiveness and lack of exposure to developmentally appropriate activities (e.g., sleeping independently, going on play dates) are hypothesized to contribute to the lower adaptive skills and achievement levels reported in individuals with CHD (Marino et al., 2012).

Behavioral and Social–Emotional Outcomes

Children with CHD appear to be at increased risk for psychological maladjustment compared to normative samples, with studies documenting emotional and/or behavioral problems in up to 41% of children with CHD (Latal, Helfricht, Fischer, Bauersfeld, & Landolt, 2009). Parents and some children with CHD have also reported lower physical and psychosocial health-related quality of life (HRQOL) than healthy controls (Million et al., 2014).

Findings across Development

Studies examining emotional and behavioral functioning in early childhood have typically found similarities between young children with CHD and the normative population (Karsdorp et al., 2007). However, older children with CHD appear to be at significantly greater risk for internalizing symptoms and somewhat greater risk for externalizing symptoms than similar-age peers from the normative population (Karsdorp et al., 2007). Recent studies suggest that children with CHD may also be at greater risk for attention-deficit/hyperactivity disorder and autism spectrum disorder than the general population (DeMaso et al., 2014; Marino et al., 2012; Razzaghi, Oster, & Reefhuis, 2015).

Psychosocial difficulties may become even more prevalent during adolescence (Karsdorp et al., 2007), with internalizing problems, including social withdrawal, anxiety, somatic complaints, and depressive symptoms, being more common than externalizing symptoms (Marino et al., 2012). In addition, social cognition and peer relations appear to be areas of weakness for adolescents with CHD (Marino et al., 2012). Studies suggest that psychosocial difficulties (e.g., depressed mood, poor self-esteem) may be among the strongest predictors of HRQOL for adolescents with either CHD or acquired heart disease (Cohen, Mansoor, Langut, & Lorber, 2007).

Risk and Resiliency

Type and severity of heart condition have been inconsistently associated with child social-emotional and behavioral problems (Karsdorp et al., 2007). However, neurodevelopmental deficits and long-term complications (e.g., arrhythmias) appear to increase risk for emotional and behavioral concerns (Latal et al., 2009). Characteristics of the

environment also place children with CHD at greater risk for social-emotional and behavioral concerns. Specifically, parental stress has been associated with more emotional and behavioral concerns in children (Latal et al., 2009), with parental stress levels being a stronger predictor of adolescent psychosocial functioning than physical illness severity (DeMaso et al., 2014). Finally, child variables including understanding and perception of illness have been associated with adjustment. Among adolescents with either CHD or acquired heart disease, self-perceptions regarding health, self-worth, and competence explained a larger proportion of the variance in behavioral problems than did demographic and medical factors (Mussatto, Sawin, et al., 2014). In another study, perceived severity of disease was a stronger predictor of HRQOL than was objective disease severity (Cohen et al., 2007).

Family Impact

CHD not only alters a child's neurodevelopmental and psychological functioning, but can also have a tremendous impact on the family system. Whereas some parents learn about the diagnosis prenatally, others are informed that their newborn is critically ill hours before he or she is transferred to the cardiac intensive care unit (CICU), often located in a different city or state from the hospital where the mother is recovering from labor and delivery. During the hospital stay, which can range from weeks to months, parents may not be able to feed, comfort, or even hold their baby, and are often far from home and their support networks. Parents report high levels of fear and stress (Cohn, 1996; Helfricht, Latal, Fischer, Tomaske, & Landolt, 2008), which can be exacerbated by disruptions in normative parent–infant bonding, separation from other children, and an unpredictable medical course.

For many parents, negative psychosocial effects persist well beyond the time of diagnosis and surgery. Even years later, parents of children with CHD endorse higher rates of psychological maladjustment (Davis, Brown, Bakeman, & Campbell, 1998), distress and hopelessness (Lawoko & Soares, 2002), and parenting stress (Uzark & Jones, 2003), as well as lower quality of life (Lawoko & Soares, 2003), compared to parents of children from the normative population. Parents of children with CHD may also experience chronic medical traumatic stress (Franich-Ray et al., 2013; Helfricht et al., 2008)—a set of psychological and physiological responses including intrusive thoughts, avoidance, negative mood, and hyperarousal (Kazak et al., 2006; see Kazak, Price, & Kassam-Adams, Chapter 14, this volume, for additional information on this topic). Parental traumatic stress and other negative psychosocial effects do not appear directly related to CHD severity and complexity, but are instead associated with parental perceptions, coping style, social support, and family sociodemographic characteristics (Davis et al., 1998; Lawoko & Soares, 2003).

Siblings of children with CHD are an important but understudied group. During hospitalizations, siblings are often cared for by relatives and may experience extended separation from parents. Sibling adjustment difficulties typically depend on age and developmental stage; these problems may include jealousy about attention given to the child with CHD, worry about the health and prognosis of the child with CHD, or emotional and behavioral challenges related to parental separation and changes in routine (Janus & Goldberg, 1997). Research focused specifically on the social-emotional and behavioral functioning of siblings of children with CHD is needed.

MANAGEMENT OF ILLNESS

Learning and Neurodevelopment

Given increased risk for neurodevelopmental deficits among children with CHD, the American Heart Association (AHA) recommends routine surveillance, screening, evaluation, and reevaluation (Marino et al., 2012). Psychologists can play a key role in meeting this recommendation by conducting standardized assessments at multiple time points throughout infancy, childhood, and adolescence (Brosig, Butcher, et al., 2014; Marino et al., 2012). Because delays among children with CHD are often subtle and cumulative, and may not occur in areas that are part of a standard school evaluation, these assessments are ideally conducted by a psychologist familiar with CHD. Goals of these assessments include monitoring developmental progress over time; providing parent consultation; and developing recommendations for early intervention, school services, or supportive services to remediate deficits and optimize child outcomes. Consultation with other professionals, including medical providers (e.g., cardiologists and pediatricians), early interventionists, and school system personnel, is crucial to meeting these goals. Pediatric psychologists and neuropsychologists are currently leading efforts to develop standardized assessment batteries for children with CHD and often start, or take a major role in, neurodevelopmental follow-up programs (Brosig, Butcher, et al., 2014).

Although the role of psychologists in neurodevelopmental assessment of children with CHD is becoming more established, their role in preventing or reducing neurodevelopmental deficits is less understood. Research studying modifiable risk factors for neurodevelopmental deficits, especially those associated with a child's environment, is needed. In a recent meta-analysis, Robinson, Kaizar, Catroppa, Godfrey, and Yeates (2014) examined the efficacy of cognitive interventions (e.g., computerized training) designed with the intention of improving outcomes in attention, memory, or executive functions for children with central nervous system or neurodevelopmental disorders. Results indicated that these interventions may improve performance on attention and memory tasks, and, to a lesser extent, academic achievement and scores on behavioral rating scales. However, effects appear to be larger for children with acquired brain injuries rather than neurodevelopmental disorders (Robinson et al., 2014).

McCusker et al. (2010, 2012) have conducted some of the only intervention studies targeting development/school functioning in children with CHD. Their first intervention was designed for parents of infants who required cardiac surgery as neonates; it involved six parental sessions focused on adjustment to diagnosis, feeding interactions, and coping with anxiety (McCusker et al., 2010). Six months after the intervention, infants in the intervention group demonstrated higher scores in mental development, but no differences in psychomotor development compared to the control group. Mothers in the intervention group were breastfeeding more frequently and had lower levels of anxiety and health-related worry compared to controls. McCusker et al. (2012) then tested an intervention for children with CHD prior to the transition into school, which involved a day-long parent workshop focused on problem-solving skills, psychoeducation, and parenting strategies, as well as one individual follow-up session with more tailored recommendations. Ten months later, children in the intervention group had fewer days of missed school and were perceived as "sick" less often by their mothers, compared to children in the control group. Mothers in the intervention group reported

improved overall mental health and reduced personal strain associated with having a child with a chronic illness, compared to control participants.

Acute/Hospital Care

Pediatric psychologists can play an important role in supporting children and families from the time of diagnosis (Kowalcek, 2007) through hospitalization for cardiac surgery or catheterization. Psychologists can assist the parents of infants with CHD in managing stress related to the children's medical condition and hospitalization. Many parents report significant anxiety related to feeding their babies, as infants with CHD often have difficulty learning to suck and swallow (Hartman & Medoff-Cooper, 2012). Psychologists can work with feeding therapists and nurses to facilitate more relaxed feeding interactions between parents and infants.

For older children with CHD, pediatric psychologists can work with families, child life specialists, and other members of the cardiac staff to promote developmentally appropriate conversations about upcoming procedures and hospitalizations, as well as effective child coping during aspects of care (e.g., bandage changes, chest tube removal; LeRoy et al., 2003). Extended absence from school, restricted peer interactions, and limited physical activity due to illness and hospitalization have been shown to place children at risk for poor adjustment, depression, and behavior problems (Roberts & MacMath, 2006). Pediatric psychologists can work with children and families to help them stay connected with teachers and peers, and can provide consultation to physical and occupational therapists when anxiety, mood, or behavioral difficulties impede participation in rehabilitative therapies or other physical activity during the hospitalization (Taylor, Wilson, & Sharp, 2011). Psychologists can work with parents and staff members to reinforce the importance of consistent limit setting and behavior management even while a child is hospitalized (LeRoy et al., 2003), and can assist with the development of behavior management plans. In some cases, when a child is given a new diagnosis, a pediatric psychologist can work with the child and family to support emotional adjustment to this new diagnosis and to assess and treat symptoms of medical traumatic stress in the child, a parent, or a sibling (Kazak et al., 2006).

Returning home after an extended hospitalization poses a variety of challenges, regardless of the child's age. Infants often continue to have problems with feeding and weight gain, and such a child often goes home with a feeding tube, which increases the complexity of the medical regimen and may add to parents' anxiety about caring for a medically fragile infant outside the security of the hospital setting (Hartman & Medoff-Cooper, 2012). Young children may struggle with developmental tasks and routines that they had previously mastered, such as motor milestones or sleeping independently or through the night (Marino et al., 2012). If limit setting did not occur during the hospitalization, behavioral difficulties may persist upon the return home (LeRoy et al., 2003). School-age children may have difficulty reentering the school environment, and may worry about fitting in, being subjected to unwanted attention and questions, or falling behind academically (Roberts & MacMath, 2006). Pediatric psychologists can assist with preparing children and families for hospital discharge and school reentry from an emotional and developmental perspective. For example, psychologists can provide consultation to parents on limit setting, behavior management, and sleep retraining, and can work with children on managing anxiety and developing plans for handling

unwanted attention and questions. In some cases, children and families may benefit from continuing to work with pediatric psychologists on an outpatient basis during this time of transition; models for integrating pediatric psychology services into outpatient cardiology clinics and determining which families are most in need of services are being explored (Brosig, Yang, Hoffmann, Dasgupta, & Mussatto, 2014; Struemph, Barhight, Thacker, & Sood, 2016).

Long-Term Illness Management

The role of pediatric psychologists in supporting adjustment extends well beyond the acute care stay. Often families need additional support once the initial shock of the diagnosis wears off and they are working to incorporate illness management into their daily lives. Psychologists can work with children and parents on managing their anxiety about potential complications and identifying beliefs about child health and vulnerability that may be negatively affecting parenting and quality of life (Cohen et al., 2007; McCusker et al., 2012). Research suggests that children often have limited understanding of their illness and the long-term implications of their condition (Veldtman et al., 2000), and that parents often do not remember or understand the medical information that has been presented, resulting in significant gaps in their medical knowledge (Cheuk, Wong, Choi, Chau, & Cheung, 2004). Psychologists can assist the medical team in providing information to children that is developmentally appropriate, and in tailoring medical information to parents who may have limited health literacy.

Another role for psychologists is helping children and families adhere to the medical regimen. Similar to children with other chronic illnesses and their families, families/children affected by pediatric cardiovascular conditions may struggle with taking medications as prescribed, following a heart-healthy diet, or achieving sufficient physical activity. Parents of children with cardiac conditions are often anxious and uncertain about allowing their children to exercise, and often impose more physical activity restrictions on the children than cardiologists recommend (Longmuir & McCrindle, 2009). Psychologists can assist parents in managing their own anxiety to promote physical activity in their children. For youth with newly imposed exercise restrictions (e.g., a high school athlete who is newly diagnosed with cardiomyopathy after suffering sudden cardiac arrest), psychologists may assist such patients in coping with changes in their lifestyle (e.g., no longer being able to play competitive sports).

DIVERSITY/HEALTH DISPARITIES

Health disparities based on race, ethnicity, and SES have been documented for pediatric patients with CHD and their families. Infants from ethnic minority and impoverished families are at elevated risk for mortality, hospital readmission/reintervention, and neurodevelopmental impairment (Ghanayem et al., 2012; Lasa, Cohen, Wernovsky, & Pinto, 2013; Marino et al., 2012). Disparities in morbidity and mortality typically become apparent in the months following surgery and hospital discharge (Ghanayem et al., 2012; Lasa et al., 2013), when primary caretaking responsibilities for a medically complex infant are transferred from hospital to home. Ethnic minority and impoverished families disproportionately face risk factors for poor health outcomes (Berry,

Bloom, Foley, & Palfrey, 2010), including lower parental education level and social support, more frequent issues with housing and transportation, and lower-quality general pediatric care, all of which can have a negative impact on postdischarge care.

Health disparities have also been documented for parents of children with CHD. Parents with limited financial and educational resources are at elevated risk for parenting stress, medical traumatic stress, and poor quality of life (Davis et al., 1998; Lawoko & Soares, 2003). These negative psychosocial effects can also have an impact on the family environment, compounding the aforementioned risk factors for poor health outcomes among ethnic minority and impoverished families, and placing already vulnerable children at even higher risk for psychosocial problems (DeMaso et al., 2014). Future studies are needed to identify the specific psychosocial needs of low-income and ethnic minority families in the months following infant cardiac surgery, and to evaluate targeted psychosocial interventions that could begin to address disparities in infant and family health following cardiac surgery.

EMERGING AREAS

Developmental/Psychosocial Care Initiatives in the CICU

Recent studies document a robust relationship between prolonged hospitalization and poorer neurodevelopmental outcomes (Marino et al., 2012), highlighting the importance of cumulative experiences in the CICU and hospital environment. Developmental care is an individualized approach that attempts to minimize the mismatch between the immature brain's expectations and the experiences of stress and pain inherent in intensive care unit environments (Als, 2008). Developmental care in the neonatal intensive care unit setting, which may include attention to light and noise levels, developmentally appropriate positioning and holding, and supporting parents and family members as the primary caregivers, has been shown to reduce length of hospital stay and improve weight gain and neurodevelopmental outcomes for preterm infants (Als, 2008). There have been recent efforts to define and implement developmental care for infants with CHD hospitalized in the CICU (Torowicz, Lisanti, Rim, & Medoff-Cooper, 2012), including recommendations for addressing the feeding/growth issues in this population (Medoff-Cooper & Ravishankar, 2013). Many centers have formed developmental care committees and initiated developmental care rounds and education to promote these practices (Sood et al., 2016). Research is needed to empirically examine the relationship between developmental care practices in the CICU and child and family outcomes.

Targeted efforts to identify parents and families at high risk for negative psychosocial effects, and to provide intervention within the CICU and hospital environment, are in the early stages of clinical investigation and practice. Tools for screening family psychosocial risk that have been validated with other patient populations may prove to be useful with this population (Hearps et al., 2014). There is also evidence that family-based psychosocial interventions may decrease parental anxiety and worry, improve feeding practices, and enhance infant neurodevelopment (McCusker et al., 2010; White-Traut et al., 2013). It will be important for screening tools and family-based interventions developed or adapted for this patient population to be feasible and acceptable for diverse families, including those with low SES, so that they may begin to address disparities in infant and family health following cardiac surgery.

New Technology/Devices

In recent years, VAD technology, a method of mechanical circulatory support that involves the use of an implanted device that pumps blood when the heart is unable to do so, has been extended from use in adults to infants and children. VADs are most commonly used for heart failure caused by acute myocarditis, cardiomyopathy, and CHD; they typically are bridges to transplantation and offer alternatives to ECMO, given ECMO's significant risk for adverse outcomes. However, VADs are not without risk; approximately 25% of children die while on a VAD, most commonly due to neurological dysfunction (Almond et al., 2013). Most VADs require extended hospitalization, which can be difficult for child/family coping. Newer devices have now been approved, allowing some patients to go home on a VAD while waiting for transplant. However, this requires extensive training on the part of the caregivers, which can also increase family stress. Indeed, preliminary research suggests that patients who receive a VAD and their caregivers often experience depression and/or anxiety shortly after VAD placement, possibly due to responsibility of caring for the VAD, fear of complications, altered self-perceptions and body image associated with being attached to a machine, and limitations on social functioning (Ozbaran, Kose, Yagdi, Engin, Erermis, Uysal, et al., 2012; Ozbaran, Kose, Yagdi, Engin, Erermis, Yazici, et al., 2012). Psychologists can assist families in coping with the stress related to the VAD medical regimen and to waiting on a transplant list following VAD placement, whether in the hospital or at home (see Eaton et al., Chapter 28, this volume, for additional information on transplantation).

Other devices now being used in children are ICDs, which are intended to manage lethal arrhythmias in children diagnosed with cardiomyopathy or CHD. These devices may be life-saving, but they are associated with high rates of complications, including inappropriate shocks (20–25% incidence), lead failure (up to 21%), blood clots, and infection (DeWitt & Abrams, 2015). Many children are also advised to avoid contact sports for the duration of ICD use, to prevent damage to the ICD and its leads. Children with ICDs report frequent worry about receiving shocks (DeMaso et al., 2004), and exhibit higher rates of anxiety disorders and lower physical quality of life than do children with pacemakers alone (Sears et al., 2011; Webster et al., 2014). Given these issues, this may be another subset of cardiac patients who would benefit from psychological support.

Transition to Adult Care

The number of young adults with CHD is rising exponentially, but fewer than 30% of these adults are seen by appropriate specialty adult CHD providers (Sable et al., 2011). Due to the medical risk of poor transition to adult care, along with the concern that adults with CHD have problems with adaptive functioning, the AHA has developed guidelines that outline transition tasks by developmental stage for physical/medical domains as well as social-emotional/behavioral domains (Sable et al., 2011). Despite these best-practice guidelines, transition in adult CHD remains an understudied area, and more research is needed. A recent study by Mackie et al. (2014) suggested that a structured educational intervention for adolescents with CHD or cardiomyopathy was effective in increasing cardiac knowledge and preparing adolescents for transition. Psy-

chologists could play a significant role in developing and evaluating programs that prepare adolescents/young adults with CHD and their families for transition to adult care (see Devine, Monaghan, & Schwartz, Chapter 47, this volume, for more information).

FUTURE DIRECTIONS

Although psychological interventions have been shown to reduce mortality and morbidity in adult patients with cardiovascular disease (Linden, Phillips, & Leclerc, 2007), little has been written until recently about the role of pediatric psychologists for children with cardiac conditions. As the number of survivors of pediatric cardiac disease continues to grow, there will be an increasing demand for psychologists who specialize in working with children with these conditions and their families. As such, psychology training programs should partner with psychologists working in pediatric cardiac centers to facilitate training experiences with this population at the practicum, internship, and postdoctoral fellowship levels. In addition, although the increased risks for cognitive, emotional, and behavioral problems have been well documented in the CHD population, additional research is needed on the psychological impact of acquired heart disease and other cardiac conditions, as well as further study of interventions that address the psychosocial aspects of illness for children and families affected by all cardiovascular conditions.

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CHAPTER 28

Organ Transplantation

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Transplantation of the kidney, heart, liver, lung, and small intestine is now performed at pediatric medical centers worldwide. In the United States alone, more than 20,000 pediatric transplants were performed between 2005 and 2015 (Organ Procurement and Transplantation Network [OPTN], 2014). Outcomes for pediatric solid organ transplantation have continued to improve, with 5-year survival rates for liver, kidney, and heart transplant at nearly 80% (Colvin-Adams et al., 2014; Matas et al., 2014; OPTN, 2014). The 5-year survival rates for pediatric lung and intestine transplant recipients are approximately 50%, and also improving (OPTN, 2014). Given these increased survival rates, researchers and clinicians have increasingly attended to promoting health-related quality of life (HRQOL) and adjustment among pediatric transplant recipients.

THE ROLE OF PEDIATRIC PSYCHOLOGY IN SOLID ORGAN TRANSPLANTATION

The United Network for Organ Sharing (UNOS) has identified posttransplant physical and developmental effects as critical areas for assessment and intervention in pediatric patients. UNOS requires that each transplant program have designated members of the transplant team whose primary responsibilities are managing the psychosocial needs of transplant candidates, recipients, living donors, and their families (OPTN, 2014). This role is often filled by pediatric psychologists, who work with patients and families in a compassionate and culturally sensitive manner to facilitate coordination of care before and after transplantation. Pediatric psychologists routinely participate in pretransplant psychosocial evaluations and posttransplant treatment of transplant

candidates and their families (Annunziato, Fisher, Jerson, Bochkanova, & Shaw, 2010). As patients shift from the pre- to posttransplantation periods, pediatric psychologists help patients and families cope with the challenges of having a chronic medical condition, which can place stress on families and affect HRQOL, psychosocial functioning, medication adherence, and long-term health. Overall, pediatric psychologists have a significant, positive impact at each stage of the transplant process on behavioral and medical outcomes.

THE PRETRANSPLANT PERIOD

Multiple pathways can lead to transplantation. Some families have anticipated transplantation since a child's birth and diagnosis with a congenital disease, whereas other diseases are emergent. Regardless, the process of organ transplantation begins once a child is referred for a pretransplant evaluation. Evaluations are typically conducted when transplantation is medically indicated to improve a child's long-term outlook and HRQOL—that is, when a chronic illness has no established treatment, when treatments have failed or stopped working, and/or when an illness would otherwise result in death (Shellmer, Brosig, & Wray, 2014). The comprehensive and multidisciplinary pretransplant evaluation is designed to identify factors that may place a patient at risk for poor posttransplant outcomes, and to educate families about transplantation, stressors, risks, and available psychosocial resources (Annunziato et al., 2010). Even though pretransplant evaluations are routine, there are no standardized batteries or agreed-upon, psychometrically valid assessment tools for use with pediatric patients. Annunziato et al. (2010) have suggested factors to consider in the pretransplant evaluation process and in developing a standard pretransplant screening measure, including patient knowledge of the transplant process, past adherence, cognitive and psychological functioning, financial resources, and caregiver stress and mental health. See Lefkowitz, Fitzgerald, Zelikovsky, Barlow, and Wray (2014) for more information on assessment and suggested measures in the pretransplant period.

Once transplantation is determined to be the optimal treatment plan, patients and their families enter a period of uncertainty and unpredictability. Time spent waiting for a transplant can vary from days to years, with over 1,800 children awaiting an organ transplant at any given time (OPTN, 2014). Waiting times are due to the severe organ shortage, which is heightened for pediatric patients because they require size-matched organs. Organ allocation is also influenced by geographic location, with variability in waiting time by region (Reese et al., 2014). Since OPTN began tracking patients in 1995, approximately 3,700 children have died while waiting for an organ. Although the majority of transplants are from deceased donors, live donation is currently possible for a kidney, a liver segment, a portion of the pancreas, or a lobe of the lung.

During the pretransplant period, patients live with end-stage organ failure and require medical management. Disease processes and treatments often have a negative impact on patients' psychosocial, cognitive, and academic functioning, as well as attainment of developmental milestones. Limited data are available on patients' psychosocial functioning during the pretransplant period, as most research has been conducted after transplantation. However, young patients awaiting heart or heart–lung transplant demonstrate lower levels of emotional and social functioning than those of normative

samples (Wray & Radley-Smith, 2004). Patients with end-stage renal disease receiving dialysis have decrements in HRQOL and academic functioning, with poorer functioning as time on dialysis increases (Neul, Minard, Currier, & Goldstein, 2013). Caregivers of children awaiting heart or heart–lung transplant have also reported higher emotional distress than normative samples (Wray & Radley-Smith, 2007).

During pretransplantation, infants and children are at risk for missing opportunities for interactions that promote healthy development, due to illness and associated treatment. Factors including premature birth, malnutrition, infections, circulatory deterioration, and increased toxin levels in the bloodstream (e.g., ammonia) place children at further risk. Patients who miss school may also experience lower cognitive and academic development. Developmental level should be used instead of age, to personalize assessment and intervention for this population (Lefkowitz et al., 2014). In an investigation of intellectual and academic functioning in children undergoing evaluations for kidney, liver, or heart transplant, patients' intellectual and academic functioning was within the average to low-average range overall, though both were significantly lower than norms (Reed-Knight, Lee, Cousins, & Mee, 2015). Early and consistent communication with schools may help initiate appropriate academic and developmental accommodations.

Much of the literature examining patients' pretransplant functioning is outdated, and medical advances have improved the transplantation process and outcomes over time (Anthony et al., 2014). The number of paths by which a child can come to require a transplant further complicates the generalizability of the pretransplant literature. Finally, the many varieties of illness and end-stage disease presentations create heterogeneity in both medical and psychological presentations.

THE TRANSPLANT SURGERY: PERITRANSPLANT PERIOD

The transition from the pretransplant waiting period to the immediate post-transplant period (peritransplant) can be stressful for children and their families. The preoperative phase entails waiting for a suitable organ, with accompanying apprehension, helplessness, and worry reported by parents (Rodrigue et al., 1997). Transplant surgery may be scheduled with little advance notice. Thus the homeostasis of waiting is suddenly disrupted when an organ becomes available, and the patient and family face the gravity of major surgery. Although parents are often relieved after a successful transplant surgery, they also face a bevy of additional emotions, including fear of infection and/or rejection, and concerns about postoperative care.

Transplant Hospitalization and Recovery from Surgery

The hospital stay for an uncomplicated solid organ transplant typically ranges from 7 to 14 days. Length of stay may vary, depending on the child's age, insurance status, and perioperative complications. During acute postsurgical hospitalization, attention is focused on initiating immunosuppressant medications and achieving medical stability. Transplant recipients often experience decreased physical strength and exercise tolerance following transplant surgery, due to physical deconditioning resulting from bed rest, medications, and surgery (Brosig et al., 2014). Early implementation of physical

and occupational rehabilitation to promote mobility and return to daily living skills is essential during the peritransplant period and planning for discharge.

Transition from Hospital to Home: Discharge Planning

Transition from hospital to home requires planning, communication among health care providers, and tailored family education regarding posttransplant care. The extent to which teaching is "hands-on" and individualized influences parents' confidence in their ability to manage postoperative care at home (Lerret et al., 2014). Similarly, perceived support and availability of the transplant team also increases parental confidence prior to discharge.

Adjusting to a "New Normal"

The peritransplant period is also a time during which patients adjust to a "new normal" of having a chronic condition. As families adjust to their posttransplant lifestyle (e.g., following a strict medical regimen, frequent medical appointments), parents report worry about postsurgical complications and their children's adjustment (Lerret et al., 2014). Persistent distress and poor coping in this period can be associated with nonadherence, suggesting that families struggling to adjust may benefit from intervention to minimize distress and improve regimen adherence.

THE EARLY YEARS POSTTRANSPLANTATION

During the first 3 years posttransplantation, or "early years" (Brosig et al., 2014), patients adjust to the reality that taking medications and attending clinic visits will continue for the rest of their lives. They may become more aware of the side effects of medications, including increased risk of infections, weight gain, and emotional and behavioral changes (Annunziato, Jerson, Seidel, & Glenwick, 2012). Failure to take medications as prescribed can result in negative medical events, including hospitalizations, need for biopsies, organ rejection, and death (Fredericks, Lopez, Magee, Shieck, & Opipari-Arrigan, 2007). As patients and families adjust to the complex posttransplant medical regimen, there is growing awareness of the burden of having a chronic condition (e.g., taking medications, lower HRQOL, missing school).

Medication Adherence

Long-term management posttransplantation involves daily and on-time medication adherence to maintain therapeutic serum immunosuppressant levels (Shemesh et al., 2004). Possibly due to greater focus on adherence in the early years, less time since transplantation has been associated with better adherence in pediatric transplant recipients (Berquist et al., 2008). Medication adherence is monitored via multiple methods. Self-reported adherence is obtained from patient and/or caregiver reports of patient adherence (Zelikovsky & Schast, 2008), though this method is subject to issues of accurate recall and reporter bias (Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008). Serum assays allow calculation of standard deviations of immunosuppressant

blood levels over time, with higher standard deviations reflecting more erratic medication taking (Shemesh et al., 2004). Monitoring serum levels is an efficient, informative, and relatively unbiased method to measure medication adherence in the days immediately preceding the blood draw. Electronic monitoring (e.g., via Medication Event Monitoring System Caps) provides *in vivo* adherence measurement, but it is subject to mechanical failure and reactivity, and it can be prohibitively expensive (Quittner et al., 2008) for clinical use. There is no "gold standard" for assessing adherence, and use of multiple methods is recommended.

Adherence can be compromised by barriers that interfere with following medical regimens. Barriers are assessed via self-report of impediments to following medical regimens as prescribed (Simons & Blount, 2007). In adolescent and young adult (AYA) transplant recipients, greater barriers predicted nonadherence and negative medical outcomes (e.g., rejection episodes, hospitalizations, and death; Eaton et al., 2015; Simons, McCormick, Devine, & Blount, 2010). Furthermore, barriers tend to be stable across time without intervention (Lee et al., 2014). Barriers have also been shown to mediate the relationship between greater patient internalizing symptoms of anxiety, depression, and posttraumatic stress, and medication nonadherence (McCormick King et al., 2014).

A small but growing number of interventions have been developed to enhance pediatric transplant recipients' adherence. Increasing the frequency of clinic visits for nonadherent patients (Shemesh et al., 2008) and sending text-messaging reminders to caregivers (Miloh et al., 2009) have resulted in improved adherence for pediatric transplant recipients.

Health-Related Quality of Life

HRQOL, particularly the physical health component, improves after transplantation (Cole et al., 2004); yet posttransplant pediatric patients continue to demonstrate lower HRQOL (Alonso et al., 2010) and engage in less physical activity, compared to healthy controls. Continued deficits in HRQOL may be linked to physical illness and medication regimens and their side effects, which limit the ability to socialize and attend school (Alonso et al., 2010).

Patient and Family Psychosocial Adjustment to Transplantation

Risk for rejection episodes, hospitalizations, and death is the reality for every transplanted patient, including those who follow their medical regimens exactly as prescribed. Risk for negative medical outcomes can be emotionally taxing for families. Even though patients' psychosocial functioning often improves after transplantation, some patients continue to endorse significant emotional distress (e.g., Mintzer et al., 2005). Transplantation is also stressful for caregivers, who may endorse elevated levels of posttraumatic stress symptoms related to lower perceived child health, greater family impact of the transplant, and poorer attitudes toward children's medical providers (Young et al., 2003). Many caregivers report lower family functioning within 2 years of transplantation (Alonso et al., 2008) and make significant adjustments to family routines to accommodate the children's needs (Denny et al., 2012).

School Reintegration

School reintegration represents a return to normality. Families may be concerned, however, that their children's academic performance will suffer due to missing school to attend medical appointments, and that peers may negatively react to the children's medical needs. Missing school is common, with more recently transplanted children likely to miss at least 10 days of school (Gilmour, Sorensen, Anand, Yin, & Alonso, 2010). Weil, Rodgers, and Rubovits's (2006) school reentry program protocol calls for conducting a pretransplant assessment of a child's cognitive, emotional, and behavioral functioning; establishing contact among the family, medical team, and school; and developing a reentry plan. To facilitate successful academic reintegration, family members should communicate with the school and jointly plan for accommodations recommended by medical providers.

THE LATER YEARS

After the first 3 years posttransplantation, pediatric patients enter the "later years" (Fredericks, Zelikovsky, Aujoulat, Hames, & Wray, 2014). This period, typically characterized by greater stability, has received increased attention as medical and pharmacological progress has led to enhanced graft survival rates and improved long-term prognoses (e.g., Colvin-Adams et al., 2014). HRQOL and adherence continue to be areas of research and clinical attention, with increased emphasis on AYAs' assumption of responsibility for medical care and readiness to transfer from pediatric to adult care providers.

HRQOL and Psychosocial Adjustment

As time since transplantation increases, patients continue to experience improved HRQOL (e.g., Bucuvalas et al., 2003). However, as in the early years, the majority of evidence suggests that pediatric patients are at increased risk for long-term difficulties across domains of psychosocial functioning, even when compared to children with other medical conditions (Fredericks et al., 2007). Researchers have identified individual, contextual, and medical factors linked to better HRQOL in the later years, including younger patient age at the time of transplantation, adherence, higher parent HRQOL, family functioning, longer time since transplantation, and fewer rejection episodes (Alonso et al., 2010). Income, adherence, missed clinic appointments, organ rejection, and family conflict predicted HRQOL 18 months later, after baseline levels of HRQOL were accounted for (Devine et al., 2011). Also, although caregivers' and patients' reports of AYAs' HRQOL tend to agree, caregivers report lower HRQOL than AYAs do on several HRQOL domains (Devine, Reed-Knight, Simons, Mee, & Blount, 2010).

Cognitive and School Functioning

Pediatric transplant recipients have consistently demonstrated lower than expected cognitive abilities. Below-average scores have also been documented on domains of verbal

comprehension, working memory, and executive functioning (Sorensen et al., 2014). Cognitive difficulties in these domains can pose academic challenges. Compared to norms for healthy youth, solid organ recipients as a group perform in the borderline to average ranges across measures of academic achievement (Sorensen et al., 2014).

Medication Adherence

Medication nonadherence remains an important risk factor for negative medical sequelae in the later years. Adolescence and young adulthood are developmental stages marked by high nonadherence rates, ranging up to 43% (Dobbels et al., 2010). Adherence also tends to decrease over time (Berquist et al., 2008), making this a particularly vulnerable period.

Transition of Responsibility and Transfer from Pediatric to Adult-Based Health Care

Transfer from pediatric- to adult-based health care is a delicate process for pediatric transplant recipients, who are at increased risk for medication nonadherence during this period (Annunziato et al., 2011). Given the vulnerable nature of the transition period, particularly following the transfer to adult care, assessment tools have been developed to measure transition readiness among transplant recipients (Gilleland, Amaral, Mee, & Blount, 2012). Researchers have begun identifying factors associated with greater readiness to transition, including older age, more medication knowledge, better AYA–caregiver relationship quality, better AYA psychological adjustment, more disease knowledge, and greater AYA responsibility (Fredericks et al., 2010; Gilleland et al., 2012). Some institutions have implemented systemwide organizational changes aimed at promoting successful transition to adult care among pediatric transplant recipients (Fredericks et al., 2015).

ECONOMIC COSTS OF PEDIATRIC SOLID ORGAN TRANSPLANTATION

Pediatric solid organ transplantation is an effective surgical intervention, but at significant economic cost. The average reimbursement for transplant recipients with primary Medicare coverage from transplant through the first year is estimated to range from $83,401 in kidney transplant recipients (Matas et al., 2014) to $298,628 for heart transplant recipients (Colvin-Adams et al., 2014). Additional inclusion of Medicare Part D raises the average Medicare cost to approximately $200,000–375,000 in the first year posttransplant and approximately $30,000–45,000 in subsequent years (Colvin-Adams et al., 2014; Matas et al., 2014). For all transplant recipients, rehospitalization due to complications and infections is a primary factor underlying the variation in cost of care. Financial pressure associated with a lifetime of medical care has the potential to affect adherence and long-term health outcomes (Benfield, 2007). As experts in behavior change, pediatric psychologists are equipped to identify and intervene accordingly in psychosocial factors, including financial barriers, that may influence adherence and subsequent related health care costs.

FUTURE DIRECTIONS AND CONCLUSION

Transplantation is a chronic medical condition, with unique challenges from the pretransplantation phase through transfer to adult care and beyond. Prospective longitudinal research is needed to measure the trajectory of patients' emotional functioning, HRQOL, adherence, and medical functioning from pre- to posttransplantation. Family members should be included in studies, as they too are affected by their children's conditions and contribute to their care and medical outcomes. In addition to research including parents, there is a paucity of research addressing the impact and roles of siblings, peers, and teachers. Identification of pretransplant risk and protective factors that predict posttransplant psychosocial, cognitive, and medical outcomes could guide the design of prevention and early intervention programs to improve medical and psychosocial outcomes. Greater emphasis should be placed on risk and protective factors that are malleable (e.g., barriers to adherence) versus fixed (e.g., sex, socioeconomic status), as these offer the greatest opportunities for intervention. These investigations could also help determine whether certain psychosocial domains pose greater challenges for children throughout the various stages of the transplant process. Most of the research in this area has focused on AYAs, and there is a dearth of research on factors affecting younger transplant recipients. Longitudinal investigations from pretransplant to the later years also may facilitate consensus across transplant centers for standardizing pretransplant assessment batteries (Anthony et al., 2014) that best identify patients at risk for poorer posttransplant outcomes.

Other areas in need of additional investigations are the process of transferring health care responsibility from caregivers to AYAs, and AYAs' readiness to transfer to adult health care providers. Both topics are salient for pediatric transplant recipients, due to the high incidence of medication nonadherence during this process (Annunziato et al., 2011). Effective, interdisciplinary interventions that promote long-term adherence, HRQOL, and improved medical outcomes for pediatric transplant recipients are needed. Lastly, there is a paucity of research following transplant recipients through the transfer process to identify factors that facilitate or hinder success, and identify challenges recipients face before and after transferring to adult health care providers.

Pediatric transplantation is a journey for patients and families that begins in the pretransplant period and continues through the recipients' lifetimes. This journey, while stressful and uncertain at times, is a second chance at life, with increased life expectancy and improved HRQOL for many patients. With increasing numbers of patients receiving and surviving transplantation, pediatric psychologists are uniquely positioned to use their expertise to promote the physical and emotional well-being of patients and families throughout the transplantation process. From the pretransplant period through transfer to adult medical care, pediatric psychologists are assessing neurocognitive, socioemotional, and disease management concerns and delivering interventions that promote positive development and well-being in patients and their families. In addition, pediatric psychologists are actively conducting cutting-edge empirical research to continue informing the provision of psychological and medical care to this population. As key figures on interdisciplinary teams, pediatric psychologists use their expertise in science and practice to educate medical professionals and policy makers about the importance of emotional and behavioral health in promoting positive outcomes for pediatric transplant recipients.

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CHAPTER 29

Abdominal Pain–Related Gastrointestinal Disorders

Irritable Bowel Syndrome and Inflammatory Bowel Disease

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Chronic abdominal pain is a common complaint in children that has become recognized as a global health concern. Prevalence is estimated at 0.3–19% (median 8.4%) in Western populations (Chitkara, Rawat, & Talley, 2005), with similar rates documented worldwide (Devanarayana et al., 2011; Zhou, Yao, Cheng, Chen, & Li, 2011). Complicating advancement in its understanding and treatment is the fact that a variety of different gastrointestinal (GI) disorders present with persistent abdominal pain, either on its own or in tandem with other symptoms. This chapter focuses on two of the more common abdominal pain-related GI disorders: irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD). Although recognized as two distinct conditions, IBS and IBD demonstrate considerable overlap in both clinical presentations and underlying pathophysiological mechanisms. A number of these mechanisms are directly relevant to pediatric psychologists, as they involve interactions between psychological functioning and biological factors, including inflammation mediated through the gut–brain axis (and, in many cases, the microbiome–gut–brain axis). This chapter highlights current theory and evidence available to guide evaluation and intervention by a pediatric psychologist within the context of a multidisciplinary treatment team, highlighting treatment targets common across IBS and IBD, as well as those more relevant to one condition or the other.

BACKGROUND, PREVALENCE, AND COURSE

Irritable Bowel Syndrome

IBS is one of several functional gastrointestinal disorders (FGIDs) that previously would have been included under the umbrella term of "recurrent abdominal pain" (RAP), which was first described in the 1950s (Apley & Naish, 1958). Over the past 25 years, efforts have been underway to divide this broad group of children into more distinct symptom-based subgroups, which would be better suited to guide research and clinical decision making in the absence of clinical practice guidelines. The Rome diagnostic criteria, developed by consensus from an expert panel and currently in their fourth revision (i.e., Rome IV; Hyams et al., 2016), represent the best available classification system for children with RAP or chronic abdominal pain and constitute the basis for entry into most therapeutic trials at this time.

The Rome IV criteria define IBS as abdominal pain occurring at least 4 days per month for 2 months in association with at least one or more of the following: relationship to defecation, a change in stool frequency, and/or a change in stool form (Hymans et al., 2016). Further, in children with constipation, pain must not fully resolve with resolution of the constipation. Children may be considered to have a constipation-predominant, a diarrheal-predominant, an alternating profile based on stool form, or an unspecified IBS subtype within the Rome IV classification system. A diagnosis of IBS is based on the presence of certain symptoms and does not require formal diagnostic workup. Historically, the Rome criteria stated that there should be no evidence of an inflammatory, anatomic, metabolic, or neoplastic process that explains the patient's symptoms. In other words, active organic disease could not be present. However, the definition of "organic disease" was not universal, and the presence of mild nondiagnostic inflammation on biopsies did not preclude an IBS diagnosis (Chogle, Dhroove, Sztainberg, Di Lorenzo, & Saps, 2010). In fact, a shift away from this strict "functional–organic" dichotomy has occurred over time, and been made more explicit with the recent publication of Rome IV. The Rome IV criteria now states that symptoms should not be attributable to another medical condition, but specifically acknowledges that FGIDs may coexist with other medical conditions such as IBD. Most children who would previously have been classified as having RAP meet criteria for at least one Rome-defined FGID, with IBS being one of the most common (Schurman et al., 2005; Walker et al., 2004). IBS, alone or in combination with another FGID, accounts for 40–70% of pediatric patients referred for subspecialty evaluation of chronic abdominal pain, with population estimates of approximately 10% (Hyams et al., 1995; Schurman et al., 2005; Walker et al., 2004).

IBS has a variable course both within and between individuals, which may be attributed to many factors. First, there currently are no clinical practice guidelines for the assessment and/or treatment of IBS (Di Lorenzo et al., 2005); this lack has led to substantial variability in clinical practice and associated outcomes at both the primary care and subspecialty practice levels (Schurman, Hunter, & Friesen, 2010; Schurman, Kessler, & Friesen, 2014). Furthermore, IBS is increasingly understood to be quite complex, arising from and maintained by a variety of biological, psychological, and social contributors that are interactive with one another and vary among patients. Thus some of the variability in outcomes may result from the unique contributors for a given patient, with each contributor being more or less active in generating symptoms at any

given time and more or less amenable to treatment efforts. Although few generalizations can confidently be made about the course of IBS, it is fair to say that, untreated, over 50% of patients will have symptoms persisting into adulthood (Christensen & Mortensen, 1975).

Inflammatory Bowel Disease

IBD is an organic disease defined by chronic or relapsing GI inflammation resulting from dysregulation of the immune system. Current data show an increasing incidence of IBD in children and young adults (e.g., 9.5 per 100,000 children in 1994 vs. 11.4 per 100,000 in 2005) in both developed and developing nations, as well as a trend of earlier disease onset (Benchimol et al., 2009; Malaty, Fan, Opekun, Thibodeaux, & Ferry, 2010). IBD comprises two main types: Crohn disease (CD) and ulcerative colitis (UC). CD may occur at any point in the GI tract and is marked by inflammation of the full thickness of the bowel wall with areas of intervening normal mucosa. UC is limited to the large intestine and to superficial layers of the colonic mucosa. Patients with IBD who do not fit cleanly into either category are designated as having indeterminate colitis. IBD shares a number of symptoms with IBS, including abdominal pain and stool alterations such as diarrhea, and also can present with a chronic and relapsing course. A clear diagnosis is imperative, however, as the medication treatments for IBS and IBD are radically different even when the presenting symptoms are similar. Specific symptoms (e.g., blood in the stool, substantial weight loss over a short period of time) may increase the index of suspicion for a diagnosis of IBD, but a positive diagnosis must be based on a combination of lab work, endoscopy/colonoscopy, and/or other imaging studies. Patients with IBD are at risk of significant and potentially life-threatening complications, including intestinal stricture with bowel obstruction, fistulae with abscess formation, excessive bleeding, and growth failure. When complications occur, more intense medication regimens or even surgery may be required.

The long-term course of IBD, particularly CD, is quite variable. As in IBS, the course may be influenced by a multitude of genetic, environmental, and other factors. Even in the new era of biological treatment agents, over 20% of patients relapse within 2 years and one-third within 3 years of initiating therapy (Hyams et al., 2009). Furthermore, patients with IBD may experience IBS-like symptoms even when their disease is not deemed to be active. Recent evidence indicates that IBS-like symptoms are as common in remission as with active disease (Vivinus-Nébot et al., 2014; Greenley, Kunz, Schurman, & Swanson, 2013). It appears that many patients with quiescent IBD and IBS-like symptoms have persistent low-grade inflammation that may be perpetuating symptoms, although some patients are truly in remission when these symptoms occur and may indeed have both conditions (Lee & Park, 2014; Spiller & Lam, 2011).

ETIOLOGY

IBS is best understood through a biopsychosocial model in which symptoms are thought to result from a variety of factors, including biological/physiological (e.g., inflammation, altered microbiome, mechanical or sensory dysfunction), psychological (e.g., anxiety, depression, somatization), and social/environmental (e.g., interactions with parents,

teachers, and peers) factors, which may be interactive with each other. Although IBD is known to result from an autoimmune process requiring the presence of chronic inflammation, recent evidence indicates that many principles of the biopsychosocial model also are clinically relevant in IBD.

BIOLOGICAL CONTRIBUTORS

Although each has its own variations, IBS and IBD share a number of biological characteristics. These include immune activation, increased permeability of the intestinal wall, and alterations in the enteric microbiome (i.e., the composition of microorganisms in the intestinal tract), as well as mechanical or sensory dysfunction. Interestingly, these biological factors appear to have bidirectional relationships with stress, anxiety, and other psychosocial issues relevant to IBS and IBD, which are discussed in further detail later in this chapter. Animal models and some human data suggest that the effect of stress on the GI tract is mediated through immune activation, which signals pain, increases sensitivity and permeability, alters the microbiome, recruits other inflammatory cells, and likely affects central nervous system (CNS) function and mood (Friesen, Schurman, Colombo, & Abdel-Rahman, 2013). In addition, the gut–brain axis functions in such a way that microbes in the gastrointestinal tract may communicate directly with the CNS in a bidirectional fashion; in effect, the stress response alters the microbiome, and in turn the microbiome can have effects on CNS function, mood, anxiety, and pain (Grenham, Clarke, Cryan, & Dinan, 2011). Symptoms in both IBS and IBD also may result from the secondary effects of inflammation on sensory nerve structure and function, resulting in visceral hypersensitivity and/or altered motility.

PSYCHOLOGICAL CONTRIBUTORS

Compared to healthy children, youth with chronic medical conditions in general are at risk for more difficulties in psychosocial functioning. In the case of IBS and IBD, the diagnosis and ongoing management of painful and/or embarrassing symptoms can be emotionally, physically, and socially taxing. As a group, youth with IBD have been found to present with more emotional symptoms overall, and more internalizing symptoms in particular, than either healthy children or youth with other chronic health conditions (Mackner & Crandall, 2007; Greenley et al., 2010). However, some data suggest that a relatively small subset (e.g., 20%) of children with IBD endorse clinically significant emotional and/or behavioral symptoms (Mackner & Crandall, 2005), with prevalence rates of anxiety and depressive disorders estimated at 14–28% (Burke, Neigut, Kocoshis, Chandra, & Sauer, 1994; Szigethy et al., 2004). Certain demographic (e.g., adolescent age), family (e.g., conflict), and disease-related (e.g., disease activity) factors appear to place youth with IBD at greater risk of poor psychosocial functioning (Mackner et al., 2013).

Limited data exist on pediatric patients with IBS alone, as most previous studies have collapsed all children with RAP or chronic abdominal pain into a single group. Children with abdominal pain-related FGIDs or RAP tend to be more anxious and/or depressed than their peers (see Korterink, Diederen, Benninga, & Tabbers, 2015, for a

review of this literature). In one study that examined specific abdominal pain-related FGIDs, 35–45% of children and adolescents indicated clinical elevations in anxiety, while only 13% reported more intense and broad-based psychological problems (including externalizing issues); no differences were found between youth with IBS and youth in the other diagnostic groups (Schurman et al., 2008).

These data indicate that some youth with IBS and IBD are at increased risk for concurrent problems with anxiety and depression. Understanding and addressing this risk are important, because there appears to be a bidirectional relationship between biological and psychological factors at work for both conditions. While it has almost universally been accepted that IBS is negatively affected by problems with psychological functioning, the same appears true for IBD. Stressful life events, perceived stress, and negative affect are associated with IBD flares in adults (Spiller & Lam, 2011). Likewise, increases in depressive and internalizing disorders in youth with IBD are significantly related to higher levels of disease activity (Mackner et al., 2013).

SOCIAL CONTRIBUTORS

IBS and IBD have an impact on the entire family system. Disease management responsibilities can be substantial—including managing medications, attending clinic appointments, and making dietary modifications—and often are shared by youth and their parents. The relapsing course of these conditions requires a high level of flexibility within families, as roles and responsibilities may need to change suddenly to accommodate flareups or exacerbations in symptoms. As many as 25% of families who have a child with IBD report clinically elevated difficulties across domains of family functioning, particularly in terms of family roles/responsibilities, the degree to which family members are involved in one another's lives, problem solving, and communication (Herzer, Denson, Baldassano, & Hommel, 2011). Parents of children with IBD worry about the impact of the condition on their children's current and future functioning, including future jobs, marriage, independence, and problems their children may experience in school (Akobeng et al., 1999). Mothers of adolescents with chronic pain, including RAP, also report restrictions on family social life and problems dealing with the stress of the children's pain (Hunfeld et al., 2001). Siblings are not immune to this family stress, reporting higher levels of emotional or behavioral problems than peers without a sibling with an abdominal pain-related FGID (Guite, Lobato, Shalon, Plante, & Kao, 2007).

The broader social context of youth with IBS and IBD also can be disrupted. Disease symptoms can result in school absences, cause difficulty staying focused in class, and contribute to increased anxiety and worries in the school setting. Children with IBS miss a significantly greater number of school days than healthy peers (Varni et al., 2006; Korterink et al., 2015). Similarly, a subset of youth with IBD can experience poorer school functioning across a variety of domains, including school absences, academic achievement, grade retention, need for special education services, and school-related quality of life (Mackner, Bickmeier, & Crandall, 2012). Based on published work and our own clinical anecdotal evidence, diarrhea, abdominal pain, and fatigue are primary causes reported by caregivers for keeping youth with IBD home from school (Mackner et al., 2013), and similar reasons are likely contributing to absenteeism in youth with IBS. School absences incurred secondary to symptoms and medical appointments

also may limit time spent with peers and contribute to feeling socially disconnected. As might be expected, youth with IBD report significantly poorer social functioning than that of their healthy peers (Greenley et al., 2010). Data on health-related quality of life (HRQOL) in youth with IBS and IBD provide further support, reflecting lower HRQOL than that of healthy peers across physical, social, emotional, and school domains (Greenley et al., 2010; Korterink et al., 2015). Taken together, IBS and IBD can negatively affect several important social systems in the life of a child, and this stress can contribute to further symptom generation in the patient.

OTHER CONTRIBUTORS

Several potential contributors to the biopsychosocial model of symptom generation and maintenance are difficult to classify as solely biological, psychological, or social in nature. Instead, they exist at the intersection of two or more areas, but are no less important as potential contributors to the overall system. Sleep is one such example. Disrupted sleep is associated with higher levels of emotional problems, including anxiety and depression (e.g., Johnson, Chilcoat, & Breslau, 2000). Insufficient or disrupted sleep also has been theorized to (indirectly) lower a child's pain tolerance, interfere with effective use of coping skills, and increase functional disability (Huntley, Campo, Dahl, & Lewin, 2007; Kundermann, Krieg, Schreiber, & Lautenbacher, 2004). By contrast, adequate sleep appears to promote tissue healing, immune function, and the body's natural analgesic efforts, all of which in turn aid in pain relief and recovery (Lewin & Dahl, 1999; Opp, 2006). Sleep disturbances occur in approximately half of children and adolescents with IBD, and similar rates have been documented for those with abdominal pain-related FGIDs, including IBS (Kinnucan, Rubin, & Ali, 2013; Schurman et al., 2012). In IBD, poor sleep quality is more common with active disease (Ali, Madhoun, Orr, & Rubin, 2013; Kinnucan et al., 2013) and is associated with higher levels of abdominal pain, depression, and anxiety (Benhayon et al., 2013). Similarly, sleep is associated with both emotional symptoms and functional disability in youth with abdominal pain-related FGIDs, with physical symptoms mediating the relationship between sleep and disability (Schurman et al., 2012). In other words, higher levels of disease and symptom activity are likely to impair sleep quality, which in turn worsens emotional and physical symptoms, and by extension impairs daily functioning.

Another important and cross-cutting issue is that of adherence. Adherence to a given treatment plan can be challenging for any patient, and roughly 50–75% of children and adolescents with chronic medical conditions fail to adhere adequately to their treatments (Rapoff, 2010). Although certainly relevant to consider in IBS, the lack of clinical practice guidelines and the highly variable treatment regimens complicate investigation of adherence in this population. Furthermore, the stakes are much higher for youth with IBD, given the potential for serious complications of the disease. Poor adherence to oral medication in IBD has been linked to a *fivefold* increased risk of relapse (Kane, Huo, Aikens, & Hanauer, 2003), a 12.5% increase in annual health care costs (Higgins, Rubin, Kaulback, Schoenfield, & Kane, 2009), and greater health care use (i.e., hospitalizations, emergency department visits, outpatient visits; McGrady & Hommel, 2013). Despite this increased risk, reported prevalence of nonadherence to oral

maintenance treatment in adolescents with IBD ranges from 2 to 93%, depending on the method of measurement (see Spekhorst, Hummel, Benninga, van Rheenen, & Kindermann, 2016, for a more detailed discussion).

IBD treatment itself poses risks to good adherence because it is often complex and time-consuming, with numerous medications that have unique dosing schedules and, at times, unpleasant side effects (e.g., weight gain, facial swelling, nausea). Treatment is often comprised of steroids to induce remission; the steroids are often followed by immunomodulators (e.g., 6-MP), which weaken the immune system to decrease inflammation, or aminosalicylates, which treat at the site of inflammation rather than altering the immune system to fight the inflammatory response. Biological therapies (e.g., Remicade, Humira) also are used for more advanced or aggressive disease. Identified barriers to treatment adherence have included forgetfulness, interference with other activities, difficulty swallowing pills, lack of knowledge about medications, oppositionality, being away from home, and limited perceived benefit of taking medication (Spekhorst et al., 2016). Numerous psychosocial factors have been associated with adherence issues, including treatment regimen complexity, family conflict, and depressive symptoms (Hommel, Hente, Herzer, Ingerski, & Denson, 2013). In addition, research suggests that comorbid psychosocial concerns (e.g., internalizing symptoms, attention difficulties) may compound risk for nonadherence (Gray, Denson, Baldassano, & Hommel, 2012; Reed-Knight, Lewis, & Blount, 2013). Importantly, intent may play an important role in adherence concerns (i.e., purposeful or accidental failure to complete a treatment regimen) and have implications for other disease-related factors, such as symptom severity or overall impairment (Schurman, Cushing, Carpenter, & Christenson, 2011).

IMPLICATIONS FOR CARE

The biopsychosocial model outlined above establishes the relevance, and indeed necessity, of psychological assessment and intervention in the treatment of both IBS and IBD. This need demands a conceptual shift away from the historic biomedical perspective toward an integrated health care model (see Cushing, Friesen, & Schurman, 2012, for more in-depth discussion). Practically speaking, the pediatric psychologist typically serves as an ancillary service provider and/or referral source for the medical team in the biomedical model, given the primary focus on biological, psychological, and social factors as separate entities that can be treated independently of one another. In contrast, the integrated care model stresses consideration of these factors in interaction with one another, as well as independently, throughout the assessment and treatment process. Thus the pediatric psychologist will serve a more central role, functioning as a core member of the multidisciplinary health care team. Close collaboration among health care professionals is required to achieve a shared perspective that integrates relevant biological, psychological, and social factors and to develop a comprehensive and coordinated treatment plan. Co-location of services, while not strictly necessary, certainly can enhance coordination and integration in practice (Williams, 2012). Whether executed within an integrated multidisciplinary clinic or another practice setting, however, the principles of evaluation and treatment for pediatric IBS and IBD remain the same.

EVALUATION

As noted above, a thorough assessment necessitates comprehensive evaluation of all potential contributors that may be at play across biological, psychological, and social domains. Thus, from the pediatric psychology perspective, the initial evaluation should assess the patient's emotional functioning (e.g., coping/adjustment to the diagnosis, pain management, stress, anxiety, depression), academic/school functioning (e.g., receipt of school-based services, existing accommodations, frequency of absences), social functioning (e.g., extracurricular activities, interference of disease on preferred activities, peer relationships), and family functioning (e.g., division of treatment-related tasks, parental response to symptom complaints/episodes, parent–child conflict), as these are all factors that may complicate or exacerbate symptoms. Given their strong link to psychosocial factors and their impact on physical health, sleep and adherence are additional essential targets of routine assessment.

Routine psychosocial screening has the potential to identify patients and families who may benefit from psychosocial intervention early in their treatment. The importance of intervening early with any existing or burgeoning psychosocial issues cannot be overstated. Both IBS and IBD carry significant potential for long-term negative impact on academic, social, emotional, and behavioral development. Routine screening also can be used to identify changes in a patient's psychosocial functioning over time, which may reflect underlying changes in disease processes, side effects of treatment(s), or developing psychopathology. Continuing reassessment can contribute not only to more nimble tailoring of individual care, but also, if done in a standardized way, to quality improvement efforts at the population-based level. A number of brief, validated questionnaires are available for use that can be collected as part of routine assessment and supplemented by a few targeted questions posed during history taking (see Maddux, Deacy, & Lukens 2014, for a review of relevant evidence-based measures).

TREATMENT

To date, no "cure" for either IBS or IBD has been found. Consequently, current approaches are aimed at providing effective symptom relief, intervening with any associated modifiable factors to promote health and minimize relapse, and enhancing daily functioning. Within the context of a multidisciplinary team, simultaneous treatment of as many identified biopsychosocial contributors as possible is likely to provide the best opportunity to break the cycle of pain and disability that exists for many children and adolescents with IBS and IBD.

Behavioral interventions, in conjunction with requisite medications, have been shown to provide greater symptom relief and less associated impairment (Grover & Drossman, 2011). In fact, cognitive-behavioral approaches—including cognitive strategies (e.g., reappraisal of maladaptive thoughts, distraction-based pain management techniques), relaxation techniques (e.g., diaphragmatic breathing, progressive muscle relaxation, imagery), and parent coaching (e.g., contingency training to reinforce non-pain-focused and healthy coping behaviors)—have the greatest support for improving pain and functional disability in children with abdominal pain-related FGIDs such as IBS (see Brent, Lobato, & LeLeiko, 2009, for a review of this literature). Similar support

for cognitive-behavioral approaches for reducing depressive symptoms and improving global functioning in adolescents with IBD has been found (Szigethy et al., 2007). To the extent that behavioral interventions also improve adherence and/or positively affect the microbiome–brain–gut axis by reducing physical or emotional stress, they also may theoretically improve long-term outcomes for IBD, including severity and frequency of relapses. However, this remains speculative at present. Several evidence-based behavioral interventions can be easily employed within the context of a multidisciplinary care team, and even within the structure of a brief follow-up visit, thereby improving access to care and minimizing potential stigma associated with referral to a psychologist for mental health treatment.

Education and behavioral coaching are staples of the cognitive-behavioral approach to IBS and IBD. In terms of education, clearly communicating the biopsychosocial nature of these conditions can help to provide a context for multicomponent treatment, which in turn sets the stage for better adherence to initial recommendations and acceptance of later referrals if a higher level of care is warranted. For IBS, provision of reassuring messages that the pain is real, is understood, is not dangerous, and can be treated can be helpful in reducing a child's and family's anxiety, as well as in minimizing future health care seeking in the form of emergency room visits, invasive medical/diagnostic procedures, and "doctor shopping" (Di Lorenzo et al., 2005). Although education alone is not sufficient, evidence suggests that it is critical as a foundation for successful treatment; children whose parents accept a biopsychosocial conceptualization of abdominal pain and its treatment report the intention to follow through on treatment recommendations at higher rates (Schurman & Friesen, 2010) and, perhaps as a result, appear more likely to experience symptom improvement (Scholl & Allen, 2007).

Behavioral coaching frequently involves parents' learning skills to help them maintain developmentally appropriate expectations for their children in terms of daily functioning, including expectations for participation in school, extracurricular, family, and other social activities. This coaching should cover effective use of positive reinforcement (e.g., praise, privileges, rewards) to encourage adherence to various aspects of treatment and use of positive strategies for managing stress and pain, in tandem with minimizing attention to pain/symptom complaints and behavior consistent with adoption of the "sick" role (Crushell et al., 2003). For children already debilitated by pain and other GI symptoms, emphasis should be placed on halting further decline in functioning and working with family members to create a plan to increase demands gradually, rebuilding confidence in addition to strength and stamina, until the children are returned to full participation in their usual activities. Discussing this as a rehabilitative model with families can help provide a context for not simply waiting until children feel better to encourage functioning. Given the negative impact of physical and/or emotional stress on GI function, sensitivity, and inflammation, it is important to remember that a slow and steady approach is typically more successful; overdoing it can inadvertently exacerbate issues and prolong the symptom course.

Referral for physical therapy evaluation and treatment may be helpful for a subset of patients who have become truly deconditioned secondary to the onset of their GI condition. Developing a home exercise plan tailored to a child's current state, and incorporating preferred activities, can both promote more rapid recovery of physical function. For a small group, the outpatient rehabilitation approach described above may be insufficient to promote progress. For these children, who continue to experi-

ence significant pain symptoms and/or continued decline in functioning, an intensive day treatment or inpatient program may be required. These programs typically provide a more structured, controlled, and therapeutic environment to help families push past initial barriers and position patients to build on gains when they are transferred back to the treatment team in the outpatient setting.

School presents a unique set of challenges for children with IBS and IBD, and thus warrants specific mention here. Accommodations such as providing easy access to a private bathroom and encouraging brief breaks to engage in relaxation and other stress/pain management skills can be immediately helpful in reducing perceived barriers to school attendance across the population of children with IBS and IBD, and can typically be implemented with relative ease via a formal educational plan (e.g., a Section 504 plan in the United States) for health issues. For patients with a history of frequent or prolonged absenteeism secondary to pain and other GI symptoms, additional accommodations may be needed to reduce the backlog and/or modify timelines for completion of outstanding work, to reduce stress and allow patients to move forward. This subset of patients also may require a graduated approach to school reentry. Although variations probably exist, such an approach typically involves starting with a small block of time attended daily, regardless of symptoms, and adding time in small increments at regular intervals (e.g., once per week) as tolerated without evidence of substantial symptom increase. This approach allows patients to be reintegrated gradually into the school setting as strength and stamina improve, while encouraging a redirection of focus away from pain and toward functioning. This approach also tends to reduce fear and avoidance, allowing children to gain confidence in their ability to manage pain and stress in the school setting over time (Walker, 2004; Walker, Beck, & Anderson, 2009). Balancing demands with supports in this way can be critical in successfully returning patients to school and maintaining them there.

Many children and adolescents benefit from brief and targeted work to develop their skills for pain and stress management as part of the larger treatment package. The three modalities with the greatest evidence base in treating abdominal pain-related FGIDS, including IBS, are cognitive-behavioral therapy, hypnotherapy, and biofeedback-assisted relaxation training, which share a focus on changing thoughts and/or behaviors in order to alleviate physical symptoms (Brent et al., 2009). Due to the role of the sympathetic nervous system in stress reactivity and arousal, and their combined contribution to symptom flareups and functional impairment in IBS and IBD, the relaxation-based approaches employed across these modalities appear logical as part of intervention. Gaining specific skills and confidence in the ability to manage stress and physical symptoms may also have a beneficial impact on subclinical anxiety and depression, as it can promote positive self-efficacy and support behavioral activation efforts as outlined above. However, in situations where anxiety and/or depression are preexisting or have risen to the level of diagnosable disorders, more intensive mental health services focused directly on these issues may be warranted.

Behavioral and multicomponent interventions also show great promise for improving adherence among youth with chronic medical conditions such as IBS and IBD (Kahana, Drotar, & Frazier, 2008). Behavioral interventions emphasize behavior change to improve adherence behaviors, and include goal setting, reward systems, and adherence monitoring. Multicomponent interventions combine behavioral interventions with other treatment approaches (e.g., educational, organizational, family-centered). Multicompo-

nent interventions may include strategies such as behavior contracting (e.g., a youth earns points, incentives, or privileges for remembering to take medication a specified number of times each week), increased monitoring by the youth and caregivers (e.g., keeping daily logs on the refrigerator and checking these off when a particular medication has been taken, checking pill containers), and guided problem solving of adherence barriers, among others. Practical strategies such as use of a daily or weekly pill box, simplification of dosing schedule by medical providers, increasing the frequency of contact with a GI provider, increasing both youth and parent involvement in disease management, and teaching families conflict resolution skills can be of benefit in promoting adherence within the clinical setting (Greenley, Kunz, Walter, & Hommel, 2013). However, emerging evidence from adolescents with IBD indicates that tailoring multicomponent interventions to an individual patient's unique adherence needs may result in more substantial improvements in oral medication adherence (Hommel, Greenley, Herzer, Gray, & Mackner, 2013).

Integrally tied to the concept of adherence is that of transition. Youth with IBS and IBD have complex treatment regimens that are often lifelong and complex, and thus require ongoing medical care—and ongoing adherence—across the pediatric and adult care continuum. Few adolescents can independently manage their illness/treatment; most lack the necessary health knowledge and skills to make appropriate health decisions and maintain health-promoting behaviors; and few understand health insurance basics and differences between pediatric and adult services. Furthermore, data suggests that most patients ages 16–18 with IBD defer responsibility almost entirely to parents for health maintenance tasks, including scheduling appointments, requesting refills, and communicating with providers (Fishman, Barendse, Hait, Burdick, & Arnold, 2010). These gaps in knowledge and skills are believed, in part, to be due to significant variability in transition practices in pediatric IBD, limited knowledge among GI providers of published transition practice guidelines, and logistical barriers to transition programming efforts (Gray & Maddux, 2016). Nevertheless, these gaps in knowledge and skills might explain why transition from child-centered to adult-oriented health care systems is associated with worsening disease and symptoms, decreased adherence (Annunziato et al., 2007), and increased health care utilization (e.g., hospitalizations and emergency admissions; Gurvitz et al., 2007). According to recent guidelines (Leung, Heyman, & Mahadevan, 2011), youth should be supported in acquiring greater understanding of their GI condition, including medications and procedures as well as the impact of lifestyle behaviors (e.g., drugs and alcohol) on the illness, taking a more active role in medical visits, understanding insurance coverage, and taking increasing responsibility for all aspects of their health care (Hait, Arnold, & Fishman, 2006). Important to note is that transition is a developmental process that occurs over time within a family context, making it an important and appropriate ongoing target of intervention for the pediatric psychologist caring for these patient populations.

CONCLUSIONS

IBS and IBD are common and complex abdominal pain-related GI conditions associated with substantial personal, familial, and societal costs. Although these conditions arise from different underlying disease processes, they share a number of overlapping features

in terms of both clinical presentation and pathophysiological mechanisms. A biopsychosocial model that highlights the interactive nature of all three domains in the generation, maintenance, and exacerbation of abdominal pain and other GI symptoms is relevant to both IBS and IBD. This model would suggest that targeted psychological interventions have the potential to improve not only psychological functioning and quality of life for pediatric patients with IBS and IBD, but also symptoms and perhaps even disease severity itself. Although knowledge in this area continues to evolve, it appears likely from current evidence that patients will be best served within the context of a multidisciplinary care team, including a pediatric psychologist. Individual pediatric patients with IBS and IBD are likely to derive greatest benefit from proactive assessment across all domains of the biopsychosocial model, combined with employment of targeted interventions directed at all identified contributors.

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CHAPTER 30

Pediatric Burns

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Burn injuries are among the most painful and debilitating health conditions, sometimes requiring extensive and costly medical care, and leading to long-term psychological and physical repercussions. Although young children (age ≤ 2 years) are at highest risk for scald burns, and older children (ages 3–17) are more likely to sustain contact burns (e.g., from flames or hot objects), burn injuries also can be caused by electrical, friction (e.g., treadmill), cold (e.g., frostbite), and chemical (e.g., household solvents) sources (Kagan et al., 2009). Demographic variables (e.g., parental education, family income, race), psychological difficulties, and parenting characteristics (e.g., supervision, safety knowledge) have been shown to be significant predictors of pediatric burn injuries (e.g., Joseph, Adams, Goldfarb, & Slater, 2002). This chapter provides an overview of medical and psychological considerations in working with pediatric burn patients, specifically focusing on evidence-based assessment and interventions.

MEDICAL ASPECTS OF BURN INJURIES

Burn injuries are classified by their depth: first-degree (affecting only the epidermis), second-degree or partial-thickness (extending into the top part of the dermis), third-degree or full-thickness (involving the lower portion of the dermis), and fourth-degree (involving muscle, tendon, and bone) (Kagan et al., 2009). First-degree and superficial second-degree burns usually heal in 2–3 weeks, with little to no scarring or functional impairment. Deeper burns usually require surgical intervention, take anywhere from 3 weeks to several months to heal, and typically lead to hypertrophic or raised scarring and possible functional limitations (e.g., restricted range of motion). Burns also are characterized by their size, or the percentage of total body surface area (TBSA) affected,

with larger burns defined as ≥ 20% TBSA. Burn depth and TBSA are key factors in making decisions with respect to wound care, such as hospitalization.

Superficial second-degree burns are treated with daily dressing changes (e.g., debridement and topical antimicrobial agents), while deep partial-thickness and full-thickness burns typically require surgical excision (removal of necrotic tissue with a scalpel) and grafting (transplantation of skin). Whereas excision is performed under anesthesia, debridement usually is not and can be excruciatingly painful. Debridement usually involves first soaking the wound to soften the tissue (e.g., in a hydrotherapy tank or bathtub) and subsequently removing dead or damaged tissue via forceps, scissors, and/or bluntly rubbing the area with gauze or cloth. Autologous skin grafts (i.e., grafts for which the patient serves as donor) are preferred; however, if a burn injury is too extensive for donor skin to be sufficient, or if other health complications exist, skin substitute dressings (e.g., cadaver allograft, pig skin, engineered tissue) may be used temporarily to allow autografting to occur in stages. Grafting promotes healing, improves cosmetic and functional outcomes, and reduces demands on the immune and metabolic systems resulting from increased energy expenditure and protein metabolism. Patients are prescribed a high-calorie, high-protein diet to address these metabolic changes and healing needs.

Family members are directed to complete daily dressing changes at home after hospital discharge or when a burn survivor is receiving outpatient care. Because deep-partial and full-thickness burns take months and even years to heal, long-term rehabilitation procedures consisting of physical and/or occupational therapy (e.g., range-of-motion or stretching exercises) and pressure garment use are part of home care. To control scarring and prevent contractures, exercises are performed daily, while garments are worn at all times (except for bathing). See Kagan et al. (2009) for a detailed description of burn care.

PSYCHOLOGICAL ASPECTS OF BURN INJURIES

Given the pain associated with burns and their treatment, as well as the concomitant emotional, psychological, and physical implications of burn injuries, pediatric psychologists often work with patients and families during the acute and rehabilitative phases of care to promote the best possible outcomes. As members of a multidisciplinary health care team, these psychologists assess and treat psychological concerns within the context of a child's hospitalization or a clinic visit. Common psychosocial concerns are coping with pain and itching, acute and long-term psychological adjustment to injury and care, family issues, and adherence to the burn care regimen.

Pain and Itching

Pain after a burn injury depends on factors related to the injury itself (e.g., size, location, depth) and its treatment (e.g., debridement; Stoddard et al., 2002). There are many well-established assessment measures for pediatric pain (see Cohen et al., Chapter 12, this volume, for a discussion of such measures, as well as reviews by Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006, and von Baeyer & Spagrud, 2007), and these measures have demonstrated utility with pediatric burn patients (Stoddard et al., 2002).

In addition to pain, burn survivors often experience pruritus, or itching, during the healing process. The Numerical Rating Scale (NRS) Itch Intensity and NRS Itch Distress (Schneider et al., 2015) and the Itch Man Scale (for ages 6 and above; Blakeney & Marvin, 2000) are useful in measuring this form of discomfort. Validated behavioral observational systems are useful in measuring pain during acute medical procedures such as dressing changes (e.g., Foertsch, O'Hara, Stoddard, & Kealey, 1998), as well as pruritus in young children (e.g., Everett et al., 2015). Observational coding systems are particularly useful in young children who are not developmentally capable of self-reporting pain levels. Though these systems may not be practical in some clinical settings, they can serve as resources for conceptualizing and monitoring pain behaviors in young children.

Pharmacotherapy is used frequently to manage discomfort and distress in pediatric burn survivors. To address pain, nonsteroidal anti-inflammatory drugs and opioids (Ratcliff et al., 2006), as well as dissociative (e.g., ketamine), stimulant, and antidepressant medications (Stoddard et al., 2002), may be used. Benzodiazepines are used to reduce anxiety and distress during wound care procedures (Ratcliff et al., 2006), while antihistamines and topical agents are used to control pruritus (Martin-Herz et al., 2003). Though these medications can be helpful, psychologists often are consulted to deliver adjunctive psychotherapy, typically from a cognitive-behavioral therapy (CBT) framework (see Law, Noel, Nagel, & Dahlquist, Chapter 11, and Cohen et al., Chapter 12, this volume, for reviews of evidence-based pediatric pain management). As an example, a multicomponent CBT intervention (e.g., coaching in distraction, guided imagery, diaphragmatic breathing) successfully reduced distress in pediatric burn survivors ages 5–12 during dressing changes and physical therapy (Elliott & Olson, 1983). Similarly, biofeedback and progressive muscle relaxation (Knudson-Cooper, 1981), as well as other forms of distraction (e.g., portable electronic devices; Brown, Kimble, Rodger, Ware, & Cuttle, 2014), have been associated with decreased anxiety and pain in pediatric burn survivors. Distraction administered via virtual reality also has been shown to be effective for youth undergoing dressing changes (e.g., Kipping, Rodger, Miller, & Kimble, 2012) and range-of-motion exercises (Schmitt et al., 2011). Though such technology has traditionally been expensive, more economical versions have been developed (e.g., Google Cardboard), offering possible avenues for wider clinical application. Yet some studies have not yielded such positive effects for CBT approaches (e.g., Foertsch et al., 1998) in pediatric burn care. Due to pain intensity and other associated factors in dressing changes (e.g., length of procedure, trauma experience), traditional pain management techniques may help but may not consistently produce a significant impact on pain behavior (Foertsch et al., 1998).

Researchers also have examined the role that adults, such as parents and health care staff members, can play in promoting pain management in child burn survivors. For instance, massage therapy has proven effective in reducing itching, pain, and distress in young children (Hernandez-Reif et al., 2001) and adolescents (Gurol, Polat, & Akcay, 2010). Studies on parental presence during wound care procedures, on the other hand, have generated mixed findings. Some researchers suggest that parental presence may increase distress among children (e.g., Foertsch, O'Hara, Stoddard, & Kealey, 1996), while others have reported reduced patient anxiety when parents have appropriate involvement in care and education from staff (George & Hancock, 1993). Because parents often accompany their children to burn clinic visits, additional studies need to

identify how pediatric psychologists can best teach parents to support their children during wound care.

Acute and Long-Term Adjustment to Injury and Care

Trauma- and Stressor-Related Disorders

Children who have sustained burn injuries may be at risk for developing acute stress disorder (ASD) or posttraumatic stress disorder (PTSD) (Noronha & Faust, 2007), given the potentially traumatic nature of these injuries and their treatment. Indeed, it is not uncommon for children to experience nightmares in reaction to sustaining burn injuries. These nightmares often dissipate on their own in time; however, some children continue to experience them frequently, and may also develop other ASD or PTSD symptoms such as intrusion, avoidance, and hyperarousal. In addition to evidence-based self-report and/or parent report structured interviews for anxiety, trauma-specific screening questionnaires (e.g., the Impact of Event Scale—Revised; Weiss & Marmar, 1997) can be used to evaluate ASD/PTSD in the pediatric burn population. Though trauma-based psychological interventions using psychoeducation, cognitive restructuring, and trauma narratives have not been extensively researched, they have been evaluated for use with pediatric burn survivors (e.g., Kramer & Landolt, 2014). This intervention approach has been found to reduce internalizing symptoms, but not ASD or PTSD symptoms; therefore, much more research is needed to identify effective strategies for promoting adjustment in pediatric burn patients experiencing significant trauma reactions.

General Psychosocial Functioning

While most studies suggest that pediatric burn survivors adjust well postinjury (e.g., Landolt, Grubenmann, & Meuli, 2002), a subset of patients may experience significant difficulties, such as depression, anxiety, and lowered quality of life (e.g., Noronha & Faust, 2007; Maskell, Newcombe, Martin, & Kimble, 2013). For instance, during the acute phase of care, in anticipation of the significant pain associated with wound debridement, children may develop tremendous anticipatory anxiety in the hydrotherapy tub. Regarding long-term outcomes, even though wounds are healed, children can experience significant emotional and behavioral difficulties several years after injury (e.g., Maskell et al., 2013). Indeed, the lifetime prevalence of any major mental health disorder (e.g., depression, anxiety, PTSD) for young adults who experienced major burn injuries as children was found to be 59.4%, a much higher rate than would be expected in the general population (Meyer et al., 2007). Several risk factors have been identified as being associated with poorer adjustment after burn injuries, including female gender, life stressors before the injuries, parental adjustment, and family functioning (Bakker, Maertens, Van Son, & Van Loey, 2013). Consequently, when pediatric psychologists are assessing postinjury psychosocial functioning, it is important to consider that adjustment may vary across time and the healing process, as well as over the course of a child's development (e.g., social concerns may peak at age of dating).

In addition to evidence-based general screening questionnaires, several measures specific to burn injuries are available. For example, preliminary evidence supports the utility of the Psychosocial Adjustment to Burn Questionnaire, a parent report screening

tool to assess emotional and behavioral symptoms (e.g., child developmental regression, parent functioning) in children ≤ 5 years of age (Pelley et al., 2013). The Burn Outcomes Questionnaire (for ages 5–18; Daltroy et al., 2000) and the Health Outcomes Burn Questionnaire for Infants and Children (for ages ≤ 5 years; Kazis et al., 2002) also can be used as broad assessments of functional outcomes (e.g., physical functioning, appearance, emotional health, family disruption) in pediatric burn survivors. A significantly altered or disfigured appearance and loss of function may lead patients to feel self-conscious, alienated, and flawed; hence pediatric psychologists should consider using well-validated tools to assess factors such as body image, self-esteem, and social difficulties (e.g., embarrassment, teasing). These measures may include the brief version of the Burn Specific Health Scale (Kildal, Andersson, Fugl-Meyer, Lannerstam, & Gerdin, 2001) for adolescents (ages ≥ 16), as well as the Social Comfort Questionnaire and the Perceived Stigmatization Questionnaire (Lawrence, Rosenberg, Rimmer, Thombs, & Fauerbach, 2010) for children (ages ≥ 8). Finally, the Living with a Chronic Illness Questionnaire (Adams, Streisand, Zawacki, & Joseph, 2002), a validated measure of social difficulties, has been adapted for use in pediatric burn patients (e.g., Piazza-Waggoner, Butcher, Adams, Goldfarb, & Slater, 2004).

Pediatric psychologists can play a pivotal role in devising, evaluating, and implementing interventions to address psychosocial adjustment in youth who have sustained burn injuries. School reentry programs designed to educate classmates about burn injuries and concomitant social issues (e.g., teasing) are used clinically, but the efficacy of such programs has been questioned (Blakeney et al., 1995). Indeed, though the benefits of school reentry programs have been reported elsewhere (e.g., Arshad et al., 2015), such reports are based on findings from uncontrolled studies. Another intervention that specifically targets social adjustment and self-image is social skills training. For example, a workshop teaching pediatric burn survivors different socialization skills through didactics, role plays, real-life generalization activities, and goal setting led to a reduction in externalizing behavior problems (e.g., aggressive behavior) among a sample of pediatric burn survivors compared to a control group, as well as a decrease in anxiety symptoms across both groups (Blakeney et al., 2005). However, social problems (e.g., not getting along with peers, being teased by peers) were not significantly affected. Another promising approach in targeting social adjustment has been to capitalize on recent advances in cosmetic techniques. Youth who used cosmetic camouflage (a liquid makeup designed to match a patient's skin color) reported better quality of life, fewer emotional and social problems, and better family functioning than youth in the wait-list control group (e.g., Maskell, Newcombe, Martin, & Kimble, 2014). Together, these findings imply that directly targeting pediatric burn patients via social skills training and cosmetic options may be a more effective way to promote adjustment than targeting their peers through school reentry visits. That being said, however, school-based programs offer other key benefits, including an opportunity to share burn prevention education with a wide audience.

Family Issues

Families provide the context within which pediatric burn survivors receive acceptance, continued burn care, and support. Prior studies suggest that family relationships and other family variables are related to positive quality of life in pediatric burn survivors

(Landolt et al., 2002). It is important to consider the possibility that family members may experience considerable stress and perhaps guilt in response to a child's injury and treatment. They also may struggle with symptoms of PTSD (e.g., Graf, Schiestl, & Landolt, 2011). Questionnaires measuring the impact of the injury on parents, such as the PTSD Checklist (Weathers, Litz, Herman, Huska, & Keane, 1993), have been used in burn populations (e.g., Odar et al., 2013) and can be helpful in evaluating and monitoring parental and family adjustment to burn injuries.

Another factor to consider in family functioning is the possibility that child abuse accounts for burn injuries. It is estimated that 10–20% of burns and scalds in children stem from suspected or reported abuse or neglect (e.g., Chester, Jose, Aldyami, King, & Moiemen, 2006; Dissanaike et al., 2010). Qualities of a burn (e.g., clearly demarcated stocking or glove appearance to burns on the hands and feet) may serve as potential indicators (Kagan et al., 2009). A psychologist also should evaluate child abuse potential when the reported explanation for the injury is incompatible with a child's developmental ability (e.g., an infant does not sit without support and therefore could not turn a faucet in a bathtub) or is inconsistent with the distribution pattern of the burn. Maguire, Moynihan, Mann, Potokar, and Kemp (2008) and Peck and Priolo-Kapel (2002) are excellent resources for assessing the potential of abuse in burn and scald injuries.

Adherence to Burn Care Regimen

Given the multifaceted, potentially painful, and long-term aspects of burn care, it is not surprising that nonadherence can be a significant concern for many patients. Nonetheless, regimen adherence is critical to medical (e.g., need for additional surgeries), cosmetic (e.g., scar appearance), and physical functioning outcomes. Research has determined that multiple factors—including knowledge of the burn care regimen, physical characteristics of the treatment component (e.g., fit of pressure garments), beliefs about treatment efficacy, and psychosocial factors (e.g., social support, use of coping strategies)—affect patient adherence to the regimen (Szabo, Urich, Duncan, & Aballay, 2016). However, the majority of studies have been conducted with adults, and thus additional research is needed with pediatric samples to explore possible developmental differences in barriers to adherence. There are no evidence-based assessment measures specific to burn care adherence; thus providers must rely largely on their clinical skills to interview families and observe patients (e.g., performing exercises) as part of their evaluation of regimen adherence.

Studies examining adherence promotion interventions in pediatric burn survivors also are sparse. In one study, White and Kamples (1990) used a single-subject design to evaluate the effectiveness of behavioral techniques (i.e., modeling appropriate behavior, selective ignoring, and reinforcement) targeting nutritional adherence in a 5-year-old burn survivor. Results demonstrated decreased behavior problems and increased dietary adherence during the intervention phase versus the withdrawal phase. To date, no studies have examined interventions to improve adherence to rehabilitative treatment components (i.e., physical and occupational therapy exercises, pressure garment use) among pediatric burn survivors. However, studies of adult survivors have revealed that an education-based computer program increased adherence to wearing pressure garments (Lo, Hayter, Hsu, Lin, & Lin, 2010), while a behavioral intervention to opt out of staff-supervised physical therapy sessions for independently accomplishing daily exer-

cise goals improved adherence to physical therapy (Hegel, Ayllon, VanderPlate, & Spiro-Hawkins, 1986). These interventions offer possible directions for additional research in pediatric populations. Specifically, future researchers should consider addressing adherence specifically with youth and across a range of burn care procedures; certain interventions may be effective for some treatment components but not others, and thus a multimodal approach may be necessary (Duncan, Mentrikoski, Wu, & Fredericks, 2014).

CONCLUSIONS

Burn injuries are relatively common in children; they result in significant costs in terms of medical care, psychological difficulties, and physical impairment. Youth with burn injuries are a unique and challenging population, particularly because these injuries can vary widely in their severity and subsequently in their medical treatment. With improvements in health care, mortality rates are decreasing; some of the most severe cases (e.g., burns > 85% TBSA) are now surviving, but with protracted and complicated recoveries. Psychological consultation in pediatric burns requires skilled assessment and treatment of a range of issues, from potential for child abuse to pain to psychosocial functioning. Evidence-based assessment measures, both general and burn-specific, are available to contribute to a multi-informant, multimethod approach in evaluating and conceptualizing psychological concerns common to pediatric burn injuries. Psychologists must also be well versed in a variety of interventions (e.g., distraction, relaxation training, social skills training) to address the individual and varied needs of each case. Because of limited research specific to this population, clinicians often are left to adapt or tailor existing evidence-based CBT approaches. Undoubtedly, psychological approaches to pediatric burn care constitute an area in tremendous need of further research, so that patients and their families can benefit more fully.

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CHAPTER 31

Feeding and Vomiting Problems in Pediatric Populations

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Primary care and specialist physicians frequently evaluate feeding problems and disorders associated with vomiting, nausea, and rumination. Pediatric psychologists are consulted for management of these difficulties, often when medical interventions are ineffective. This chapter reviews literature pertinent to feeding, vomiting, nausea, and rumination with regard to (1) symptoms and diagnosis; (2) psychological and developmental aspects; (3) management of illness, with emphasis on the role of pediatric psychologists; (4) evidence-based assessments and treatments; (5) cultural issues related to care; and (6) emerging areas.

FEEDING PROBLEMS

Symptoms and Diagnosis

Feeding problems are quite common, occurring in 15–45% of typically developing children (Bentovim, 1970; Manikam & Perman, 2000), in up to 70% of children with chronic medical conditions (Davis, Bruce, Cocjin, Mousa, & Hyman, 2010; Douglas & Bryon, 1996; Thommessen, Heiberg, Kase, Larsen, & Riis, 1991), and in up to 80% of children with developmental disabilities (Manikam & Perman, 2000). Severe feeding problems, which require medical attention and threaten long-term growth and development, are estimated to affect 3–20% of children and account for approximately 1–5% of hospital admissions (Bithoney & Rathbun, 1983; Kerwin, 1999), making feeding problems one of the most common concerns in pediatrics. Unfortunately, prevalence rates of feeding problems are expected to rise as the survival rates of children with severe medical and/or developmental disabilities continue to increase (Silverman & Tarbell, 2009).

Feeding problems may include food refusal, disruptive mealtime behavior, rigid food preferences, and failure to master feeding skills consistent with a child's developmental level (Silverman & Tarbell, 2009). Researchers estimate that up to 85% of feeding difficulties stem from a combination of factors (Burklow, Phelps, Schultz, McConnell, & Rudolph, 1998), which may include physical illness, oral–motor deficits, developmental problems, behavioral problems, and social challenges (e.g., food scarcity or poverty). Feeding problems often are identified in the first 1–3 years of life when a child manifests weight faltering or does not progress from one developmental feeding stage to the next (e.g., from a puree diet to table foods). Although feeding problems may be diagnosed at later ages, the occurrence rate for older children is unknown but presumed to be much lower than in younger children, especially as food selectivity typically decreases as children age (Silverman, 2015). Feeding problems should not be confused with eating disorders such as anorexia nervosa or bulimia nervosa, which typically have an onset in adolescence or early adulthood. Eating disorders are characterized by an entirely different etiology, in which an affected individual experiences disturbances in perception of body shape and weight, and engages in compensatory behaviors such as restricting or purging to manage body mass (see Rancourt & Boepple, Chapter 33, this volume).

Feeding disorders have been reclassified in the *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition (DSM-5) as avoidant/restrictive food intake disorder (ARFID) (American Psychiatric Association, 2013). ARFID is characterized by an eating or feeding disturbance manifested by persistent failure to meet appropriate nutrition needs. It is associated with significant weight loss; nutrition deficiency; dependence on enteral feeding or oral nutrition supplements; or interference with psychosocial functioning that is not better explained by a lack of available food, cultural practices, or the co-occurrence of another eating disorder. These criteria include a broader set of symptoms than those described in earlier editions of DSM, and thus better capture the heterogeneous nature of feeding problems. Yet many practitioners may choose to use the feeding difficulties diagnosis from the medical diagnostic system of the *International Classification of Diseases,* 10th revision (ICD-10) (Leon-Chisen, 2017), especially those practitioners who use health and behavior billing codes. Readers are encouraged to review Berlin and colleagues' latent class analysis for an alternative empirically derived classification scheme (Berlin, Lobato, Pinkos, Cerezo, & LeLeiko, 2011).

Psychological Aspects

Feeding is an interactive process involving both a child and the adult caregivers who feed that child (Davies et al., 2006). In a typically developing child, feeding success depends on the caregiver's ability to create an environment that facilitates the child's ability to attend to cues of hunger and satiety. In some instances, caregivers may not be aware of a child's developmental readiness to advance his or her diet. Although texture advancement guidelines are readily available to adult caregivers, these guidelines are not appropriate for all children. Attempts to advance a child's diet prematurely may result in a developmental mismatch between foods offered and those foods that a child is able and ready to accept (e.g., chopped foods when a child has skills for a puree diet only). In such instances, well-intentioned caregivers may cause the child to develop feeding aversion, due to the complexity of the feeding demands. In other instances, feeding

problems may occur when caregivers are overly concerned about the child's health status. Behavioral feeding problems often have their genesis in earlier medical problems, including acute medical conditions (e.g., gastroenteritis) that cause decreased appetite, fatigue, nausea, and abdominal pain; or chronic conditions that are of greater long-term concern (e.g., cleft lip/palate, trisomy 21), as they can lead to nutrition compromises in affected children (Kirby & Noel, 2007). In some instances, feeding safety concerns stemming from aspiration prohibit oral feeding during sensitive periods, resulting in disrupted oral–motor skill development (Field, Garland, & Williams, 2003). Conditions that require nasal or gastric tube feeding may disrupt the child's association of oral feeding with satiation of hunger (Blackman & Nelson, 1987; Silverman et al., 2013). In such situations, caregivers may perceive the child as fragile, and may conclude that feeding demands will elicit anxiety or distress from the child and therefore should be avoided, disrupting attainment of feeding milestones. Alternatively, overcontrol of meals stemming from caregiver concerns about child health, weight, and food consumption (Birch & Marlin, 1982; Johnson & Birch, 1994) can disrupt the child's self-regulation of food intake and increase the frequency and severity of behavioral feeding problems. In general, feeding problems are associated with high levels of caregiver stress (Garro, Thurman, Kerwin, & Ducette, 2005; Greer, Gulotta, Masler, & Laud, 2008), which in turn may adversely affect family relationships (Lindberg, Bohlin, Hagekull, & Thunstrome, 1994). In addition, feeding problems may contribute to financial burdens on families, in terms of direct medical expense and lost work for adult caregivers (Williams, Riegel, Gibbons, & Field, 2007).

Management

Pediatric psychologists work both with the families of affected children and with professionals from several other disciplines (dietitians, speech–language pathologists, physicians) (Silverman & Tarbell, 2009). Common behavioral concerns include comorbid psychiatric diagnoses; missed or delayed stages of feeding development; learned feeding avoidance due to aversive conditioning (e.g., choking event, force-feeding history); frequency and severity of inappropriate mealtime interactions; behavioral refusals that may have been inadvertently reinforced by caregivers (allowing a child to self-select diet); and inappropriate family or cultural expectations for feeding (Silverman, 2015). Psychologists provide a developmental and behavioral perspective on feeding disorders, assess for the presence of comorbid behavioral or psychiatric conditions in the child or the within the broader family system, provide intervention, and in some cases facilitate referrals to other providers (Silverman, 2010).

Assessments and Interventions

Assessment should clarify a family's treatment objectives, identify the nature of the feeding problem, and determine whether the family's goals are appropriate and achievable. Two recent detailed reviews may be particularly useful to readers: a systematic review of mealtime behavior measures (Poppert, Patton, Borner, Davis, & Dreyer Gillette, 2015), and a systematic review of psychological interventions for pediatric feeding problems (Lukens & Silverman, 2014).

Typically, assessment comprises a medical record review, caregiver-completed ques-

tionnaires, a clinical interview, and observation of the child while being fed (Silverman, 2010). Interdisciplinary assessments, including those completed by a physician, speech–language pathologist and/or occupational therapist, dietitian, and pediatric psychologist, are particularly well suited to understanding the etiology of feeding problems (Silverman & Tarbell, 2009). Assessment of a child's medical, developmental, and environmental status can be facilitated by the use of questionnaires (Poppert et al., 2015). Questionnaires have been developed to assess the severity of behavioral problems occurring during meals (Archer, Rosenbaum, & Streiner, 1991; Berlin et al., 2010; Crist & Napier-Phillips, 2001; Davies et al., 2006), and to assess the effects of feeding problems on the caregiver–child relationship (Berlin, Davies, Silverman, & Rudolph, 2011; Davies, Ackerman, Davies, Vannatta, & Noll, 2007; Johnson & Birch, 1994; Musher-Eizenman & Holub, 2007). Caregivers may also be asked to report on their own psychosocial functioning, using the Symptom Checklist 90—Revised Derogatis, 1983) and/or the Parenting Stress Index (Abidin, 1995).

The clinical interview is used to clarify the family's concerns and to obtain information for making a diagnosis and developing treatment strategies. The interview focuses on the child's medical and developmental history, feeding milestones, family mealtimes/daily routines, onset/nature of the specific feeding problems, and previous attempts at interventions (Silverman, 2010). Questions regarding cultural meal practices can provide important information regarding the family's mealtime expectations; perception of feeding problems; and desire to engage in medical, behavioral, and/or other therapeutic interventions. The interview is also useful for assessment of the family's mental health history and current family stressors.

Observation of the child and caregiver interacting during a meal is essential to a feeding assessment. The goal of the observation is to determine whether the caregiver–child interaction is reinforcing the feeding problem (e.g., coaxing a child to eat) (Silverman & Tarbell, 2009). Typically, feeding observations are done *in vivo,* simulating a meal. Ideally, a meal is simulated at a time when the child would be expected to be hungry (e.g., 2 or more hours of fasting), with the clinician observing remotely to minimize the effects of direct observation on the feeding interactions. Preferred and nonpreferred foods are presented, with the psychologist recording behaviors such as bites accepted and refusals. To complement the observation, objective observation rating scales have been developed to assess caregiver–child interactions. These include the Mother–Infant/Toddler Feeding Scale (Chatoor, 1986), the Dyadic Interaction Nomenclature for Eating (Stark et al., 1997); and the Mealtime Observation Schedule (Sanders, Patel, Le Grice, & Shepherd, 1993). Descriptions of other observational scales can be found in Poppert et al. (2015).

The preponderance of evidence supports the use of behavioral approaches in the treatment of a broad variety of feeding problems (Lukens & Silverman, 2014). Behavioral methods of treatment have been well described and discussed in review articles (Kerwin, 1999; Linscheid, 2006; Lukens & Silverman, 2014; Sharp, Jaquess, Morton, & Herzinger, 2010; Williams, Field, & Seiverling, 2010). Such treatments typically include elements of the following: (1) modifications to the feeding environment, (2) modifications to the feeding schedule to promote appetite, (3) implementations of behavior management strategies (e.g., differential reinforcement, shaping), and (4) parent training (Kedesdy & Budd, 1998; Silverman, 2010). Environmental interventions create an environment that reduces ambiguity about the tasks associated with feeding,

to enhance a caregiver's control over the feeding interaction. A consistent feeding environment (e.g., meals in a high chair or booster seat with a strap; elimination of television and toys) is easily implemented and may be highly effective, and thus is a logical first attempt at intervention (Drotar, Eckerle, Satola, Pallotta, & Wyatt, 1990; Mathisen, Skuse, Wolke, & Reilly, 1989). Manipulations to the feeding schedule are designed to promote appetite and increase motivation to eat. These interventions allow a child to experience the natural consequences of hunger after a low-volume or "failed" meal, and thus teach the child to be responsive to internal cues of hunger and satiety (Linscheid, 2006). However, given the acute nutrition compromises that can arise with appetite manipulation, these strategies should be conducted in consultation with a dietitian and/or a pediatrician (Silverman et al., 2013).

Behavioral management strategies, which generally include differential reinforcement techniques, can be used to promote eating new foods, advance acceptance of foods with different textures, increase caloric intake, decrease dependence on milk or supplemental feedings, and reduce negative feeding behaviors. Strategies to increase behaviors include use of positive and negative reinforcement and discrimination training. Extinction, satiation, punishment, and desensitization are used to reduce maladaptive behaviors (Linscheid, 2006; Sharp et al., 2010; Williams et al., 2010). Typically, these strategies are used in combination to create the strongest treatment effects in the shortest period of time (Lukens & Silverman, 2014). Finally, it is essential that caregivers learn from providers how to use these strategies to maintain treatment gains. Parent training often includes (1) the provision of written descriptions about intervention techniques; (2) therapist modeling of intervention techniques during a simulated meal; (3) *in vivo* coaching; and (4) review of video-recorded feeding in the natural environments in which the child eats (Silverman & Tarbell, 2009).

Cultural Issues

Little scientific attention has been given to how cultural factors may affect feeding problems. This is a curious oversight, given that cultural norms affect the choice between breast and bottle feeding, which types of food are offered, age at which solid foods are introduced, and so on. Cultural beliefs (Kedesdy & Budd, 1998), such as the belief that "the bigger the baby, the healthier the baby," may also influence caregivers' perceptions. As cultural factors may have a significant impact on feeding problems, this is an area that is ripe for investigation.

Emerging Areas

Thanks to the medical advances made in recent decades, the survival rates of low-birthweight infants and children born with life-threatening conditions (e.g., extreme prematurity, severe birth defects) have increased. Feeding problems have thus become prevalent, and are likely to become even more prevalent (and perhaps more complex in nature) as medical advances continue to be made. With the expected incidence rates of feeding disorders increasing, there is a substantial need to train more clinicians to treat these children. To fill the void, innovative treatment methods (including telemedicine and/or mHealth strategies) may provide valuable adjuncts to the services now being provided by pediatric psychologists.

CYCLIC VOMITING SYNDROME

Symptoms and Diagnosis

Cyclic vomiting syndrome (CVS) is a disorder characterized by recurring episodes of high-intensity vomiting lasting hours to days, accompanied by unrelenting nausea, retching, and abdominal pain (Li, 2000). Diagnostic criteria for CVS include (1) five episodes in any interval, or three or more episodes over 6 months; (2) stereotypical episodes with regard to onset, duration, and associated symptoms; and (3) return to baseline health between episodes (Li et al., 2008). CVS is diagnosed only after other serious medical conditions that may mimic its symptoms (e.g., intestinal malrotation) are excluded (Li, 2000). Although CVS is associated with intense vomiting, requiring intravenous hydration in about 60% of affected children, the lack of an identified pathophysiology has led to its classification as a functional disorder (Li & Balint, 2000). CVS prodromal symptoms include loss of appetite, nausea, pallor, lethargy, social withdrawal, and irritability (Li & Misiewicz, 2003). Onset of the vomiting commonly occurs in the early morning hours or upon awakening (Li & Misiewicz, 2003). Notably, the vomiting does not relieve symptoms of nausea and abdominal discomfort, as is typically the case for gastroenteritis or influenza. Associated signs and symptoms can include fever, diarrhea, light and noise sensitivity, vertigo, headache, and excess salivation (Li, 2000; Li & Misiewicz, 2003).

CVS has a prevalence rate of about 2% (Tan, Liwanag, & Quak, 2014); however, poor recognition of CVS leads to an average delay in diagnosis of 2.5 years (Li, 2000). The median age of onset is 4.8 years, but CVS can also begin in adolescence or adulthood (Li, 2000). Most children with CVS (82%) have a subtype considered to be a migraine variant (Li & Misiewicz, 2003; Stickler, 2005). This subtype is so named because of the similarities to migraine headaches in symptoms, response to antimigraine therapies, and family history of migraines. The triggers for a CVS episode are also similar to those for a migraine headache. These include both positive stressors (e.g., birthdays, holidays) (Li & Misiewicz, 2003) and negative stressors (e.g., school or family problems, sleep changes, missed meals, inadequate fluid intake) (Li & Balint, 2000). Fewer episodes tend to occur during in the summer, perhaps due to the reduction in school-related stressors and infections, as well as to increased sleep duration (Li & Misiewicz, 2003). Younger age of onset of CVS, and co-occurring headaches, are associated with an increased risk for the development of migraine headaches (Lin, Ni, Weng, & Lee, 2011).

Psychological Aspects

There is considerable academic and social turmoil associated with CVS, for both the affected child and the family as a whole. Children often miss school (median number of days = 11), which not only compromises their education, but also interferes with their social and recreational activities (Tarbell & Li, 2013). Parents attending to their sick child both at home and during hospitalization spend time away from their other children; miss days at work; and in some cases lose or quit their jobs, due to multiple absences related to caring for the sick child. Health-related quality of life in CVS is significantly poorer than that for children with irritable bowel syndrome and healthy children, with school functioning the lowest domain, and social functioning a relative

strength (Tarbell & Li, 2013). Failure to recognize CVS can make it difficult to obtain appropriate educational support for a child. Modest adjustments, such as a delayed school start time, can be quite helpful. Schools need to be informed that the child is not suffering from a contagious illness and should allow for the child to return to school once symptoms have resolved. Helpful information for families can be obtained from the Cyclic Vomiting Syndrome Association (*www.cvsaonline.org*).

Children with CVS have a high prevalence of internalizing psychiatric symptoms, especially anxiety (Tarbell & Li, 2008). Forbes, Withers, Silburn, and McKelvey (1999) reported that children with CVS had significantly higher Total Problems scores than age- and gender-matched controls had on the Child Behavior Checklist, and scores on the Internalizing, Somatic Complaints, and Anxious/Depressed scales tended to fall in the clinical range. There is also evidence of an increased prevalence of internalizing psychiatric disorders in parents of children with CVS, especially mothers (Tarbell & Li, 2008). The diathesis–stress model may be helpful for understanding the relationship between CVS and anxiety symptoms. The basic premise of this model is that stress activates a diathesis, which is an enduring, endogenous predisposition to illness (Monroe & Simons, 1991). Endogenous vulnerabilities for anxiety in youth with CVS are not yet known. However, pediatric CVS has been found to be associated with maternal anxiety (Tarbell & Li, 2008), as well as with family histories of migraine and mitochondrial dysfunction, both known to be associated with psychiatric comorbidity (Boles et al., 2015; Jette, Patten, Williams, Becker, & Wiebe, 2008); all these findings are suggestive of biological or genetic vulnerabilities. Other potential explanations include anxiety serving as a trigger for CVS episodes and vice versa, as well as anticipatory anxiety associated with these highly aversive, often unpredictable vomiting attacks (McDonald & Fleisher, 2005). Substance use has also been noted in adolescent and young adult patients with CVS, particularly cannabis, which users report ameliorates their symptoms of nausea and vomiting (Venkatesan et al., 2014). Limited evidence has also linked cannabis use to hyperemesis (i.e., persistent, severe vomiting) (Miller et al., 2010). These findings suggest that psychiatric screening of youth with CVS is integral to the development of a comprehensive treatment plan.

Management

The pathogenesis of CVS is unknown, but several mechanisms are under study. Medical treatment can reduce the duration and frequency of CVS episodes, but children may continue to have intermittent CVS attacks. Medical management includes preventive, abortive, and palliative strategies (Li et al., 2008). Generally, the sooner the medical intervention is offered in the setting of an acute attack, the better the chance of symptom control. For those whose CVS cannot be managed on an outpatient basis, emergency room visits or hospital admissions are used to restore electrolyte imbalances, provide intravenous hydration, and promote symptom relief. Adolescent patients with CVS presenting for emergency care should also be screened for the use of cannabis and other psychoactive drugs (Morris & Fisher, 2014). There is generally poor recognition of CVS in emergency rooms, which can lead to delays in its diagnosis and treatment (Venkatesan et al., 2010). The annual treatment cost for a child with CVS was estimated to be $17,035 in 2000 (Li & Balint, 2000)—a sum that has likely increased in the ensuing years, placing a significant financial impact on the family and the health care system.

Family members can benefit from recommendations regarding CVS management provided by their physician for visits to the emergency department, so as to expedite treatment and improve recognition of CVS.

Published reports of psychological treatment of CVS are limited. One case report describes the successful treatment of CVS in an adolescent, resulting in the sustained relief of symptoms (Slutsker, Konichezky, & Gothelf, 2010). Treatment included (1) psychoeducation about the association between psychological stress and episodes; (2) identification of modifiable triggers for episodes, such as decreased sleep; (3) cognitive restructuring to address anticipatory anxiety related to vomiting attacks, and core beliefs related to control of symptoms; (4) relaxation training and biofeedback to address sympathetic arousal; and (5) parent training to coach the child in the use of self-management skills. Psychological intervention for youth with CVS that combines the evidence-based techniques used for the behavioral treatment of pediatric headache (e.g., Powers et al., 2013) and the cognitive-behavioral methods for treating anxiety and depression in children and adolescents (e.g., Silverman, Pina, & Viswesvaran, 2008) may best meet the needs of these medically and psychiatrically vulnerable youth.

Changes in functional status and quality of life associated with treatment can be evaluated with measures developed to assess functional status in children with migraine, such as the PedMIDAS; Hershey et al., 2001) or by a more general assessment of quality of life (e.g., the Pediatric Quality of Life Inventory or PedsQL; Varni, Seid, Knight, Uzark, & Szer, 2002). Changes in the frequency or intensity of the vomiting episodes and associated psychiatric comorbidity can also be assessed. There are few validated scales for assessing nausea and vomiting in children and adolescents. The Nausea Profile, a 17-item scale that assesses the somatic, gastrointestinal, and emotional dimensions of nausea, developed for use in adults (Muth, Stern, Thayer, & Koch, 1996), has been used with adolescents (Tarbell, Shaltout, Wagoner, Diz, & Fortunato, 2014), but its validity has not yet been established. There is also a pictorial scale developed for children ages 7–18 to rate nausea intensity, and this scale has preliminary evidence of psychometric validity (Baxter, Watcha, Baxter, Leong, & Wyatt, 2011).

CHRONIC IDIOPATHIC NAUSEA

Symptoms and Diagnosis

Chronic idiopathic nausea is defined as the presence of bothersome nausea, occurring several times per week and not typically associated with vomiting, in the absence of medical abnormalities that would explain the nausea. These criteria need to be fulfilled for the past 3 months, with symptom onset at least 6 months before diagnosis (Tack et al., 2006). This disorder has received little attention until recently. A large school-based study of functional gastrointestinal disorders found that 23% of children reported nausea (Saps, Nichols-Vinueza, Rosen, & Velasco-Benitez, 2014). Kovacic et al. (2014) compared charts of children seen in a pediatric gastrointestinal clinic that had nausea as a primary complaint to youth with functional abdominal pain and associated nausea. The former group was significantly more likely to include European American adolescent females with severe daily nausea that peaked in the morning with comorbid anxiety, fatigue, dizziness, or other symptoms of autonomic dysfunction, plus a personal or family history of migraine. Chronic nausea has also been reported in youth

with orthostatic intolerance (i.e., symptoms made worse upon standing and improving with recumbence), with the nausea being significantly associated with anxiety symptoms (Tarbell et al., 2014).

Management

No evidence-based psychological treatments have been developed for the management of idiopathic nausea; however, emerging treatments for the management of CVS and other functional disorders may be considered for idiopathic nausea, given similarities in hypothesized etiology (autonomic dysfunction, migraine) and comorbid anxiety. Medical treatments directed at nausea associated with orthostatic intolerance include medications and lifestyle modifications to increase fluids, salt intake, and exercise (Fortunato et al., 2011; Shibata et al., 2012).

RUMINATION

Symptoms and Diagnosis

The Rome III diagnostic criteria for pediatric functional gastrointestinal disorders define rumination as the repeated regurgitation of gastric contents into the mouth, which are either rechewed and reswallowed or expectorated (Drossman et al., 2006). These symptoms manifest themselves soon after a meal and occur only when a child is awake. Rumination is not accompanied by retching and does not respond to treatment for reflux (Rasquin et al., 2006). Medical conditions that could explain these symptoms, and eating disorders such as bulimia nervosa, need to be ruled out. Diagnostic criteria need to be fulfilled at least once per week for at least 2 months (Rasquin et al., 2006). In infants, the diagnostic criteria stipulate that the symptoms (1) begin between 3 and 8 months of age; (2) are not responsive to hand restraint, formula changes, gavage, or gastrostomy feedings; (3) are absent when the infant is interacting with others; and (4) are present for at least 3 months (Hyman et al., 2006). Rumination is reported to be most common in infants and in children with developmental disorders (Malcolm, Thumshirn, Camilleri, & Williams, 1997). However, a number of reports describe the prevalence and management of rumination in typically developing adolescents and adults. A review by Chial, Camilleri, Williams, Litzinger, and Perrault (2003) reported that the diagnosis of rumination in children and adolescents is often delayed. Rumination symptoms can lead to a child's missing school and to hospitalization for treatment of complications associated with rumination, such as persistent weight loss, malnutrition, dental erosions, electrolyte abnormalities, and functional disability (Chial et al., 2003).

Management

Currently there are no evidence-based medical treatments for rumination. Behavioral therapy is the only empirically supported treatment for rumination, and thus involvement of a pediatric psychologist represents the standard of care (Kessing, Smout, & Bredenoord, 2014). Psychosocial problems such as caregiver neglect or lack of stimulation are considered to be predisposing factors in infants and those with developmental disabilities (Lyons-Ruth, Zeanah, Benoit, Madigan, & Mills-Koonce, 2014). However,

Lavigne, Burns, and Cotter (1981) identified a population of infants with rumination who were developmentally normal and had healthy parent–child interactions. These infants responded to an intervention that included punishment (scolding), time out from positive social reinforcement, and differential reinforcement of nonruminative behaviors. Although there have been no randomized clinical trials testing the efficacy of behavioral treatment of rumination, case studies detail a variety of effective behavioral interventions using functional behavioral analysis, with treatment directed to the factors maintaining rumination in individuals with developmental disabilities (Lang et al., 2011; Woods, Luiselli, & Tomassone, 2013).

Cognitive-behavioral therapy and biofeedback also have been successfully used to treat rumination in youth without developmental delays. Green, Alioto, Mousa, and Di Lorenzo (2011) have developed an interdisciplinary program for the management of chronic rumination that was successful in treating all five children described in their report. Schroedl, Alioto, and Di Lorenzo (2013) successfully treated rumination in a developmentally normal adolescent in an inpatient program that included baseline observations of eating and ruminative behavior, patient ratings of abdominal discomfort/pressure associated with the urge to ruminate, structured meals to increase awareness and self-regulation of ruminative symptoms, and biofeedback to increase awareness of body responses to eating and the role of associated anxiety in maintaining ruminative behavior. Habit reversal, such as diaphragmatic breathing as a competing response for rumination, also has been found to be effective for management of rumination (Chitkara, Van Tilburg, Whitehead, & Talley, 2006).

EMERGING AREAS FOR VOMITING, NAUSEA, AND RUMINATION

Improved recognition and diagnosis of CVS, idiopathic nausea, and rumination by both medical and behavioral providers affords the opportunity to develop interventions directed to reduce these aversive symptoms and improve health-related quality of life for these children and their families as a whole. A pediatric psychologist can contribute to the care of these patients by adapting evidence-based treatments for other functional disorders such as functional abdominal pain and migraine, and by translating initial case studies into larger trials to establish a more robust evidence base for providing relief to these children, for whom few treatment options currently exist.

SUMMARY

Feeding problems, vomiting problems, nausea, and rumination are conditions associated with significant medical and psychosocial morbidity. These disorders often involve extensive medical care utilization, which may or may not improve the symptoms of these disorders, and which exposes these children to the risk of iatrogenic problems. Pediatric psychologists working in interdisciplinary teams have the potential to collaborate with physicians and allied health care professionals to approach the management of these conditions within a biopsychosocial model of care, which has the potential to improve health care outcomes, reduce health care utilization, and improve the patients' and families' experience. There is a significant need for pediatric psychologists to help

advance the care of these disorders, given the increased prevalence of feeding disorders and the increased recognition of vomiting, nausea, and rumination disorders, where there is a dearth of evidence-based behavioral treatments.

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CHAPTER 32

Pediatric Obesity

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"Obesity" is defined as abnormal or excessive adiposity in relation to total body weight (World Health Organization, 2013). Nearly 17% of American youth ages 2–19 years are obese, including 8.4% of preschool-age children, 17.7% of school-age children, and 20.5% of adolescents (Ogden, Carroll, Kit, & Flegal, 2014). Although trend data indicate that obesity prevalence rates in the United States appear to have stabilized (Ogden et al., 2014), rates of severe obesity—associated with the greatest level of immediate and future health risks—continue to rise (Skinner & Skelton, 2014). In contrast to the stabilization seen in the United States, global estimates of overweight and obesity among youth suggest an increase in prevalence rates over the last two decades, with higher rates observed in developed countries than in developing countries (see Ng et al., 2014, for a more comprehensive review of global obesity rates).

After considerable debate, the American Medical Association (2013) recently voted to define obesity as a disease. One of the primary arguments against doing so was the poor sensitivity of diagnostic measures that are currently in use to assess obesity (Council on Science and Public Health, 2013). Dual-energy radiograph absorptiometry and air displacement plethysmography are considered the "gold standards" for the assessment of obesity, as they directly measure body fat (see Freedman & Sherry, 2009, for a full description of these measures). However, because these measures are expensive and frequently inaccessible in clinical settings, body mass index (BMI), a measure of an individual's weight in kilograms divided by the square of height in meters (kg/m^2), is the most widely used measure to diagnose obesity (Council on Science and Public Health, 2013). In children, BMI varies as a function of age and sex, such that BMI percentiles (BMI in relation to a standard reference population) are used to identify overweight (≥85th and <95th percentile for age and sex) and obesity (≥95th percentile for age and sex) (Barlow, 2007). Several measures derived from the absolute BMI, including BMI

z-score (Flegal & Ogden, 2011) and percent overweight (Paluch, Epstein, & Roemmich, 2007), can also be used as indices of obesity and are often recommended over absolute BMI, as they account for age and gender (Altman & Wilfley, 2014). Despite the existence of clear criteria, identification of obesity in young children can be challenging, as pediatricians often misclassify young children with excess weight as having healthy weight and do not consistently screen for obesity (Patel et al., 2010).

Childhood obesity is a multisystem disease that has significant health consequences across the lifespan. Many of the disease processes by which obesity predicts increased morbidity and mortality, including atherosclerosis, insulin resistance, hypertension, and dyslipidemia, begin in childhood (Daniels, 2009; Tryggestad & Willi, 2015). These processes make obesity a risk factor for a range of physical health complications, including cardiovascular disease, Type 2 diabetes mellitus, musculoskeletal disease, and some cancers, and underscore its ranking among the top five leading causes of death worldwide for adults (World Health Organization, 2013). During childhood, excess weight also increases the risk for asthma, sleep apnea, precocious puberty, and a host of psychosocial complications, including disordered eating, poor quality of life, and depression (Daniels, 2009; Puder & Munsch, 2010). Considering that children who are obese are more likely to remain obese as adults, and that adults with obesity are more likely to have children who struggle with excess weight, both childhood obesity prevention and treatment are warranted (Ludwig, 2012).

Although obesity results from a complex combination of individual- and environmental-level factors, an imbalance between energy consumed versus expended explains obesity at the most basic level. Well-established dietary risk factors for childhood obesity include increased consumption of empty calories (Reedy & Krebs-Smith, 2010), particularly sugar-sweetened beverages (Ludwig, Peterson, & Gortmaker, 2001); eating more meals away from home (Must, Barish, & Bandini, 2009); and increased portion sizes (Rolls, Engell, & Birch, 2000). Similarly, physical activity levels below 1 hour of moderate to vigorous physical activity each day (e.g., brisk walking, sports such as soccer or swimming), and sedentary screen time greater than 2 hours daily, are established obesity risk factors (Barlow, 2007). Whereas energy balance accurately depicts excess weight gain at the individual level, obesity is often considered multifactorial, as evidence supports genetic, environmental, and epigenetic contributors to excess weight gain (Ebbeling, Pawlak, & Ludwig, 2002).

OBESITY AMONG ETHNIC AND RACIAL MINORITY YOUTH

Obesity disproportionately affects ethnic and racial minority youth in the United States, with the highest prevalence of obesity documented in Hispanic boys (28%) and Hispanic girls (23%) ages 6–11 (Ogden et al., 2014). Culturally based ecological models have been used to illustrate the complex interactions that occur among individuals, families, and the community to shape weight-related health behaviors among minority youth (Wilson, 2009). At the familial level, cultural influences, such as traditional culinary practices and the symbolic meaning of food within families, influence eating behavior and may place children at greater risk for obesity (Sealy, 2010). At a societal level, characteristics of the built environment in which ethnic minority and low-income children live—such as a higher concentration of fast-food restaurants and a lower con-

centration of supermarkets and parks—have been shown to affect the foods available for consumption and opportunities for physical activity, as well as subsequent obesity risk (Powell, Slater, Mirtcheva, Bao, & Chaloupka, 2007).

PSYCHOLOGICAL ASPECTS OF ILLNESS

Studies of children who are overweight, obese, or overweight/obese have shown excess weight to be associated with a number of negative psychosocial and psychological health correlates. Studies of children who are obese or overweight/obese have shown excess weight to be associated with a number of negative psychosocial and psychological health correlates. One of the more prevalent concerns among youth who are overweight or obese is their engagement in unhealthy weight control behaviors. Across community and treatment-seeking samples, youth who are overweight/obese have greater weight- and eating-related pathology than youth who are at a healthy weight, with nearly 30% of overweight treatment-seeking youth reporting binge eating (Glasofer et al., 2007) and over 15% of girls and approximately 5% of boys reporting the use of extreme measures (e.g., taking laxatives) to control their weight (Neumark-Sztainer, Story, Hannan, Perry, & Irving, 2002). Given the overlapping prevalence of disordered eating and obesity, there has been a recent movement to consider obesity and eating disorders as part of the same continuum of weight-related disorders (Neumark-Sztainer, 2005).

Compared to peers who are at a healthy weight, children who are overweight/obese also have significantly higher body dissatisfaction (Eisenberg, Neumark-Sztainer, & Paxton, 2006), lower self-esteem (Wardle & Cooke, 2005), poorer quality of life (Schwimmer, Burwinkle, & Varni, 2003), and more social and interpersonal difficulties (Hayden-Wade et al., 2005). A well-documented finding in the literature is the relationship between health-related quality of life (HRQoL) and obesity. Some research suggests that youth with obesity report more impairment in HRQoL than those with other medical conditions (Ingerski et al., 2010), and several studies document that the level of impairment is positively associated with the severity of obesity (Schwimmer et al., 2003).

Difficulty with social relationships, teasing by family and peers, and stigma are also common problems faced by children who are overweight/obese (Goldfield et al., 2010). Studies have shown that youth who are overweight and youth who are obese report more frequent teasing and social isolation, compared to peers who are at a healthy weight (Hayden-Wade et al., 2005; Pearce, Boergers, & Prinstein, 2002). Furthermore, children who are obese experience teasing and stigma from multiple sources, including peers, family, educators, and health care providers (Neumark-Sztainer, Story, & Harris, 1999); this finding is concerning, given the robust support for the deleterious impact of teasing experiences on social and emotional development (Goldfield et al., 2010).

Some community-based studies suggest that youth who are overweight have more psychological symptoms such as anxiety and depression than youth who are not overweight (Crow, Eisenberg, Story, & Neumark-Sztainer, 2006), while others offer minimal support for this perspective (Wardle & Cooke, 2005). In treatment-seeking samples, youth with obesity consistently demonstrate higher rates of psychiatric disorders, including mood and anxiety disorders (Britz et al., 2000; Erermis et al., 2004). This difference may be especially pronounced in adolescence, at which time the relationship between

obesity and depression may strengthen. In one study, approximately one-third of a small treatment-seeking sample of adolescents met criteria for major depressive disorder (Erermis et al., 2004); another study showed that adolescents with obesity reported suicidal thoughts and attempts more often than their peers who were at a healthy weight (Van Wijnen, Boluijt, Hoeven-Mulder, Bemelmans, & Wendel-Vos, 2009).

An interesting new area of research has focused on the relation between obesity and attention-deficit/hyperactivity disorder (ADHD). A review of studies showed that while rates of ADHD were higher in four out of five overweight treatment-seeking samples, no differences emerged in the one community-based sample (Cortese & Vincenzi, 2012). Future work clarifying the relation between ADHD and obesity is warranted, in addition to identifying the likely interactions among demographic factors, social problems, and eating pathology that predict which youth who are overweight are likely to experience elevated psychopathology. These factors may also underlie the differences in rates of obesity-related psychological problems in clinical versus nonclinical populations. Youth with higher levels of psychosocial and psychiatric comorbidity may be more likely to experience distress related to obesity, and therefore more likely to enter treatment.

MANAGEMENT OF ILLNESS

Lifestyle Interventions

The recommended structured obesity treatment is a comprehensive lifestyle intervention, including standard behavioral therapy comprising goal setting, self-monitoring, and reinforcement, in the context of a reduced-calorie diet and a program to increase physical activity and decrease sedentary behavior (Barlow, 2007). Behavioral interventions for obesity are typically family-based, are administered in outpatient settings by psychologists and nutritionists, and may be offered in group or individual format (i.e., individual families). A recent study compared the efficacy of group-only treatments and mixed-format treatments (group + family/individual-based) and found that while group-only treatments were more cost-effective, magnitudes of postintervention weight change were greater in mixed-format treatment (Hayes, Altman, Coppock, Wilfley, & Goldschmidt, 2015). These results suggest that group-only treatments without a family or individual component may not be optimal for sustaining long-term weight loss in pediatric obesity. Interestingly, very few studies have compared interventions delivered to families on an individual basis with a multiple-family group format. In some cases, treatment carried out among individual families may be more appropriate, such as for children whose group participation is limited by developmental, behavioral, or social issues, or when participation in a group is constrained due to scheduling, transportation, or other reasons. Although most of the data are available on group-based programs, in practice many interventions are delivered to individual families.

There have been several reviews examining the efficacy of lifestyle interventions for pediatric weight control (see Altman & Wilfley, 2014, for a more comprehensive review). Evidence-based lifestyle treatments are either family-based (involving both child and parent in weight control activities), parent-only, or adolescent-only. Family-based group treatment, in which parents set and implement weight-related goals for themselves and their children, has been categorized as a well-established treatment for children (Altman & Wilfley, 2014). Although most of the work in this area has been conducted with

school-age children, family-based group treatments with an individual/family component have also been used successfully to decrease weight status in preschool children (Stark et al., 2011). Parent-only group interventions (Janicke, 2013) and parent-only group interventions with an individual component (Boutelle, Cafri, & Crow, 2011), in which the parent acts as an agent of change and models healthy behaviors, have also been described as well-established interventions for children and have been shown to be as effective as family-based treatment. By comparison, behavioral weight loss group treatment that includes some family involvement, without specifically targeting parents, is considered possibly efficacious (Altman & Wilfley, 2014). In general, the intensity of parent involvement in treatment can vary inversely with the age of the child being treated, such that interventions among adolescents often include parents in a supportive (rather than a central) role. Adolescent behavioral weight loss treatments including parental support and inclusion of peer-enhanced physical activity have led to significant decreases in weight status and improvements in self-concept, maintained at 24 months (Lloyd-Richardson et al., 2012).

Regardless of the format for delivery, lifestyle weight control interventions include dietary and leisure-time activity prescription and training in a series of behavioral strategies. Dietary intervention is typically focused on establishing a hypocaloric diet with recommended intake from specific food groups (Raynor, 2008). The Traffic Light Diet, in which foods should be consumed frequently ("green"), moderately ("yellow"), or infrequently ("red"), is a well-studied, empirically supported approach to dietary change utilized with children and their parents (Epstein, Valoski, Koeske, & Wing, 1986). Leisure-time activity prescription includes an increase in time spent in physical activity to a goal of 60 minutes daily, combined with limiting of screen time to <2 hours/day (Barlow, 2007).

Key behavioral strategies utilized to support changes in diet and activity include goal setting, self-monitoring, stimulus control, and reinforcement of behavior change. Self-monitoring, use of stimulus control, and use of reinforcement were supported as key components of behavioral interventions in a meta-analysis (Kamath et al., 2008). Self-monitoring is typically the first skill taught in weight loss interventions. In spite of data regarding the limited accuracy of self-monitoring, typically in the form of underreporting (Fisher, Johnson, Lindquist, Birch, & Goran, 2000), tracking has utility for building awareness of dietary patterns and provides a family and interventionist with samples of a patient's behavior in order to guide subsequent interventions. Children who self-monitor have been shown to lose more weight during treatment (Germann, Kirschenbaum, & Rich, 2007). Depending on a child's age, developmental stage, and level of independence, the child may track his or her intake independently (e.g., at age 13+); the parent and child may share responsibility (e.g., at ages 8–12); or the parent may complete all tracking (e.g., at ages 7 and under). Reinforcing monitoring behavior, and utilizing electronic monitoring strategies such as text messaging or phone applications (Cushing, Jensen, & Steele, 2011; Shapiro et al., 2008), can be used to enhance compliance with self-monitoring. Stimulus control is another key behavioral strategy; it involves modifying the environment in order to enhance the likelihood of successful implementation of diet and exercise changes—for example, removing unhealthy food choices or increasing the salience of cues for physical activity. Finally, positive reinforcement can be used to increase engagement in healthy weight control behaviors.

Some treatments for obesity have incorporated elements of cognitive-behavioral

therapy (CBT) into traditional behavior therapy. The inclusion of cognitive components in weight control interventions is based on the notion that among the causal or maintaining factors in obesity are specific beliefs and cognitions related to weight, such as lack of self-efficacy (Cooper, Fairburn, & Hawker, 2003). Cognitive restructuring is used to address maladaptive cognitions related to weight loss, and thereby to improve a patient's self-efficacy. Additional CBT techniques utilized for weight management include problem solving and assertiveness training, applied to help the patient manage difficult situations related to weight management. Therapies including a CBT component are as efficacious as behavioral therapies and superior to no treatment, but whether the addition of cognitive techniques increases efficacy is not certain (Tsiros, Sinn, Coates, Howe, & Buckley, 2008). The overlap between techniques employed in behavior therapy alone versus CBT complicates evaluation of the relative efficacy of each approach.

To increase the accessibility of weight control treatment, recent efforts have focused on the dissemination of interventions in community settings, such as the YMCA (Foster et al., 2012) or Cooperative Extension Service offices in rural areas (Janicke et al., 2008). In general, results of these efforts suggest that interventions incorporating standard principles of behavioral weight control can be effectively delivered to families of children ages 6–12 in community settings, with children who receive the interventions losing more weight than control children. Outcomes for adolescents who participate in community-based programs, however, reveal lower effectiveness, potentially due to the lower intensity of the interventions (e.g., fewer in-person sessions, lack of specialized clinicians),; these findings suggest a need to continue improving community-based interventions to enhance weight outcomes.

Interventions among Ethnic Minority Youth

Ethnic minority status is consistently shown to be a predictor of attrition in pediatric weight management (de Niet, Timman, Jongejan, Passchier, & van den Akker, 2011). This may result from the fact that interventions are not optimally tailored for minority youth and lack cultural relevance. A meta-analysis examining obesity prevention and treatment studies among minority youth showed that including parents in the intervention and addressing three or more components (e.g. nutrition, increasing physical activity, sedentary behavior reduction) was associated with improved outcomes (Seo & Sa, 2010). Findings from many, but not all, studies suggest that culturally tailored interventions are superior to those that are not thus tailored. In addition, novel interventions that include modifying the built environment in which children live to increase proximity to parklands and decrease access to convenience stores have resulted in decreases in BMI *z*-scores (Epstein et al., 2012). Randomized clinical trials examining the effectiveness of culturally adapted weight control treatments are needed to improve our understanding of factors that may bolster treatment outcomes among ethnic minority youth.

Intensive Interventions

For youth who do not respond to behavioral interventions, a number of more intensive interventions may be available, including pharmacotherapy, intensive immersion programs (e.g., summer camps), and bariatric surgery (Han & Yanovski, 2008). Efficacy for even the best medications (e.g., orlistat, metformin) is only moderate, and several

medications with the highest efficacy have been withdrawn due to adverse events (e.g., sibutramine) (Sherafat-Kazemzadeh, Yanovski, & Yanovski, 2013). Immersion programs, including overnight camps and residential programs, capitalize on the opportunity to control all aspects of patients' environments, and treatments typically produce greater weight loss and lower attrition rates than nonintensive lifestyle programs do (Kelly & Kirschenbaum, 2011). However, weight regain following treatment is common once an individual returns to his or her traditional environment, and therefore a focus on maintenance is needed (refer to Wilfley et al., 2007 for a more comprehensive review of weight maintenance).

As traditional noninvasive treatments have demonstrated limited efficacy with adolescents with severe obesity, weight loss surgery (WLS) has become a more common treatment (Black, White, Viner, & Simmons, 2013). Clinical guidelines mandate that to qualify for WLS, youth must have a BMI of at least 35 kg/m^2 with an obesity-related comorbidity, have reached physical maturity, demonstrate emotional and cognitive maturity, and have unsuccessfully attempted other weight control methods (Michalsky et al., 2012). A recent meta-analysis examining WLS outcomes reported an average BMI decrease of –13.5 kg/m^2 at 1 year after surgery. Roux-en-Y gastric bypass was associated with the largest reduction in BMI (–17.2 kg/m^2), followed by sleeve gastrectomy (–14.5 kg/m^2) and then adjustable gastric banding (–10.5 kg/m^2; Black et al., 2013). In addition to reductions in weight, the first postoperative year is also associated with reductions in depressive symptoms, improved HRQoL, and better self-concept (Sysko et al., 2012). Across surgical procedures, rates of adverse events (30 days postsurgery) are generally low (no deaths; major complications, 8%; minor complications, 15%) (Inge et al., 2014); however, there are limited data available on long-term outcomes of bariatric surgery with adolescents.

Interventions for Youth with Comorbidities

Although not all youth who are overweight/obese experience elevated psychopathology, concerns indicating psychological maladjustment are disproportionately high among treatment-seeking youth, and require assessment and attention by the provider. Important facets to be assessed and monitored throughout treatment include disordered eating behaviors (e.g., binge eating, unhealthy and extreme weight control behaviors), psychopathology (e.g., depression), and general psychosocial functioning. Addressing behaviors such as loss of control or binge eating in treatment should be a priority, as these behaviors pose a risk for the future development of eating disorders (Tanofsky-Kraff et al., 2014) and predict continued weight gain (Neumark-Sztainer, 2005). In adults, CBT and interpersonal therapy have demonstrated equal efficacy for improving binge eating among adults with binge-eating disorder (Wilfley et al., 2002) and both of these have been adapted to address binge/loss-of-control eating in adolescents and demonstrated preliminary efficacy (Debar et al., 2013; Tanofsky-Kraff et al., 2014).

Depressive symptoms, such as anhedonia and impaired motivation, are associated with obesity treatment attrition in youth (Zeller, Kirk, et al., 2004), and predict poorer weight loss treatment outcomes in adults (Price et al., 2013). Youth who meet criteria for a diagnosis of major depression are commonly referred for treatment for depression prior to initiating obesity treatment if it is determined that depressive symptoms are likely to interfere with obesity treatment. A pilot study of a combined treatment

approach, integrating CBT for depression and obesity, suggested superior efficacy for weight management and equal efficacy for depressive symptoms compared to CBT for depression alone (Jelalian et al., 2016).

EMERGING AREAS

Approximately one-third of U.S. youth continue to struggle with excess weight. Although lifestyle interventions have established efficacy, their reach can be limited. Recent expansion of Medicaid and the Children's Health Insurance Program to cover obesity counseling in primary care offers one avenue for increasing the reach of obesity prevention and treatment efforts. A recent study documents that an intervention based on motivational interviewing (Miller & Rollnick, 2013) and delivered to parents of young children by pediatricians and registered dietitians led to significant decreases in the children's BMI percentiles over a 2-year period (Resnicow et al., 2015). Additional research to identify effective strategies for early detection and intervention within primary care are clearly warranted and consistent with the mission of integrated primary care.

Long-term amelioration of the obesity epidemic will require increased attention to prevention and early detection and intervention. Representative of this line of inquiry are studies focused on prevention of weight gain in pregnant women and infants, as well as the study of epigenetics. For example, an ongoing trial targets reduction of weight gain in infants born to adolescent mothers (Horodynski, Silk, Hsieh, Hoffman, & Robson, 2015). Another area receiving considerable attention is the role of epigenetics in fetal programming and weight gain trajectory. There is evidence to suggest that an impoverished prenatal environment results in changes to the epigenome, through factors such as DNA methylation (Desai, Jellyman, & Ross, 2015). This "programming" can result in changes to the endocrine system that promote a trajectory of excess weight gain (Desai et al., 2015). Understanding these pathways holds considerable promise for disrupting the cycle of obesity transmission across generations.

Recent work has focused on identifying key neurocognitive circuits, such as reward and cognitive control circuitry. According to the concept of "reinforcement pathology," adapted from the addiction literature, excess consumption of food results from a combination of motivational and executive function factors (Carr, Daniel, Lin, & Epstein, 2011). According to this framework, obesity risk results from a combination of high food reinforcement (motivation) and low impulse control or deficiency in the ability to delay reward (executive function) (Carr et al., 2011). These constructs may interact with environmental characteristics, such as access to alternatives to unhealthy foods (both food and nonfood resources), to determine success in behavioral weight control interventions. Neuroimaging studies have begun to examine regions of the brain that may underlie phenotypes such as reinforcement pathology or loss of control eating. For example, a recent study using functional magnetic resonance imaging found that a particular area of the brain (i.e., the fusiform face area) was activated when youth with loss-of-control eating were challenged with an interpersonal stressor, and that this activation was related to dietary intake (Jarcho et al., 2015). An innovative possibility stemming from this line of research is the development of interventions such as working memory training that could be combined with lifestyle intervention to improve executive functioning and enhance weight loss outcomes (Liang, Matheson, Kaye, & Boutelle, 2014).

Advances in scanning technology and interdisciplinary work with colleagues from neuroscience provide further opportunities for pediatric psychologists to play a primary role in this area of inquiry. Novel intervention targets will evolve from linking behavioral phenotypes with underlying pathways and developing strategies that address these pathways. For example, cognitive training focused on improving attentional and memory skills may serve as an adjunct to standard behavioral weight loss strategies. Recent work suggests that "episodic future thinking," which involves engaging memory to experience future events, can lead to decreased calorie intake in obese adults (Daniel, Stanton, & Epstein, 2013). Pediatric psychologists can continue to play a key role in such advances by virtue of their knowledge of cognitive and emotional processes, expertise in intervention development, strong interdisciplinary collaborations, and ability to translate research findings into clinical practice.

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CHAPTER 33

Eating Disorders

Diana Rancourt and Leah Boepple

Current diagnostic systems—including the *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition (DSM-5; American Psychiatric Association, 2013) and the *International Classification of Diseases,* 10th revision (ICD-10; World Health Organization [WHO], 1992)—recognize a number of specific eating disorders that collectively are characterized by persistent alterations in the way food is consumed and used, and that are associated with significant psychological or emotional distress. In addition to the ongoing development of the ICD criteria, the DSM diagnostic criteria have been recently revised to increase their developmental appropriateness to pediatric populations, and to be less gender-specific (i.e., to better describe males suffering from eating disorders) (Keel, Brown, Holm-Denoma, & Bodell, 2011). This chapter provides an overview of several specific eating disorders in the context of a pediatric population.

DIAGNOSTIC CATEGORIES

Anorexia Nervosa

According to widely accepted diagnostic systems (e.g., DSM-5, ICD-10), primary elements of anorexia nervosa (AN) include deliberate and induced weight loss and/or maintenance of very low weight; persistent fear or dread of weight gain; and distorted body image. Among children and adolescents, low weight does not necessarily need to occur in the context of actual weight loss; the failure to make expected weight gain or maintain a normal developmental weight trajectory is sufficient (Rosen & American Academy of Pediatrics Committee on Adolescence, 2010). This is particularly relevant to pediatric cases, as the low-weight criterion has the most predictive validity for AN among youth (Loeb et al., 2011). Two subtypes of AN have been described in the literature (Elran-Barak et al., 2014). A "restricting type" of AN is characterized as maintaining below-normal weight without binge eating or purging. In contrast, a "binge-eating/purging type" of AN is described as maintaining very low weight by means of recurrent

bouts of overeating (i.e., bingeing) and purging. In youth, weight status is often based on the ratio of height to weight compared to other youth of the same age and gender (i.e., body mass index [BMI] percentile; Mei et al., 2002).

Bulimia Nervosa

Primary elements of bulimia nervosa (BN) include repeated binge eating episodes, frequent use of compensatory behaviors as a means of avoiding gaining weight, and self-evaluation that is highly influenced by body image (American Psychiatric Association, 2013; WHO, 1992). A binge eating episode is commonly understood to comprise eating an unusually large amount of food in a short period of time, and feeling a loss of control over eating during that period. Compensatory behaviors can include self-induced vomiting, misuse of laxatives or other medications, limiting caloric intake, and excessive exercise. To meet criteria for a formal diagnosis of BN, binge eating episodes and subsequent compensatory behaviors must occur with some regularity (see American Psychiatric Association, 2013, for specific DSM-5 diagnostic criteria). However, it is important to note that the predictive validity of these specific criteria among youth is unknown (Loeb et al., 2011).

Binge Eating Disorder

The literature has also described an eating disorder characterized by the presence of frequent binge eating episodes associated with significant distress (Mathes, Brownley, Mo, & Bulik, 2009). Binge eating disorder (BED) is associated with a range of specific symptoms (see American Psychiatric Association, 2013; Keel et al., 2011), but must include the presence of binge eating episodes and the absence of compensatory behaviors. Importantly, children and adolescents can experience binge eating and loss-of-control eating episodes without consuming an objectively excessive amount of food (Tanofsky-Kraff et al., 2011).

Other Diagnoses

The two "catch-all" diagnostic categories are other specified feeding or eating disorder (OSFED) and unspecified feeding or eating disorder (UFED). OSFED captures individuals who present with a constellation of eating disorder symptoms that do not meet full criteria for AN, BN, or BED. For example, individuals who meet all criteria for AN except that they are of normal weight and/or have not fallen off their personal weight trajectory (atypical AN), or those with a low frequency of binge eating and/or purging behaviors (low-frequency BN or BED), would receive a diagnosis of OSFED. Two proposed diagnoses also are included under OSFED: purging disorder and night eating syndrome. Purging disorder is characterized by frequent episodes of purging (i.e., use of vomiting, misuse of laxatives) to change or maintain weight or shape without binge eating episodes. Night eating syndrome is characterized by the excessive consumption of calories at night (e.g., after waking from sleep). DSM-5 has successfully decreased the number of youth receiving a "catch-all" diagnosis (Machado, Goncalves, & Hoek, 2013); however, OSFED is likely to remain the most common diagnosis. UFED was added to capture individuals who screen as "at risk" for an eating disorder, or who oth-

erwise present with insufficient information for a diagnosis (e.g., an emergency department situation), but the clinical utility of UFED remains to be seen.

EPIDEMIOLOGY

Lifetime prevalence ranges for any formal eating disorder diagnosis are estimated to be 5.7–15.2% for girls and 1.2–2.9% for boys (Allen, Byrne, Oddy, & Crosby, 2013; Smink, van Hoeken, Oldehinkel, & Hoek, 2014; Stice, Marti, & Rohde, 2013). The most common diagnoses among girls are AN and BED (Smink et al., 2014), and a diagnosis early in adolescence is predictive of a diagnosis in late adolescence (Allen et al., 2013). The most common diagnosis among boys is BED (Smink et al., 2014), and a diagnosis in late adolescence is predictive of a diagnosis as a young adult (Allen et al., 2013). Although age of onset is similar across genders (Norris et al., 2012; Smink et al., 2014), girls are more likely to have earlier onset for restrictive eating disorders (Pinhas, Morris, Crosby, & Katzman, 2011). The most common diagnostic crossover occurs between BN and BED (Allen et al., 2013; Stice et al., 2013).

Lifetime prevalence estimates for AN are 0.8–1.7% for girls and 0.1% for boys (Allen et al., 2013; Smink et al., 2014; Stice et al., 2013). Mean age of onset is 15.1 years (Smink et al., 2014), whereas median age of onset, based on DSM-IV-TR, is 12.3 years (Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011). Peak onset for girls is estimated to occur between 19 and 20 years (Stice et al., 2013), and peak prevalence is estimated at age 17 (Allen et al., 2013). AN rates are highest among non-Hispanic white youth (Swanson et al., 2011).

Lifetime prevalence estimates for BN are 0.8–2.6% for girls and 0.1% for boys (Allen et al., 2013; Stice et al., 2013). Mean age of onset is 16.0 years (Smink et al., 2014), and DSM-IV-TR-based median age of onset is 12.4 years (Swanson et al., 2011). Peak onset is estimated to occur between ages 16 and 20 years for both girls and boys (Allen et al., 2013; Stice et al., 2013). Hispanic youth have the highest prevalence rates of BN (Swanson et al., 2011).

Lifetime prevalence estimates of BED are 2.3–3.0% among girls and 0.7% among boys (Smink et al., 2014; Stice et al., 2013). Mean age of onset is 13.9 (Smink et al., 2014), and median age of onset, based on DSM-IV-TR, is 12.6 years (Swanson et al., 2011). Peak onset for girls occurs between ages 18 and 20 years (Stice et al., 2013). Peak prevalence is estimated to occur at age 20 for girls (Allen et al., 2013) and age 17 for boys (Allen et al., 2013). Racial/ethnic minority youth tend to have a higher prevalence of BED than non-Hispanic white youth (Swanson et al., 2011).

OSFED is the most common eating disorder diagnosis at 12.1% (Smink et al., 2014). Prevalence rate ranges of OSFED are 3.6–4.1% among girls and 0.7–0.9% for boys (Allen et al., 2013). Approximately 3.4% of youth meet criteria for UFED (Smink et al., 2014).

PSYCHIATRIC AND MEDICAL COMORBIDITIES

Over half of all youth diagnosed with an eating disorder meet criteria for at least one additional lifetime psychiatric diagnosis. Youth comorbidity rates range from 55.2%

(AN) to 83.5% (BED) to 88.0% (BN) (Swanson et al., 2011), with psychiatric comorbidity occurring more frequently among males (Raevuori, Keski-Rahkonen, & Hoek, 2014). Mood and anxiety disorders are the most common comorbidities among all youth (Swanson et al., 2011). Among adolescent males, anxiety disorders are the most frequent secondary diagnosis, followed by depression (Norris et al., 2012). Suicidal ideation, plans, and attempts are highest among youth diagnosed with BN, although levels of suicidal ideation are notable across all diagnoses (AN, 31.4%; BN. 53%; BED, 34.4%; Swanson et al., 2011). Other comorbidities include substance use disorders (Mann et al., 2014); attention-deficit/hyperactivity disorder, particularly among males (Bleck & DeBate, 2013); and, as recent data suggest, autism spectrum disorder (Huke, Turk, Saeidi, Kent, & Morgan, 2013). In an initial investigation, approximately 5% of youth with an eating disorder also met criteria for avoidant/restrictive food intake disorder (American Psychiatric Association, 2013), supporting the latter as a distinct diagnosis (Norris et al., 2014).

In terms of medical comorbidities, eating disorders have one of the highest mortality rates among major psychiatric disorders, with an estimated standardized mortality ratio of 6.6 for adolescents and young adults (Hoang, Goldacre, & James, 2014). Youth with eating disorders are at significant risk of developing renal, respiratory, dental, gastrointestinal, liver, metabolic, neurological, cardiac, electrolyte, and hematological complications (Norrington, Stanley, Tremlett, & Birrell, 2012; Peebles, Hardy, Wilson, & Lock, 2010). Youth with BED are at higher risk of developing obesity (Field et al., 2012). Across all eating disorders, sleep disturbances are common (Mayes et al., 2014).

RISK FACTORS

Biological Factors

Significant heritability and genetic contributions are supported for eating disorder symptoms and diagnosis. Twin and adoption studies have found moderate to high rates of heritability of AN, BN, and BED (range 20–85%; Culbert, Racine, & Klump, 2011; Trace, Baker, Penas-Lledo, & Bulik, 2013). Among boys, genetic risk is relatively stable before, during, and after puberty (51%). In contrast, girls' prepubertal genetic risk is 0%, but increases to over 50% during and after puberty (Klump et al., 2012). There also is increasing evidence of neurobiological underpinnings of eating disorders, such as the size of the orbitofrontal cortex and abnormalities in taste–reward processing; however, specific abnormalities may vary across diagnoses (Frank, 2015). Levels of hormones related to regulation of food intake (e.g., leptin, ghrelin) also may have an impact on biological reward processes (Monteleone & Maj, 2013) and contribute to eating disorder risk.

Other biological risk factors include gender, weight, and sexual orientation. Females are more likely to develop an eating disorder than males (Allen, Byrne, & Crosby, 2015; Allen, Byrne, Forbes, & Oddy, 2009), and having a higher BMI is associated with disordered eating behavior among both males and females (Liechty & Lee, 2013). Recent research suggests that sexual minority status, particularly among adolescent males, is associated with an increased risk of disordered eating behavior (Austin, Nelson, Birkett, Calzo, & Everett, 2013).

Environmental/Sociocultural Factors

A recent meta-analysis suggests that peer influence on dieting behavior is greater among girls than boys, and that behavior modeling has the greatest influence on both male and female adolescents' binge eating and purging behaviors (Marcos, Sebastian, Aubalat, Ausina, & Treasure, 2013). Boys and youth with overweight/obesity are particularly vulnerable to peer teasing (Domine, Berchtold, Akre, Michaud, & Suris, 2009; Vander Wal, 2012). In addition, idealized media images are associated with both girls' and boys' body dissatisfaction and disordered eating behavior (Dakanalis et al., 2015; Field et al., 2008). The internet and social media have preliminary support as potential risk factors for adolescent girls (Tiggemann & Slater, 2013).

Family Factors

Parents' misperception of their children who are of healthy weight as overweight is a strong predictor of youths' eating disorder development (Allen et al., 2009). Critical weight-related comments by family (Allen et al., 2015) and fewer family meals are associated with a range of disordered eating behaviors (Allen et al., 2009). Maternal thin ideal internalization, higher maternal BMI, and maternal dieting are associated with offspring eating disorder diagnoses, and for boys, living at or below the poverty level increases the likelihood of disordered eating behavior (Allen et al., 2009).

Behavioral Factors

Dieting is supported as a risk factor for any eating disorder diagnosis (Goldschmidt, Wall, Loth, Le Grange, & Neumark-Sztainer, 2012; Rohde, Stice, & Marti, 2015), and persistent loss-of-control eating is predictive of the development of BED specifically (Hilbert & Brauhardt, 2014). Girls consistently report higher levels of disordered eating behavior than boys (Neumark-Sztainer, Wall, Larson, Eisenberg, & Loth, 2011); however, muscle-gaining behaviors have recently emerged as a risk factor, particularly for boys (Eisenberg, Wall, & Neumark-Sztainer, 2012). Female elite athletes participating in aesthetic or weight-oriented sports may also be at particular risk of developing an eating disorder (Francisco, Narciso, & Alarcao, 2013).

Psychological Factors

Higher levels of body dissatisfaction, thin ideal internalization, perceived pressure to be thin, negative affect, and perfectionism, and lower levels of social self-efficacy, are established psychological risk factors (Allen et al., 2009; Keel & Forney, 2013; Rohde et al., 2015). Social difficulties (Allen et al., 2009), negative urgency (i.e., the tendency to act impulsively when distressed; Pearson, Combs, Zapolski, & Smith, 2012), and depression (Liechty & Lee, 2013) also increase risk. Drive for muscularity is a risk factor for boys, especially gay or bisexual male youth (Calzo, Corliss, Blood, Field, & Austin, 2013), whereas drive for thinness has an impact on all youth (Pearson, Combs, & Smith, 2010; Rohde et al., 2015). Overestimation of weight by adolescents who are of healthy weight, and accurate estimation of weight by adolescents with overweight/obesity, are

associated with disordered eating behaviors (Eichen, Conner, Daly, & Fauber, 2012). Deficits in cognitive flexibility and set-shifting ability also are receiving attention as potential eating disorder risk factors (Wildes, Forbes, & Marcus, 2014).

ASSESSMENT

Structured Interviews

The Eating Disorder Examination (EDE; Fairburn, Cooper, & O'Connor, 2008) remains the most commonly used diagnostic interview for eating disorder identification among adults and has been updated to reflect DSM-5 diagnoses (the current version is 17.0D; Fairburn, Cooper, & O'Connor, 2014). However, its performance with adolescent samples is less robust (Darcy et al., 2012; Wade, Byrne, & Bryant-Waugh, 2008), and its utility with males is unclear (Berg et al., 2012; Darcy et al., 2012). Recent research supports an adapted eight-item version for use with children (ChEDE) as a reliable nondiagnostic assessment of children's eating disorder symptoms (Jongenelis, Byrne, Pettigrew, Allen, & Watt, 2014).

Self-Report Measures

The Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 2008) is the self-report adaptation of the EDE. Although the EDE-Q and the EDE are highly correlated, the EDE-Q generates higher scores, less stable reports of binge eating (Berg et al., 2012), and is not diagnostic. Furthermore, the use of the EDE-Q with adolescents is not well supported, and it may not adequately capture males' eating disorder symptoms (Berg et al., 2012; White, Haycraft, Goodwin, & Meyer, 2014). A children's version has been developed (ChEDE-Q; Bryant-Waugh, Cooper, Taylor, & Lask, 1996), but psychometric research on it is limited.

The Eating Attitudes Test (EAT; Garner & Garfinkel, 1979) and the Eating Disorder Inventory–3 (EDI-3; Garner, 2004), continue to be popular symptom assessments. An 18-item version of the EAT has demonstrated good psychometrics and utility across racial/ethnic groups and weight categories as a screening tool (Maiano, Morin, Lanfranchi, & Therme, 2013); however, its utility as a diagnostic tool is limited (Siervo, Boschi, Papa, Bellini, & Falconi, 2005). The EDI-3 now includes adolescent norms and demonstrates acceptable psychometric properties, according to the technical manual (Garner, 2004). The Children's Eating Attitudes Test (ChEAT) has versions that are appropriate for children as young as 10 years old (Erickson & Gerstle, 2007), but research with preadolescent girls suggests low sensitivity and low positive predictive values (Colton, Olmsted, & Rodin, 2007), suggesting limited diagnostic ability.

Parent Report Measures

To date, no well-developed parent assessments of eating disorders exist; thus parent reports are typically gathered in a semistructured format or with a structured interview (e.g., the EDE). Although parent–youth agreement on youths' eating disorder symptoms as assessed by the EDE is relatively poor (Mariano, Watson, Leach, McCormack, &

Forbes, 2013; Swanson et al., 2014), their disagreement supports the utility of collateral reporters in the assessment of eating disorders.

TREATMENT

Given the psychological, nutritional, and medical complexity of eating disorders, it benefits the patient, the family, and the treatment providers to use a multidisciplinary approach, with experts in each of the affected domains (i.e., psychologist, nutritionist, psychiatrist, pediatrician; Academy for Eating Disorders, 2012).

Anorexia Nervosa

Family-based treatment (FBT) is the most effective approach for adolescent AN (Watson & Bulik, 2013); however, favorable long-term outcomes remain relatively low, with only about half of youth receiving FBT achieving remission (Lock et al., 2010). Individual treatment has potential utility (Merwin, Zucker, & Timko, 2013), but FBT currently has better long-term outcomes (Couturier, Kimber, & Szatmari, 2013). Other AN interventions for youth receiving attention include cognitive remediation therapy (Dahlgren, Lask, Landro, & Ro, 2014) and enhanced cognitive-behavioral therapy (CBT) (Dalle Grave, Calugi, Doll, & Fairburn, 2013).

Malnutrition is associated with changes in brain functioning that are theorized to maintain AN (Kaye, Fudge, & Paulus, 2009). Consistent with this view, early weight gain predicts symptom improvement and recovery (Forman et al., 2014). Weight gain is predicted by family unitedness, lack of criticism, externalization of the illness, and parental control (Ellison et al., 2012). Treatment dropout among youth with AN is predicted by low therapeutic alliance (Ellison et al., 2012), lower initial BMI, and higher number of hospitalizations, and is more likely when a patient is living with one parent (Hubert et al., 2013).

Bulimia Nervosa

Preliminary findings for youth with BN support FBT and CBT (Couturier et al., 2013), but treatment outcomes for males are lacking. Other treatments garnering support include self-help (Pretorius et al., 2009; Wagner et al., 2013) and outpatient dialectical behavior therapy (DBT) (Fischer & Peterson, 2015). Less severe baseline depression is associated with better treatment outcome (Le Grange, Crosby, & Lock, 2008) and early symptom reduction predicts remission (Le Grange, Doyle, Crosby, & Chen, 2008).

Binge Eating Disorder

There are no empirically supported treatments for youth with BED. CBT and DBT for adolescent BED are currently being examined (Mazzeo, Gow, & Bulik, 2013; Mazzeo, Kelly, et al., 2013). Cue exposure treatment, manualized CBT for binge eating, interpersonal therapy, and general weight control interventions have some preliminary support for reducing binge eating and loss-of-control eating among youth (Bishop-Gilyard et al.,

2011; Boutelle et al., 2011; Debar et al., 2013; Tanofsky-Kraff et al., 2014). Of note, preliminary data suggest that reduction of binge eating does not reduce body weight (Boutelle et al., 2011) and to date there are no interventions that successfully target both eating disorders and obesity in pediatric populations.

Pharmacological Interventions

There is no support for youth's improved weight or behavioral outcomes from pharmacological treatment (Balestrieri, Oriani, Simoncini, & Bellantuono, 2013; van den Heuvel & Jordaan, 2014). Furthermore, there are frequent reports of aversive side effects, including new-onset BED, with second-generation antipsychotics (Balestrieri et al., 2013; Moore, Watson, Harper, McCormack, & Nguyen, 2013; Norris et al., 2011).

CONCLUSIONS AND CONSIDERATIONS

Although there has been an increased interest in specifying the etiology of eating disorders, more work is needed on the identification and treatment of these disorders in the pediatric population. In particular, the diagnostic utility of the current criteria for identifying eating disorders among youth needs further examination. Given the gender differences in prevalence rates, a better understanding of the extent to which current criteria accurately capture young males suffering from eating disorders is vital. Finally, more attention to developing effective treatment approaches for the pediatric population is imperative.

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CHAPTER 34

Elimination Disorders

Enuresis and Encopresis

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Elimination disorders are common in childhood and are characterized by the absence of bladder or bowel control that would be expected for a child's age or developmental status. In addition to the psychosocial implications, these functional disorders have physiological concomitants that provide an extra dimension to the evaluation and treatment process. This chapter provides an overview of the two predominant elimination disorders identified in the *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition (DSM-5; American Psychiatric Association, 2013) and in the *International Classification of Diseases,* 10th revision (ICD-10; World Health Organization, 1992): enuresis and encopresis.

ENURESIS

According to the two major classification systems (DSM-5 and ICD-10), enuresis is characterized by recurrent inappropriate elimination of urine, by day or night, among individuals who would (developmentally) be expected to maintain urinary continence. Specific criteria for the disorder vary by diagnostic system (i.e., DSM vs. ICD), but generally include frequency criteria, restrictions on age or developmental level, and the requirement that symptoms not be attributable to some other medical cause or emotional/behavioral problem. This chapter focuses primarily on nocturnal enuresis.

Biological and Psychobehavioral Factors

Enuresis and subclinical bedwetting are common in school age children, with estimates indicating that 20% of those in first grade experience occasional bedwetting, and 4%

wet the bed at least twice per week (Butler et al., 2008). Overall, it is estimated that 10% of school-age children have nocturnal enuresis, whereas 2–3% experience diurnal enuresis (Mellon & McGrath, 2000; von Gontard & Nevéus, 2006). Enuresis is more prevalent in boys than girls, as rates are estimated at 7–9% compared to 3–6%, respectively (Byrd, Weitzman, Lanphear, & Auinger, 1996). The prevalence of enuresis steadily declines with age, with 20% prevalence at age 5 compared to 1–2% prevalence in late adolescence/early adulthood (Glazener & Evans, 2004). Heritability estimates suggest that almost 80% of children with enuresis have a first-degree relative with a history of the condition (von Gontard, Schaumburg, Hollmann, Eiberg, & Rittig, 2001).

A small subset of the population with nocturnal enuresis experiences concurrent urinary dysfunction during the day, and up to one-third experiences comorbid constipation (McGrath, Caldwell, & Jones, 2008; Schmitt, 1997). Maturational delays in some children with nocturnal enuresis can impair their ability to detect a full bladder overnight (Campbell, Cox, & Borowitz, 2009). Urine retention difficulties at night can also be results of the diminished production of the hormone vasopressin, reduced functional bladder capacity, or excessive fluid intake before bedtime (Patel et al., 2012; Norfolk & Wooton, 2012). Behaviorally, children with nocturnal enuresis are often reported by parents to be heavy sleepers, but empirical evidence is sparse (Nevéus, Stenberg, Läckgren, Tuvemo, & Hetta, 1999).

Psychosocial and behavioral correlates of nocturnal enuresis are widely discussed, but findings remain inconsistent. Some estimates suggest that the condition is accompanied by behavioral difficulties in 20–30% of cases, which is consistent with rates for children with other chronic medical conditions (Hirasing, van Leerdam, Bolk-Bennink, & Bosch, 1997; Liu, Sun, Uchiyama, & Okawa, 2000). However, limitations related to inconsistencies in diagnostic criteria, reliance on small convenience samples, and use of diverse psychosocial measures across studies have made it impossible to establish a causal relationship between enuresis and psychological and/or behavioral problems (Wolfe-Christensen, Veenstra, Kovacevic, Elder, & Lakshmanan, 2012). Psychological problems may exist, including a child's ongoing feelings of embarrassment, social stressors, and the stigma associated with the urinary accidents. Some studies, based on parent report data, have demonstrated elevated rates of clinically significant problems related to internalizing, acting out, and attentional difficulties in children with enuresis, while others have found no significant differences between children with nocturnal enuresis and controls (De Bruyne et al., 2009; Friman, Handwerk, Swearer, McGinnis, & Warzak, 1998; Hirasing et al., 1997; Joinson, Heron, Emond, & Butler, 2007). Early literature suggests that negative parental response to the bedwetting, including punishment or shaming, contributes to emotional difficulties in children with enuresis (Sharf & Jennings, 1988).

Empirically Based Treatment Approaches

The spontaneous remission rate for nocturnal enuresis is approximately 15% per year, with the condition fully remitting by the time most youth reach adolescence (Forsythe & Redmond, 1974). Without treatment, remission takes several years, underscoring the importance of initiating treatment as early as practicable to help minimize or prevent further psychosocial consequences for a child and his or her family. Following a comprehensive assessment by the child's pediatrician or urologist to rule out an underlying

medical problem, first-line treatment strategies for enuresis are typically carried out by the physician and include medications and general behavioral strategies (e.g., monitoring fluid intake and scheduled toileting), or treatment of comorbid constipation prior to referral for more intensive behavioral management (Norfolk & Wooton, 2012; Vogel, Young, & Primack, 1996).

Medical Interventions

Pharmacological intervention, specifically desmopressin, may also be employed at times when fast-acting effects are desired (e.g., sleepovers) or when more intensive behavioral treatment is deemed impractical (e.g., complex psychosocial situations where regimented strategies cannot be consistently carried out; Norfolk & Wooton, 2012). However, efficacy rates are variable, and although desmopressin is generally successful at reducing urinary accidents, bedwetting resumes when the medication is discontinued (Glazener & Evans, 2004; Norfolk & Wooton, 2012). Long-term use of desmopressin is costly and approximately three times more expensive than a 12-week course of urine alarm treatment (Houts, 2000). Other medications, such as tricyclic antidepressants, have demonstrated efficacy in reducing frequency of bedwetting, though adverse side effects typically outweigh the benefits and are only recommended when all other treatment approaches have been unsuccessful (Deshpande, Caldwell, & Sureshkumar, 2003; Nevéus et al., 2010).

Behavioral Interventions

The urine alarm is the most empirically supported treatment for nocturnal enuresis (Glazener, Evans, & Peto, 2005). In this intervention, an alarm is activated by moisture sensors that are either worn on the child's pajamas or placed on the mattress. The urine alarm has ample evidence supporting its efficacy as the primary approach to treatment, with an average success rate of approximately 78% (see Mellon & McGrath, 2000 for a review). Behaviorally, the urine alarm requires considerable investment of time and effort from families, which may contribute to underutilization or discontinued use of this treatment strategy (Shepard, Ritterband, Thorndike, & Borowitz, 2014). Therefore, an important role of the pediatric psychologist is to prepare families for the associated demands and to identify any potential barriers, as well as to continue to educate medical colleagues on the urine alarm's efficacy to facilitate or strengthen lines of referral (Houts, 2000; Norfolk & Wooton, 2012).

Dry-bed training (DBT) is a multicomponent intervention for nocturnal enuresis that pairs the urine alarm with behavioral strategies. Specifically, this approach incorporates a rigorous nighttime waking schedule, positive practice (i.e., the child practices getting out of bed to do toilet sits despite the lack of urge to urinate), and overcorrection for bedwetting via cleanliness training (i.e., having the child change soiled bedding and pajamas; Azrin, Sneed, & Foxx, 1974). Remission of bedwetting is typically achieved in a matter of a few weeks, and the average remission rate is estimated to be over 75% (Mellon & McGrath, 2000). There is some evidence that DBT is superior to urine alarm treatment in long-term remission of bedwetting (Nawaz, Griffiths, & Tappin, 2002). However, the protocol is demanding on families, and findings suggest that the pediatric psychologist plays a crucial role in implementing these strategies effectively (Bollard & Nettlebeck, 1981).

Designed to be a less demanding alternative to DBT, full-spectrum home training (FSHT) is another multicomponent, manualized behavioral intervention for nocturnal enuresis that pairs the urine alarm with several behavioral strategies. Treatment components include retention control with monetary rewards, cleanliness training, self-monitoring/parental monitoring, and graduated overlearning (i.e., drinking increasing quantities of water before bedtime; Houts, 2008), Average success rates of FSHT are similar to those of DBT but with fewer demands on the family, as no differences were found with the addition of the rigorous waking schedules that are included in DBT (Houts, Liebert, & Padawer, 1983; Whelan & Houts, 1990). Relapse rates at 1 year postintervention range from 16 to 24%; the higher rate was significantly associated with prior imipramine use (Houts et al., 1983; Whelan & Houts, 1990).

ENCOPRESIS

Major classification systems (e.g., DSM, ICD) characterize encopresis as the repeated inappropriate elimination of feces by individuals who would developmentally be expected to maintain fecal continence. Specific criteria for the disorder vary by diagnostic system (i.e., DSM vs. ICD), but generally include frequency requirements, restrictions on age or developmental level, and the requirement that symptoms not be attributable to some other medical cause. The literature describes a number of subtypes of encopresis (von Gontard, 2013), including—*but not limited to*—those subtypes described in the DSM system (i.e., with/without constipation and overflow incontinence; American Psychiatric Association, 2013). Encopresis is a functional disorder with unknown pathophysiology, as no organic cause can be found in 90% of pediatric cases (Loening-Baucke, 1993). The condition is common in school-age children, affecting between 1.5 and 7.5% of youth between 6 and 12 years of age (Doleys, 1983; Levine, 1975; Olatawura, 1973).

Biological and Psychobehavioral Factors

Most youth with encopresis have a history of chronic constipation, which typically develops in the first 3 years of life and is associated with infrequent bowel movements, fecal incontinence, and stool-withholding behaviors (Benninga et al., 1996). In the context of such large, painful, and difficult-to-pass stools, retentive behaviors are a common fearful response (Shepard et al., 2014). With increased retention, however, defecation then becomes even more difficult, as bowel movements get progressively larger and more difficult/painful to pass (Rasquin et al., 2006). Active retention may also result from specific toilet phobias, including aversions to public or unfamiliar bathrooms (Benninga, Voskuijil & Taminiau, 2004; Borowitz et al., 2003).

Chronic stool retention paired with long-term constipation may lead to acquired megacolon, where the rectum walls are stretched to accommodate a large amount of stool, and the child's ability to feel the urge to defecate is reduced (Voskuijl et al., 2006). As a result, fecal matter leaks around the retained mass of stool, known as "overflow incontinence." Overflow incontinence typically improves following a thorough bowel cleanout, and defecation sensation and rectal muscle tone often return to normal within several months if the bowels remain clean (van Dijk, Benninga, Grootenhuis, Nieuwenhuizen, & Last, 2007). Approximately 45–70% of youth with chronic constipation and encopresis develop abnormal defecation dynamics, including paradoxical contraction

of the external anal sphincter (EAS) muscle (Loening-Baucke & Cruikshank, 1986; Van der Plas et al., 1996). Paradoxical contraction, or failure to relax the EAS, is a conditioned response likely stemming from early painful defecation experiences, which ultimately contributes to ongoing constipation (McGrath, Mellon, & Murphy, 2000).

Limited research exists on the psychosocial correlates of chronic constipation and encopresis. In fact, there is only one published screening measure to date, the Virginia Encopresis–Constipation Apperception Test (Cox et al., 2003). Parental distress associated with the chronicity of a child's incontinence is commonly reported in clinical settings. A child's dishonesty about soiling, and the parental burden of frequently laundering or disposing of soiled clothing, serve as added stressors (Cox et al., 2003). In fact, many parents attribute the ongoing incontinence to laziness, carelessness, or willfulness on the child's part (Fishman, Rappaport, Schonwald, & Nurko, 2003). Parents, upon learning about the underlying physiological components of the condition, may also experience feelings of guilt for taking an authoritarian or punitive approach with the child (Campbell et al., 2009). For older children, psychosocial consequences often involve being teased by peers (e.g., labeled as "dirty" or "stinky"), which can persist even after the fecal incontinence resolves (Shepard et al., 2014). Ongoing teasing and peer rejection may result in social isolation, poor self-esteem, decreased academic achievement, anger, or continued fecal soiling as a result of learned helplessness (Har & Croffie, 2010).

Empirically Based Treatment Approaches

Medical Interventions

Given the physiological components of the condition, medical interventions are often the first-line treatments for children with chronic constipation and encopresis. Core components of medical intervention include education, disimpaction of the colon, and maintenance laxative therapy (Baker et al., 1999). Educating families at the outset of treatment is crucial, particularly regarding the physiological nature of the condition and to dispel any parental misconceptions about the deliberate nature of the incontinence (Shepard et al., 2014). Given the high comorbidity of chronic constipation and encopresis, medical treatment generally begins with colonic disimpaction, either via enemas or high-dose oral laxatives, and continues with prolonged laxation to promote daily, soft bowel movements to prevent future reimpaction (Borowitz et al., 2003; van Dijk et al., 2007). Efficacy of laxative therapy alone is difficult to establish, as the majority of studies combine the use of laxatives with behavioral interventions, and most research focuses on youth who have not responded to medication alone.

Behavioral and Psychological Interventions

It is common for medical practitioners to incorporate straightforward behavioral strategies (e.g., scheduled toilet sittings) in a child's treatment plan (Sutphen, Borowitz, Hutchison, & Cox, 1995). In cases where these strategies are of limited benefit, a referral is then made to a pediatric psychologist for implementation of more intensive behavioral management, such as positive reinforcement, exposure, and continued skills building (e.g., scheduled toilet sittings, instruction in defecation dynamics). These strategies aim to decrease fecal accidents, improve adherence, establish regular bowel habits,

and resolve fears about toileting (Borowitz et al., 2003; Campbell et al., 2009). Because of the negative psychosocial impact and learned helplessness that youth with encopresis experience, it is important for the pediatric psychologist to utilize an empathic, empowering approach, in which even small gains are reinforced. Data on efficacy vary, but overall, combined medical–behavioral interventions, with and without dietary recommendations, appear to be the most promising interventions to date (see Brazzelli & Griffiths, 2007; McGrath et al., 2000).

Enhanced toilet training (ETT), a combined medical–behavioral approach, has demonstrated efficacy in the treatment of encopresis. ETT incorporates the following strategies: skills building, positive reinforcement of self-initiated toileting and lack of fecal accidents, instruction to parents and child about the physiology of overflow incontinence, training and modeling of appropriate defecation dynamics, and exercises promoting the child's ability to control the EAS muscle (Borowitz et al., 2003). There is evidence that ETT is more effective than medication management alone, as ETT demonstrated significantly greater reduction in symptoms, required significantly fewer treatment sessions, and utilized lower daily doses of maintenance laxatives, with gains maintained up to 12 months following treatment (Cox, Sutphen, Ling, Quillian, & Borowitz, 1996; Borowitz et al., 2003). ETT was recently adapted into an internet-based program, entitled "U Can Poop Too," to promote increased access for children with encopresis and their parents (Ritterband et al., 2003). Recent randomized controlled trials indicate that it is a promising method for the delivery of enhanced behavioral treatment of encopresis, with evidence that children experience significantly fewer fecal accidents up to 1 year postintervention than children receiving routine care do (Ritterband et al., 2003, 2013).

Biofeedback has also been used in the treatment of constipation and abnormal defecation dynamics, though it is not used as widely as other approaches. Biofeedback utilizes electromyographic monitoring to instruct the child how to relax the EAS during straining (Borowitz et al., 2003). Early studies have demonstrated some benefits in decreasing paradoxical contraction of the EAS; however, given the multicomponent nature of outcome studies, its independent effects remain unclear and indicate that its use has not added a significant benefit to other medical–behavioral interventions (Cox et al., 1994; Cox, Sutphen, Borowitz, Kovatchev, & Ling, 1998).

FUTURE DIRECTIONS

Increased involvement of pediatric psychologists in the evaluation and treatment of elimination disorders has helped to advance our knowledge of these conditions and to make clinically meaningful strides in treatment. Despite these useful contributions, the existing body of research continues to have limitations. Specifically, some studies utilize diagnostic criteria that are poorly defined or are too restrictive, resulting in small sample sizes and the possible exclusion of children who may otherwise benefit from treatment (von Gontard, 2013). Moreover, in the case of encopresis, intervention studies often do not parse out the subtypes (i.e., encopresis with and without constipation and overflow incontinence), which undoubtedly affects conclusions about efficacy and clinical implications (McGrath et al., 2000). In addition, future studies would benefit from more clearly defined outcome descriptors (e.g., cure rate vs. success rate), in order to identify treatment efficacy more accurately.

It is apparent that multicomponent interventions for both enuresis and encopresis are effective, but the degree to which they are effective is unclear, due to difficulty in identifying the specific treatment components responsible for symptom improvement. A noted exception exists in the enuresis literature, where there is ample evidence to support the efficacy of the urine alarm, an integral component of combined treatment packages. Many of the multicomponent interventions, while studied extensively in some cases, have been conducted in the context of one research laboratory and need to be systematically replicated on a larger scale, including across various investigators. Examples of these interventions include FSHT in enuresis treatment and ETT in encopresis treatment. Likewise, outcome research has largely used convenience samples, specifically those made up of youth for whom medical intervention has failed and who require more intensive behavioral treatment (Stark, 2000).

It is not surprising that, given the physiological concomitants of elimination disorders, medical management is often the first-line treatment approach taken by physicians and medical practitioners. However, pediatric psychologists can continue to foster interdisciplinary relationships and help to educate colleagues about the existing evidence for efficacious and "probably efficacious" (see Chambless & Ollendick, 2001) psychobehavioral interventions in an effort to facilitate more widespread dissemination of these treatments. In addition to professional collaboration and education, some behaviorally based interventions have been adapted into internet-based programs to make treatment more widely available to families that might otherwise not be able to access them (Ritterband et al., 2013). In addition to larger-scale dissemination, internet-based programs have the potential for cost savings, underscoring the significance of future feasibility trials.

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CHAPTER 35

Pediatric Sleep

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Across development, children and adolescents spend an average of 40% of their time sleeping (Mindell & Owens, 2015). When children and adolescents do not obtain sufficient sleep, there are numerous consequences, affecting growth, development, cognitive functioning, performance, health, mood, and family functioning (Beebe, 2011). Sleep problems are common even in healthy, typically developing children, with 25–40% experiencing some type of sleep problem (Mindell & Owens, 2015). Furthermore, disrupted sleep can often be associated with physical or psychiatric illness. This chapter reviews normal sleep during development; evaluation for sleep problems; common pediatric sleep disorders and associated treatment approaches; and special issues related to sleep in children and adolescents with medical or psychiatric issues.

NORMAL SLEEP IN CHILDREN AND ADOLESCENTS

The amount and timing of sleep change over the developmental lifespan, especially for children and adolescents. It is important for all clinicians to consider how much sleep a child needs versus how much he or she is currently obtaining. Insufficient sleep can contribute to poor emotion regulation, negative mood, increased behavior problems, and worse cognitive performance (Mindell & Owens, 2015). Even mild sleep deprivation (e.g., 1 hour per night for 1 week) may cause clinically significant impairment (Beebe, 2011). Similarly, extending sleep by small amounts (e.g., 30 minutes) can yield benefits such as improved mood and decreased impulsivity (Gruber, Cassoff, Frenette, Wiebe, & Carrier, 2012). Table 35.1 provides a basic overview of typical sleep duration, sleep characteristics, and recommended guidance for families across age groups. While the

guidelines are appropriate for most youth, it is important to note individual variability in sleep need, with the degree of normative variability decreasing across development (Galland, Taylor, Elder, & Herbison, 2012).

TABLE 35.1. Normal Sleep by Age

Age group	Recommended sleep duration	Sleep characteristics	Anticipatory guidance
Newborns (0–3 months)	12–17 hours	• Short sleep periods (45 minutes–3 hours) • Little differentiation between night and day	• Attention to maternal sleep needs • Importance of safe sleep practices (e.g., placing infant on back to sleep; room sharing but *not* bed sharing)
Infants (4–11 months)	12–15 hours	• Sleep consolidates, with longer stretches at night (8–10 hours) and two to three naps per day • Majority of infants are sleeping through the night by 9 months • Healthy infants generally do not require night feedings after 6 months of age	• Introducing a consistent bedtime routine • Putting infant down drowsy but awake
Toddlers (1–2 years)	12–14 hours	• Transition from two naps to one nap between 12 and 18 months • 25–30% of toddlers have sleep problems, often related to bedtime struggles and night wakings	• Delaying transition from crib to bed (preferably not before the age of 3 years)
Preschoolers (3–5 years)	11–13 hours	• Cessation of naps between ages 3 and 5, though 25% of 5-year-olds continue to nap • Obstructive sleep apnea (OSA) and parasomnias peak in this age group • Nighttime fears and bedtime struggles common	• Setting firm limits around bedtime • Importance of consistent bedtime routine
School-age children (6–12 years)	10–11 hours	• Other activities (e.g., schoolwork, sports, electronic media use) increasingly compete with sleep time • Fear and worries may interfere with sleep onset • Parents less involved with sleep routines	• Assessing for daytime sleepiness, which indicates insufficient or disturbed sleep • Avoiding caffeinated beverages in the afternoon and evening
Adolescents (13–18 years)	8.5–9.5 hours	• Continue to need more sleep than adults • Normative circadian delay in sleep timing • Early school start times make it difficult to obtain sufficient sleep	• Prioritizing a regular bedtime that allows sufficient sleep • Avoiding significant weekend oversleep • Emphasis on dangers of drowsy driving

EVALUATION OF SLEEP PROBLEMS

Sleep History

Although parents are the primary reporters of sleep problems in young children, it is important to interview school-age children and adolescents directly, as parents may not be aware of all relevant factors. A comprehensive sleep history should include multiple components, which are reviewed below.

Bedtime Routine

Along with the actual time a child goes to bed (including weekdays, weekends, and school breaks), questions should also focus on bedtime resistance and how parents respond to these behaviors; the amount of time it takes the child to fall asleep (sleep onset latency); and whether the child requires any sleep onset association (e.g., parental presence, television turned on) to fall asleep. A sleep onset latency of greater than 30 minutes is generally considered problematic.

Sleep Environment

It is important to find out where a child falls asleep (e.g., own room, parents' bedroom), as well as information about the room conditions. Bedrooms ideally should be cool, dark, quiet, and technology-free (e.g., no smartphones or television).

Events during the night

Information about what happens while the child is sleeping includes the timing, frequency, and duration of night wakings (and parental response); symptoms of sleep-disordered breathing (e.g., snoring, pauses in breathing); presence of parasomnias (e.g., sleepwalking); and whether the child has seizures or enuresis.

Daytime

Questions about the child's daytime should focus on what time the child wakes in the morning on weekdays, weekends, and school breaks; whether it is difficult to wake the child; the timing and duration of naps; caffeine use, if any; daytime behavior problems; fatigue; and daytime sleepiness. "Fatigue" is defined as lethargy without sleep initiation and often involves subjective perceptions of low energy and motivation, whereas "sleepiness" pertains to an inability to maintain wakefulness during wake episodes and is characterized by unintended drowsiness or sleep lapses (Mindell & Owens, 2015).

Additional Measures of Sleep Problems

To complement the clinical interview, sleep diaries, questionnaires, actigraphy, and polysomnography (PSG) can be used to help with the diagnosis and treatment of sleep disorders. Sleep diaries are daily records of sleep patterns from which several indices can be calculated and used diagnostically. Two weeks of sleep diaries typically provide suf-

ficient information for clinical purposes. Sleep diaries are useful in measuring baseline sleep patterns, evaluating response to treatment, and viewing differential patterns (e.g., comparing weekday to weekend sleep), but completing the diary requires effort and organization on the part of the child and family. A number of questionnaires are also available to assess sleep patterns and daytime sleepiness (for reviews, see Lewandowski, Toliver-Sokol, & Palermo, 2011; Spruyt & Gozal, 2011). Compared to sleep diaries, sleep questionnaires are easy to use and can likewise be used to measure response to treatment, but lack detail about day-to-day variability that can be helpful in treatment planning.

An actigraph is a watch-sized activity monitor worn on the wrist (or ankle in infants) to estimate sleep–wake patterns for extended periods. These devices have been found to provide reliable estimates compared to PSG (Meltzer, Montgomery-Downs, Insana, & Walsh, 2012); their use can supplement the clinical interview, or can provide additional information for family members who may be poor historians. Although actigraphy may provide more objective data compared to sleep diaries or questionnaires, the cost of the devices may be prohibitive for some clinicians.

PSG is an overnight sleep study conducted in a laboratory used to examine sleep stages, breathing quality, periodic limb movements, and arousals during sleep. PSG is considered the "gold standard" for the diagnosis of sleep apnea, but is not indicated for the diagnosis of insomnia. For patients with excessive daytime sleepiness who have a sufficient amount of sleep and no underlying sleep disrupters such as sleep apnea, a multiple-sleep-latency test (MSLT) can be conducted the following day to diagnose narcolepsy or hypersomnia. An MSLT consists of four or five naps spaced 2 hours apart, providing objective information about daytime sleepiness. PSG and MSLT both involve a modified electroencephalogram (EEG), as well as monitors of respiratory effort, ventilation, airflow, heart rate, respiratory rate, oxygen saturation, body movements, snoring, and muscle tone.

PEDIATRIC SLEEP DISORDERS

Sleep disorders vary in their presentation and treatment recommendations, with similar symptoms representative of different disorders (e.g., sleeplessness, daytime sleepiness). Furthermore, there is often a comorbid presentation of physiological sleep disorders (e.g., obstructive sleep apnea) and behavioral sleep issues (e.g., poor sleep habits).

Insomnia

The *International Classification of Sleep Disorders,* third edition (ICSD-3; American Academy of Sleep Medicine [AASM], 2014) includes both chronic insomnia disorder, in which symptoms have been present 3 months or longer, and short-term insomnia disorder, in which symptoms have been present less than 3 months. A patient or caregiver must observe difficulty falling asleep, difficulty staying asleep, waking up earlier than desired, bedtime resistance, or difficulty sleeping without caregiver intervention. In addition, the sleep disturbance must result in some type of daytime impairment and must occur despite adequate opportunity (e.g., enough time) and circumstances (e.g., appro-

priate sleep environment). Whereas the prevalence of short-term insomnia in children is unknown, symptoms suggestive of chronic insomnia disorder are seen in 10–30% of infants, toddlers, and children, and in 10–12% of adolescents (AASM, 2014).

Although the diagnosis of behavioral insomnia of childhood has been removed from ICSD-3, the constructs of "sleep onset association" and "limit-setting difficulties" are still helpful in conceptualizing insomnia in young children. A sleep onset association is a condition required for a child to fall asleep at bedtime and return to sleep following normal nighttime arousals. Children who have developed negative sleep onset associations, such as those who require another person or situation beyond their immediate control in order to fall asleep (e.g., nursing, rocking), often have difficulty returning to sleep without that association, resulting in the need for caregiver intervention throughout the night. Limit-setting difficulties present most often as complaints of bedtime problems, particularly bedtime stalling or resistance.

A number of effective treatment approaches for insomnia in pediatric populations have been identified (Meltzer & Mindell, 2014; Mindell et al., 2006). Behavioral treatments designed to decrease sleep onset associations and improve limit setting, including extinction, modified extinction, and weaning of parental presence, are highly effective in addressing problematic sleep onset associations in infants and toddlers (see Honaker & Meltzer, 2014, for a review of these treatments). In addition, a bedtime routine as a stand-alone intervention has been shown to reduce sleep onset latency, bedtime resistance, and night wakings (Mindell, Telofski, Wiegand, & Kurtz, 2009). Other effective strategies include the utilization of the "bedtime pass," a system designed to reduce a child's bids for parental attention after bedtime (e.g., a drink of water, another hug). Children receive one or more passes that can be exchanged for allowable brief parent interactions (Moore, Friman, Fruzzetti, & MacAleese, 2007). Another intervention is "bedtime fading," which involves temporarily delaying a child's bedtime to coincide more closely with the child's typical time of sleep onset.

It is important to note that there are no medications approved by the U.S. Food and Drug Administration for the treatment of pediatric insomnia. However, cognitive-behavioral treatment for insomnia (CBT-I) has been shown to be highly effective in the treatment of insomnia for adults (Edinger & Means, 2005), and superior to medications in the long term (National Institutes of Health, 2005). There is also limited but growing evidence to support the use of CBT-I for adolescents (e.g., de Bruin, Oort, Bogels, & Meijer, 2014; Paine & Gradisar, 2011). Different components of CBT-I have been evaluated independently and in combination (Morgenthaler et al., 2006). Sleep hygiene, the only component that is not effective as an independent intervention, involves patient instructions in regard to health practices (e.g., exercise, caffeine) and environmental factors (e.g., light, temperature) that may affect sleep. Stimulus control therapy involves strategies to reassociate the bed with sleep (e.g., using the bed for sleep only). With sleep restriction therapy, time in bed is limited to more closely reflect the amount of time the individual is sleeping. Cognitive therapy is indicated for patients with maladaptive beliefs and attitudes about sleep and insomnia, and involves challenging these beliefs. Finally, relaxation training is indicated and effective in reducing somatic and cognitive presleep arousal that interferes with sleep. For detailed information on implementing each of the previously described behavioral sleep treatments, see Meltzer and Crabtree (2015) or Perlis, Aloia, and Kuhn (2011).

Delayed Sleep–Wake Phase Disorder

Delayed sleep–wake phase disorder (DSWPD) is a type of circadian rhythm sleep–wake disorder seen primarily in adolescents, although it also can be diagnosed in children. DSWPD can be conceptualized as a misalignment between an individual's delayed endogenous circadian rhythm, which encourages a late bedtime and rise time, and the external environment, which often necessitates an early rise time for school. The presenting complaint for DSWPD is typically difficulty falling asleep before the early hours of the morning, combined with difficulty waking for school. The diagnostic criteria for DSWPD also include a 3-month duration of symptoms; improved sleep quality and duration when individuals sleep on a preferred delayed schedule; and sleep log or actigraphy monitoring showing a habitual delay (AASM, 2014). A delay in the circadian timing system is normative in adolescence, with a delay in melatonin and body temperature systems coinciding with pubertal development (Carskadon, Wolfson, Acebo, Tzischinsky, & Seifer, 1998). However, in DSWPD the delay is usually more than 2 hours relative to conventional or socially acceptable sleep onset. A feature distinguishing between DSWPD and insomnia is that an adolescent with DSWPD will have no problem falling asleep at the delayed hour, while a patient with insomnia is likely to have difficulty falling asleep regardless of his or her bedtime.

Behavioral recommendations for DSWPD include avoiding electronic screen exposure at night, not napping, and avoiding significant weekend oversleep (e.g., waking no more than 1–2 hours later on weekends). Chronotherapy is a common treatment for DSWPD, and involves delaying the sleep–wake schedule by 3 hours per day until the desired sleep schedule is reached. The reader is referred to Wyatt (2011) or Meltzer and Crabtree (2015) for more details. For treatment to be successful, adolescents must be highly motivated to maintain a consistent sleep schedule seven nights a week. Bright light therapy and melatonin have also been recommended as adjuncts to treatment for DSWPD (Morgenthaler et al., 2007).

Sleep Terrors, Nightmares, and Other Parasomnias

"Parasomnias" are undesirable events or experiences that may occur during sleep or transitions to and from sleep. Those that occur during non-rapid-eye-movement (NREM) sleep include confusional arousals, sleep terrors, and sleepwalking. Common features of NREM-related parasomnias include (1) the timing of the events (typically the first third of the night, when slow-wave sleep is the predominant sleep stage); (2) the appearance of being awake, but typically being nonresponsive; (3) the length of the events (typically 5–15 minutes, but they may last longer); (4) ending suddenly with a rapid return to sleep; and (5) retrograde amnesia, with the child or adolescent having no memory of the event the following morning (AASM, 2014). Confusional arousals often involve sitting up in bed and appearing confused, though remaining in bed. If the individual leaves the bed and walks or runs, the parasomnia has progressed to sleepwalking. With sleep terrors, an individual will appear extremely distressed and fearful, and is nonresponsive to a caregiver's attempts to provide comfort. Parasomnias occur regularly in approximately 3% of children, with 15–40% of children sleepwalking on at least one occasion (Mindell & Owens, 2015). Most children outgrow sleep terrors

in adolescence, whereas sleepwalking is more likely to continue for 5–10 years or even persist into adulthood (Mindell & Owens, 2015).

The most common triggers for parasomnias are insufficient or poor-quality sleep (e.g., related to sleep disorders such as sleep apnea or illness). There appears to be a strong genetic component, with many patients having an identifiable first-degree relative with a history of parasomnias (Mason & Pack, 2007). Treatment includes increasing sleep time (as little as 15–30 minutes per night can be sufficient); maintaining safety (e.g., a system to alert family members when the child sleepwalks); providing reassurance that these events do not indicate underlying psychopathology; and instructing parents not to wake the patient, as this can prolong the duration of the parasomnia event (Mindell & Owens, 2015).

Though often confused with sleep terrors, nightmares are a distinct problem. Nightmares occur during REM sleep (primarily during the last third of the night); they are remembered by the individual upon awakening; and more frequent and severe episodes may be associated with emotional disturbance, such as trauma or anxiety (AASM, 2014). While 60–75% of children will experience occasional nightmares, frequent, recurrent nightmares are much less common, occurring in an estimated 1–5% of children (AASM, 2014). A diagnosis of nightmare disorder is appropriate only when nightmares cause persistent distress or impairment for the patient or caregiver. As with NREM parasomnias, increasing total sleep time can be beneficial, as sleep deprivation can result in increased proportion of REM sleep. Imagery rehearsal therapy, a technique that involves rescripting recurrent nightmares (Krakow & Zadra, 2006), is also indicated for persistent nightmares.

Other Sleep Disorders

In assessing symptoms such as daytime sleepiness or difficulty initiating or maintaining sleep, a number of additional sleep disorders should be considered. Obstructive sleep apnea (OSA) occurs in an estimated 1–3% of children (Marcus et al., 2012). In young children, the most common causes of OSA are enlarged tonsils and adenoids, which result in airway obstruction during sleep. The American Academy of Pediatrics recommends that all children with regular snoring be further evaluated for OSA (Marcus et al., 2012).

Narcolepsy is a disorder that presents as excessive daytime sleepiness. Prevalence rates in children and adolescents are unknown but thought to be extremely low. Onset typically occurs between ages 10 and 25 years (AASM, 2014). Along with excessive daytime sleepiness, symptoms of narcolepsy may include cataplexy (a weakening of muscle tone following a strong emotion), sleep paralysis, and hallucinations at sleep onset/offset. Narcolepsy is diagnosed by overnight PSG (to rule out other sleep disorders), followed by an MSLT. Treatment for narcolepsy includes the use of stimulant medications, regular sleep–wake schedules, and scheduled daytime naps.

Restless-legs syndrome (RLS) or Willis–Ekbom disease (WED) is a clinical diagnosis in which a patient reports an urge to move the legs, usually accompanied by uncomfortable sensations (e.g., "creepy-crawly" feelings, tingling). This discomfort is at least partially relieved by movement and is worse in the evening (AASM, 2014). In children and adolescents, the most common cause of RLS/WED is low ferritin, with treatment focusing on supplemental iron (Durmer & Quraishi, 2011). Pediatric prevalence rates are estimated at 2–4% (AASM, 2014). For additional information about symptoms,

etiology, and treatment approaches for OSA, narcolepsy, and RLS/WED, see Mindell and Owens (2015).

MEDICAL AND PSYCHIATRIC ISSUES AND SLEEP

Although sleep problems are common for all children, sleep disturbances are even more likely to occur with comorbid medical illnesses or psychiatric disorders (Lewandowski, Ward, & Palermo, 2011). Studies evaluating behavioral sleep intervention in children and adolescents with medical and psychiatric conditions are extremely limited (Meltzer & Mindell, 2014); however, evidence from adult populations, as well as a few studies on treatment for children with autism spectrum disorder (e.g., Malow et al., 2014) and adolescents with pain (e.g., Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009), suggest that the same behavioral treatment approaches may be effective. Much remains to be learned about the relationship of sleep and these disorders, as well as the efficacy of treatment approaches, but studies have begun to document the frequency and consequences of sleep disruptions in children with chronic physical or mental illness and their families.

Medical Issues

Pain

There is a complex bidirectional relationship between sleep and pain, with pain predicting sleep disruption, and poor or insufficient sleep predicting pain severity (Valrie, Bromberg, Palermo, & Schanberg, 2013). Sleep disturbances have been reported in children with juvenile rheumatoid arthritis (Butbul et al., 2011); adolescents with musculoskeletal pain (Meltzer, Mindell, & Logan, 2005); and youth with migraine headaches (Bellini, Panunzi, Bruni, & Guidetti, 2013), sickle cell disease (Graves & Jacob, 2014), and functional abdominal pain (Schurman et al., 2012). Across studies, patients often report short sleep duration, frequent night wakings, and poor sleep quality (Lewandowski et al., 2011).

Asthma

Studies using both objective measures (PSG and actigraphy) and subjective measures of sleep (sleep diaries) have found that children with asthma have more night wakings and poorer sleep quality than healthy controls do (Stores, Ellis, Wiggs, Crawford, & Thomson, 1998). Adolescents with severe asthma are more likely to report poor sleep practices, insomnia symptoms, and insufficient sleep (Meltzer, Ullrich, & Szefler, 2014). Several consequences of these sleep disturbances have been found, including asthma exacerbation (Strunk, Sternberg, Bacharier, & Szefler, 2002) and worse daytime functioning (Stores et al., 1998).

Traumatic Brain Injury

Most studies examining sleep in children and adolescents with traumatic brain injury have found higher rates of sleep disturbance than in healthy controls or those with

orthopedic injuries, with highest prevalence rates typically found during the acute postinjury time period (Beebe et al., 2007). In addition, poor sleep predicted poorer functional outcomes in areas such as communication and activity (Tham et al., 2012).

Hospitalization

Sleep disruptions during hospitalization are commonly accepted. However, given that sleep is related to health and healing, sleep during hospitalization has begun to receive more attention in recent years. Studies of sleep patterns in hospitalized youth have found significant sleep disruptions (Herbert et al., 2014; Meltzer, Davis, & Mindell, 2012). Further, a recent pilot randomized controlled trial showed improved sleep duration and continuity in hospitalized children who received a behavioral intervention focusing on sleep education and relaxation (Papaconstantinou, Hodnett, & Stremler, 2016).

Injury

An underreported consequence of insufficient sleep in children is unintentional injury. Several studies have found increased rates of injuries as a result of sleep deprivation in young (Owens, Fernando, & McGuinn, 2005) and school-age (Rafii, Oskouie, & Shoghi, 2013) children. In a longitudinal study using a nationally representative sample, even mild sleep loss was found to predict increased risk of injuries after the researchers controlled for a number of external covariates (e.g., maternal depression, socioeconomic status, externalizing behaviors; Schwebel & Brezausek, 2008). In adolescents, poor sleep has also been related to risk-taking behaviors (O'Brien & Mindell, 2005), and sleep restriction resulted in impaired pedestrian safety in a virtual environment (Davis, Avis, & Schwebel, 2013).

Other Illnesses/Conditions

Several other illnesses and conditions have also recently received increased attention in their relation to sleep. These include eczema (Silverberg & Simpson, 2013), HIV infection (Foster et al., 2012), cystic fibrosis (Meltzer & Beck, 2012), cancer (Crabtree et al., 2015), fetal alcohol spectrum disorders (Chen, Olson, Picciano, Starr, & Owens, 2012), cerebral palsy (Simard-Tremblay, Constantin, Gruber, Brouillette, & Shevell, 2011), feeding disorders (Tauman et al., 2011), Type 1 diabetes (Monaghan, Herbert, Cogen, & Streisand, 2012), and epilepsy (Larson et al., 2012).

Psychiatric Issues

Attention-Deficit/Hyperactivity Disorder

Sleep problems are commonly reported in children with attention-deficit/hyperactivity disorder (ADHD), including difficulties falling asleep, prolonged or frequent night wakings, and early morning awakening. Studies have shown that sleep patterns and sleep quality are more disrupted for both medicated and unmedicated children with ADHD than for healthy controls (Moreau, Rouleau, & Morin, 2014). Interestingly, studies using objective measures of sleep disturbance have not consistently shown more sleep

disruption (Yoon, Jain, & Shapiro, 2012). However, the fact that children with ADHD have more sleep disturbances may in part be attributable to the same arousal mechanism as the one involved in the ADHD (Corkum, Moldofsky, Hogg-Johnson, Humphries, & Tannock, 1999). Conversely, insufficient or disrupted sleep can contribute to an increase in ADHD symptoms. Studies also indicate that medication for ADHD can disrupt sleep (Corkum, Panton, Ironside, Macpherson, & Williams, 2008). Furthermore, a number of children with ADHD may have undiagnosed underlying sleep disorders, including OSA and RLS/WED.

Autism Spectrum Disorder

Overall, 44–83% of children with autism spectrum disorder have been reported to have sleep disruptions, including prolonged sleep onset latency, multiple or prolonged night wakings, and early morning awakenings (Miano & Ferri, 2010; Wiggs & Stores, 2004). Although the cause of sleep problems in this group has yet to be determined, suggested etiologies include poor stimulation regulation, abnormal melatonin production, brain pathology, anxiety, and/or abnormal sleep EEG (Wasdell et al., 2008). Questions also remain about the impact of these sleep disruptions on the children's daytime behavior (including stereotypic symptoms of autism and related disorders), as well as on parents' sleep and daytime functioning (Meltzer, 2008; Schreck, Mulick, & Smith, 2004). Effective treatment approaches include parental education about sleep and behavioral intervention approaches (Malow et al., 2014) and the use of exogenous melatonin (Malow et al., 2012).

Depression

The prevalence of sleep problems in children and adolescents with depression is between 66 and 90% (Ivanenko, Crabtree, & Gozal, 2005), and higher rates of sleep disruption have also been found in studies utilizing PSG (Forbes et al., 2008). The relationship between sleep and depression is complex and often bidirectional (Harvey, Alfano, & Clarke, 2013). That is, sleep disturbances (i.e., insomnia and hypersomnia) are reported as symptoms of depression in children and adolescents (Liu et al., 2007), in addition to exacerbating the other symptoms of depression (Breslau, Roth, Rosenthal, & Andreski, 1996). It has been suggested that sleep disruptions may be prodromal symptoms of depression, with multiple studies demonstrating that children and adolescents with sleep disturbances are at an increased risk for developing later depression (Harvey et al., 2013). The medications children and adolescents take for depression also need to be considered, as some antidepressants can cause either insomnia or hypersomnia (Ivanenko et al., 2005).

Anxiety

Sleep disturbances and anxiety are also interrelated, with sleep problems both symptoms of and functional impairments that result from anxiety disorders (Chorney, Detweiler, Morris, & Kuhn, 2008). A recent study found that 90% of youth with anxiety disorders reported at least one sleep-related problem, and 82% experienced two or more (Chase & Pincus, 2011). Children who are anxious during the day may have difficulties

initiating sleep due to worries or fears, and the resulting shortened sleep can exacerbate their symptoms of anxiety.

SUMMARY

Sleep problems in children and adolescents are common and represent a wide range of disorders. It is essential for all pediatric psychologists to understand normal sleep across development and to inquire about sleep. Further evaluation by a sleep specialist may be needed to rule out underlying sleep disorders (e.g., OSA). In addition, there is a complex and bidirectional relationship between sleep and both physical and psychiatric illnesses. Pediatric psychologists need to recognize how an illness or disorder can result in sleep problems, as well as how sleep disturbances can exacerbate an illness or disorder. Finally, behavioral interventions are highly efficacious for the treatment of behaviorally based sleep disorders. Pediatric psychologists are uniquely positioned to identify and provide treatment for sleep issues in children and adolescents.

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CHAPTER 36

Autism Spectrum Disorder and Developmental Disabilities

Jonathan M. Campbell, Rachel K. Hammond, and Kirsten A. Scheil

In this chapter, we introduce defining symptoms, associated features, etiological considerations, diagnosis and assessment, and intervention guidelines for autism spectrum disorder (ASD), developmental disabilities (DDs), and intellectual disability (ID). The diagnostic definition of ASD has recently changed, and our review of ASD is based largely on literature using prior definitions of autism. Our discussion of DDs and ID highlights common conditions associated with ID as opposed to DDs in general.

AUTISM SPECTRUM DISORDER

Symptoms, Diagnosis, and Scope

ASD is currently conceptualized as a neurodevelopmental disorder defined by (1) social-communicative (SC) impairments, and (2) impairing restrictive/repetitive behaviors or interests (RRBs); impairments in both domains appear early in development. ASD is estimated to affect 1 in 68 children age 8 years in the United States, with males affected at rates roughly four times greater than females (Centers for Disease Control and Prevention [CDC], 2014). First symptoms are often noted between 12 and 24 months, and typically involve language delay accompanied by lack of social engagement, social responsiveness (e.g., lack of response to name being called), and social interest. During children's early development, caregivers often report concerns that their children may be deaf. Early evidence of RRBs includes unusual toy play (e.g., carrying around parts of toys, lining up toys), repetitive interests (e.g., watching the same video clip over and over), and repetitive movements. Roughly 30% of individuals with ASD experi-

ence developmental regression (i.e., a loss of previously acquired skills, most often language), which often occurs between the ages of 20 and 24 months (Barger, Campbell, & McDonough, 2013). Individuals with ASD show a wide range of abilities across cognitive, language, social, behavioral, and adaptive skills. ASD is considered a lifelong disability without a known "cure"; however, for a minority of children (2–25%), significant improvement occurs, age-appropriate functioning is achieved, and diagnostic criteria for ASD are no longer met (i.e., "optimal outcome"; Fein et al., 2013). Early identification and sustained, programmatic intervention tends to produce more favorable outcomes for individuals with ASD. Due to the various cognitive, language, social, adaptive, and behavioral difficulties associated with ASD, multidisciplinary assessment and intervention services that are tailored to the needs of the individual are recommended (Volkmar et al., 2014).

Individuals with ASD differ widely from one another, such as in degree of interest in social interaction and presence or absence of speech. ASD heterogeneity is perhaps best captured within the domain of intellectual functioning, which can range from ID to superior cognitive ability. Persons with ASD also frequently demonstrate a remarkable range of intraindividual variability. For example, children with ASD can show a combination of well-preserved or age-appropriate abilities in the presence of severe disability. Such discrepancies include "savant" abilities (which occur in roughly 10% of individuals with ASD); these are unusually developed talents in the presence of profound ID (Treffert, 2009).

Diagnostic Standards

Arguably, no revisions to the *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition (DSM-5; American Psychiatric Association, 2013) have generated more controversy than those for autism and related disorders (e.g., Tsai & Ghaziuddin, 2014). Within the DSM-IV text revision (DSM-IV-TR; American Psychiatric Association, 2000), multiple diagnoses, such as autistic disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS), were identified under an umbrella of conditions described as "autism spectrum disorders"; childhood disintegrative disorder and Rett's disorder were delineated as two additional PDDs. All prior PDD diagnoses are collapsed into the larger category of ASD in DSM-5. DSM-5 also features a new diagnostic category, social communication disorder (SCD), included to describe SC impairment in the absence of RRB symptomatology.

Significant revisions for DSM-5 include, among others, (1) symptom numbers and grouping, (2) numbers of symptoms necessary for diagnosis, (3) onset criteria, and (4) modified specific symptom descriptions, among others. Consistent with prior conceptualizations of autism, defining features are SC impairment and impairing RRBs. DSM-IV-TR separated social impairment, communication impairment, and RRBs into three diagnostic symptom groups, the "autism triad"; however, the current definition features only two domains, SC and RRB symptoms, with the DSM-IV-TR communication symptoms now included in the two DSM-5 domains. Diagnostic criteria have been reduced from 12 to 7, with all 3 SC symptoms and at least 2 of 4 RRB symptoms necessary for diagnosis. DSM-5 requires at least 5 of 7 symptoms, versus 6 of 12 required in DSM-IV-TR. The onset criteria for ASD have also been changed to require that symptoms must be present in the early developmental period without specified age of onset, which was

36 months for autistic disorder in DSM-IV-TR. Furthermore, symptom descriptions have been revised to allow for milder manifestations of symptoms to meet criteria.

DSM-5 also includes new specifiers with intent to capture the heterogeneity of ASD. The new specifiers allow for coding, among other things, (1) the presence of a neurobiological condition (e.g., ASD with fragile X syndrome [FXS]); (2) the presence of a cognitive and/or language impairment; and (3) symptom severity across SC and RRB domains (American Psychiatric Association, 2013). Severity codes adopt terminology from ID diagnosis by using levels of support needed for each domain; for example, Level 1 SC symptoms are those "requiring support," and Level 3 RRB symptoms are those "requiring very substantial support" (American Psychiatric Association, 2013). DSM-5 also allows for comorbid diagnosis of attention-deficit/hyperactivity disorder (ADHD)—a practice that was prohibited in the DSM-IV-TR system. At present, it is unclear what impact the DSM-5 revisions will have on the field; however, initial findings suggest that DSM-5 results in a 31% decrease in the number of individuals who met DSM-IV-TR criteria for PDDs, particularly individuals previously diagnosed with PDD-NOS (70% decrease; Kulage, Smaldone, & Cohn, 2014). We expect changes in diagnostic definitions to be a short-term and long-term area of investigation in the field.

Comorbid Conditions

Children with ASD often present with comorbid neurocognitive, psychological, and medical disorders. ID frequently co-occurs with ASD. Historical estimates of ID within ASD ranged between 70 and 80%; however, recent reports reveal much lower rates of ID, with 31% of individuals with ASD having IQs less than 70, 23% having borderline-range IQs (71–85), and 46% having average or above-average IQs (CDC, 2014). Children with ASD frequently show problems with various aspects of attention and executive functioning, such as sustaining attention and organizing tasks. Medical disorders frequently comorbid with ASD include epilepsy (up to 42%); neurocutaneous syndromes, such as tuberous sclerosis and neurofibromatosis (1–4%); and chromosomal disorders, such as FXS (Volkmar et al., 2014). Internalizing disorders co-occur with ASDs, with estimates up to 58% for depressive disorders and 84% for anxiety disorders (Howlin, 2014).

Etiological Considerations

ASD is associated with neurobiological dysfunction; however, the exact nature of the dysfunction has not yet been determined. Genetic liability is a known risk factor for the presence of an ASD; for instance, autism concordance rates for monozygotic twins consistently exceed 75%, and heritability estimates for ASD range between 60 and 90% (Rutter & Thapar, 2014). Researchers have attempted to account for autistic symptomatology via basic neurocognitive deficits such as impaired attention/executive functioning and weak central coherence, among others. Executive functioning appears related to social-cognitive tasks, such as joint attention (e.g., sharing experience), social attribution, and social reasoning tasks, and there is some suggestion that executive functioning impairment may be associated with RRB symptoms.

Neurobiological research has focused on varied brain areas, such as overall brain size, cerebellar anomalies, and brain structures relevant to social cognition. Macroceph-

aly (i.e., enlarged head circumference) is found in roughly 10–30% of older children and adults with autism. Structural magnetic resonance imaging reveals brain overgrowth early in the developmental period, particularly in the temporal lobe (e.g., Hazlett et al., 2011). Early brain overgrowth in autism has been described as "growth without guidance," suggesting that typical patterns of synaptogenesis, neuronal growth, and neuronal differentiation guided by experience and environmental influence are disrupted for young children with ASD. Early overgrowth of white matter may lead to abnormal connectivity, which has been documented for areas important in social cognition via diffusion tensor imaging (Barnea-Goraly et al., 2004).

Environmental variables have also been implicated in the cause of ASD, particularly in light of the growing prevalence of ASD. One study exploring environmental factors implicated the potential role of measles–mumps–rubella (MMR) vaccinations (Wakefield et al., 1998) and thimerosal in particular. The majority of subsequent research has not supported the etiological role of MMR vaccines or thimerosal for ASD, and the professional consensus is that there is no causal link between MMR and ASD (see Hertz-Picciotto, 2011, for a review). Moreover, the Wakefield et al. (1998) paper has been redacted, and authors from the original paper have withdrawn support for its findings. The co-occurrence between MMR vaccination scheduling and onset of autism symptomatology, coupled with more recent research findings, suggests a correlational versus causal relationship. We mention this controversy due to the possibility that parents may inquire about the safety of vaccines.

Evidence-Based Assessment

Due to the fact that parents typically first express concerns about their children's development to pediatricians and other early health care providers, it is important for health care providers to be able to identify concerns and systematically assess children with ASD. The American Academy of Pediatrics outlined recommended procedures for screening, assessment, and diagnosis for ASD, and stated that pediatricians should screen for ASD at 18- and 24-month well-child visits (Johnson & Myers, 2007). The "comprehensive developmental approach" (CDA) serves as a framework for assessing individuals referred for an evaluation due to the presence of ASD-like symptoms (Klin, Saulnier, Tsatsanis, & Volkmar, 2005). The CDA model specifies six principles for assessment: (1) assessment of multiple areas of functioning, (2) adoption of a developmental perspective, (3) emphasis on variability of skills, (4) focus on variability across settings, (5) emphasis on functional adjustment, and (6) need for evaluation of delays and deviance. Given the variability and inconsistency of functioning among children with ASD, the CDA approach is especially useful because it emphasizes a comprehensive assessment of individuals' functioning across multiple settings and contexts. Specifically, the CDA model suggests interpreting individuals' developmental functioning, behavioral adjustment, and functional skills within the context of their individual cognitive development. The CDA model also emphasizes assessment of developmental delays by comparing individual functioning to normative expectations, and identification of deviance in development by documenting any behaviors that are not typical for particular developmental stages (Klin et al., 2005).

Various procedures and measures exist for documenting both delays and deviance

in development across the autism spectrum; however, we believe that clinicians should select measures according to evidence-based assessment (EBA) guidelines (Campbell, Ruble, & Hammond, 2014). EBA guidelines recommend use of tests, methods, and measures that feature strong evidentiary support. It can be difficult to assess, however, whether a measure is empirically sound, since no absolute criteria exist for judging test development, norming, or various types of reliability and validity evidence. In addition, assessment measures have diverse purposes, such as screening, diagnosis, and treatment planning/monitoring, which should be kept in mind when clinicians choose measures to assess children with ASD and other disorders.

Ozonoff, Goodlin-Jones, and Solomon (2005) have recommended a core psychological assessment battery for suspected or confirmed cases of ASD that includes diagnostic assessment as well as cognitive, language, and adaptive behavior assessment. EBA should incorporate multiple informal and formal measures and feature an interdisciplinary approach that includes family involvement and clinician observation (Campbell et al., 2014). Standardized diagnostic instruments, such as the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) and the Autism Diagnostic Interview—Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003), are considered to be the "gold standard" in ASD assessment and diagnosis; the ADOS-2 and ADI-R are especially helpful when used together. The ADOS-2 is a standardized, semistructured observation of communication, social interaction, and play, which can be used for diagnosis from the toddler years through adulthood. The ADI-R is an extensive standardized interview completed with a knowledgeable caregiver to assess individuals' SC behavior, reciprocal social interactions, and RRB symptoms (Rutter et al., 2003). Given the prognostic utility of IQ and language functioning, and the practicalities of adaptive behavior for intervention planning, comprehensive assessment should include evaluation within each domain (Ozonoff et al., 2005). In addition, it is important to involve multiple professionals from various disciplines (such as psychology, medicine, and speech–language pathology) to observe test administration, and to share input when making diagnostic decisions and planning intervention.

Evidence-Based Intervention

Due to the complex presentation of symptoms, individuals and families affected by ASD will interface with various disciplines (such as pediatrics, psychology, psychiatry, and speech–language pathology) and utilize varied systems of care (such as special education services, vocational rehabilitation services, and outpatient clinics). Indeed, due to the language, social, and behavioral features of autism, treatment for ASD will almost invariably involve educational and clinical professionals at some point. Interventions for children with ASD are either "focal" (or "skills-based") or "comprehensive." Focal interventions (FIs) are designed to target specific core symptoms of ASD, such as increasing appropriate toy play, or to target associated features of ASD, such as reducing self-injury. Examples of FIs include using differential reinforcement of alternative behavior to decrease self-injury, or prescribing a selective serotonin reuptake inhibitor (SSRI) to improve mood. Comprehensive intervention (CI) approaches, such as early intensive behavioral intervention, are designed to target a wide range of symptoms and improve the long-term outcomes of children with ASD (Wong et al., 2013).

Psychosocial Approaches to Intervention

Approaches to intervention vary widely and differ along key dimensions, such as target (broad vs. specific symptom change), level of intensity, and adult- versus child-directed delivery of intervention. For CIs, there is general consensus that programming should consist of (1) early and intensive intervention, (2) parent training and support, (3) a curriculum that targets core deficits, (4) ongoing assessment of progress, (5) transition planning, and (6) highly trained staff (National Research Council, 2001). Such variables appear to constitute a set of common factors present in various CIs that benefit young children with autism when the CIs are delivered with high fidelity (Boyd et al., 2014).

Many, if not most, young children with ASD will not have access to CI programming as described above and are likely to receive a patchwork of FIs across various service settings, particularly special education. To date, 27 FI practices have been identified as "evidence-based practices" (EBPs) for targeting a range of outcomes (e.g., social, behavioral, communication) across a range of ages (see Wong et al., 2013, for a comprehensive review). In general, EBPs for ASD are interventions that are generally rooted in basic behavioral techniques (e.g., prompting, reinforcement) and may be combined with other techniques to produce a replicable intervention, such as functional communication training (Wong et al., 2013). Therapeutic approaches employing applied behavior analysis are widely recommended for direct teaching and for managing disruptive behaviors. The field is moving toward improving dissemination of EBPs within various service delivery settings, particularly public schools, which serve as the de facto service providers for many individuals with ASD.

Psychopharmacological Interventions

Myers and Johnson (2007) noted that 45% of children and adolescents and up to 75% of adults with ASD are treated with psychotropic medications. No psychopharmacological interventions have been shown to improve the core SC and RRB symptoms that define ASD; therefore, pharmacotherapy is utilized to manage various concomitant symptoms of ASD, such as attentional difficulties, irritability, aggression, and self-injurious behavior (Scahill, Tillberg, & Martin, 2014). Antipsychotics, SSRIs, mood stabilizers, and stimulants, among other agents, have been evaluated for use with individuals with ASD. Of these, risperidone (Risperdal) and aripiprazole (Abilify) have been approved by the U.S. Food and Drug Administration for use in treatment of irritability and severe tantrum behavior in individuals with ASD (see Volkmar et al., 2014, for a review of randomized controlled trials).

Prognosis and Outcomes

For many adults with ASD, outcomes are frequently categorized as "poor" or "very poor" (up to 48%; Howlin, 2014). For such individuals, SC impairments, residential placement, and few independent adaptive skills define these outcomes. "Good" to "very good" outcomes occur for roughly 20% of adults with autism (Howlin, 2014), and such outcomes are defined by employment, friendship, and independent living. In general, higher cognitive ability during childhood and meaningful speech use by age 5 or 6 years

predict better outcomes (Magiati, Tay, & Howlin, 2014). The number of adult individuals with ASD graduating from special education services has produced a pressing need for successful transition programming—a need that will continue to grow in the future.

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Symptoms, Diagnosis, and Scope

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law No. 106-402, 2000) defines a DD as a severe, chronic disability that (1) is attributable to a mental or physical impairment or combination of mental and physical impairments; (2) is present prior to 22 years of age; (3) is likely to continue indefinitely; (4) results in substantial restrictions in several life activities, such as self-care, learning, daily living skills, and economic sufficiency; and (5) reflects the person's need for a combination and sequence of lifelong interdisciplinary care, treatment, or support services. Many types of DDs exist, such as ASD, cerebral palsy, Down syndrome (DS), fetal alcohol syndrome (FAS), FXS, and ID. Due to the fact that ID is a common DD, we highlight ID in this chapter. The American Association on Intellectual and Developmental Disabilities (AAIDD) guidelines (Schalock et al., 2010) and DSM-5 (American Psychiatric Association, 2013) are commonly used to define and diagnosis ID. It is important, however, for pediatric psychologists to be aware that public schools utilize educational diagnostic standards that differ from medical diagnostic standards.

Diagnostic Considerations

AAIDD GUIDELINES

In the newest edition of its guidelines, the AAIDD defines ID as "characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills" (Schalock et al., 2010, p. 1). The AAIDD also specifies that the disability must be present before the age of 18. In defining ID, the AAIDD manual outlines five assumptions: (1) Limitations in intellectual and adaptive functioning should be considered within environmental contexts; (2) assessment should focus on cultural and linguistic diversity factors; (3) individual limitations often coexist with strengths; (4) an important purpose of describing limitations is developing a profile of needed supports; and (5) individualized, sustained supports have the ability to generally improve the life functioning of individuals with ID.

Consistent with the 1992 and 2002 AAIDD definitions, the 2010 manual describes a systematic approach to diagnosing and classifying ID based on multidimensional and etiological frameworks, which recognize various biological and social factors related to ID and highlight the interaction of individuals with ID within their environments. The 2010 AAIDD manual also emphasizes the view that ID is not a static disability, but a condition in which symptoms can improve with individualized, sustained supports. Moreover, the 2010 manual departs from previous versions in that it provides associated dimensions (e.g., intellectual ability, adaptive behavior, health, participation, and context), which allow clinicians to focus on the key role that supports play in helping individuals lead more successful, satisfying lives (Schalock et al., 2010). Taken together,

the changes align with a functional classification system that allows clinicians to assess individuals within an ecological framework, in order to develop individualized systems of supports based on their unique needs. Lastly, the 2010 manual expands on the importance of using clinical judgment in assessing for ID and designing individualized supports.

DSM–5 STANDARDS

DSM-5 incorporates suggestions provided by AAIDD in defining ID; therefore, it is compatible with the 2010 AAIDD system (American Psychiatric Association, 2013). In addition, DSM-5 adopted a change in terminology by retiring the term "mental retardation," which was used in DSM-IV-TR. DSM-5 characterizes ID as a DD with impairments in cognitive and adaptive functioning across several domains (e.g., social, practical; see American Psychiatric Association, 2013, for specific criteria). Adaptive functioning refers to how well individuals participate in everyday tasks and challenges within conceptual, social, and practical domains. Intellectual functioning is measured by assessing an individual's performance on intelligence tests; however, DSM-5 now emphasizes that additional information on intellectual functioning beyond IQ tests is needed.

Adaptive functioning determines the level of supports required; therefore, DSM-5 defines levels of ID severity (mild, moderate, severe, profound), based on individuals' ability to function within conceptual, social, and practical domains. The classification based on adaptive functioning is new to DSM-5, as DSM-IV-TR described individuals' level of impairment based on IQ test scores alone. Both the DSM-5 and AAIDD standards mention that interventions have the ability to improve adaptive functioning over the course of an individual's lifetime.

Prevalence Rates

DDs affect roughly 14% of all children, and, as in ASD, boys are more likely than girls to be affected (Society of Pediatric Psychology, 2014). Estimates of the prevalence of ID range between 1 and 2% of the population (Leonard & Wen, 2002). Average prevalence rates for severe ID (IQ < 35–50) range from 1.4 to 3.8 per 1,000, and those for mild ID (IQ = 50–70) from 5.4 to 10.6 per 1,000, based on previous classifications of ID using IQ test scores (Leonard & Wen, 2002). Males are more frequently diagnosed with ID than females, at rates of 1.4–1.7:1 in the severe range and 1.6–1.9:1 in the mild range (Leonard & Wen, 2002).

Heterogeneity

Although all individuals with ID must show delayed intellectual and adaptive functioning, individuals with ID are a heterogeneous group, and ID has multiple causes (American Psychiatric Association, 2013). By definition, onset of ID occurs during the developmental period, but age of onset and characteristics expressed at onset depend on a variety of etiological factors and severity of brain dysfunction. In some cases, ID is associated with genetic syndromes (e.g., DS); other cases of ID occur after experiences such as head injury, birth trauma, or sudden illness (e.g., meningitis). By considering

the heterogeneity within ID, practitioners can design more individualized interventions tailored to individuals' unique needs.

Comorbid Conditions

Comorbid conditions occur with ID and other DDs in various areas, including medical disorders; behavioral disorders, such as ADHD and oppositional defiant disorder (ODD); and psychological disorders, such as anxiety and depression (e.g., American Academy of Child and Adolescent Psychiatry [AACAP], 1999). In one review, Oeseburg, Dijkstra, Groothoff, Reijneveld, and Jansen (2011) found that the conditions most commonly co-occurring with ID were epilepsy (22.0%), cerebral palsy (19.8%), anxiety disorders (17%), ODD (12.4%), DS (11%), autism (10.1%), and ADHD (9.5%). In their review of psychological comorbidities, Einfeld, Ellis, and Emerson (2011) found variation in reported rates of disorders ranging from 30 to 50%, and in relative risk from 2.8 to 4.5, for presence of a psychological disorder in individuals with ID versus individuals without ID.

Pediatric psychologists should be cognizant of cognitive, learning, and behavioral challenges presented by children with ID and other DDs in the educational setting. Children with ID will typically possess deficits in abstract reasoning and verbal comprehension—both components of cognition that become increasingly important in the school setting. Individuals with ID thus will often experience difficulties with complex academic concepts, such as synthesizing, summarizing, and interpreting information. In contrast, rote academic skills, such as sight word reading and math calculation (e.g., addition, multiplication facts), are more readily acquired by children with ID. Families often will need support to contribute to and collaborate with school professionals to support individualized education programs for students. Children with other DDs may have more heterogeneous academic profiles. For example, some individuals may need limited academic intervention but significant social and behavioral support, while others may need significant accommodations associated with health concerns or physical mobility limitations.

Etiological Considerations

Parritz and Troy (2014) note that "organic" causes (i.e., causes due to specific physiological or physical origin), and "nonorganic" causes (i.e., causes due to familial or cultural/familial origin), are the most common differential factors in the etiology for ID. Organic causes are associated with more severe levels of ID, and have been reported across all socioeconomic backgrounds (Parritz & Troy, 2014). Within the organic causes are genetic or other congenital conditions associated with both ID and other DDs; some of the most commonly noted include FXS, DS, and fetal alcohol spectrum disorder (FASD). For children with ID with severe impairments, Einfeld and Emerson (2008) have reported that chromosomal abnormalities are found in 20%, while environmental causes are found for 8% of such individuals. For many individuals with ID (22–77%), however, no etiology is identified, particularly for individuals functioning in the range of mild disability (see Leonard & Wen, 2002, for review).

DS is the most common known cause of ID (Geelhoed, Bebbington, Bower, Deshpande, & Leonard, 2011) and the most commonly diagnosed chromosomal condition in

the United States, occurring in roughly 1 out of every 700 live births (CDC, 2015). DS results from trisomy of all or part of chromosome 21. Three types of trisomy exist: (1) the trisomy 21 subtype, which accounts for approximately 95% of cases; (2) the "translocation" subtype, due to a portion of chromosome 21 being attached to other chromosomes, which accounts for about 3–4% of cases; and (3) the "mosaicism" subtype, which refers to the presence of normal and trisomic cells and occurs in about 1–2% of cases. Common physical characteristics associated with DS include weak muscle tone, a flat facial profile, and oblique palpebral fissures. Maternal age, specifically age over 40, has been linked to increased risk of having a baby with DS (Ivan & Cromwell, 2014). For children with DS, a significant number of associated health conditions can co-occur, including hearing loss, congenital heart defects, and eye disorders. Thus early pediatric visits will often include intensive parent counseling and physical examinations (Ivan & Cromwell, 2014). For older individuals, a well-established component of the DS phenotype is the increased risk of developing Alzheimer-type dementia.

FXS is the most common inherited form of ID and the most common genetic cause of ASD, accounting for roughly 30% of ASD cases. A mutated repetition of the cytosine–guanine–guanine sequence on the long arm of the X chromosome is the case of FXS. The repetition inhibits production of the fragile X mental retardation protein. FXS has been noted to affect up to 1 in 4,000 males and 1 in 6,000 females; although it can be diagnosed prenatally, it often goes undiagnosed until the third year of life (Roberts et al., 2009). Common physical features for boys include hyperextensible finger joints, large ears, narrow face, and macroorchidism (i.e., enlarged testicles). Outcomes for children with FXS vary; females typically show less significant intellectual impairment than males do (Roberts et al., 2009). The full FXS mutation in males is typically associated with moderate ID, although a decline of cognitive functioning in individuals with FXS has been reported into adolescence (Einfeld & Emerson, 2008). Tonnsen, Malone, Hatton, and Roberts (2013) have described a variety of symptoms shown by children with FXS, including aggression, hyperactivity, and social avoidance. Tonnsen et al. (2013) also note that the most common comorbid conditions for children with FXS include autism, ADHD, and anxiety disorders.

FASD has been defined as "a non-diagnostic umbrella term identifying the range of outcomes from gestational alcohol exposure" (Riley, Infante, & Warren, 2011, p. 74); the most severely affected children exhibit FAS. National and world prevalence data for FAS have varied between 0.2 and 2 per 1,000 births; the prevalence for children affected by the range of FASD is estimated to be about 1% (Riley et al., 2011). FAS is characterized by the presence of prenatal and/or postnatal growth delay, abnormalities of the face and head (e.g., microcephaly), and central nervous system dysfunction. The characteristic facial phenotype of FAS includes small eyes, smooth philtrum (i.e., indistinct groove between upper lip and nose), and a thin upper lip. Exposure to alcohol during gestation results in various structural and functional brain abnormalities that affect varied cognitive functions, such as executive functioning, attention, verbal memory, and learning (Nunez, Roussotte, & Sowell, 2011).

Evidence-Based Assessment

The EBA recommendations for individuals with ID and other DDs are similar to those for youth with ASD: multidisciplinary evaluation using well-established measures of

intellectual functioning, behavioral adjustment, psychological functioning, and adaptive functioning. Specifically regarding measurement of cognitive functioning, Campbell, Brown, Cavanagh, Vess, and Segall (2008) identified eight commonly used measures of general intellectual functioning, such as the Wechsler scales, that met "well-established" criteria. For students with ID or other DDs who were having comorbid problems with hearing impairments or for whom English was their second language, three nonverbal measures were reviewed and found to be well established (Campbell et al., 2008). For early detection of DDs, general developmental screenings are recommended for 9-, 18-, and 30-month visits to identify potential delays in development (American Academy of Pediatrics, 2006).

Assessment of Psychopathology and Diagnostic Overshadowing

Although individuals with ID and DDs are at greater risk for various behavioral and psychological disorders, such disorders tend to be underdiagnosed in clinical settings due to "diagnostic overshadowing"—that is, the tendency to attribute psychopathology to ID or to view psychopathology as less significant than cognitive deficits (e.g., Rush, Bowman, Eidman, Toole, & Mortenson, 2004). In order to assess for psychopathology, clinicians need to be cognizant of the increased risk for psychopathology and how it might manifest in a child with ID or another DD. Typical assessment measures, such as interviews and self-report scales, are often of limited use with children and adolescents with ID and other DDs. Likewise, third-party behavior rating scales have usually not been validated for individuals with ID, and such scales do not consider different manifestations of mental disorders (Einfeld et al., 2011). For example, Tonnsen et al. (2013) noted that assessment of comorbid anxiety for children with FXS often has to rely on parent reports, due to these children's cognitive and verbal deficits. Comparisons to previous functioning through record reviews and interviews may be helpful in determining whether psychopathology has developed. Due to known risk for psychological disorders, clinicians working with children or adolescents with ID and other DDs should inquire about changes in functioning (e.g., loss of interest, changes in appetite, truancy/absences) to screen for comorbid behavioral and psychological conditions.

Evidence-Based Interventions

As is the case for ASD, no medications have improved the core cognitive and adaptive deficits defining ID; rather, psychotropic medications are used to target specific behavioral symptoms and comorbid psychological disorders encountered within this group. Handen and Gilchrist (2006) reviewed the efficacy of psychotropic medications with individuals with ID, and concluded that individuals with ID generally show a poorer response and greater occurrence of side effects than individuals without ID do. For example, children with ID respond to methylphenidate 45–66% of the time, compared to 77% of children with ADHD alone. The AACAP (1999) reported several commonly occurring problems in psychopharmacology for individuals with ID: (1) lack of informed consent; (2) failure to integrate medication into a comprehensive treatment plan; (3) failure to monitor side effects, especially for nonverbal individuals; and (4) failure to match medication with comorbid diagnosis of record. Unfortunately, Einfeld and Emerson (2008) cautioned that even for adults with ID, alternatives to

medications were infrequently investigated, and evaluations of side effects were rare. Poorer response and greater chance for untoward effects calls for increased monitoring, lower initial dosages, and slower increases for individuals with ID (Handen & Gilchrist, 2006).

In another similarity to recommendations for individuals with ASD, early intervention is recommended for young children with ID and other DDs. For these children, clinicians should be cognizant of the importance of multidisciplinary interventions to ameliorate delays across language, preacademic skills, behavior, and social functioning. Much of the ID/DD intervention literature has focused on behavioral interventions (see Matson, Terlonge, & Minshawi, 2008). In light of comorbid psychopathology, such as anxiety and depression, EBPs such as cognitive-behavioral therapy have been shown to be moderately effective for individuals with ID, although the research literature is limited by few rigorous studies (Prout & Browning, 2011). Clinicians should consider implementation of EBPs for these special populations, with potential accommodations to meet the unique characteristics of each child with ID or another DD.

The predominant psychosocial approach to intervention with ID employs behavioral methods to increase adaptive skills and decrease maladaptive behaviors. Behavioral techniques, such as task analysis, shaping, chaining, and prompting, are frequently used in combination to teach adaptive skills in a systematic manner. Once adaptive skills are reliably performed within one setting, intervention focuses on teaching the individual to generalize the skills to other settings. Numerous single-subject research studies have documented the efficacy of behavioral teaching methods to improve self-care, social, academic, and vocational skills. Given the high percentage of individuals with ID who exhibit maladaptive behaviors, disruptive behaviors such as aggression toward self or others should be documented in terms of frequency, intensity, and duration. Furthermore, a functional assessment or analysis has shown to be useful for improving behavioral intervention outcomes for individuals with ID. For individuals exhibiting maladaptive behaviors, identifying the function of each behavior (e.g., attention, escape) provides guidance for planning behavioral interventions.

SUMMARY AND CONCLUSIONS

It is important for pediatric psychologists to appreciate the heterogeneity that exists for individuals with ASD, ID, or other DDs. The heterogeneity is accompanied by varied etiological factors, such as genetic, biological, and environmental influences, that give rise to these disorders. Heterogeneity necessitates individualized intervention for youth with ASD, ID, or other DDs. Within the DSM nosology, a single diagnosis now exists for ASD, representing a significant departure from recent practice; the change in diagnosis has generated controversy and will most certainly generate research focused on the validity and utility of the revised definition. For ASD, a host of EBPs are available for various difficulties and for individuals across developmental stages. Despite the necessary tailoring of interventions, the literature on outcomes for individuals with ASD, ID, and DDs consistently concludes that high-quality early intervention produces the most optimal outcomes. Within the group of psychological interventions, the strongest empirical support exists for behaviorally based approaches.

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CHAPTER 37

Attention-Deficit/Hyperactivity Disorder in the Pediatric Context

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The present chapter aims to provide an overview of the etiology, common comorbidities, evidence-based assessment and treatment, and emerging areas in pediatric attention-deficit/hyperactivity disorder (ADHD).

ETIOLOGY

ADHD is the most commonly diagnosed mental disorder of childhood (~8–9% of school-age children; Merikangas et al., 2010). Genetic, neuropsychological, neurobiological, and environmental etiological indicators have all been identified based on research comparing patients with ADHD and typically developing (TD) controls.

Genetics

Genetic heritability contributes prominently to the ADHD phenotype. Twin studies suggest that over 70% of the variance in the ADHD phenotype can be explained through heritability (Faraone & Mick, 2010). Some genetic studies have found higher rates of specific genetic polymorphisms among patients with ADHD; however, no single genetic polymorphism has been consistently identified across studies, nor does any polymorphism appear to have a large effect on the ADHD phenotype (i.e., odds ratio of 1.3–1.4; Coghill & Banaschewski, 2009; Neale et al., 2010).

Neuropsychological Functioning

Patients diagnosed with ADHD tend to perform more poorly on neuropsychological tests, including tests assessing attention, working memory, and response inhibition

(Willcutt, Doyle, Nigg, Faraone, & Pennington, 2005). Perhaps the most ubiquitous neuropsychological performance deficit among patients with ADHD is increased intra-individual variability in reaction times on cognitive tasks (Kofler et al., 2013).

Some ADHD experts have proposed that specific ADHD-related neuropsychological deficits may represent core deficits responsible for the behavioral manifestation of ADHD. For example, impaired behavioral inhibition (Barkley, 1997), deficient extinction response (Sagvolden et al., 2005), and impaired working memory (Rapport et al., 2009) have all been identified as core deficits, because patients with ADHD perform poorly on tests measuring these constructs. However, due to interindividual variability in the types of cognitive deficits among patients with ADHD, the prevailing theory is that there are likely to be multiple cognitive pathways to the ADHD phenotype (Nigg, Casey, & Nigg, 2005).

Neurobiological Abnormalities

Several neurobiological abnormalities have been reported in patients with ADHD. For example, patients with ADHD appear to have reduced global gray matter volumes and smaller basal ganglia structures (Nakao, Radua, Rubia, & Mataix-Cols, 2011). In addition, cortical mapping indicates that some cortical areas are thinner among patients with ADHD than among TD controls, suggesting a delay in cortical maturation (Shaw et al., 2007).

Functional magnetic resonance imaging assessing brain activation during task performance, particularly during tasks requiring executive functioning, indicates that cortical and subcortical structures required for successful completion of some tasks (e.g., right inferior frontal gyrus on response inhibition tasks) show less activation among patients with ADHD than among TD controls (Dickstein, Bannon, Castellanos, & Milham, 2006). Moreover, accumulating evidence suggests that patients with ADHD may be less effective at deactivating the default mode network (DMN) during task completion (Fassbender et al., 2009). The DMN is a neural network that is active when the brain is at rest (Raichle et al., 2001).

Another neurobiological correlate of ADHD is abnormalities in central nervous system neurotransmission. Evidence supporting an abnormality in dopaminergic and adrenergic system is that stimulant medications are quite effective at remediating ADHD symptoms. Stimulants largely exert their effect by blocking dopamine and norepinephrine transporters, leading to increased extracellular dopamine and norepinephrine in brain synapses (Prince, 2008).

Environmental Factors

Finally, associations have been reported between the ADHD phenotype and a number of pre-, peri-, and postnatal factors, including low birthweight and exposures to maternal smoking, pesticides, food additives, television, poor nutrition, and so on (Froehlich et al., 2011). However, there is inconsistency across study findings, with prematurity and prenatal exposure to smoking being the only factors that seem to have a reliable effect on ADHD across studies (Coghill & Banaschewski, 2009). It must be noted that environmental factors explain less than 25% of the ADHD phenotype (Coghill & Banaschewski, 2009). Hence these exposures are likely to be etiological contributors for

only a small percentage of patients with ADHD, or possibly require a specific genotype in order for the exposures to exert their negative effects. Indeed, since neither genes nor environment fully explain the ADHD phenotype, examining gene × environment interactions is a promising method of studying the combined and possibly synergistic effects of genes and environmental exposures (Nigg, Nikolas, & Burt, 2010).

COMORBIDITIES

Up to two-thirds of children with ADHD have been diagnosed with another mental disorder (Larson, Russ, Kahn, & Halfon, 2011). The most common comorbid mental health diagnoses observed among individuals with ADHD are oppositional defiant disorder and conduct disorder, with a combined comorbidity rate for these disorders between 30 and 60% (Jensen et al., 2001, Larson et al., 2011; Wilens et al., 2002). Other commonly occurring mental disorders include anxiety and depression (14–47%; Larson et al., 2011; Wilens et al., 2002) and learning disorders (reading and math, 24–38%; writing, 59–65%; DuPaul, Gormley, & Laracy, 2013). A range of other mental and medical disorders—including autism spectrum disorder, Tourette's disorder, and communication disorders (Hanson et al., 2013; Larson et al., 2011)—also tend to occur at higher rates among patients with ADHD than among TD children, but are less frequent (i.e., <25% of all children with ADHD). Finally, there are some medical disorders, such as epilepsy and traumatic brain injury, that do not occur at elevated rates among children with ADHD (Max et al., 2004; Williams, Schulz, & Griebel, 2001), but for which there are elevated rates of ADHD among these populations (e.g., Dunn, Austin, Harezlak, & Ambrosius, 2003).

The presence of comorbidity is not inconsequential. Studies show that individuals with more comorbidities exhibit greater problems in functioning across a variety of domains (Larson et al., 2011). Moreover, comorbidities (e.g., anxiety) may affect responses to ADHD intervention and may signal the need for ancillary intervention strategies (Jensen et al., 2001).

DEVELOPMENTAL CONSIDERATIONS

As a neurodevelopmental disorder, ADHD is chronic and often persists into adolescence and adulthood. In fact, most (~80%) children diagnosed with ADHD continue to meet diagnostic criteria for the disorder as adolescents (Biederman, Petty, Clarke, Lomedico, & Faraone, 2011), and 40 to 60% continue to meet ADHD criteria as adults, depending on sample ascertainment and the criteria used to define ADHD (Faraone, Biederman, & Mick, 2006).

Functional impairments in adolescents are similar to those observed among children with ADHD, including social and academic/educational domains (Wolraich et al., 2005). In addition, adolescence as a developmental period is marked by increased independence and significant developmental milestones, leading to new developmentally relevant impairments for individuals with ADHD. For example, adolescents with ADHD evidence driving difficulties (Aduen, Kofler, Cox, Sarver, & Lunsford, 2015), elevated rates of substance use (Molina et al., 2013), and increased risk for sexually transmit-

ted diseases (Flory, Molina, Pelham, Gnagy, & Smith, 2006). These findings highlight the need for mental health care providers to screen carefully for the presence of these impairments in adolescents.

ASSESSMENT

Evidence-based ADHD assessment requires assessing for the presence–absence of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)-defined diagnostic criteria (i.e., symptoms, age of onset, pervasiveness, impairment, and assessment of other medical and psychological conditions). Core components of the ADHD evaluation include clinical interviewing, rating scales, and observation of the patient. Another evaluation component that typically occurs separately is a medical exam.

Clinical Interviewing

For a pediatric patient, the child's parents/legal guardians are typically interviewed. If the patient is older (typically age 12 or above), it can also be helpful to interview the child. During interviewing, the clinician should ascertain the presence of ADHD symptoms and ADHD-related impairments, acquire a developmental timeline for ADHD symptoms and impairment, assess ADHD risk factors, and explore potential psychological and medical comorbidities. Clinicians can accomplish this task by using established interviews such as the Schedule for Affective Disorders and Schizophrenia for School-Age Children—Present and Lifetime Version (K-SADS-PL; Kaufman et al., 1997).

The clinical interview should assess whether each DSM ADHD symptom criterion is met. This requires a determination of whether behaviors occur more frequently than would be considered normal for the child's age. One particular challenge of the ADHD assessment is to contextualize behaviors in relation to the child's stage of development, to ensure that only children who are exhibiting rates of ADHD behaviors at atypical levels for their developmental level are given the ADHD diagnosis. This can be difficult for some children (e.g., children with intellectual disabilities, traumatic brain injury), since ADHD behaviors can be rather typical in these populations.

The clinical interview should assess how ADHD symptoms are affecting the child's daily functioning across multiple domains (e.g., academics, school behavior, social relations). The interviewer should also assess for a variety of risk factors known to be associated with ADHD. Some key risk factors are family history of ADHD and other comorbidities, the child's medical history, the child's developmental history, and the child's history of interventions for mental health issues. The presence of risk factors can provide clues that may help support or rule out an ADHD diagnosis.

Finally, the clinician should inquire about potential medical and psychological comorbidities. It is very important to understand whether other medical and psychological problems are causing the manifestation of ADHD symptoms, or whether these other conditions are instead comorbid with the ADHD diagnosis. Ascertaining and understanding these potential etiologies and comorbidities may affect case conceptualization, as well as recommendations for management of ADHD. Psychological comorbidities can be assessed by using an interview such as the K-SADS-PL, or by targeted question-

ing of family members about specific comorbid conditions, based on the results from parent- and teacher-rated broad-band rating scales.

Rating Scales

All consensus guidelines state that parent and teacher ratings of child behavior are essential components of an evidence-based ADHD assessment (American Academy of Pediatrics [AAP], 2011; American Academy of Child and Adolescent Psychiatry, 2007). Indeed, parent and teacher ratings of ADHD behaviors are highly predictive of an ADHD diagnosis (Pelham, Fabiano, & Massetti, 2005). Perhaps the greatest benefit of behavioral ratings is that they provide an efficient and convenient method to acquire parent and teacher feedback regarding a child's behavior and impairments at home and school. Moreover, many behavioral rating scales have normative data that allow quantification of whether the child's behavior deviates from that of peers of comparable age and gender. However, ratings should not be used alone to make or refute a diagnosis, especially since many existing rating scales do not provide all of the necessary information to ascertain the entire set of DSM criteria (e.g., age of onset of symptoms).

Rating scales used in the ADHD diagnostic process can generally be divided into two types: (1) ADHD-specific ratings and (2) broad-band ratings. ADHD-specific ratings are those that are limited to assessing ADHD behaviors. Rating scales such as the ADHD Rating Scale–5 (DuPaul, Power, Anastopoulos, & Reid, 2016) and the Vanderbilt ADHD Diagnostic Rating Scales (Wolraich et al., 2003) ask parents and teachers to indicate how often children exhibit each of the 18 DSM ADHD symptoms. Notably, parents and teachers demonstrate only moderate agreement on ratings of ADHD symptoms (correlation ~0.3; Narad et al., 2014). Hence one goal of the clinical interview is to explore inconsistencies across settings, as these inconsistencies may provide relevant information about whether the child meets ADHD diagnostic criteria and may also indicate targets for intervention.

Broad-band ratings ask parents, teachers, and/or children to rate items covering a diverse and broad range of childhood behaviors (depression, anxiety, oppositionality, etc.). Most broad-band rating scales have normative data, therefore allowing the computation of *T*-scores, which allow the clinician to determine whether a child's behavior is outside the typical range for the child's age and sex. Commonly used broad-band measures are the Achenbach System of Empirically Based Assessment (ASEBA; Achenbach & Rescorla, 2001), the Behavioral Assessment System for Children, Third Edition (BASC-3; Reynolds & Kamphaus, 2015), and the Conners 3 (Conners, 2008). Some of these rating scales (e.g., the Conners 3) incorporate the 18 DSM ADHD symptoms, negating the necessity of using both ADHD-specific and broad-band scales.

Functional impairment can also be assessed by using rating scales. Some rating scales have been developed that focus specifically on ADHD-related functional impairment (e.g., the Impairment Rating Scale; Fabiano et al., 2006). Other scales have integrated ratings of functional impairment (e.g., the Vanderbilt ADHD Diagnostic Rating Scales).

Whether to obtain patient self-report is a complicated issue. Younger children tend to be relatively unreliable in their self-report of externalizing behaviors (Goodman, 2001). For adolescents, self-report versions of ADHD ratings, such as the Conners 3 Self-Report, can provide useful information. When clinicians are assessing for comor-

bid internalizing symptoms, obtaining self-report from children and adolescents can be valuable and is worthwhile.

Observation

Observation of the child in a natural (e.g., school) or analogue environment can provide useful clinical information. There are established methods for performing observations, such as the BASC-3 (Reynolds & Kamphaus, 2015) and the ASEBA Test Observation Form (McConaughy & Achenbach, 2004), which provide observational strategies for observing and quantifying the child's behavior at home or in the classroom. However, under most circumstances, such observation is difficult to accomplish in a typical clinical setting, and therefore is rarely used.

Another form of observation that is more convenient and may have some clinical utility is observing the child's behavior during the clinical visit. Although young children are typically involved in a limited fashion during the ADHD assessment process, it is useful to interact with and informally observe children. It is important to note that children, particularly those with ADHD, can control their behavior for a limited time, especially when placed in a novel environment. If a child does exhibit ADHD symptoms during interactions/testing, this can be indicative of an ADHD diagnosis. Probably the most clinically relevant information one can get from interacting with the child is information suggesting the possibility of a developmental disorder.

Testing

Consensus guidelines for ADHD assessment suggest that in-office measures of cognition and attention *not* be included as components of the ADHD assessment process (AAP, 2000). Though some objective measures (e.g., cognitive testing, neuroimaging) can discriminate groups of children with ADHD from TD controls, the inability of these tests to classify children as having ADHD or not indicates that their use is not merited in an ADHD evaluation.

Psychoeducational testing, including the administration of a standardized intelligence and/or achievement test, can provide information about general intellectual ability as well as whether a learning disorder may be present. However, children with ADHD often experience academic impairment, whether they have a learning disorder or not (Loe & Feldman, 2007). Indeed, poor academic achievement can result from the negative impact of ADHD symptoms on a child's ability to learn. Given that psychoeducational testing is not covered by most insurance plans as part of an ADHD evaluation, many experts do not recommend that psychoeducational assessments be included in a typical ADHD assessment battery. Instead, it is often recommended that a psychoeducational battery be administered only if there is specific evidence of a learning disorder (e.g., impairment in a single academic subject), or if the child's achievement continues to be impaired after ADHD symptoms have been addressed.

Medical Exam

Proximal to the clinician's evaluation of ADHD, the child's physician should perform a medical exam. The medical exam has two primary purposes. First, there are a number

of medical conditions that can cause a child to exhibit ADHD symptoms (e.g., lead poisoning, sleep problems). The second purpose of the medical exam is to evaluate for coexisting conditions, so that the clinician can take these conditions into account when providing recommendations for intervention. For example, since stimulant medication is a commonly used intervention strategy, it is important to make sure that the child does not have a medical condition that would contraindicate the use of stimulants (e.g., a cardiac problem).

EVIDENCE-BASED INTERVENTIONS

Evidence-based ADHD interventions include psychopharmacological and behavioral interventions.

Psychopharmacological Interventions

Stimulant medications are the most commonly prescribed (Olfson, Gameroff, Marcus, & Jensen, 2003) and most effective class of medications for addressing the core symptoms of ADHD (Newcorn et al., 2008). Stimulants produce a marked attenuation in ADHD symptoms (i.e., effect size ~1.0) in as many as 70–90% of children when adequately titrated (Elia, Borcherding, Rapoport, & Keysor, 1991). Other classes of medication, such as norepinephrine reuptake inhibitors and selective alpha-2-adrenergic agonists, have also been shown to be effective in reducing ADHD symptoms, but the effect sizes for these other classes of medications tends to be smaller (~0.7) than that of the stimulants (Newcorn et al., 2008; Spencer & Biederman, 2002).

The most commonly reported side effects of stimulant medications are appetite suppression, abdominal or headache pain, and sleep problems (Barkley, McMurray, Edelbrock, & Robbins, 1990). Less frequent side effects include tics, nervousness, and rebound (i.e., increased irritability in the evening hours when stimulant effects wear off). Rare side effects include hallucinations and cardiac problems. Due to their quick action, stimulant medications can be rapidly titrated to an optimal dose. Physicians are encouraged to acquire parent and teacher ratings during the titration process, in order to select the medication and dosage that produce the largest effects on behavior with the least side effects. Moreover, physicians should periodically collect parent and teacher ratings during medication maintenance, to ensure that medication is continuing to be efficacious with minimal side effects.

Behavioral Interventions

Evidence-based psychosocial management of ADHD includes parent training in behavior contingency management programs and school-based behavioral interventions (Pelham & Fabiano, 2008). Parent training can be delivered in either group or individual formats. Although parent training programs may differ in terms of number of sessions or sequencing, they contain common components, including (1) psychoeducation; (2) teaching techniques for building, strengthening, and promoting a positive parent–child relationship; (3) teaching techniques to promote positive/appropriate behaviors and reduce negative/inappropriate behaviors (e.g., praise, differential attention, effective commands, token

economies, time out); (4) educating parents about using the Individuals with Disabilities Education Improvement Act of 2004 to advocate for their child at school; (5) teaching parents how to work with the child's teacher to set up school-based behavioral systems (e.g., a daily report card); and (6) teaching parents strategies for managing their child's behavior in public (Chronis, Chacko, Fabiano, Wymbs, & Pelham, 2004).

School-based interventions focus on providing teachers with behavior management techniques that can be applied in the classroom setting, including effective commands, praise, planned ignoring, and time out (Chronis et al., 2006). In addition to interventions using behavioral principles to target classroom behavior, similar interventions using behavioral strategies have been developed to target organizational skills in children with ADHD (Abikoff et al., 2013; Langberg et al., 2011). Each of these behavioral strategies requires (1) identification of behavior targets via a functional assessment of difficult behaviors, including antecedents and consequences; (2) provision of specific, frequent feedback to children by teachers; and (3) rewards based on children's progress toward behavioral goals. The average effect size (averaged across outcomes) for parent training and school-based interventions for ADHD is moderate (~0.44; Pelham & Fabiano, 2008). Given that behavioral interventions target ADHD-related impairments, it is not surprising that behavioral interventions tend to exert their greatest effect on such impairments rather than on ADHD symptoms.

Multimodal (Combined) Interventions

The Multimodal Treatment Study of Children with ADHD (MTA; MTA Cooperative Group, 1999) demonstrated that medication intervention alone was superior to behavioral intervention alone at reducing ADHD symptoms. In addition, combining medication and behavioral strategies did not produce greater symptom reduction than medication alone. However, for certain groups of individuals and families (including families on income assistance and children with comorbid anxiety), a combined strategy was more effective than medication alone (Swanson et al., 2008). Children receiving the combined intervention also required lower doses of medication, compared to children receiving medication only (Swanson et al., 2002). Moreover, parents reported the greatest satisfaction for the combination of medication and behavioral interventions (MTA Cooperative Group, 1999). For these reasons, evidence-based guidelines (AAP, 2011) recommend combining psychopharmacological and behavioral interventions for the management of ADHD.

Developmental Considerations

Evidence-based guidelines clearly recommend that for children with ADHD under the age of 5, the first-line intervention should be behavioral intervention (AAP, 2011). Stimulant medications for preschool-age children are recommended only in severe cases where children's safety is a concern (e.g., significant impulsivity that could result in injury), or after families actively engage in psychosocial intervention with insufficient improvement and persistence of "moderate to severe" impairment. Also, if medication intervention is initiated, evidence-based guidelines recommend starting at lower doses and cautiously titrating medication, as this age group is especially prone to negative side effects at higher doses (AAP, 2011).

Although evidence-based guidelines continue to promote a multimodal strategy of medication and behavioral interventions for adolescents (AAP, 2011), research clearly shows that adolescents with ADHD have significant problems with maintaining adherence to medication (Sibley, Kuriyan, Evans, Waxmonsky, & Smith, 2014); these findings highlight the importance of psychosocial interventions for this age group. Several intervention manuals are available for clinicians working with adolescents with ADHD, including *Your Defiant Teen* (second edition; Barkley & Robin with Benton, 2014) and *Negotiating Parent–Adolescent Conflict: A Behavioral–Family Systems Approach* (Robin & Foster, 1989) for difficult/defiant behaviors, and *Homework, Organization, and Planning Skills (HOPS) Interventions* (Langberg, 2011) for addressing academic problems.

Management versus Treatment

Clinicians are advised to be careful in their discussions with families regarding "management" as opposed to "treatment" of ADHD. In particular, use of the word "treatment" is discouraged, as this word implies that ADHD can be cured. Because ADHD is a chronic neurodevelopmental disorder, there is no "cure" for it. Instead, ADHD symptoms and impairments can be managed and are only managed as long as families continue to use psychopharmacological and behavioral strategies. Families find metaphors especially useful in discussions of this concept. For example, explaining that glasses only work when the person needing them wears them can be a useful metaphor.

EMERGING AREAS

Due to the high prevalence of pediatric ADHD and the relatively few mental health professionals to meet these children's needs, the vast majority of children with ADHD receive ADHD care from their primary care physicians (typically pediatricians) rather than mental health specialists (Zito, Safer, Magder, Gardner, & Zarin, 1999). Although having pediatricians provide ADHD care solves access-to-care issues, research indicates that in these settings children are not receiving evidence-based ADHD care (Epstein et al., 2014). The AAP has attempted to address the low rates of evidence-based ADHD care among pediatricians by developing a set of consensus guidelines and recommendations for ADHD care (AAP, 2000, 2001, 2011) and disseminating an ADHD toolkit. Even with these initiatives, ADHD care in typical community-based pediatric settings is inadequate. For example, pediatricians are collecting parent and teacher rating scales as part of the ADHD assessment for only about half of all children assessed for ADHD; the vast majority of children cared for in pediatric settings are not receiving behavioral interventions; and parent and teacher ratings are rarely collected (i.e., <11% of patients) to monitor medication effects (Epstein et al., 2014). A significant challenge for the future is devising strategies to improve the quality of ADHD care in pediatric settings. Potential intervention strategies include the use of electronic medical records (Carroll et al., 2013) or web portals (Epstein et al., 2011) to help automate, and remind pediatricians to implement, evidence-based ADHD care. Though such interventions have been developed and proven effective, the challenge is to get pediatricians to adopt their use.

Another emerging area that requires additional attention is increasing access to behavioral interventions. Although a multimodal intervention strategy is the recommended strategy, most children with ADHD receive medication interventions only (Hoagwood, Kelleher, Feil, & Comer, 2000). A challenge for the future is to identify methods for increasing patient access to behavioral interventions. Although group-based parent training interventions can effectively be implemented as an outpatient community service (Loren et al., 2015), this model is largely limited to locations with an ADHD specialty center. Alternative models that use technology or telehealth might be useful for disseminating behavioral interventions elsewhere.

A final emerging area is the customization of interventions to target ADHD-specific areas of impairment. Increasingly, interventions are being introduced that target specific ADHD-related impairments, such as poor driving skills in adolescents. For example, Fabiano et al. (2011) have developed a multicomponent intervention that targets driving impairments among adolescents with ADHD by teaching parents and adolescents to negotiate the transition to independent driving. There are many more areas of impairment among children with ADHD that are inadequately targeted by existing interventions, including poor peer relationships, difficulties with the transition to adulthood, and substance use—each of which will eventually need a customized intervention.

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PART IV

PUBLIC HEALTH ISSUES AND SYSTEMS

CHAPTER 38

Racial and Ethnic Health Disparities

Celia M. Lescano and Guitele J. Rahill

Health disparities have an impact on pediatric populations and their caregivers around the world. In this chapter, we first define "health disparities"; highlight the key demographic factors that contribute to pediatric health disparities, both in the United States and globally; identify key organizations and agencies that have focused on mitigating disparities; emphasize why race, ethnicity, and immigrant status are important factors to consider in discussing health disparities; and offer some useful frameworks for understanding health disparities. We continue with barriers that contribute to health disparities, particularly access to and quality of care; we then describe recent U.S. efforts to address health disparities. We conclude with suggestions for moving forward.

DEFINING HEALTH DISPARITIES

The term "health disparities" typically refers to differences in health outcomes or in experiences of disease that are observed between populations. Although the term is often used specifically in the context of racial/ethnic disparities, characteristics such as biological sex and gender, age, ability or disability level, and sexual identity/orientation all contribute to the experience of health versus disease in populations (Office of Disease Prevention and Health Promotion, 2014). Health disparities are further "shaped by the interaction of multiple factors, including: social, environmental, behavioral, and biological factors . . . [which] vary in their impact depending upon when in the life course they occur, access to appropriate and timely health care, and the existence of effective policies and interventions" (National Institutes of Health, 2009, p. 14).

Because our focus in this chapter is on health disparities affecting children and youth, we use the terms "health disparities" and "pediatric health disparities" interchangeably hereafter.

KEY DEMOGRAPHIC FACTORS PERTAINING TO HEALTH DISPARITIES

Race, ethnicity, socioeconomic status, age, biological sex and gender, country of birth, disability, and health insurance status are relevant factors to consider in light of existing health disparities, and those who have "multiple minority" status (i.e., who are minorities or are at a disadvantage within any combination of these categories) are seen to be at heightened risk for health disparities. In 2010, approximately 37% of the U.S. population consisted of racial or ethnic minorities; nearly 15% lived in poverty; 24% were younger than age 18; over half were female; and nearly 13% were foreign-born (U.S, Census Bureau, 2013). An additional 8% of persons younger than 65 reported a disability, and over 15% were without health insurance. Globally, exposures to wars, toxic chemicals, physical injury, preventable infectious diseases, poverty, child trafficking, malnutrition and unsafe water, child labor, and poverty afflict millions of children, especially but not exclusively those who reside in developing countries (United Nations Children's Fund [UNICEF], 2013).

ORGANIZATIONS AND AGENCIES TARGETING PEDIATRIC HEALTH DISPARITIES

Pediatric health disparities have been highlighted in several contexts over the past decade by several organizations and agencies, including the American Academy of Pediatrics (AAP, 2009), the Agency for Healthcare Research and Quality (AHRQ, 2013), and the U.S. Department of Health and Human Services (U.S. DHHS, 2011a, 2011b). They are also highlighted in publications stemming from the Children of Immigrants Longitudinal Study (CILS; Portes & Rumbaut, 2001). In addition, the World Health Organization (WHO) has provided some guidance regarding these disparities on a global scale (WHO, 2014).

Examples of significant pediatric health disparities targeted by these groups include poor nutrition/obesity; tobacco use and its effects; prenatal, early childhood, and maternal health; flu vaccination; injuries; and asthma (AAP, 2009). In all of these areas—including the experience of chronic diseases (such as HIV/AIDS and certain types of cancers); congenital diseases; pulmonary problems; and orthopedic, ophthalmological, and renal issues—racial and ethnic minorities have significantly higher rates of morbidity and mortality than those of age-matched comparison groups. When hospitalized for these issues, racial and ethnic minorities are also likely to incur higher financial charges than majority group patients (AAP, 2009).

In 2009, the AAP, acknowledging the existence of differences in health outcomes and the experiences of disease for children and youth, set forth 10 principles geared toward establishing health equity for children and toward guiding research and practice in this area. These include honoring the rights of children; understanding the factors that affect their health (including language, behavioral, socioeconomic, and societal

factors); and promoting culturally competent care that is grounded in scientific evidence. Additional principles established by the AAP (2009) underscore the importance of promoting a diverse clinical population; facilitating culturally sensitive health care settings equipped with duly trained practitioners; and systematically conducting culturally competent assessment and evaluation of health care delivery.

The AHRQ (2013) report on national health disparities documented that racial and ethnic minorities receive poorer quality of care and face more barriers in seeking care than their nonminority counterparts do. The AHRQ further emphasized the needs of people with disabilities, including children with special health care needs. Quality of care and barriers to care may be particularly salient in cases where children have multiple minority statuses, such as a combination of minority status in age, race, and ethnicity, perhaps in addition to a disability or minority sexual orientation.

Since an early Surgeon General's Report (U.S. Department of Health, Education and Welfare, 1979), the Office of Disease Prevention and Health Promotion has progressively established "Healthy People" initiatives. These initiatives first emphasized the reduction of health disparities (Healthy People 2000); then the elimination of health disparities (Healthy People 2010); and now, with Healthy People 2020, the achievement of health equity (U.S. DHHS, 2011a). Healthy People 2020 comprises close to 600 objectives and more than 1,300 measures to monitor the improvement of health of all Americans (U.S. DHHS, 2011a). Related to goals for reducing pediatric health disparities, Healthy People 2020 highlights the health of adolescents with 11 objectives. These objectives include improving community and school safety, with the support and collaboration of school officials; increasing wellness checks; increasing the proportion of children in grades 9–12 who get adequate sleep, in order to prevent sleep disorders and improve productivity and quality of life; and increasing positive involvement and health education of caregivers in the lives of adolescents (U.S. DHHS, 2011a). Healthy People 2020 also includes a renewed focus on children in the early to middle stages of development. Moreover, it prioritizes the health of lesbian, gay, bisexual, and transgender (LGBT) youth, including well-being, safety (violence prevention in schools, neighborhoods, and housing), and access to health care (U.S. DHHS, 2011a).

A new addition to the goals in Healthy People 2020 is the achievement of health equity. "Health equity" is defined as the potential and capacity of all persons to achieve positive health outcomes, regardless of their socioeconomic status, and is based on broad societal acceptance of the idea that everyone has the right to be healthy; in addition, health equity requires purposeful attention by members of one's social context, geared at making reparations for past ills and at preventing oppression and denial of basic and health rights in the future (U.S. DHHS, 2011a). These goals are consistent with WHO's recent recommendations for reducing disparities around the globe. WHO (2014a) recommended that by 2015, all governments should be accountable for conducting regular and systematic evaluations of the amount of money they spend on health care (particularly on reproductive, maternal, and child health care), with the eventual aim of eliminating disparities in all countries. WHO further recommended that extant inequities in other areas, such as human rights and sex/gender, be linked to spending and health objectives, and called for an increased research focus on addressing health disparities related to those areas. Furthermore, WHO (2014a) endorsed closer collaboration between researchers and policy makers, as well as building the research capacity of developing countries (which experience the greater burdens of disparities) and

identifying and equipping indigenous researchers to partner with national and global partners.

WHY A FOCUS ON RACE, ETHNICITY, AND IMMIGRANT STATUS IS IMPORTANT

As noted above, racial and ethnic minorities receive health care of poorer quality and face more barriers to care. Also, findings from the CILS indicate that children of individuals who immigrate to other countries in search of improved conditions and quality of life also experience social, emotional, and health disparities in the new host country. Several examples of health (and other) disparities affecting racial and ethnic minorities are cited in publications stemming from the CILS (Portes & Rumbaut, 2001). Analysis of data from that study revealed the consequences of migration among second-generation immigrants in the United States, and several factors emerged as significant. These included the context of immigration and the host communities in which immigrant youth reside; economic and educational disparities; and psychological consequences of modes and context of migration, including low self-esteem, affective disorders, and identity issues. In addition, pediatric populations and their caregivers whose religious beliefs diverge from that of the host society often experience religious intolerance, and this intolerance accounts for a great proportion of discrimination against diverse religious groups (Lum, 2011). Moreover, acculturation stressors, including dissonant acculturation (in which parents and children acculturate at different rates; also known as the "acculturation gap") and pressures to assimilate can result in identity issues and can have an impact on health. Therefore, creating health care settings for racial/ethnic minorities and immigrants that enable clinicians to address the psychological facets of illness and injury and to prevent disease, while concomitantly promoting behaviors in children and their family members that can result in long-term positive health outcomes, is of great significance.

Interestingly, an "immigrant paradox" can be found across several behavioral (e.g., internalizing/externalizing behaviors), health (e.g., adolescent sexual risk behaviors), and academic (e.g., achievement and engagement) outcomes: Recently immigrated youth display favorable outcomes until they become more acculturated to mainstream American culture (Garcia Coll & Marks, 2012). Another important factor to consider is that traditional health beliefs and practices can persist across international borders and be transmitted across generations. In many racial, ethnic, and immigrant cultures, seeking conventional medical care is often a "last resort" option, after beginning with traditional remedies and proceeding to a variety of healers. The inability to afford conventional health care from medical doctors is also often an issue in this reluctance.

FRAMEWORKS FOR UNDERSTANDING HEALTH DISPARITIES

The concept of "social determinants of health" means that the contexts of individuals' birth, socialization, development, and education are influenced by broader economic and sociopolitical forces, which also influence the foods they eat, the illnesses they experience, and the kind and quality of care they have access to. This concept has long

been a useful framework for understanding health disparities. Within this framework, health inequalities are preventable and occur not only between and across developed and developing countries, but within nations, regardless of their levels of development (WHO, 2014b). In regard to health disparities specifically, the social and economic status of individuals has a great deal to do with their propensity to become sick, to prevent disease, and to treat symptoms when they arise.

Another useful framework for considering disparities is "syndemics theory" (Singer, 2009). If applied to pediatric health disparities, syndemics theory would enable health care professionals to move from traditional treatments of diseases as if they exist outside of individuals' social contexts, or as if a given biological condition does not interact with mental, social, or other biological conditions. "Syndemics" refers to the confluence of two or more health-related conditions in a population, such that the interaction of these conditions intensifies the deleterious health outcomes of one or all of the conditions (Singer, 2009). In regard to health disparities, syndemics are likely to develop in contexts of poverty, stress, or structural violence, and contribute to disparate occurrences of disease in affected populations. More specifically, syndemics theory emphasizes interactions between and among sociopolitical, economic, and health-related conditions in a population. The syndemics framework can contribute to understanding the interactions among risk factors and eliminating the barriers that contribute to health disparities. Below is an example of such interactions among sociopolitical, educational, racial, ethnic, and individual factors in the context of health disparities, together with ideas for how to address them.

In the United States, limited English-language proficiency can exacerbate health disparities, particularly for those who are preliterate or who are not familiar with medical and clinical terminology (Seth, Isbel, Atwood, & Ray, 2015). To address language and literacy barriers, recent research indicates that facilitation of pediatric client–clinician communication by interpreters must take into account the clients' or caregivers' type and level of emotion about engaging a medical provider; the accessibility of professional interpreters; and acknowledgment that racial and ethnic minority clients often prefer trusted friends and significant others to interpret for them, rather than professional interpreters (Riera et al., 2015). Riera and colleagues suggest that reviewing challenges that occurred during clinical sessions with clients and interpreters after each such session is important in resolving miscommunication and maintaining rapport. They also recommend systematically assessing racial and ethnic minorities' language proficiency prior to care, to determine the type of language assistance that may be needed. We would add that assessment of medical literacy level may also be helpful, as many racial and ethnic minorities in the United States can face challenges in understanding medical and clinical terms.

BARRIERS CONTRIBUTING TO HEALTH DISPARITIES

Table 38.1 summarizes various types of barriers contributing to health disparities. A factor that is not included in the table, but should also be mentioned, is this: In the United States, the "digital divide" is an additional barrier to health care for pediatric populations whose families do not own a computer or lack internet service. These families thus lack access to much information about health care services, and increasing numbers of

such services themselves may be unavailable to them. For most such families, the costs of technology remain prohibitive (Altarum Institute, 2015).

Access to and Quality of Care as Major Barriers

The 2013 National Healthcare Quality and Disparities Reports (AHRQ, 2013) indicated that the overall quality of health care in the United States was improving, but that access to care was declining, and consequently health care disparities continued at higher rates. More specifically, hospital care and an increase in adolescent vaccines were seen as successes in the quality of care, while areas that were lagging included ambulatory care, diabetes care, and maternal and child health. In regard to access, the availability of providers by telephone was improving, but significant difficulties in accessing care remained for a large proportion of the population, particularly minorities; in part, these difficulties were attributable to the "digital divide" described above. Other factors in lack of access to care included such things as lack of accessible health care sites, particularly in remote areas; patients' and providers' lack of ability to communicate effectively with each other (including in written form); and inadequate cultural competence on the part of providers.

RECENT U.S. EFFORTS TO ADDRESS PEDIATRIC HEALTH DISPARITIES

The Affordable Care Act

Recent efforts to address pediatric health disparities in the United States are numerous. First, as discussed previously, lack of insurance has been demonstrated as a major

TABLE 38.1. Factors That Contribute to Health Disparities

- Country of residence
- Demographic factors, such as racial and ethnic diversity
- Language barriers and parental preliteracy (in global or local enclaves)
- Immigration status and acculturation stressors
- Traditional health beliefs of parents and caregivers, which can sometimes help but may sometimes have a negative impact on the health of youth
- Varying explanatory models of illness between pediatric populations and their families on the one hand, and health care providers and policy makers on the other
- Inequities and lack of access to care based on socioeconomic status
- Developmental disabilities and physical/mental trauma that can result from the prenatal environment, as well as from geographical, structural, neighborhood, and domestic violence
- Lack of cultural competence and/or cultural humility among well-intentioned researchers and practitioners
- Funding bodies whose policies and descriptions of populations fail to disentangle the subtle differences among cultural groups that share race and/or ethnicity, thus inadvertently failing to provide support for research and interventions that address the specific nuances unique to diverse subpopulations
- Inequities in prenatal care and lack of access to childhood vaccines
- Lack of health insurance

factor in these disparities. In 2010, significant numbers of Americans were completely uninsured: 29.4% of Hispanics, 20.4% of African Americans, and 11.2% of European Americans (AHRQ, 2011). Most of the uninsured were living in segregated, high-poverty communities with fewer primary care providers, hospitals, and clinics.

With the passage of the Patient Protection and Affordable Care Act (ACA) in 2010, the issue of being un- or underinsured in the United States is at last being addressed. A 2013 report issued by the U.S. DHHS indicated that with the implementation of the ACA, several positive outcomes were anticipated to occur (Beronio, Po, Skopee, & Glied, 2013). These included helping to end insurance discrimination (e.g., by providing coverage for preexisting conditions), expand the affordability of coverage, increase funding for underserved communities, strengthen cultural competence for health care providers, and provide incentives for professionals serving in underrepresented areas (Beronio et al., 2013). As of 2016, enrollment for the ACA was in full swing. Nearly 11.2 million people had purchased health insurance in the ACA marketplace, with many more expected; the uninsured rate was at a record low (10.9%), and improving most among African Americans and lower-income Americans (Gallup, 2016; U.S. DHHS, 2014).

Essential health benefits included in the ACA are numerous. Benefits specific to pediatrics and pediatric psychology include oral and vision care, preventive and wellness services, and chronic disease management. In addition, the Mental Health Parity and Addiction Equity Act, enacted in 2008, requires comprehensive mental health and substance use treatment coverage; this act thus provides coverage for more than 30 million people who did not have these services as part of their plans previously (Beronio et al., 2013). On a practical level, these legislative efforts mean that pediatric psychologists can and should be integrated into interdisciplinary health care teams that serve as patients' "health homes." Through this concept, as well as through improving mental and behavioral health care by preserving Medicare benefits to psychologists, patients can have more access to and better quality of care from pediatric psychologists. These health homes should essentially provide "one-stop shopping" for consistent and ongoing services that range from preventive care to management of chronic illness. They should also include the use of integrated data systems and quality assurance, which should serve to improve access to and quality of care, as well as to foster regular and accurate communication between patients and providers as well as between providers (Clay, 2010). Within this framework, pediatric psychologists would do well to find a niche and capitalize on it, ensuring that the services that they offer are clearly stated and are collaborative in nature. In addition, finding a particular niche that is related to working with underserved populations (particularly language minorities) would be beneficial. Finally, the ACA also looks to emphasize prevention, to potentially reimburse the delivery of evidence-based interventions, and to support psychological research through the funding of federal research agencies (Clay, 2010).

Community Health Center Programs

Since 1970, the Health Resources and Services Administration (HRSA) has been funding community-based and patient-directed health centers that serve underserved and vulnerable populations (HRSA, 2015). Each state has at least 3 such centers (e.g., there are 3 in Delaware), with a maximum of 151 (in California). These health center programs must meet various criteria: Each one must be located in or serve a medically

underserved area or population; be governed by a board composed primarily of community members; provide comprehensive primary health care services; provide services to all, but operate on a "sliding" scale; and meet outlined performance and accountability requirements. There are three types of health centers in this program—grant-supported federally qualified health centers (FQHCs), non-grant-supported health centers ("look-alikes"), and outpatient health programs operated by Native American tribal organizations. In 2003, these programs served more than 22 million patients, 93% of whom were 200% below the poverty level, 73% of whom were 100% below the poverty level, and 33% of whom were uninsured. Twenty-nine percent of patients in the FQHC and 32% of those in the look-alikes were under the age of 18 (HRSA, 2015). Although there is evidence that FQHCs increase access to care, improve health outcomes, and decrease overall medical expenditures, the jury is still out on whether these programs have a significant impact on health disparities (HRSA, 2015).

Communities Putting Prevention to Work

Communities Putting Prevention to Work (CPPW), a Centers for Disease Control and Prevention initiative, targets 50 million people in 50 U.S. communities (*www.cdc.gov/nccdphp/dch/programs/communitiesputtingpreventiontowork*). It is focused on reducing obesity and tobacco use—which are the two leading causes of morbidity and mortality in the United States, and are disproportionate problems for members of racial and ethnic minorities. The implementation of CPPW seeks to advance health equity by reducing barriers to health care faced by these populations, and enacting policy, systems, and environmental changes that enhance the likelihood of meaningful, positive behavior changes.

Other Federal Initiatives to Reduce Disparities

Other examples of programs that target racial and ethnic minorities and other underserved populations in order to reduce health disparities include the Let's Move! campaign initiated by Michelle Obama (*www.letsmove.gov*), which focuses on reducing childhood obesity by increasing physical activity, educating children and caregivers about nutrition, and providing access to healthy, affordable food. In addition, the National HIV/AIDS Strategy focuses on reducing the disproportionate burden of HIV disease experienced by several racial/ethnic and sexual orientation minority groups, by focusing on HIV testing and prevention initiatives in minority and underserved communities (*www.aids.gov/federal-resources/national-hiv-aids-strategy/overview*). Vaccination is yet another major health issue in which disparities exist in pediatric populations, and the U.S. DHHS has recently expanded its efforts to improve flu vaccination among minorities.

SUMMARY AND CONCLUSIONS

A substantial body of published and presented data now testifies to the reality of health disparities due to racial and ethnic minority status. Although gains are being made, particularly in the area of access to care for those who were previously un- or underin-

sured, there are still many barriers to access and quality of health care for minority youth and families. Pediatric psychologists can provide strong leadership in this regard. With increasing cultural competence and humility, we must consider not only what we know (and need to learn) about the group with which a person or family identifies, but also personal traits, family characteristics, and cultural nuances that are not readily observed, when developing our treatment and research protocols. Advocating for our underserved and underrepresented patients, and ensuring the enactment of efficient and effective policies that will enhance our work with them, should be priorities for us and will assist in achieving health equity for all. Specifically, our focus should be on evaluating and implementing evidence-based and best practices; evaluating, disseminating, and implementing effective interventions; and determining which "best practices" are best for whom, in which situations, and conducted by whom. The American Psychological Association has steering committees (particularly the National Steering Committee on Health Disparities) focused on answering these strategic questions. Those of us who want to make strides in the area of health equity would do well to get involved in these committees and share this important information with our pediatric psychologist colleagues.

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CHAPTER 39

Understanding and Preventing Pediatric Unintentional Injury

Barbara A. Morrongiello and David C. Schwebel

Society has made great advances in minimizing child mortality due to infectious disease, poor nutrition, and unsanitary conditions, especially in high-income nations. Unintentional injury, however, has not declined to the same extent (World Health Organization [WHO], 2008). In the United States, injuries remain the *leading* cause of death for children ages 1–18 (National Center for Injury Prevention and Control [NCIPC], 2015). Child injury statistics are staggering. In the United States in 2012, there were over 9 million unintentional injuries among children under 20 years that resulted in visits to an emergency department (about 25,000/day), and an additional 8,067 (about 22/day) that were fatal (NCIPC, 2015). The term "unintentional injury" has replaced "accident" in the literature, because the latter denotes a chance event that cannot be prevented, whereas research suggests that 91% of children's injuries could have been prevented if an individual or community had done something to change the circumstances leading to the injury (Rimsza, Schackner, Bowen, & Marshall, 2002).

Calls for primary prevention initiatives to address childhood injury have a long history in the United States (Finney et al., 1993; Tremblay & Peterson, 1999) and internationally (WHO, 2008). Prevention approaches have evolved considerably and now are often multidisciplinary in scope (e.g., engineering, public health, medicine, psychology), to address the fact that injuries are multidetermined events that involve both person characteristics (e.g., attitudes, beliefs, behaviors) and environmental ones (e.g., hazardous features of the built environment). This chapter reviews behavioral risk factors associated with child injury, and then discusses prevention approaches. Although behavior change is often at the core of injury prevention initiatives, a review of health behavior theories is beyond the scope of this chapter (see Gielen & Sleet, 2003). Similarly, although one might expect integrative theories that explain pediatric childhood injury processes, such theories are uncommon. In fact, most research in the field is neither

theory-driven nor attentive to relevant child development issues (see Morrongiello & Schwebel, 2008, for discussion).

BEHAVIORAL RISK FACTORS FOR CHILD INJURY

Identifying behavioral risk factors that predict who is at risk of child injury facilitates targeting prevention efforts to those in greatest need. This section considers demographic, child, and parent characteristics that are associated with childhood injury. Environmental factors also influence risk of injury, often in rather obvious ways (i.e., greater hazards create greater risk), and these factors are discussed below in the section on prevention.

Demographic Characteristics

Age

Children experience injuries throughout development, but trends in the location and types of injuries vary with age and developmental level. Knowledge about such trends has implications for intervention development, including who should be targeted in prevention efforts (e.g., children vs. caregivers) and what mechanism of injury should be prioritized (e.g., falls down staircases vs. off playground equipment).

Young children (ages 1–5) are often injured in and around the home, with peaks in injury rates occurring at times when youngsters first achieve motor development milestones (Agran et al., 2003). There is a spike in fall-related injuries, for example, corresponding to the onset of climbing. Other common injuries among young children include suffocation, poisoning, burns, and drowning (NCIPC, 2015), which are all injuries that could be prevented with active and sustained supervision by caregivers and/or appropriate environmental modifications.

Elementary-school-age children and teenagers are more often injured when engaging in activities away from home, independently or with peers, and when direct adult supervision is lacking (Shannon, Bradshaw, Lewis, & Feldman, 1992). Common causes of school-age children's injuries include sports and recreational activities, and crossing streets as pedestrians or bicyclists (NCIPC, 2015). Peers often influence the decisions and behaviors that lead to injury through modeling risk behaviors, engaging in verbal persuasion, providing opinions about use of protective equipment, and even expressing social norms about risk and safety behaviors (Morrongiello, Corbett, & Sandomierski, 2013; Morrongiello, McArthur, Kane, & Fleury, 2013). During adolescence, driving becomes a significant injury risk activity, and motor vehicle crashes are the leading cause of death for 15- to 19-year-olds (NCIPC, 2015). Speeding, substance use, sleepiness, and distracted driving are common teen driver risk behaviors (Sleet, Ballesteros, & Borse, 2010).

Gender

One of the most consistent predictors of injury risk is gender: At virtually all ages, boys experience more injuries than girls (NCIPC, 2015). Explanations for this gender difference are diverse and include discussions of constitutional differences between boys and girls in attributes that influence behavior (e.g., dispositional behavioral tendencies like

impulsiveness or sensation seeking), as well as socialization-based factors (e.g., reinforcement by peers and caregivers for risky play activities). For example, boys receive more encouragement for risky play behaviors than girls (Morrongiello & Dawber, 1999). Most likely, multiple factors contribute to create the robust gender disparity in child injury rates, with differences in socialization of boys and girls exaggerating biologically based differences to cause boys to engage in more risk-taking behavior (Morrongiello & Dawber, 1999).

Injury appraisals also differ for boys and girls, with different factors predicting risk taking by each gender. Research suggests that girls tend to think in terms of "Will I get hurt?" (i.e., injury vulnerability), and if they appraise vulnerability as high, they avoid the behavior. In contrast, boys tend to think in terms of "How hurt might I get?", so they are prepared to engage in risk behaviors that might lead to injury as long as the perceived injury severity is within what they are willing to tolerate. Boys also attribute past injuries more often to bad luck, whereas girls attribute injuries to their own behavior, leading to repeated injury risk behaviors by boys but not girls (Morrongiello & Rennie, 1998).

Socioeconomic Status

A health–income gradient exists for most types of child injuries, whereby decreasing income is associated with higher injury morbidity and mortality. Explanations for this relation include greater exposure to hazards in lower-income homes and neighborhoods (Shenassa, Subbendick, & Brown, 2004) and reduced access to safety resources and protective gear for children in lower-income families (Lang, 2007). Differences in parenting as a function of socioeconomic status may also contribute to create differential injury risk for children. More disadvantaged caregivers may be less educated or less aware of or able to implement effective safety practices such as active supervision (Dush, Schmeer, & Taylor, 2013; Matheny, 1986).

Child Characteristics

Temperament

A number of dispositional or temperament attributes influence child injury risk, including sensation seeking, impulsivity, and inhibitory control. Sensation seeking (the desire for varied, novel, and complex sensations and experiences, and the willingness to take physical risks for the sake of the experience) predicts risk taking and injuries among children and adolescents (Morrongiello, Sandomierski, & Valla, 2010). Similarly, scoring high in impulsivity (quick reactions to novel, exciting, or appealing stimuli) and low in inhibitory control (capacity to inhibit prohibited behaviors and comply with rules) is associated with higher injury risk (Schwebel & Barton, 2006).

Psychopathology

Externalizing behavior disorders such as attention-deficit/hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD) are linked to unintentional child injury risk (Barkley, Murphy, & Kwasnik, 1996; Schwebel, Speltz, Jones, & Bardina, 2002). Symptoms of ADHD include impulsive behavior patterns and poor attention—both factors that can lead to childhood injury, especially in traffic situations. ODD may

contribute to injury risk due to problematic parent–child communication, which results in behavioral noncompliance in injury risk situations. Developmental effects may exist in the links between externalizing psychopathology and injury risk: Younger children may have greater injury risk from ODD symptoms because of noncompliance with rules and supervisors' requests, whereas older children may have greater injury risk from ADHD because inattentive and impulsive decisions can lead to injury-causing behaviors when the children are unsupervised.

Cognitive Functioning

As children develop cognitively, they are increasingly able to evaluate injury risk, remember and follow safety rules, and make decisions that permit safe engagement with and exploration of their environment. In particularly dangerous settings, advancements in cognitive capacities permit safe and independent negotiation of the environment. For example, crossing a street is a cognitively demanding task that involves judging speed, distance, and acceleration of multiple oncoming cars; evaluating one's own walking speed and the distance across roads; and handling any number of distractions or unexpected complications (e.g., an ambulance approaching with siren going). This skill is not mastered by typically developing children without training until at least 10 years of age (Schwebel, Davis, & O'Neal, 2012). Developments in cognitive functioning also allow older children, in comparison to younger ones, to identify hazards more readily, consider causality, generate preventive measures, and appreciate that injury risk depends not just on the presence of risks but the nature of them (Hillier & Morrongiello, 1998). Despite these improvements in risk appraisal skills, however, researchers report greater rates of risk taking at older than younger ages in some circumstances (DiLillo, Potts, & Himes, 1998), suggesting that greater knowledge and understanding does not necessarily lead to safer behaviors.

Research on children's knowledge of safety rules indicates that parents expend considerable effort to teach young children safety rules (Gralinski & Kopp, 1993), but that parents tend to overestimate young children's understanding of these safety rules (Morrongiello, Midgett, & Shields, 2001) and fail to recognize many hazards in their children's environment (Gaines & Schwebel, 2009). Moreover, children's knowledge of rules is insufficient to protect them from injury. Higher knowledge scores are not associated with fewer injuries; rather, compliance with rules predicts fewer injuries in children (Morrongiello et al., 2001). Thus, children's knowledge of risks and safety rules is necessary but not sufficient to prevent injuries.

Parent Characteristics

A number of parent characteristics influence children's risk of injury, particularly early in development, when children have limited understanding of hazards and their own behavioral capabilities.

Personality

Studies of parent personality and children's risk of injury have focused mostly on conscientiousness and neuroticism. Generally, conscientiousness is associated with positive parent safety practices and fewer child injuries (Morrongiello, Corbett, McCourt,

& Johnston, 2006). Parents scoring high in neuroticism have children who experience more frequent injuries (Davidson, Hughes, & Richards, 1987), perhaps because the parents engage in ineffective supervision practices (Morrongiello, Corbett, McCourt, et al., 2006).

Parenting Style

Parents often use a blend of "authoritative" (highly responsive, combined with behavioral supervision and discipline), "authoritarian" (obedience-oriented, demanding, and close monitoring, but less responsive), and "permissive" (nondirective, lenient, avoidant of confrontation) approaches, with the expression of these parenting styles dependent on the individual child, the issue at hand, and the environmental context (Baumrind, 1991; Darling & Steinberg, 1993). Child injury research generally finds that high permissiveness predicts greater injury risk (Morrongiello, Ondejeko, & Littlejohn, 2004b), perhaps because permissive parents engage in less teaching about safety and also use less effective teaching strategies (Morrongiello, Corbett, Lasenby, Johnston, & McCourt, 2006).

Psychopathology

Maternal depression is a risk factor for child injury. Although multiple causal factors may exist, the strongest evidence implicates supervision practices. In a longitudinal study of children from birth to age 3, for example, mothers with higher depressive symptoms reported significantly greater total amounts of time supervising their children, but a significantly smaller proportion of this time was spent in an "intense" style of supervision (continuously watching) than was spent by mothers with fewer depressive symptoms (Phelan et al., 2014).

Risk Practices

"Do as I say, not as I do" is a popular parental refrain, but this fails to reflect the reality of how children behave. In fact, parents influence children's behavior both by what they teach or say *and* by what they model or do (Morrongiello, Corbett, & Bellissimo, 2008). What is being taught and is expected (e.g., safety rule compliance) is among the best predictors of children's current practices, probably because parents can threaten punishment for failing to comply with rules. However, what parents do and the risk behaviors they model predict children's future risk-taking intentions quite strongly. When parents model unsafe practices, such as failing to use safety gear (e.g., helmet with biking), then children often assume that safety gear is only for youth and that they will not need it as they grow older (Morrongiello, Corbett, & Bellissimo, 2008).

Supervision

Advances in conceptualization and measurement (for reviews, see Morrongiello, 2005; Petrass, Finch, & Blitvich, 2009) have paved the way for rigorous research on the issue of how caregiver supervision influences children's risk of injury. Although more research is needed with lower-income and minority populations, the findings to date support a number of conclusions.

Attentive supervision reduces child risk behaviors through multiple means. First, an attentive supervisor can intervene when a child engages in a dangerous activity. Second, children change their risk behaviors in response to the presence of a supervisor, engaging in more risk behaviors when supervisors are more distant physically (Barton & Schwebel, 2007; Morrongiello, Ondejko, & Littlejohn, 2004a, 2004b) or distracted (Boles & Roberts, 2008). Similarly, child swimmers violate more rules in public pools when fewer lifeguards are present (Harrell, 2001) or when surveillance is of poorer quality (Schwebel, Lindsay, & Simpson, 2007).

Gender and personality differences in children's reactions to a supervisor's presence also have been found. Generally, boys and more impulsive/undercontrolled children are influenced more substantially by supervision than are girls and less impulsive/undercontrolled children (Morrongiello et al., 2004b; Schwebel, Brezausek, Ramey, & Ramey, 2004). In one study, for example, a reduction in children's overestimation of ability in physical tasks was found when they were supervised by parents, but this effect was most dramatic for children who scored high in impulsive and undercontrolled traits (Schwebel & Bounds, 2003).

Supervision behavior is conceptualized in terms of three dimensions: watchfulness, proximity, and the extent of continuity in these (Saluja et al., 2004). With this framework in mind, lower levels of supervision predict both home-treated and medically attended injuries (Morrongiello et al., 2004b; Morrongiello, Corbett, & Brison, 2009; Schnitzer, Dowd, Kruse, & Morrongiello, 2015). Moreover, high levels of supervision serve a protective or risk-reducing function and actually counter the effect of temperamental attributes that elevate children's risk of injury (Morrongiello, Klemencic, & Corbett, 2008; Schwebel et al., 2004). Such findings indicate that level of supervision interacts with children's behavioral attributes to influence risk of injury.

Similarly, supervision needs vary not only with child characteristics, but also with situational context. On farms, for example, having children proximal to supervisors (which usually reduces risk of injury) can actually *increase* injury risk by exposing children to hazards that the supervisors are engaging with, such as large animals or moving machinery (Morrongiello, Marlenga, Berg, Linneman, & Pickett, 2007). What constitutes "adequate" supervision, therefore, may be impossible to ascertain without a careful consideration of the characteristics of the child *and* those of the environment (Morrongiello, Pickett, et al., 2008). This is why professionals vary greatly in their judgments about supervision, and why there is no "gold standard" for what constitutes adequate supervision (Peterson, Ewigman, & Kivlahan, 1993).

APPROACHES TO INJURY PREVENTION

Interventionists must consider many factors when formulating injury prevention strategies, including the nature of the approach, the level at which the intervention is implemented, and the type of intervention.

Active and Passive Approaches

Intervention efforts to prevent injury are often conceptualized as "passive" or "active" interventions. Passive interventions require no action by an individual. These may be

modifications to the environment to reduce/remove hazardous conditions (e.g., improvements to the surfacing of playgrounds) or to prevent access to these or to hazardous products (e.g., redesign of cribs, changes to medicine packaging). Often these modifications are legislated, with penalties (e.g., fines) for failing to comply. When compliance is high, the impact on injury rates can be substantial. For example, revising manufacturing standards for crib designs reduced infant strangulations and suffocations (McDonald, Girasek, & Gielen, 2006).

In contrast, a completely active intervention necessitates that an individual do something to reduce risk of injury, and the action needs to be repeated each time the person faces a similar situation. For example, the benefit of wearing a seat belt is only realized if one consistently engages in the practice.

Generally, passive approaches are very effective in reducing injuries, but not all risk behaviors and injuries can be addressed through passive approaches. Furthermore, many passive approaches (e.g., child-resistant medicine closures) still require individual actions (e.g., adults must replace the lids correctly), highlighting that active and passive approaches are complementary (Damashek & Peterson, 2002; Wilson & Baker, 1987) and that success can be enhanced by integrating these. For example, when helmet usage by children when bicycling was implemented as a legislated behavior change, the addition of social marketing and publicity/educational campaigns shifted attitudes and social norms, resulting in a significant increase in helmet usage over a 5-year period after the helmet law was passed (Rivara, Thompson, Patterson, & Thompson, 1998).

Levels of Intervention

Interventions can be implemented at a variety of levels. Several factors influence the level at which an intervention is implemented, including the risk behavior of interest and the segment of the population targeted for intervention. A typical hierarchy goes from broad to narrow in scope: national, state, community/municipality, family/peers, and individual (caregiver or child). National initiatives are usually legislated and consist of federal laws that address an issue at a population level. The Refrigerator Safety Act, for example, mandated that all manufacturers in the United States revise construction to prevent children from becoming trapped inside refrigerators (Robertson, 1983). States also make decisions about injury and safety policies (e.g., helmets for motorcyclists, car seats for infants), as do communities/municipalities (e.g., backyard pool fencing requirements), with some implementing legislation to mandate safe practices and others not.

Family/peer group and individually focused interventions typically target specific risky behaviors. For example, interventions to promote seat belt usage that target *both* children and their parents provide the opportunity for them to remind, encourage, and reinforce one another, which can produce positive behavior change within entire family units (Chang, Dillman, Leonard, & English, 1985; Roberts & Turner, 1986).

Types of Interventions

Legislative/Environmental Changes

Interventions implemented at a population level often have a significant injury-reducing impact, and there are many such examples. Legislation requiring child-resistant light-

ers led to a 58% decrease in fires, deaths, and injuries (Smith, Greene, & Singh, 2002). Vehicular-related deaths as passengers have substantially declined for children in the United States, now that every state has implemented laws requiring young children to be restrained as passengers in vehicles, and many states have now extended these laws to include booster seat requirements for older children (Winston, Kallan, Elliott, Xie, & Durbin, 2007). Similarly, graduated licensing laws, in which new drivers are only permitted to drive in more risky conditions over time and with increasing experience, reduce teen mortality rates. Environmental modifications to reduce the height of playground equipment and improve the shock-absorbing characteristics of the undersurface have significantly reduced the number of medically attended fall-related injuries (MacArthur, Hu, Wesson, & Parkin, 2000; Vidair, Hass, & Schlag, 2007).

On the basis of these and other examples, many argue that legislative interventions are the best approach to prevention, because they achieve broad impact at a population level. Nonetheless, government is often resistant to mandating citizens' health-promoting behaviors, particularly because personal liberty to choose how to behave is a valued freedom granted by the United States Constitution. Firearms, for example, are a leading cause of mortality (particularly among teenagers) in the United States, yet gun control remains a widely debated issue, and societal resistance to firearm regulation remains strong (see Shaw & Ogalla, 2006, for discussion).

One alternative to imposing regulatory solutions when product changes are needed is to seek voluntary action by manufacturers or other bodies. The Gas Appliance Manufacturers' Association, for example, instituted voluntary self-regulations to reduce thermostat settings on hot-water heaters at time of manufacturing to prevent scalds to children, whose skin burns much more quickly than that of adults (Roberts, Brown, Boles, Mashunkashey, & Mayes, 2003).

Education/Social Marketing

Interventions that simply target education of children and/or caregivers about safety issues assume that knowledge of injury risks will lead to safer practices. Despite a variety of different approaches to presenting information (e.g., brochures, posters, discussion with safety experts, neighborhood groups, television campaigns, and websites), however, the most typical result is that any improvements in knowledge do *not* translate into long-term behavior change (Deal, Gomby, Zippiroli, & Behrman, 2000; Schwebel, Morrongiello, Davis, Stewart, & Bell, 2012).

One factor that seems to improve the likelihood of knowledge's influencing behavior is physicians' delivering injury prevention information to parents. Parents see physicians repeatedly for checkups as their children develop, so there are repeated opportunities for health care providers to counsel parents about injury prevention. In fact, the American Academy of Pediatrics recommends that doctors provide anticipatory guidance about injury prevention regularly, with targeted issues based on a child's developmental status (Gardner, 2007). Parents who receive more frequent anticipatory guidance have infants who experience fewer medically attended injuries (Simon et al., 2006), although there seems to be greater short- than long-term impact (DiGuiseppi & Roberts, 2000).

Embedding educational information within a broader social marketing media campaign creates multiple opportunities for exposure by the target audience and is another strategy that can enhance results. "Social marketing" is the use of strategic marketing

practices to evoke social change that benefits the target audience (Andreasen & Kotler, 2003). This approach can be effective to evoke behavior change (Snyder et al., 2004; Wakefield, Loken, & Hornik, 2010), particularly if impediments to adopting the safe practice are removed, such as giving away or reducing the cost of child safety seats or bike helmets (DiGuiseppi et al., 1989; Robinson et al., 2014).

Behavior Change

Behavior is complex, and habits can be hard to change. Moreover, interventions that target lasting changes of specific behaviors can be costly to implement, because these typically require repeated sessions that are delivered individually. Nonetheless, there are many examples of programs that, through rehearsal and reinforcement, have improved children's safety practices (e.g., seat belt usage: Roberts, Fanurik, & Wilson, 1988; fire safety behaviors: Jones, Kazdin, & Haney, 1981; Morrongiello, Schwebel, Bell, Stewart, & Davis, 2012) and/or changed the practices of parents (e.g., using car seats for children: Roberts & Turner, 1986) and other caregivers (e.g., supervisors at preschool playgrounds: Schwebel, Summerlin, Bounds, & Morrongiello, 2006; Schwebel, Pennefather, Marquez, & Marquez, 2015). Generally, programs that offer booster sessions at a later time show greater likelihood of sustaining these behavior changes (Peterson, 1984; Whisman, 1990), which otherwise can dissipate over time (Christophersen & Sullivan, 1982). Importantly, programs that can be administered in small groups or to full classrooms are less costly and also have demonstrated efficacy (Hazinski, Eddy, & Morris, 1995; Peterson & Thiele, 1988).

Tailoring (or matching) injury prevention programming to particular characteristics of children, caregivers, or situations also has been shown to improve effectiveness of prevention efforts. Given the different risk-taking behaviors of boys versus girls, for instance, interventionists may tailor a program to their different behavior patterns. As an example, this issue is relevant to preventing injuries in teens' work settings (Breslin, Polzer, MacEachen, Morrongiello, & Shannon, 2007) and in many other contexts. Of course, tailoring can be accomplished more readily when the intervention is computer-based. Basic programming can facilitate user input (e.g., gender, age, race/ethnicity) to dictate the injury prevention message or programming delivered to the user. Early work used such tailoring in an emergency department (Gielen et al., 2007), and more recent efforts have demonstrated efficacy of such programs when delivered via the internet (van Beelen, Beirens, Hertog, van Beeck & Raat, 2014).

Emerging Trends in Injury Prevention

Technological innovations are increasingly used to advance injury prevention. eHealth incorporates delivery of health promotion, education, and behavioral interventions via a broad range of strategies, including the internet, text messaging, and social media. Online programs to improve safety are proving successful (Schell, Morrongiello, & Pogrebtsova, 2015). Social media marketing (e.g., Google ads, Tweets, Facebook pages) are commonly used by organizations to advocate for child safety and to reach parents and/or youth. In addition, mobile phones/smartphones provide unique opportunities for interventions to occur "in the moment" exactly when a person has to choose between a risky and a safe behavior. The potential impact of these intervention strategies has yet

to be fully realized. Nonetheless, as research confirming the usefulness of eHealth interventions accumulates (Bates & Gawande, 2003), more studies of eHealth interventions to reduce childhood injuries can be expected.

Geographic information systems (GIS) mapping is a computer-based approach that integrates different sources of information to examine how spatial variations in physical and social aspects of the environment *converge* to influence injury risk. This can provide insights into relationships between and among diverse factors, suggesting testable hypotheses about determinants of injury risk and recommendations for changes that would reduce injuries. A GIS analysis of actual child pedestrian injuries, for example, led to recommendations about how traffic density, road design, and home dwellings could be managed in a way to reduce injury risk (Lightstone, Dhillon, Peek-Asa, & Kraus, 2001), and a similar approach has improved safety on college campuses (Schneider, Khattak, & Zegeer, 2001).

Virtual reality (VR) technology is an ecologically valid way to study a person's behavior under highly realistic conditions, but still ensure the person's safety. This technology is providing insights into how child pedestrians cross streets and how risk of injury arises under different traffic conditions. The latest VR systems actually track walking behaviors as a child crosses a road, creating new opportunities to study what children do to evade an approaching vehicle that is on a "hit" course (Morrongiello, Corbett, Milanovic, Vierich, & Pyne, 2015). Training children in safe pedestrian behaviors is another way that VR technology is being used in child injury prevention (Schwebel, McClure, & Severson, 2014).

CONCLUSIONS

There is no refuting the statement that "children have the right to health, a safe environment, and protection from injury" (Harvey, Towner, Peden, Soori, & Bartolomeos, 2009, p. 393). Yet unintentional injury remains the leading cause of death among children and youth 1–18 years of age. Although significant gains in prevention have been made, there is much more work to be done to reduce the burden of this national and international public health issue. Injuries reflect complex multidetermined processes, therefore, intervention strategies that are multifaceted and based on a solid foundation of theory and evidence are likely to yield the greatest success. Innovations in technology are creating opportunities to try new approaches to prevention, and promising results are emerging.

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CHAPTER 40

Health Promotion in Children and Adolescents

An Integration of the Biopsychosocial Model and Ecological Approaches to Behavior Change

Dawn K. Wilson, Sandra M. Coulon, and Lauren E. Huffman

Given the increasing prevalence of chronic disease (e.g., Type 2 diabetes, cardiovascular disease, obesity) and health-related problems among youth (Ogden, Carroll, Kit, & Flegal, 2014), there is a need to develop effective intervention strategies that promote long-term healthy lifestyles and ultimately result in disease prevention. Although progress has been made, sound theoretical approaches have not been well integrated. This chapter highlights the importance of developing theory-based interventions for promoting healthy lifestyle behaviors (e.g., healthy diet, physical activity) and for preventing health-compromising behaviors (e.g., substance abuse, risky sexual behaviors) in children and adolescents. We provide an up-to-date review of promising conceptual approaches that integrate biopsychosocial and ecological models of health and behavior change (Bronfenbrenner, 1979, 1994/1997; Bronfenbrenner & Morris, 2006; Michie, van Stralen, & West, 2011; Schwartz, 1982; Suls & Rothman, 2004), with the perspective that health behaviors are multifaceted and dynamic, and are developed in the context of personal, interpersonal, and environmental interactions. We also review the recent advances in applied theory, differential health promotion effects due to individual differences, and the role of genetics and the environment in youth health behaviors and outcomes.

HEALTH-PROMOTING AND HEALTH-COMPROMISING BEHAVIORS

To address the ongoing health problems among youth, health care providers must focus on both decreasing health-compromising behaviors and increasing health-promoting behaviors. In regard to health-compromising behaviors, national studies show that 35% of high school students reported having consumed alcohol in the past month, 21% consumed more than five drinks, and 16% report having smoked cigarettes in the past month (Kann et al., 2014). With respect to risky sexual behaviors, national statistics indicate that over 41% of sexually active high school students have reported not using condoms during sexual encounters (Kann et al., 2014).

The exponential rise of obesity in youth, with 35% of adolescents currently classified in the obese category (Ogden et al., 2014), is also a growing public health concern (Wilson, 2009). Regarding health-promoting activities to counteract obesity, regular physical activity in childhood is linked to decreased risk for obesity, cardiovascular disease, cancer, diabetes, and high blood pressure (Physical Activity Guidelines Advisory Committee, 2008), and also to mental well-being and lower risk of depression (Brown, Pearson, Braithwaite, Brown, & Biddle, 2013). Healthy diets that are low in fat and calories have also been shown to reduce the risk of poor health outcomes (Stone, Baranowski, Sallis, & Cutler, 1995).

Given the need to continue to develop and demonstrate effectiveness of health promotion interventions in youth, investigators should continue to understand the theory and mechanisms that underlie health behavior change for both health-compromising and health-promoting activities in youth.

AN INTEGRATED MODEL OF HEALTH PROMOTION

This chapter presents an integrated biopsychosocial and ecological approach to health promotion, which posits that health behaviors are affected by biological, intrapersonal, social, cultural, and physical environmental variables within an integrated and interacting framework (Bronfenbrenner, 1979, 1994/1997; Bronfenbrenner & Morris, 2006; Michie et al., 2011). The ecological approach as outlined by Bronfenbrenner assumes that health and health behaviors are shaped by the integrated action of environmental subsystems. These include intrapersonal factors (characteristics of the individual, including biology and genetics); microsystemic factors (families and institutions); mesosystemic factors (interactions between families and institutions); exosystemic factors (communities, policies); and macrosystemic effects (all systems, micro-, meso-, and exo-, related to a culture or subculture). In this approach, these multiple subsystems are considered in order to gain a better understanding of influences on health behaviors in youth. The biopsychosocial model integrates biological factors within the context of psychological and social factors related to health behaviors (Schwartz, 1982; Suls & Rothman, 2004; Taylor, 2015). This model proposes that biological, psychological, and social factors interact in determining youth's overall health behaviors through dynamic reciprocal processes. Thus theories encompassing a broad range of interacting variables are prominent in understanding health behavior change in children and adolescents. These theories are reviewed below.

INTRAPERSONAL THEORIES OF HEALTH PROMOTION

A number of psychosocial approaches have been implemented in recent years as strategies for changing health behaviors in youth, and they continue to be important in understanding integrated system approaches to behavior change. In this section, we first examine specific aspects of social-cognitive theory (SCT), such as self-efficacy constructs, behavioral control theory, and outcome expectancy models (Bandura, 1986). Other relevant theoretical approaches include motivational approaches such as self-determination theory (SDT; Ng et al., 2012; Ryan & Deci, 2000).

SCT-Based Interventions

Bandura's (1986) SCT assumes that individual cognitive factors, environmental events, and behavior are interacting and reciprocal determinants of each other. With respect to cognitive factors, behavioral control is composed of expectancies about outcomes and confidence in personal ability (self-efficacy) to make the desired behavior change. According to Bandura (1986), individuals who adopt challenging goals and are confident that they have the abilities to meet them (i.e., who have high self-efficacy) are more effective at making long-term lifestyle changes than individuals who have less confidence in their abilities. In a recent meta-analysis of 19 behavioral change frameworks (Michie et al., 2011), the basic frameworks all come down to a relatively unified way of thinking about behavior change models. Specifically, Michie et al.'s "behavior change wheel" highlights a comprehensive approach to health that includes physical, mental, and social outcomes. More importantly, the three essential intervention elements identified as most relevant in this meta-analysis are capability (behavioral skills), opportunity (environmental conditions), and motivation (drive). These core constructs map onto interventions that promote either behavioral skills or social conditions for shaping changes in health behaviors.

SCT interventions have typically included common behavior modification components, including self-monitoring, goal setting, and behavioral skills training. In a randomized trial, a curriculum-based social inoculation intervention for adolescents called Draw the Line/Respect the Line incorporated discussions of social pressures, developing personal sexual limits, and practicing resistance skills (Coyle, Kirby, Marin, Gomez, & Gregorich, 2004). The results for boys included delayed sexual initiation and fewer perceived social norms supporting sexual intercourse, more positive attitudes toward not having sex, stronger sexual limits, and a decreased likelihood of being in risky situations (Coyle et al., 2004). In the Start Taking Alcohol Risks Seriously (STARS) trial (Werch et al., 2003), the intervention targeted protective factors based on SCT (e.g., self-efficacy, behavioral capability). Parents and children received a program tailored to children's risk and protective factors, in which children signed contracts to avoid alcohol, and parents committed themselves to reminding children of their pledge. Results from a 1-year follow-up showed that students in the STARS intervention had fewer intentions to drink in the future than control students had.

Taken together, these studies demonstrate the usefulness of integrating SCT concepts for effectively modifying long-term lifestyle habits. Future research is needed to

further our understanding of the mechanisms and mediators that are specifically linked to understanding SCT intervention components in the context of large multilevel interventions.

Interventions Based on Motivational Theories

Motivational theories are extensions of SCT that involve increasing motivation by creating cognitive dissonance (inconsistency between attitudinal beliefs and behaviors) and by increasing intrinsic (self-initiated) motivation (Ryan & Deci, 2000; Wilson et al., 2002). The underlying premise is that how individuals present themselves to others has a powerful influence on how they perceive themselves and subsequently behave (Wilson et al., 2002). Thus individuals who freely choose to commit themselves publicly to a particular identity are more likely to behave in a way consistent with that identity than are individuals who only hold such beliefs privately. This method is known as "strategic self-presentation" and has been shown to increase health promotion behaviors in adolescents (Wilson et al., 2002).

In a study by Werch and colleagues (2007), an intervention approach based on the "behavior–image" model was used to target the mechanisms underlying multiple health outcomes. Proponents of this approach argue that, similar to strategic self-presentation, activating new social images and prototypes of possible selves motivates change in divergent health risk and health promotion behaviors, based on self-regulation theory. Feedback was also given to participants in the Werch et al. study to encourage public commitment to multiple concrete goals. The effects of this intervention showed a cascade of beneficial outcomes, including decreased alcohol intake, increased fruit and vegetable intake, and increased engagement in relaxation activities. The intervention effects on relaxation activities and fruit/vegetable intake were also shown to be mediated by increases in self-efficacy.

SDT is a motivational theory focused on intrinsic factors that motivate behaviors; its proponents argue that these behaviors are more likely to be sustained than those that are extrinsically motivated (Ng et al., 2012; Ryan & Deci, 2000). That is, behavior changes motivated by intrinsic factors such as novel, enjoyable, self-driven, and satisfying experiences will sustain behavior better than those produced by extrinsic factors such as external reward or coercion (Ng et al., 2012; Ryan & Deci, 2000). Because adolescence is a time of increasing autonomy, this approach is developmentally appropriate for youth at this age, in that it acknowledges the need for independence and self-initiated behavior change. A meta-analysis showed that SDT interventions were effective at improving a broad range of both mental and physical outcomes across a variety of health domains (Ng et al., 2012).

The Active by Choice Today (ACT) program is one example of an intervention that utilized a self-determination framework to create support for autonomy, in order to increase physical activity in youth (Wilson et al., 2008, 2011). The ACT study was a randomized school-based trial, involving 24 middle schools that integrated SDT motivational constructs into lifestyle interventions for youth. ACT targeted physical activity in at-risk adolescents through a comprehensive after-school program designed to increase intrinsic motivation, enjoyment, support, self-efficacy, and perceived competence through physical activities and skills training (Wilson et al., 2008, 2011). Schools

receiving the ACT intervention demonstrated significant increases in physical activity during the intervention, compared to schools that received a general health education program, but the intervention was not effective in changing physical activity outside the school setting.

In summary, motivational approaches are becoming increasingly popular in health promotion interventions targeted at youth. In particular, investigators are integrating motivational strategies into multicomponent intervention trials for health behavior change.

ECOLOGICAL AND BIOPSYCHOSOCIAL APPROACHES TO HEALTH PROMOTION

Researchers have extended the field of health promotion to include ecological perspectives (Lawman & Wilson, 2012). Macro-level conceptual perspectives are needed to expand the field to include biological, social, and physical environmental factors.
An Institute of Medicine (2009) report urges researchers and clinicians to note the importance of providing youth with nurturing environments to promote self-regulation, prosocial behavior, and psychological flexibility, and ultimately to confer positive health outcomes and minimize opportunities for health-compromising behaviors (Biglan, Flay, Embry, & Sandler, 2012; Wilson, 2015). Below we use our integrated model to demonstrate the effective use of microsystemic (families and institutions), mesosystemic (interactions between families and institutions), exosystemic (communities, policies), and macrosystemic (all systems, micro-, meso-, exo- , related to a culture or subculture) factors to promote health in youth. In a recent meta-analysis, Cushing, Brannon, Suorsa, and Wilson (2014) conducted a systematic review of the literature and showed that there may be synergistic effects of targeting multiple settings for improving health-promoting behaviors in youth. For example, within studies that attempted to change dietary behaviors, there were significantly larger effect sizes for programs that intervened at the school and community levels than for those addressing only schools. Thus potentially relevant systems that have been effectively targeted in health promotion programs for youth are highlighted as examples below.

FAMILY- AND PEER-BASED APPROACHES (MICROSYSTEMIC FACTORS)

A review of family correlates of health behaviors in high-risk (low-socioeconomic-status, minority) youth found that parenting skills such as monitoring of behaviors, and contextual factors such as social cohesion, are important for understanding diet, physical activity, and sedentary behavior (Lawman & Wilson, 2012). For example, research has shown that tangible parental supports are linked to increased physical activity in African American girls and boys (Siceloff, Wilson, & Van Horn, 2014). A longitudinal study following children from fifth to ninth grade showed that mothers' self-efficacy for physical activity and perceived barriers to exercise predicted physical activity in girls (DiLorenzo, Stucky-Ropp, Vander Wal, & Gotham, 1998).

Interventions that involve parents have had success in improving health behaviors in youth. The Supporting Health Interactively through Nutrition and Exercise (SHINE) 6-week randomized intervention targeted family climate (parent–child communication,

parental monitoring, and social support) with the aim of reducing sedentary behavior in youth (St. George, Wilson, Schneider, & Alia, 2013). Families receiving the SHINE intervention showed increases in positive communication around health behaviors, as well as lower levels of sedentary behaviors in adolescents, compared to families receiving a general health education program. In another study, an intervention that targeted youth sedentary behavior via a family-based approach (Epstein et al., 2008) showed positive results. Youth in the intervention received a TV allowance device that limited television and computer use, slowly reducing allowed time each month (up to 50% of original use). Parents were encouraged to praise each child for meeting goals in reducing these behaviors. The intervention was successful in reducing sedentary behavior, body mass index, and overall energy intake. In summary, a growing number of studies are targeting parenting and family systems approaches to improving health behaviors in youth.

The influence of peers on youth's behavior choices is often utilized in drug prevention programs. Peer norms have also been shown to influence alcohol misuse. Wynn, Schulenberg, Maggs, and Zucker (2000) showed that the effects of the school-based Alcohol Misuse Prevention Study (AMPS) was mediated by peer norms. Middle and high school students received normative education (i.e., how common alcohol use is among peers) and skills training in peer resistance. Results showed that peer norms mediated the effectiveness of the AMPS program. This study demonstrates in particular the importance of integrating peers and school systems into health behavior change strategies. Further research should focus specifically on addressing social norms and peers, given the importance of these influences as children make the transition into adolescence.

SCHOOL-BASED APPROACHES (MICROSYSTEMIC AND MESOSYSTEMIC FACTORS)

The school environment has significant proximal influences on adolescent health behaviors, because the educational system is the main formal community institution that is responsible for the socialization of adolescents. One of the most successful drug prevention programs has been Project ALERT, a school-based prevention program that integrated cognitive, social, and behavioral skills theories into a middle school curriculum (Ellickson, McCaffrey, Ghosh-Dastidar, & Longshore, 2003). The intervention sought to change students' beliefs about drug norms and the social, emotional, and physical consequences of using drugs; help them resist social pressures to use drugs; and increase self-efficacy for resisting drugs. Eighteen months after baseline, students receiving the Project ALERT intervention had lower rates of cigarette smoking, marijuana initiation, and alcohol misuse than students in comparison schools had. A second widely studied school-based drug prevention program, the Life Skills Training (LST) Program, was designed to prevent tobacco and alcohol use (Botvin, Griffin, Paul, & Macaulay, 2003). The intervention consisted of 24 classes across three school years and focused on drug resistance, social competence, and self-regulation skills. As a result of the LST program, intervention schools' prevalence rates at postintervention were 25% lower for alcohol use and 61% lower for smoking cigarettes.

In general, school-based intervention studies have demonstrated modest changes in

students' health-promoting behaviors. The Middle-School Physical Activity and Nutrition Study (Sallis et al., 2003) was designed to increase physical activity and reduce saturated fat intake through environmental and policy changes within schools. Collaborative teams of school faculty/staff, parents, and students were created to implement policies supportive of a healthier school environment, while student health committees were formed to involve the adolescents in health promotion and social marketing. Environmental changes included promoting activity throughout the school day, increased physical education, implementing low-fat food options, and increasing student and parent education about nutrition. The intervention was successful in increasing physical activity and reducing body mass index in boys, but was not successful in producing changes for girls. The Physical Activity Across the Curriculum (PAAC) trial utilized a classroom intervention that promoted physical activity by training teachers to incorporate 90 minutes of activity into their lesson plans per week (Donnelly et al., 2009). Twenty-four elementary schools were randomly assigned to the control group or the PAAC intervention. Students receiving the intervention had significantly higher levels of physical activity both during the school day and on the weekends than comparison students. Students of teachers who were more physically active during the implementation of the physical activity exercises in their lesson plans had higher activity levels, suggesting that behavioral role models influenced student activity levels. Thus school-based approaches that are actually mesosystemic (i.e., that target multiple systems, including the school environment, peers, parents, and teachers) can facilitate long-term changes in health behaviors in youth.

COMMUNITY-BASED APPROACHES (EXOSYSTEMIC FACTORS)

Researchers have shown that community interventions through churches, community centers, supermarkets, and restaurants can influence children's and adolescent's health behaviors. Resnicow, Taylor, Baskin, and McCarty (2005) randomly assigned 10 churches to either a "high-intensity" group or a "moderate-intensity" group targeting African American adolescent girls. The high-intensity group participated in a weekly behavioral session that included a behavioral activity, engaging in physical activity, preparing healthy snacks, and attending a retreat on group cohesion. Participants in the high-intensity group also received promotional messages via a two-way pager and telephone calls based on motivational interviewing. Participants in the moderate-intensity group received information on barriers and benefits to physical activity, fad diets, and trying new foods. No significant differences were found between the groups; however, participants in the high-intensity group who attended at least 75% of sessions had significant reductions in body mass index, compared to participants who attended less than 75% of sessions.

A study examining health-compromising behaviors, conducted by Villarruel, Jemmott, and Jemmott (2006), was a randomized controlled trial of a community-based HIV prevention intervention in Hispanic adolescents. Six modules were delivered by adult facilitators in community-based organizations that promoted positive attitudes about preventing HIV/AIDS, engaging in safer sex, condom use skills, and negotiation and refusal skills. Results showed that adolescents in the intervention were less likely to report sexual intercourse, have multiple partners, or engage in unprotected intercourse,

and were more likely to report using condoms consistently, than were adolescents in a health promotion comparison program. This study demonstrated that community-level interventions can be an effective modality for decreasing risky sexual behavior in youth. Although conducting large-scale trials to test community-level effects requires intensive resources, this work would more effectively promote community prevention effects in youth.

PUBLIC POLICY APPROACHES (EXOSYSTEMIC AND MACROSYSTEMIC EFFECTS)

The field of health promotion has long endorsed the value of public policy interventions. Such interventions can play a large role in health promotion efforts, such as the enactment of legislation ensuring food safety and mandating the use of seat belts. However, the study of how public policies affect adolescent health behaviors is relatively new, and much more work is needed to conceptualize the relevant policy variables for individuals' behaviors among this population group.

Policy concerning public schools' sex education curricula has long been a topic of debate. Federal funding for abstinence-only programs reached its highest level in 2001 (Gold & Nash, 2001). In addition, results from a review of school superintendents showed that one-third of school districts in the country prohibited contraceptive education unless its purpose was to emphasize contraception's limitations (Landry, Kaeser, & Richards, 1999). Such programs have obvious influences on the kinds of information that youth receive, which may result in differential changes in behavior. Specifically, a review was published comparing randomized controlled trials of abstinence-only programs to those including contraceptive information (Bennett & Assefi, 2005). The authors concluded that while neither type of program was very effective in delaying initiation of sexual activity, the majority of abstinence-plus programs resulted in an *increase* in contraceptive use among youth. These studies show how public policy restricting contraceptive education can have an unintended effect on youth health behaviors.

In the health promotion area, Foster et al. (2008) tested the effects of a policy-based school intervention on youth overweight and obesity over 2 years. The intervention included reformation of school food and nutrition policies to remove all sugary beverages and unhealthy snacks, an addition of nutrition and physical activity education for students, a social marketing campaign to promote healthy eating, and a family outreach component. Compared to control schools, there was a 50% reduction in incidence of overweight, as well as modest decreases in sedentary behavior.

In summary, more research is needed to evaluate the impact of public policy changes on health-promoting and health-compromising behaviors in youth. These efforts could also test the synergistic effects of targeting multiple policies across multiple systems in youth.

RECENT ADVANCES IN HEALTH PROMOTION THEORY IN YOUTH

Reviews of biopsychosocial and ecological frameworks for health promotion and intervention provide collective evidence of the effectiveness of theory-based approaches and

have challenged researchers to increase integration across theories as well as across systems. A systematic review of theories for understanding how school environments influence health showed that 24 theories across 37 different studies have been used, and that their integration provides a framework with a complexity that uniquely matches the complexity of advanced interventions targeting multiple levels of health influence (Bonell et al., 2013). Although ecological systems theory was the most frequently applied/cited theory, it was deemed by the reviewers and by many studies as providing little direction in terms of specific mechanistic pathways. The reviewers provided an option for addressing this by integrating ecological and other theories (e.g., SCT, SDT) to produce four theoretical pathways through which schools influence health in students: student ties to the school, student ties to peers, student cognitions, and student behaviors (see Bonell et al., 2013).

A recent meta-analysis also showed that the theory of planned behavior (TPB; Ajzen & Fishbein, 1980), which promotes intervention almost solely at the intrapersonal level, is frequently used to target dietary behaviors, and is quite effective at promoting behavior change across a variety of settings (Riebl et al., 2015). The theory focuses on identifying personal intentions as immediate determinants of behavior. Intentions may be directly influenced by attitudes and subjective norms (social influence about what a person thinks significant others want the person to do, and the motivation to conform). Thus the TPB provides an example of how an effective intrapersonal theoretical approach can be integrated within social and environmental approaches, to extend effects and perhaps more effectively promote health in youth.

DIFFERENTIAL INTERVENTION EFFECTS DUE TO INDIVIDUAL DIFFERENCES

Nationwide delivery of effective health promotion in youth though targeted behavioral interventions is a strategic priority (Centers for Disease Control and Prevention, 2011). However, the differential effects of these interventions across individuals, or groups of individuals, are not well understood. The effects of any given intervention may vary across individuals, depending on demographic factors such as age or sex, on geographic factors such as living in rural versus urban settings, or on dispositional or hereditary factors. Traditionally, research has not accounted for this variation, and rather has only estimated the average effects of an intervention, assuming that interventions have a uniform impact on health behaviors across all individuals and communities. Despite this assumption, any insights into how interventions differentially affect each unique youth would have important implications for the design and implementation of health promotion programs and policies for youth.

New methodologies have been developed to understand whether and why one individual might respond differently from another to an intervention, and initial studies support the usefulness of exploring these differential effects. Regression mixture models are relatively new statistical methods (DeSarbo, Jedidi, & Sinha, 2001; George et al., 2013; Van Horn et al., 2014) that allow large groups to be broken down into smaller groups that are more similar in how they respond to an intervention (Van Horn et al., 2014). The unique traits of these subgroups can then be explored, to obtain a better understanding of why individuals in different subgroups might respond differently to an intervention. Recent studies justify this more nuanced conceptualization of health

promotion in youth. For example, one study provided evidence that parental guidance to prevent substance use was more effective for European American adolescents and for adolescents who reported greater levels of attachment to their neighborhoods (Fagan, Van Horn, Hawkins, & Jaki, 2013). Gender, age, self-esteem, romantic relationship status, and impulsivity are demographic, intrapersonal, and interpersonal traits that were shown in another study to moderate or influence differential relations between alcohol use and risky sexual behaviors in adolescents involved with the criminal justice system (Schmiege, Levin, & Bryan, 2009). Limitations of this work to date include a lack of studies examining the full spectrum of health behaviors, and a lack of studies examining the differential effects of randomized controlled trials in youth. Thus future exploration in this area will therefore be timely and important for advancing the field.

NEW FRONTIERS IN GENETICS AND THE ENVIRONMENT

Since completion of the Human Genome Project in 2003 and the development of advanced DNA sequencing techniques, the field of genomics has progressed at an exponential pace. Studies of the interactions among individual-level biological factors, the environment, and complex health behaviors across the lifespan have gained increasing attention. Traditionally, conceptualizations of the role of genetics have been based on more deterministic, Mendelian principles for rare behaviors and conditions. However, research findings are making it clear that more common behaviors (e.g., physical activity) and conditions (e.g., obesity) are influenced not by single genetic traits, but by many genetic traits that interact with factors at all ecological levels (Risch, 2000). "Gene × environment" interaction frameworks capture both components of this classic "nature–nurture" debate, asserting that genetic factors interact with environmental factors to influence physiology and health (Shanahan & Hofer, 2005; Dishman, 2008).

Studies in youth have shown these effects across of a host of health behaviors. The fat mass and obesity (*FTO*) gene has been associated with adiposity in African American adolescents (Bollepalli, Dolan, Deka, & Martin, 2010); children carrying two copies of the minor or risky allele have greater body mass indices and fat mass (Crocker & Yanovski, 2009). Studies also suggest that these children have greater food/energy intake and reduced satiety, but show no differences in energy expenditure (Wardle et al., 2008), and animal studies provide further support for these complex genetic interactions (Fredriksson et al., 2008). Family-based treatments have also shown that parent–child dyads with concordance of the Taq1 minor allele had more similar changes in body mass indices over 6 and 12 months of a weight loss intervention (Epstein, Dearing, & Erbe, 2010), confirming that genetics play a role in how interventions vary in their effectiveness across individuals. Another study found that experiencing community adversity during childhood interacted with dopamine- and serotonin-related genetic factors to predict variable body mass index trajectories in youth over time (Wickrama, O'Neal, & Lee, 2013). Interestingly, this study showed an interaction suggesting that higher genetic and environmental adversity was related to poorer trajectories, but that higher genetic susceptibility and a more positive environment were related to better trajectories.

The effectiveness of health promotion programs may be enhanced by gene × environment studies, as they can provide a more comprehensive and developmental understanding of health in youth, and capture both "nature" and "nurture" influences and

their combined effects. Accounting for the role of genetics in health promotion can also broaden perspectives for policy implications by helping to integrate common disease risk assessment into clinical practice, and by providing stronger foundations for policy-level interventions based on increased risk or susceptibility (Meisel, Walker, & Wardle, 2012).

SUMMARY AND CONCLUSIONS

This chapter illustrates how the field of health promotion has expanded beyond models of health that focus solely on intrapersonal risk and protective factors, to models that incorporate social, environmental, and policy-based interventions based on integrated biopsychosocial and bioecological frameworks. The future of health promotion in youth lies in the continued use of integrated theories and continued advances in our understanding of how youth responses to health promotion and intervention may vary. Focus on these key theoretical concepts will aid health care providers and scientists in developing interventions that are not only more effective at facilitating positive health outcomes for the populations and individuals being targeted, but more efficient in terms of resources.

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CHAPTER 41

Prevention

A Multilevel, Biobehavioral, Lifespan Perspective

Maureen M. Black

The 21st century has brought an increase in conditions affecting children's health that were almost unknown in prior centuries, including chronic diseases (Berry, Bloom, Foley, & Palfrey, 2010; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). Through preventive health practices (such as vaccines, sanitation, and infection control), many of the previous threats to children's health (such as infectious diseases) have been eliminated or reduced, with corresponding reductions in childhood morbidity and mortality. This chapter addresses the prevention of children's health problems and associated behavioral and developmental problems. The first section examines prevention science and national policies; the second and third sections address epidemiological and nutritional trends related to health, and describe social determinants of health; the fourth examines child health in the United States, with a focus on mechanisms that may mediate associations with child health and could therefore be targets of prevention; the fifth section addresses prevention strategies; and the final section provides recommendations for prevention as applied to pediatric psychology.

PREVENTION SCIENCE

"Prevention science" is the investigation of strategies to prevent or alleviate adverse conditions or behaviors, often operationalized through minimizing risk factors and maximizing protective factors (Weissberg, Kumpfer, & Seligman, 2003). Risk factors increase the likelihood of adverse consequences and operate at multiple levels, from indi-

vidual through environmental. They may include static factors (e.g., age, race/ethnicity, gender) and modifiable factors (e.g., smoking status, food insecurity). Risk factors tend to co-occur, and the accumulation of risk factors is often more detrimental than specific factors are (Evans & Kim, 2013). Protective factors counteract the effect of risk factors, and also operate at multiple levels (e.g., maternal education, community investment in resources) (Weissberg et al., 2003). For example, in a recent investigation of multiethnic children with asthma, cumulative risks were associated with asthma morbidity, regardless of ethnicity (Koinis-Mitchell et al., 2012). However, protective factors were ethnicity-specific, with family connectedness providing protection against asthma-related functional limitation among Hispanic families, but not among non-Hispanic families.

From a public health perspective, three levels of prevention have been described (Gordon, 1983). "Universal prevention" refers to population-based measures that are universally available and thought to be beneficial to all (e.g., policies regarding water and sanitation, vaccinations for school attendance, and public service announcements). "Selective prevention" refers to measures for subpopulations who may be at risk based on criteria that apply to select groups, such as parents of premature infants, residents of a specific area, or children with asthma or other special health care needs. "Indicated prevention" refers to measures for individuals identified through a screening process, such as children with behavior problems.

Three levels of prevention have also been defined from a medical perspective (Patterson & Chambers, 1995). "Primary prevention" refers to strategies to prevent a disorder before it occurs, often by reducing risk factors (e.g., dietary programs for school-age children designed to prevent excessive weight gain). "Secondary prevention" refers to strategies to reduce or alleviate risks in individuals at high risk for a disorder (e.g., early intervention for children at risk for developmental delays). "Tertiary prevention" refers to attempts to reduce further dysfunction among individuals who have an adverse condition (e.g., strategies to monitor and facilitate adherence among children with diabetes).

The multiple levels of prevention are reflected in the National Prevention Strategy, formulated by the U.S. Surgeon General's Office as part of the Patient Protection and Affordable Care Act (National Prevention Council, 2011). The National Prevention Strategy focuses on wellness and is designed to make the nation healthier for all Americans by laying out a series of four "strategic directions": (1) healthy and safe community environments, (2) clinical and community preventive services, (3) empowering people, and (4) elimination of health disparities. Although Koh and Sebelius (2010) have heralded the Affordable Care Act as addressing prevention as a national priority by implementing strategies to reduce childhood obesity, promote healthy nutrition and opportunities for physical activity, prevent smoking, and decrease health disparities, implementation may vary substantially throughout the country because it is based on state policies and practices. Pediatric health care professionals have raised concern about the variability in implementation of the Affordable Care Act and the need for monitoring to ensure that insurance and high-quality care are available to children, with specific attention to children from low-income families who receive care through the Children's Health Insurance Program (CHIP) (Cheng, Wise, & Halfon, 2014). The introduction of a state-level checklist, entitled "ACA Implementation: Child and Adolescent Health Checklist and Potential Solutions," is a useful step to ensure that children's rights and needs are respected.

EPIDEMIOLOGICAL AND NUTRITION TRANSITIONS

National priorities regarding prevention generally reflect national problems, which change over time. From a broad perspective, the "demographic transition" refers to changes in birth and death rates that alter the shape of the population as societies undergo modernization (Caldwell, 2001). The "epidemiological transition" (Omran, 2001) refers to changing disease patterns, which for children include dramatic reductions in malnutrition and communicable diseases, largely associated with improved public health practices in reducing exposures.

Modernization has also led to a "nutrition transition," defined by shifts in dietary patterns and lifestyle behavior (Caballero & Popkin, 2002). Energy-dense foods with high fat/oil content have become widely available, along with sugar-sweetened beverages; a dietary pattern that includes frequent snacking has also emerged. At the same time, advances in transportation and energy-saving devices have led to increases in sedentary behavior. The result has been a dramatic increase in rates of obesity, beginning in toddlerhood and extending throughout life (Ogden, Carroll, Kit, & Flegal, 2014). Obesity has compromised children's health, as demonstrated by a recent national survey showing that in 2011–2012, 1 in 10 children ages 8–17 had borderline high or high blood pressure, and 1 in 5 had adverse lipid concentrations (Kit et al., 2015).

In response to the changing health risks to children, and in keeping with the wellness focus of the National Prevention Strategy, in 2010, the U.S. Congress passed the Healthy, Hunger-Free Kids Act. The act focuses on wellness policy guidelines for schools and child-care centers, with the objective of preventing nutrition-related problems by ensuring access to healthy food in schools and child care centers.

SOCIAL DETERMINANTS OF HEALTH

The recognition that health and disease are influenced by both biological and social processes led to the formation of the Commission on Social Determinants of Health by the World Health Organization in 2005 (Marmot, Friel, Bell, Houweling, & Taylor, 2008). With a primary focus on health inequities, the commission differentiates "health inequity" from "health inequality." Although both terms refer to disparities in health conditions, inequities are considered to be modifiable and therefore could be the targets of prevention or intervention, whereas inequalities are considered to be descriptive and not necessarily modifiable. Thus, for example, access to healthy food may be an inequity, because alternative sources of food could be developed. In contrast, race or gender would be an inequality, because it cannot be changed. Since its formation, the commission has taken a lifespan perspective and gathered evidence that explains how social factors are linked to health.

Long before the formation of the Commission on Social Determinants of Health, it was apparent that life chances for health vary by social disparities ranging from birth country, to gender and racial/ethnic background, to socioeconomic status. The unequal distribution of wealth, power, and opportunity has health consequences, beginning early in life (Yoshikawa, Aber, & Beardslee, 2012). What the Commission on Social Determinants of Health highlights is that social policies and programs play a role in both causing and remediating many of these inequities (Marmot et al., 2008). Accord-

ingly, the three courses of action recommended by the commission are to improve the conditions of daily life; to adjust the inequitable distribution of power; and to approach the issue from a rigorous scientific perspective through measurement, evaluation, and the development of a workforce that focuses on alleviating the social inequities.

Equity among young children has a strong place within the Commission on Social Determinants of Health (Marmot et al., 2008), and the concern has been extended to older children (Li, Mattes, Stanley, McMurray, & Hertzman, 2009). Although adequate health care coverage is a central component in ensuring health equity, health care coverage alone is not enough (Irwin et al., 2006). Not only does access to care vary based on insurance coverage, but children have many needs that cannot be met through health care services (e.g., social protection). According to 2013 data, 8% of U.S. children through 18 years of age (almost 6 million) were uninsured (Kaiser Family Foundation, 2014). Approximately 39% (30 million) were covered through Medicaid or other public insurance, and 54% (41.7 million) were covered through parents' employers' or other private insurance. As noted in the discussion of the Affordable Care Act, health insurance for children is a critical component of preventive services.

CHILD HEALTH IN THE UNITED STATES

The United States is facing a national crisis related to childhood poverty and inequities. Rates of childhood poverty approach 21% of children, defined as below 100% of the federal poverty threshold, which is $16,317 for a family of two with one child, or $24,008 for a family of four with two children (Jiang, Ekono, & Skinner, 2016). Inequities are particularly apparent when children's chronic illnesses are considered (Berry et al., 2010; Price, Khubchandani, McKinney, & Braun, 2013). One in six children has a chronic illness or disability, and when obesity is considered, the rates increase (Ogden et al., 2014). Although survival rates have increased for children with certain illnesses, such as acute leukemia, they often vary by race/ethnicity, with lower rates among children from minorities (Berry et al., 2010). Overall, children from racial/ethnic minorities have higher rates of chronic illness and worse outcomes than children from white families (Berry et al., 2010).

Food insecurity (lack of access to enough food for an active, healthy life) is a consequence of poverty that is associated with negative health and developmental consequences for young children (Cook & Frank, 2008). The U.S. Department of Agriculture (USDA) administers two nutrition assistance programs designed to prevent food insecurity. The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides vouchers for food and nutritional counseling for pregnant and breastfeeding women, infants, and children through age 4 years, and the Supplemental Nutrition Assistance Program (SNAP, formerly the food stamp program) provides financial resources for food. Both programs have income eligibility criteria. WIC reaches over 50% of all U.S. infants (USDA, 2015), and SNAP reaches more than 25% of U.S. children prior to age 5 years (Rank & Hirschl, 2009). Both WIC and SNAP have been effective in reducing rates of food insecurity and enhancing children's health (Black et al., 2012; Kreider, Pepper, Gundersen, & Jolliffe, 2012).

Poverty is also strongly associated with low developmental and educational performance (Engle & Black, 2008). Recent evidence has extended the association to negative

health consequences, lasting throughout life (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010). Adults who have been raised in poverty are at heightened risk for cardiovascular disease and some forms of cancer, even if they are no longer living in poverty (Galobardes, Lunch, & Smith, 2008). These findings suggest that "programming" may occur early in life (perhaps prenatally), with associated health risks throughout life. For example, prenatal exposure to maternal stress increases the likelihood that a child experiences stress reactivity, along with emotional and cognitive problems (Sandman, Davis, Buss, & Glynn, 2012).

The mechanisms linking poverty to child health extend through multiple levels, in keeping with the multiple influences on children's behavior and development conceptualized in developmental and ecological theory (Bronfenbrenner & Ceci, 1994) and represented in the National Prevention Strategy. At the household level, poverty has been associated with limited resources, parenting stress, and exposure to hygienic threats. At the broad levels, children raised in low-income communities with high rates of violence not only have limited exposure to positive role models and increased risk for behavioral and developmental problems; they also have disruptions in stress-related measures, such as inflammatory reactions that could compromise their health (Moffitt & the Klaus-Grawe Think Tank, 2013). The investigation of biomarkers related to stress sensitivity has led to calls for investigations into the stress–biology connections to child health and behavior, with attention toward innovative strategies for prevention (Shonkoff, Boyce, & McEwen, 2009).

The hypothalamic–pituitary–adrenocortical (HPA) axis, an important component of the neuroendocrine regulatory system, is sensitive to stress. In response to threats, the brain activates the HPA system, which produces cortisol; cortisol production leads to arousal readiness through activation of cardiovascular tone and energy, and suppression of immune functioning (Blair, Raver, Granger, Mills-Koonce, & Hibel, 2011). In the face of chronic stress, the body maintains a readiness state, the circadian rhythm characteristic of the baseline HPA system is disrupted, and the body experiences a "weathering" process that weakens the ability to mount a response when needed (Miller, Chen, & Parker, 2011). Blood pressure may be elevated, and chronically elevated cortisol can render the immune system unresponsive, resulting in increased vulnerability to health risks. Disruption to HPA functioning (measured through cortisol production) has been associated with childhood disorders of anxiety, depression, and self-regulation, along with cognitive and attentional problems (Lupien, King, Meaney, & McEwen, 2000; Evans & Kim, 2013). The findings, taken together, indicate that the response to chronic stress early in life may prepare children for a life of adversity with a need for quick responses, but that at the same time it undermines their ability to form relationships and to concentrate on the demands of education, while increasing their vulnerability to illness (Thompson, 2014).

Although there is emerging evidence supporting early programming and vulnerability to the HPA axis associated with stress, there is substantial variability in response, with some low-income children demonstrating resilience. At least two mechanisms have been suggested. One possibility is that a transition out of poverty alleviates stress, thereby enabling the HPA axis to resettle into a regulatory pattern (Cohen, Janicki-Deverts, Chen, & Matthews, 2010). The other possibility is that a buffering process occurs through responsive parenting, whereby parents are warm and sensitive to their children's actions (Danese & McEwen, 2012). The beneficial effects of parenting and

early intervention on children's early exposure to risk have been shown by at least four unique investigations.

The first study is the Bucharest Infant Development Project (Nelson et al., 2007). Young children raised in an orphanage in Romania were randomly assigned either to reside in a foster home or to remain in the orphanage. Children placed in foster care had improved developmental quotients at 48 months and improved IQ scores at 54 months of age. However, the cognitive development of children in foster care was significantly lower than that of a reference group of children who were never institutionalized. The earlier children were placed in foster care, the stronger the cognitive benefit, suggesting that the first 2 years of life are a sensitive period for placement of abandoned infants into foster care (Nelson et al., 2007).

The second study demonstrating the beneficial effects of parenting is a longitudinal national investigation of adults that examined the association between a childhood history of poverty and adult health, measured by biological samples indicative of the metabolic syndrome (waist circumference, blood pressure, lipid panel, and blood glucose) (Miller, Lachman, et al., 2011). Low childhood socioeconomic status was associated with worse metabolic outcomes at middle age, with no protection provided by upward social mobility in adulthood. However, almost 50% of the adults with a history of low childhood socioeconomic status were protected from the metabolic syndrome by reports of maternal (but not paternal) nurturance. These findings suggest that socioeconomic status is programmed or embedded in children's physiology early in life and increases vulnerability to health risks throughout life, but that maternal nurturance can disrupt the process.

The third study that shows beneficial effects of parenting involves inflammation. Inflammation has been proposed as a possible mechanism linking childhood low socioeconomic status and adult vulnerability to the metabolic syndrome. Children in low-income households have mild, chronic inflammation as adults (Phillips et al., 2009), and inflammatory processes are involved in the metabolic syndrome (Hotamisligil, 2006). In a recent trial, Miller, Brody, Yu, and Chen (2014) showed that a family-oriented intervention administered among 11-year-old African American boys from low-income families led to significantly less inflammation on six cytokines when measured 8 years later, at age 19. By identifying the "under the skin" mechanisms that are altered by psychosocial interventions, this type of evidence has major implications for prevention.

The fourth and final study involves early intervention. It is a 35-year follow-up of a randomized trial of low-income African American children. The group randomly assigned to participate in a comprehensive preschool for 5 years had better health indicators as adults than the control group. The intervention males had lower diastolic and systolic blood pressure, and less likelihood of hypertension, metabolic syndrome, and vitamin D deficiency. The intervention females had less likelihood of prehypertension and marginally less likelihood of severe obesity. Thus the intervention group had better health indicators in adulthood and a better prognosis for future health. The disparity began during the preschool years because the control group was consistently heavier, beginning within 3 months of recruitment (Campbell et al., 2014). These findings suggest that the beneficial effect of the preschool on health outcomes was mediated by healthier growth, beginning in preschool.

Taken together, these four studies highlight the role of parenting and early intervention in preventing some of the negative consequences associated with poverty.

PREVENTION STRATEGIES

The National Research Council and Institute of Medicine (2009) report on prevention focused on mental, emotional, and behavioral problems among children. Not only do behavioral and developmental problems frequently co-occur, but they often begin early in life, with common origins that may include health problems. Recent developments in neuroscience related to stress sensitivity may underlie problems in behavior and development, as well as in health, suggesting that prevention focused on reducing or alleviating risks and stress early in life may be beneficial in multiple domains.

In addition to alleviating risks, prevention strategies often focus on altering the mediating mechanisms that link poverty to negative consequences for children, often in their proximal environments of home, school, and preschool. Biglan, Flay, Embry, and Sandler (2012) advocate for the promotion of nurturing environments by demonstrating, teaching, and reinforcing prosocial behavior, while limiting opportunities for problem behavior. The multilevel recommendations extend from families through institutions, emphasizing processes such as psychological flexibility (recognition of one's thoughts and values), the promotion of monitoring and limit setting in schools, and the reduction of toxic social and biological exposures.

Responsive caregiving is a central component of several theories related to early child health and development, including attachment theory and social-cognitive theory, and has been promoted as a critical component of early childhood prevention programs (Black & Dewey, 2014). Caregivers and young children co-regulate their interactions through mutual communications, leading to child stress regulation (Tronick & Beeghly, 2011). Caregivers are influenced by their children's behavior and by perceptions of their children's temperament. According to attachment theory, responsive caregiving is initiated by child behavior, followed by prompt and sensitive caregiver behavior. The child experiences a positive interaction, and the interaction continues. From a social-cognitive perspective, responsive caregiving reinforces the child's behavior and provides scaffolding opportunities. Children acquire skills through modeling from their caregivers, thereby promoting more advanced developmental skills.

Parenting programs can be effective in promoting responsive caregiving (Blair & Raver, 2012; Landry et al., 2012). In addition, recent evaluations of school-based programs focused on enhancing children's socioemotional learning have been positive (Durlak, Weissberg, Dymnicki, Taylor, & Schellinger, 2011). These finding illustrate the beneficial effects of parenting and children's socioemotional programs.

IMPLICATIONS FOR PEDIATRIC PSYCHOLOGY

Pediatric psychology has a long history of focusing on prevention (Roberts, 1986). With expertise in child health, behavior, and development, the field of pediatric psychology has been well positioned to examine how socioeconomic and ethnic/racial disparities relate to children's functioning when the children are confronted with chronic illnesses and disabilities (e.g., Swartwout, Garnaat, Myszka, Fletcher, & Dennis, 2010). Next steps are to develop prevention strategies to alleviate the disparities and/or to help children and families cope with adverse conditions, particularly families of children with chronic illnesses and special health care needs. Disparities accentuate the health, behav-

ioral, and developmental challenges among children with chronic illness, increasing their vulnerability (Victorino & Gauthier, 2009). Recommendations from the Commission on Social Determinants of Health and from the National Prevention Strategy can be used to formulate a plan to advance prevention strategies. The commission's recommendations to improve the conditions of daily life and to employ a rigorous scientific perspective are central to many pediatric psychology interventions. For example, a recent intervention trial to reduce child- and parent-reported internalizing and externalizing behavior among children with chronic illness reported that the effects of the intervention were moderated by characteristics of parents and children, with particular benefits to at-risk children when their parents were involved in the intervention (Scholten, 2015). Intervention trials that are rigorously designed and examine operative mechanisms are likely to yield informative findings.

Injury prevention has been an important focus within pediatric psychology for over two decades (Finney et al., 1993; see also Morrongiello & Schwebel, Chapter 39, this volume). Unintentional injuries constitute the leading cause of morbidity and mortality among children in the United States, particularly among children from low-income families (Centers for Disease Control and Prevention, 2013). In response to the high prevalence of pediatric injuries, the Centers for Disease Control and Prevention initiated the National Action Plan for Child Injury Prevention, to identify effective strategies to promote child safety. Pediatric psychologists have identified multiple innovative injury prevention strategies, ranging from environmental protection to increased child awareness to caregiver supervision (Morrongiello, 2005).

In keeping with recommendations from the National Prevention Strategy, by adopting a developmental–ecological focus (Bronfenbrenner & Ceci, 1994), pediatric psychologists can extend preventive efforts from the child and family to include environmental conditions in the home, school, and community. Partnering with public health colleagues may be effective in developing prevention programs to reduce environmental sources of health disparities. For example, ensuring that families are accessing food assistance programs and other publicly available resources may alleviate stress and provide assistance.

The recent advances in neuroscience highlight the role that stress plays in children's health, as well as the potential impact of nurturance and psychosocial interventions in alleviating the behavioral and biological indicators of stress. This research leads to several recommendations:

- Intervene early in life, especially when working with at-risk populations.
- Help families avoid the accumulation of risks; for example, obesity can increase the complexity of chronic illnesses.
- Focus on prosocial skills and psychological flexibility.
- Acknowledge the impact of the family, and develop family-oriented strategies.
- Reduce exposure to excessive stress in the home and community.
- Encourage a nurturing environment at home, at school/in child care, and throughout the community.
- Establish limits and consequences in families and schools.
- Identify accessible community resources.

- Develop rigorous prevention strategies that include systematic data collection, feedback, reevaluation, and dissemination.
- Promote equity by advocating for the rights of children, especially children with chronic illness and special health care needs.
- Keep informed on current theories and findings.

With the changing threats to children's health associated with the epidemiological and nutrition transitions, and with the recognition that the building blocks of adult health are formed early in life, prevention of childhood illnesses has attracted global and national attention. Recent evidence supports a multilevel, biobehavioral, lifespan perspective to prevention that can play a major role within pediatric psychology.

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CHAPTER 42

Pediatric Psychology and Primary Care

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Most children seen for pediatric care are not in hospitals and do not have serious chronic illnesses or debilitating medical issues, which historically have been major foci in pediatric psychology. Most health care services for children take place in outpatient pediatric and primary care settings. "Primary care" refers to a broad spectrum of health care services, both preventive and curative, delivered in outpatient (ambulatory) medical settings. The primary care clinician and office serves, among other things, as the "patient-centered medical home" (PCMH) for a child. This model of team-based care is physician-led, and it provides continuity of culturally sensitive care and care coordination across health systems. Clinic services focus on prevention of illness, promotion of health and wellness, amelioration of consequences of chronic health conditions, and behavioral health (Patient-Centered Primary Care Collaborative [PCPCC], 2007; Tynan & Woods, 2013). Primary care can be contrasted with acute and urgent care health services, which are directed toward sick or injured children. In the United States, pediatric primary care providers (PPCPs) are usually pediatricians and family medicine physicians (71% and 22%, respectively, in 2006; Freed et al., 2010), with some care also delivered by nurse practitioners, nurse clinicians, or physician assistants. Ideally, PPCPs serve as health care coordinators of all care that their patients receive.

Primary care settings that include on-site mental health services are referred to as "integrated" or "collaborative care" settings (Stancin, 2005). Collaborative care is interprofessional, coordinated patient care that attends to mental health as part of primary care for children, often through co-located services. Behavioral health providers may be co-located physically in a clinic, but they may not necessarily be "integrated" into broader clinic services (e.g., prevention and screening, consultation to staff) that ensure that behavioral health services are available to all children (Stancin & Perrin, 2014).

Although pediatric psychologists are ideally suited to partner with PPCPs and lead the development of mental health services in primary care settings, pediatric psychology has had a fairly limited presence in these settings, perhaps because of its historical focus on inpatient collaboration in the care of children with chronic medical conditions. However, integrated primary care is emerging as the foundation for the evolving health care system in the United States, and there is increasing interest in roles for pediatric psychologists in primary care (Stancin & Perrin, 2014; Stancin, Sturm, & Ramirez, 2014). This chapter describes past and present behavioral health activities in pediatric primary care, and outlines opportunities for pediatric psychologists to participate in the mental health care of children and adolescents in this setting.

HISTORICAL CONTEXT

Early pioneers in pediatric psychology, including Jerome Kagan, Logan Wright, Dorothea Ross, and Lee Salk, as well as several pediatrician leaders of the 1960s (e.g., Wilson, 1964), envisioned pediatric practice models for psychologists working in primary care settings. Smith, Rome, and Freedheim (1967) were the first in a long line of pediatric psychologists who have advocated for primary care mental health services (see Stancin & Perrin, 2014, for a review). In particular, Carolyn Schroeder (1979) raised awareness of the potential scope and impact of a primary care psychology. The practice she developed, in which psychologists had multiple roles besides therapists (i.e., educators, consultants, advocates, case managers, and outcomes researchers), stands today as a model for pediatric psychologists' activities in primary care.

NEW ROLES FOR PEDIATRIC PSYCHOLOGISTS IN RESPONSE TO CHANGING HEALTH CARE

Shorter hospitalizations for children have decreased opportunities to provide inpatient consultation and intervention services, which were previously mainstays for pediatric psychologists. Concurrently, pediatric and child mental health professional organizations have shifted their attention toward enhancing mental health services in primary care settings, for several reasons:

- Developmental, behavioral and emotional problems in youth are common (10–25%) in primary care and cause functional impairment (Stancin & Perrin, 2014).
- PPCPs are the health professionals most likely to come into contact with youth with behavioral and emotional problems. Yet they are not trained, nor do they have time, to address all the behavioral problems that arise (Stein et al., 2008).
- There is a shortage of qualified mental health clinicians, especially for children younger than 5, and for families in middle- and low-income groups and/or of minority background. Thus many children do not receive needed mental health care (Stancin & Perrin, 2014; Zuckerman et al., 2014).
- Primary care settings provide the most accessible and least stigmatizing resources for many families. Mental health services provided in primary care settings have

been shown to be more acceptable to families and to lead to better outcomes than services provided in other, more traditional outpatient settings (Kolko et al., 2014).

- It is necessary to address availability, quality, and cost issues outlined by recent health policy initiatives (e.g., the Patient Protection and Affordable Care Act of 2010).

HOW DO INTEGRATED MENTAL HEALTH PRIMARY CARE SERVICES DIFFER FROM TRADITIONAL CARE?

In traditional primary care settings, physicians and nurse practitioners provide services, and mental health care is all delivered via referrals to outside mental health providers. Offices, records, schedules, and treatments are entirely separate. If there is any behavioral health emphasis in a traditional primary care office, it is on screening and referral, with limited pharmacological management for selected conditions (e.g., attention-deficit/hyperactivity disorder [ADHD]).

In a primary care center with integrated mental health services, medical and mental health care providers collaborate as a team on patient care. Office space and records are shared, and schedules overlap. Mental health services include direct patient care as well as prevention and screening. Psychopharmacological care is monitored and managed collaboratively. Key factors that define how services are delivered are the extent to which they are co-located and integrated into practice procedures (Stancin, 2005).

Primary care mental health services tend to be delivered differently than interventions in traditional outpatient mental health settings, which typically involve relatively small client loads, 50-minute sessions over many months, fairly extensive documentation, and case closure at termination. Psychologists in an integrated primary care setting tend to have larger client loads offset by flexible time limits, brief/short-term treatments, less extensive documentation, and open-ended case plans (i.e., each child is followed as needed).

In contrast to more traditional outpatient mental health settings, where providers often treat multiple, severe problems with complex psychosocial factors, primary care interventions tend to focus more on targeted, specific problems that are of mild to moderate severity (Stancin & Perrin, 2014), with the exception of crisis evaluations (Wintersteen & Diamond, 2013). One reason for this difference is the age of patients. Although children of all ages are seen in primary care settings, the majority are infants and very young children; healthy children over age 2 years usually see their PPCPs only once per year, unless they have an acute illness or their parents have a particular concern. This predominantly infant and toddler population offers important opportunities for prevention and early intervention, such as developmental surveillance, screening for delays, promotion of healthy parent–child interactions, and detection of parental mental health problems (Briggs et al., 2012; Perrin, Sheldrick, McMenamy, Henson, & Carter, 2014; Weitzman & Wegner, 2015). Studies describing the types of problems in children seen for primary care behavioral services have shown that the most frequently

referred problems are negative behaviors such as tantrums, oppositional behavior, defiance, noncompliance, and aggression; mood and school-related problems are also common presentations (Polaha, Dalton, & Allen, 2011; Kolko, Campo, Kilbourne, & Kelleher, 2012).

Roles and communication patterns in primary care practices also differ from those in a more traditional mental health setting, which emphasize a single therapist role with little or no direct communication with a PPCP. Psychologists based in primary care often adopt multiple roles (see Table 42.1) and are visible and accessible to PPCPs, so there are ample opportunities for prompt, frequent feedback, collaboration and discussion.

TABLE 42.1. Professional Roles of Pediatric Psychologists in Primary Care

Clinical services

- Application of evidence-based evaluation and treatment of developmental and behavioral concerns
- Assessment and interventions for problems with pediatric medical conditions (e.g., adherence, pain management)
- Health behavior change interventions (e.g., for obesity)
- "Warm handoffs" (i.e., same-day consults)
- Co-management of patients with PPCPs or other health care team members (e.g., dietitians)
- Coordination of pharmacological and psychological interventions
- Supervision of master's-level clinicians
- Coordination/leadership of psychoeducational groups

Health communication

- Communication skill building of team members (motivational interviewing, coaching)
- Fostering of reflective practice by team members

Research

- Leadership of/collaboration in randomized controlled trials of adaptations of evidence-based treatments for primary care settings
- Participation in "team science"

Clinic program development

- Guidance in selection and implementation of developmental and behavioral screening programs and follow-up protocols
- Leadership of/support for continuous quality improvement programs
- Leadership of/support for selection of behavioral health outcome measures for clinic

Education

- Supervision of psychology practica, interns, and postdoctoral learners
- Participation in interprofessional education
- Transdisciplinary education of team members

Policy advocacy for psychology

- Co-development of clinical guidelines with pediatric and child psychiatry professional organizations
- Participation in cross-discipline policy development

OPPORTUNITIES FOR PEDIATRIC PSYCHOLOGISTS IN PRIMARY CARE SETTINGS

The Affordable Care Act regulations emphasize preventive services (screening and early intervention); coordination with school and social services; and, most importantly, payment for outcomes. Soon providers will receive bonuses if patients are healthier and functioning better. Opportunities to assist health practices in screening and early effective intervention for children will be available for psychologists who understand the contingencies of payment for outcomes, and who can work effectively with health care providers. Pediatric psychologists in primary care settings may be involved at every level of care (e.g., developing and carrying out screening programs; organizing and leading educational and therapeutic groups for parents and for children; providing brief individual psychotherapy to parents and to children; and facilitating referrals to community-based mental health and developmental resources). They may help coordinate the medical, mental health, and family/community care of children with chronic health conditions and their families. Moreover, behavioral research in primary care would be greatly advanced by more pediatric psychology involvement (Stancin & Perrin, 2014).

Screening

Clinical guidelines from the American Academy of Pediatrics (AAP, 2006; Johnson, Myers, & AAP Council on Children with Disabilities, 2007; Weitzman & Wegner, 2015) support routine screening for developmental concerns and autism in very young children, as well as for behavioral disorders and mental health problems in children of all ages. Screening for social-emotional developmental problems in very young children has received less attention and may benefit from psychologists' advocacy for their inclusion in universal behavioral health screening (Briggs et al., 2012). Screening for adolescent depression (Cheung et al., 2007) and maternal depression are also of interest in primary care. Ward Zimmerman and Vandetti (2014) have highlighted the impact of maternal mood disorders on the well-being of young children and have argued compellingly for regular screening in the pediatric medical home, followed by effective linkages to needed services across the first 6 months of life. With training in psychometrics as well as medical collaboration, pediatric psychologists are uniquely qualified to guide PPCPs in selecting valid and feasible methods for screening in their practices (Stancin & Palermo, 1997). Moreover, pediatric psychologists are able to direct screening and follow-up programs, provide more comprehensive developmental evaluations, and link families with additional resources in the community. Reviews of developmental and social-emotional screens can be found in Drotar, Stancin, Dworkin, Sices, and Wood (2008) and Weitzman and Wegner (2015).

Clinical Interventions

Children are more likely to receive mental health services in their primary care setting than in off-site settings (e.g., Williams, Shore, & Foy, 2006). In a multisetting, randomized controlled study, Kolko et al. (2014) examined outcomes for children referred for mental health services integrated into primary care practices, compared to those referred to usual care (community care practices). They reported higher rates of treat-

ment initiation (99.4% vs. 54.2%;) and completion (76.6% vs. 11.6%,); improvement in behavior problems, hyperactivity, and internalizing problems, as well as parental stress; remission in behavior and internalizing problems; and goal improvement, treatment response, and consumer satisfaction. Moreover, pediatricians reported greater perceived practice change, efficacy, and skills in treating ADHD. Examples of additional brief problem-focused intervention approaches for primary care can be found in Etheridge (2005) and Robinson and Reiter (2007).

Psychologists have empirically supported interventions available for the treatment of common childhood problems (disruptive behavior disorders, mood disorders, etc.), and primary care settings are proving to be appropriate environments for adapting some of these programs (e.g., the Triple P Program; Sanders, 1999). In addition, the application of technology to health care (e.g., interventions involving telehealth, web-based platforms, text messaging, video chats, phone apps, and gaming) is expanding to interventions in primary care (see Epstein Langberg, Lichtenstein, Kolb, & Simon, 2013; Harris et al., 2015; and Marsac et al., 2015). Borowsky, Mozayeny, Stuenkel, and Ireland (2004) reported that a telephone-based manualized intervention for disruptive behavior problems was more effective than standard screening, referral, and follow-up care in a primary care setting. Lavigne et al. (2008) compared three interventions for oppositional defiant disorder (ODD) in primary care: (1) nurse-led or (2) psychologist-led group manualized parent training treatment, or (3) a minimum intervention consisting of just the companion treatment book. Results indicated sustained improvements in all three conditions, with better results for parents who attended more of the intervention sessions. The authors also noted improvements with minimal interventions in this relatively more educated parent population, suggesting that intensive interventions may not be the first-line treatment of choice for all children identified with ODD in primary care.

A recent meta-analysis (Asarnow, Rozenman, Wiblin, & Zeltzer, 2015) examined whether integrated medical–behavioral health care for children and adolescents leads to improved behavioral health outcomes compared with usual primary care. These authors identified 31 randomized controlled trials representing a variety of integrated care models: *collaborative care,* in which evidence-based interventions were delivered on site; *enhanced primary care interventions* (such as telephone consultation or physician training); and *prevention efforts*. Results indicated a small and significant positive effect for integrated care interventions, with best outcomes for the collaborative care interventions.

Health Behaviors

Children with chronic physical health conditions may experience secondary psychological and social morbidity, and innovative models of care in primary care settings have been described that focus on these needs (e.g., McMenamy & Perrin, 2004). As experts in caring for children with chronic conditions, pediatric psychologists are ideally equipped to address problems with treatment adherence and disease management. Psychological interventions that have been shown to improve outcomes for conditions such as asthma can be implemented in primary care settings, including self-management training, problem-solving techniques, family-based interventions, motivational interviewing (MI), and relaxation training/biofeedback. These interventions are likely to improve outcomes for

other pediatric medical conditions, such as diabetes, seizures, cancer, sickle cell anemia, Crohn disease, migraine headaches, and pain. In addition, pediatric psychologists have developed innovative health behavior change efforts for other primary care problems, including obesity, sleep disturbances, elimination/toileting problems, and problematic feeding/eating behaviors (Stancin & Perrin, 2014). Evidence-based interventions, many of which are applicable to primary care, can be found on a Society of Pediatric Psychology webpage (*www.apadivisions.org/division-54/evidence-based/index.aspx*). Additional descriptions appear in special journal issues on evidence-based interventions in pediatric psychology (*Journal of Pediatric Psychology,* Vol. 39, No. 8*; Clinical Practice in Pediatric Psychology,* Vol. 2, No. 3).

Health Communication

A deficit in many PPCPs' training involves communication skills. These include the ability to provide office-based counseling for health behavior change, and conversations involving "bad news" with parents in a manner that is supportive, culturally sensitive, and empowering. Pediatric psychologists in clinics that serve as sites for medical learners (e.g., pediatric continuity clinics, family medicine clinics) can play an important role by attending to learners' communication skills. With changes in graduate medical education and the priority placed on PCMHs, there is new attention to the importance of medical learners' (and all team members') becoming skilled health communicators.

Medical learners can benefit from modeling and feedback by co-located pediatric psychologists on, among other skills, responsiveness to patients' emotions, participatory decision making, and adjusting communication during interaction via self-reflective practice. Occasions for such teaching include co-interviewing and co-management of cases, as well as co-precepting by faculty psychologists alongside pediatricians, in which both discuss clinical cases with learners. An example of psychologists' serving as communication coaches can be found in McDaniel's (2013) Patient- and Family-Centered Care Physician Coaching Program.

Pediatric psychologists have also taken the lead in applying MI strategies to family and adolescent issues that are common in primary care (Erickson, Gerstle, & Feldstein, 2005; Naar-King & Suarez, 2011). Although PPCPs may have some limited exposure to MI, many would benefit from consultation on applying this approach to issues that arise during well-child visits, including teen self-care for chronic medical conditions, sexual risk behavior reduction, obesity, vaccine hesitancy, and parental reluctance to pursue treatment recommendations (e.g., co-sleeping, reducing secondhand smoke exposure). Psychologists can also support MI interventions that are motivation-enhancing; that is, they can increase the likelihood that families will follow through with participation in group interventions, such as parent education groups or condition-specific groups (e.g., groups for youth obesity, ADHD, diabetes).

CULTURAL COMPETENCY IN PROVIDING BEHAVIORAL HEALTH SERVICES

Pediatric psychology services in primary care can include population-based services for common behavioral health problems, including routine surveillance, screening, and early intervention; group-based treatment models; and care coordination for children

with chronic health conditions or developmental disorders. Such services can decrease disparities in behavioral health. Disparities related to immigration and ethnic status are increasingly matters of concern. For example, ethnic disparities in autism spectrum disorder diagnoses are well established (Zuckerman et al., 2014): Hispanic children are diagnosed later and with more severe symptomatology at the time of diagnosis than white non-Hispanic children. Such delays can prevent timely early intervention services, which are considered the standard of care for this population. Undocumented families of children with autism spectrum disorder and developmental disabilities report needing more help than they often receive from health care providers (Lin, Yu, & Harwood, 2012). Likewise, when Mexican children in a California clinic were screened for problems, almost 40% of caregivers reported concerns about aggression and attention, but no anxiety or depression symptoms were identified, despite the tendency of internalizing symptoms to be pronounced in Hispanic populations (Tarshis, Jutte, & Huffman, 2006). Pediatric psychologists' expertise in selection and implementation of screening measures should ensure that they are involved in the design of clinical protocols, to prevent vulnerable populations from "flying below the radar" of developmental risk identification.

Moreover, pediatric psychologists can introduce health care providers to the emerging literature on the effects of scarcity/poverty on cognition and decision making in regard to health. Judicious weaving of evidence-based research into clinical discussions can help providers resist judgmental assumptions about parents' and/or adolescents' "problematic choices," thereby improving empathy and reducing blaming. In addition, providers can be helped to appreciate the potential strengths of the disadvantaged families they serve. A strengths-based orientation is crucial to helping providers maintain an optimistic, hopeful spirit when recommending interventions or health behavior change; it also reduces provider burnout.

TRAINING PEDIATRIC PSYCHOLOGISTS TO WORK IN PRIMARY CARE

The model of integrating mental and medical health care in primary care settings requires a different emphasis than is found in most pediatric psychology training programs. In addition to a broad clinical child and pediatric psychology background, a solid knowledge of normal child development and behavior concerns; facility with behavioral and developmental screening and assessment techniques; and competencies in deliver brief, solution-focused, and family systems treatments that are developmentally appropriate for each child's and each family's life stage are required. Psychoeducational assessment and intervention skills related to parenting and discipline topics are essential. Moreover, primary care psychologists must be knowledgeable about general pediatric medical issues, including anatomy, disease processes, and preventive medicine; knowledge about the evaluation and treatment of psychosocial aspects of chronic and acute medical conditions is essential as well. Finally, these psychologists also need to be comfortable discussing patients' needs for psychopharmacology, although not as replacements for psychiatrists.

McDaniel, Belar, Schroeder, Hargrove, and Lerman Freeman (2002) proposed an initial training curriculum in primary care psychology to supplement standard core graduate psychology training. Their curriculum includes 12 areas of core knowledge and

skills, and specific training objectives pertaining to health and illness. More recently, training for pediatric psychologists has been energized by two training competency documents sponsored by the American Psychological Association (APA) (McDaniel el al., 2014; Palermo et al., 2014). Led by the Division 54 Integrated Care Special Interest Group (K. Woods & L. Ramirez, personal communication, October 2015), efforts are underway to specify the pediatric primary care behavioral benchmarks/anchors that correspond to these general pediatric psychology competencies. This tailoring of primary care benchmarks to correspond to general pediatric psychology should assist psychology educators tasked with helping the next generation of pediatric psychologists to acquire skills for primary care.

Innovative training models for internship and postdoctoral psychology trainees in primary care setting have also emerged in recent years. The APA Education Directorate makes available a directory of internship programs with opportunities in primary care psychology (Grus & Cope, 2013). Some programs, such as those at Nemours/Alfred I. DuPont Hospital for Children (Novotney, 2014), Children's Hospital of Philadelphia, and the Nebraska Internship Consortium at Monroe-Myers Institute, have developed integrated behavioral health tracks. The pediatric and child clinical psychology internship at MetroHealth Medical Center includes substantive time (30%) in pediatric primary care continuity clinics (Nielsen, 2014). In the MetroHealth model, psychology interns and pediatric residents cross-train side by side through didactics, shadowing one another, and collaborating on clinic cases. Postdoctoral fellowships focused on primary care and integrated models are increasingly available, with some specific to pediatric settings. In Denver, Colorado, Project CLIMB (Consultation Liaison in Medical Health and Behavior) trains psychology fellows alongside psychiatry trainees in an integrated mental health program in a primary pediatric clinic; this project also includes training in "Healthy Steps" infant mental health services (Talmi et al., 2015). At the graduate school level, courses and practicum experiences in primary care would better prepare psychology trainees for future work in primary care.

CHALLENGES TO COLLABORATIVE CARE

Collaboration across disciplines and training models in primary care is a complex matter, and it requires motivation and establishment of common goals to be successful. Such apparently simple issues as scheduling and time management can become major stumbling blocks in collaborative practice. On a practical level, payment for services and communication issues are key points to be resolved very early in the process of establishing an integrated care practice.

Funding Challenges

In the current environment, there is a new emphasis on the PCMH (PCPCC, 2007) as the vehicle for team care. Primary care practices that are accredited as PCMHs are now eligible for additional payments from insurers for care management. One of the requirements for a PCMH is to have close collaboration with a mental health provider, with both co-location and the provision of prevention services considered to be essential benefits. Recent health care reform legislation requires pediatric practices are to screen for

developmental delays and autism at critical developmental periods, along with annual screening for behavior difficulties. For adolescents, there are mandates to screen for depression, alcohol/other substance abuse, and risky sexual behaviors. Counseling for obesity and risky sexual behaviors for adolescents is mandated as well. A psychologist has the requisite skills to develop these screening and brief counseling programs in a pediatric practice, but at this time cannot bill separately for preventive services. In the changing health care reimbursement environment, a pediatric practice may have its annual quality bonus based on providing these services, and will need psychologists to set them up. Because the pediatric practice needs to provide the services, there is an opportunity for psychologists to negotiate to provide them.

Although psychologists have the skills to provide these essential services, other professionals can also offer sets of services for consultation and intervention. A PCMH team can potentially include master's-level licensed mental health providers, nurse educators with specific expertise in some areas, and/or health coaches who can be either licensed health professionals or unlicensed community health workers. The challenge for psychologists in these settings is to define their own scope of practice, assist in the development of a team structure to engage all of these professionals constructively, and work with members of each profession as they define their scope of practice. Although other professionals can evaluate and intervene in behavioral difficulties, if a PCMH is going to address diagnosable behavior problems in its scope of care, it is essential that a doctoral-level mental health professional—a psychologist—be a core member of the team. In this type of setting, supervision and oversight of work done by master's-level providers could be part of the tasks carried out by a psychologist (Ramirez & Stancin, 2014). A PCMH is, by definition, physician-led (PCPCC, 2007) and would not consider addressing physical health concerns without a doctoral-level health care provider heading the team. The same standard needs to apply to behavioral concerns: leadership of the clinical team by a doctoral-level provider.

Despite recognition of the importance of delivering mental health care in outpatient settings, providers have faced difficult challenges to obtaining reimbursement for services. Coding and billing are complex issues in any mental health setting. Current insurance reimbursement usually requires a mental health diagnosis; yet mental health services in primary care settings do not always fit neatly into recognizable codes, and many insurance companies are unfamiliar with the wide range of mental health services in primary care practices. For example, brief intervention services may be recommended for problems at early stages (e.g., parent training in behavior management for a preschool child with oppositional behavior), but reimbursement may be denied because the child's conditions do not meet diagnostic criteria for a mental disorder. The newer health and behavior codes were specifically developed for psychologists intervening with patients with diagnosed physical illnesses. However, these are rarely used in primary care settings and are more often used in specialty clinics (e.g., clinics for diabetes or pulmonary care).

Unfortunately, the above-described issues are dealt with at a local level, and it is important to keep track of which diagnoses and which service delivery codes are acceptable to the local insurers. A major roadblock to fiscal viability of integrated care is the system of mental health "carve-outs" favored over the past few decades by many insurance payers. A carve-out occurs when a second insurance company with specific expertise in mental health and substance abuse claims takes over the responsibility

and risk for all areas of mental health from a health insurer (Bruns, Kessler, & Van Dorsten, 2014). Often families do not know that the mental health insurer is different from their health care plan until they go to use the services. Thus a pediatrician's office might provide access to patients with insurance coverage from many payers, but a psychologist practicing in the same office might be paid to see patients with only certain coverage policies. The added administrative inefficiency of this system has impaired the ability of primary care practices to embrace the notion of collaborative care with enthusiasm.

Thus the current system of funding—with each service provided paid for by an insurer, sometimes by a different insurer from the one funding the medical services—is complex, is poorly reimbursed, and in some cases does not provide a viable fiscal footing for practice. However, new funding approaches to health care offer opportunities for psychologists, particularly in pediatrics. The new system over the next decade will undoubtedly be a hybrid system of payment for each service delivered (fee for service) and assessment of how well the pediatric practice meets certain goals. That is, practices will be financially incentivized for implementing preventive and quality-of-care measures (e.g., "Did all patients get a developmental screening? Was body mass index calculated for each patient?") with bonus payments for a reduction in emergency room visits or in use of certain medications (e.g., inhalers for asthma). Psychologists can help in the design of programs to meet these target goals.

Communication Challenges

Communication between providers and confidentiality are issues that will need to be resolved quickly in an integrated practice. Mental health providers tend to be very protective of patient disclosures during sessions and are reluctant to share information with other providers unless this information is specifically released by a patient. This can be frustrating to a PPCP who also respects confidentiality but seeks access to information that a psychologist has, in order to respond better to a patient's medical needs. Integrated practices assume that there is open communication between mental health and medical providers. Patients and families should be informed about such communication and should provide informed consent to treatment that allows communication among all providers when they come to the practice.

Confidentiality concerns may extend to access to medical records. Providing mental health services in primary care raises challenging issues related to the protection of the privacy of mental health records and protected information, as dictated by the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA). An integrated practice would permit open access to medical and psychological records by all health care providers, so charting style would need to take this into consideration. Electronic health record systems allow for separate storage and designated access to privileged mental health records (Nielsen, 2014; Smolyansky, Stark, Pendley, Robins, & Price, 2013), so providers' access to records must be clearly communicated to the family. Families also need to be informed that third-party payers sometimes ask for records when they review a claim for services. Additional discussions that clarify confidentiality issues in primary care are provided by Etheridge (2005) and Hunter, Goodie, Oordt, and Dobmeyer (2009).

There are also clinical challenges for practitioners in pediatric primary care. These include conducting thorough crisis interventions in a setting in which psychologists are often expected to work in short time periods and wear many different "hats" in a given day. Interested readers are referred to Harrison (2013) and Wintersteen and Diamond (2013).

CONCLUDING COMMENTS

This is a time of rapid changes in the U.S. health care system. Both the federal government and major insurers have already embraced a PCMH model of care delivery, and payment is quickly becoming more focused on quality of service and outcome. Well-integrated primary behavioral health care services should focus on optimizing health care outcomes (Laderman & Mate, 2014), which should result in lowered costs. Reduced medical costs, higher rates of patient satisfaction, lower provider turnover, and increased productivity have been attributed to integrated care models in adults, although data demonstrating medical cost savings in pediatric populations have been less available (Blount et al., 2007; Rozensky & Janicke, 2012). Research evaluating patient and provider satisfaction with, and effectiveness of, mental health services in pediatric primary care has been supportive of interventions. However, these studies have been primarily descriptive, and randomized controlled trials that evaluate the efficacy of primary care interventions compared with other service systems are just emerging (Asarnow et al., 2015; Kolko et al., 2014). Studies that will most strongly influence the further inclusion of psychologists are those evaluations of PCMHs and integrated programs that include psychologists and demonstrate improved outcome for an entire patient population or a high-risk, high-cost subset of patients.

Among behavioral health professionals, pediatric psychologists bring a unique perspective to primary care, including a background in systematic research and advanced clinical training in children's health care (Stancin & Perrin, 2014). Quality of care, access to services, availability of empirically supported interventions, and economic factors (to name a few) are important issues in primary care as well as in other treatment settings. For integrated practices to survive, pediatric psychologists will need to expand their advocacy efforts to enhance reimbursement of mental health services on state and national levels. Pediatric organizations and medical care providers have responded clearly to the need to address mental health in primary care with national initiatives, as well as by learning skills or using tools that traditionally "belong" to psychology. Psychologists need to advocate and collaborate more directly with their medical colleagues to develop and test models that incorporate broad mental health considerations within the primary care setting, and also to take advantage of the rich opportunities available for innovation with prevention, intervention, and public health initiatives.

Integrated behavioral health within primary care settings may be the most promising strategy for reducing the public's misconceptions about—and improving access to—mental health services. The perceived separation of physical and mental health in pediatrics may be narrowed as families experience PCMHs' ongoing support and attention to the families' social-emotional health throughout children's development.

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CHAPTER 43

Families and Other Systems in Pediatric Psychology

Anne E. Kazak, Melissa A. Alderfer, and Steven K. Reader

Children's health-related concerns inherently and unquestionably encompass not only the children themselves, but also, in a reciprocal manner, families, schools, communities, and health care settings. There is much to be learned from a broader inclusion of families and other systems in our conceptualization of children and health. Inclusion of family members and consideration of the family as a whole are becoming more common in pediatric psychology research. As a range of individual and family responses—along the continuum from normative/adaptive to maladaptive—has begun to be elaborated, models that foster the understanding of the distribution of responses along this continuum are essential, along with models that capture the process of and factors contributing to risk or resilience during and after illness, injuries, and treatment. Similarly, research on extrafamilial systems (e.g., schools, the health care system) is also expanding. When families, as well as other relevant developmental contexts, are viewed as essential and inseparable from patients in understanding illness and adaptation, the systemic complexity of pediatric psychology becomes evident. In this chapter, we illustrate a social-ecological model of child health and illness by highlighting indications of risk and resilience across these systems. With this social-ecological framework as background, current research on family assessment and intervention in pediatric psychology is described.

A SOCIAL-ECOLOGICAL FRAMEWORK APPLIED TO PEDIATRIC PSYCHOLOGY

Social ecology is a useful model for conceptualizing the complex ways in which systems relevant to the lives of pediatric patients interact to shape development and adapta-

tion (Kazak, 1989). Based upon the work of developmental psychologist Urie Bronfenbrenner (1979), social ecology maps the various systems in which children are embedded and provides a framework for understanding relationships among these systems. Importantly, identifying aspects of the social ecology that are protective or that place a child at risk for maladaptation is key in guiding tailored intervention approaches.

In social-ecological models, the child is seen as the center of a series of highly interactive social systems or contexts (Figure 43.1). The most immediate settings in which the child directly participates—the family, the school, and (for some children) the hospital or clinic, and subsystems of these settings (e.g., parent–child relationships, siblings, peers)—make up "microsystems." Microsystems interact to form "mesosystems." For chronically ill children, these mesosystems include interactions among families, health care teams, and school personnel. These microsystems and mesosystems are the primary foci of this chapter. However, at a more distal level are "exosystems," in which children do not directly participate, but which indirectly affect them—such as parental social networks and employment, the economic status of the family and community, and the health care environment. At the outermost level of social ecology is the "macrosystem," including culture, customs, and broad social conditions. Culture and ethnicity have a significant role in shaping the values and beliefs embedded within a family unit, including how family members understand, label, and talk about illness within the family. An evaluation of cultural domains includes an exploration of these patterns and the beliefs that underlie them (i.e., religious, spiritual). Broader economic considerations, discrimination, immigration, and political history, as well as local, state, and federal laws and policies (i.e., mental health insurance coverage), are also macrosystem influences. Although broader systems issues are frequently not considered within the realm of psychological theory or intervention, neglect of these

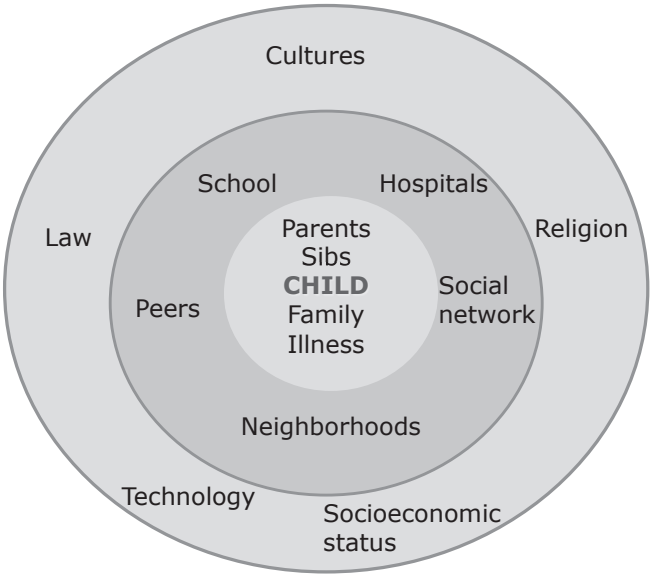

FIGURE 43.1. A social-ecological model applied to child health.

issues can result in a dangerously myopic view of children and families, and can lead to ineffective interventions.

In the remainder of this chapter, we present research to illustrate the various microsystems that constitute the immediate developmental context for a child with chronic illness, with a focus on the family as the child's primary microsystem. We then provide examples of the development and evaluation of family/systems-based interventions. We focus on studies that frame research questions and methodologies in ways that recognize the complex interplay of social-ecological variables. Our approach emphasizes family resilience and adaptive processes that families demonstrate when confronted with illness.

SOCIAL–ECOLOGICAL SYSTEMS AND PEDIATRIC PSYCHOLOGY EXAMPLES

The Child

Recent meta-analyses summarizing the literature on child adjustment reveal that children with chronic illnesses are at slightly increased risk for internalizing and externalizing problems, as well as for attentional, social, academic, and physical problems (Pinquart & Shen, 2011; Pinquart & Teubert, 2012). However, there is a discernible need for methodologically rigorous research to identify the contextual variables that place a chronically ill child at risk for ongoing difficulties across all phases of illness and treatment. In addition, consistent with medicine's organization by organ systems and diseases, much of the existing literature focuses on specific illnesses. An ecological perspective provides an opportunity to identify common parameters of illness, treatment, and family responses across conditions.

The developmental progress of children with chronic illnesses may be affected by the interplay of an illness and its treatment with normative developmental influences. For example, as families adjust early in the illness trajectory, a child may be excused temporarily from some developmentally appropriate expectations (e.g., temper tantrums may be tolerated). As treatment progresses, the child and family reorganize around the illness, with a common goal of achieving successful treatment and having the child participate in a developmentally appropriate manner. Occasionally, however, this reorganization becomes rigid and static, with a child unable to move on to more developmentally appropriate behaviors, and parents unable to support more independent behavior in their child. As adolescence unfolds, parents and the adolescent need to be flexible and gradually shift roles in order to accommodate the adolescent's increasing independence. This extended period of shared, but shifting, responsibility for illness management can set the stage for significant parent–child conflict over adherence. As prognoses improve for many serious childhood illnesses, long-term survivorship is an important developmental phase for patients and families, presenting such new challenges as facing long-term medical effects and functional impairment related to intense treatments, and adhering to complicated and potentially disruptive medical regimens that are necessary for health maintenance.

The Family Microsystem

Childhood illness affects not only the developing child, but also the family as a whole and all of the individuals within it. In turn, the family has powerful reciprocal influ-

ences on the child's adaptation to illness, just as it plays a major role in child development more broadly.

Siblings

On an individual level, siblings of children with chronic illness show slightly elevated rates of adjustment difficulties compared to controls, particularly for internalizing problems. Factors linked with increased problems are older sibling age and characteristics of the disease, such as whether it is life-threatening, affects daily functioning, and restricts siblings' social activities (Vermaes, van Susante, & van Bakel, 2012). However, most siblings are resilient. Studies of siblings of children with cancer, for example, have shown that although there are initial adjustment difficulties after diagnosis, such as distress, poor quality of life, and academic difficulties, most siblings adapt well over the long term; some even report increased maturity, empathy, and responsibility because of the experience (Alderfer et al., 2010). Open communication (including information about the illness and treatment), consistency in routines, and emotional and social support have been linked with better sibling adjustment (Incledon et al., 2013). Future research needs to examine the role that siblings play in the adjustment of a child with illness and in the adaptation of the family as a whole.

Parents

Parents are central to their children's development and effective family functioning, and thus parental mental health and well-being after a diagnosis of childhood illness are primary concerns. Much research in pediatric psychology about families focuses on parental distress and parenting. The ways in which parents respond to illness can have an impact on the way the child responds and can promote or confound the child's health outcomes. For example, parental distress is related to distress in children with spina bifida (Friedman, Holmbeck, Jandasek, Zukerman, & Abad, 2004) and to procedural distress for children with cancer (Caes et al., 2014). Maternal depression has been linked to less parental involvement and more conflict, which in turn predict poorer adherence for children with Type 1 diabetes (Mackey et al., 2014). While elevated distress for parents around the time of a child's diagnosis is commonly followed by a trajectory of adaptation and adjustment (Pai et al., 2007), parenting stress can be more enduring (Cousino & Hazen, 2013). Parenting styles also influence health care utilization, even in healthy samples (Serbin, Hubert, Hastings, Stack, & Schwartzman, 2014). Information about parents and parenting in pediatric psychology remains biased by reliance on maternal report, reflecting the focus of services on mothers and children in pediatric health care. Understanding the role and functioning of fathers remains an important area for future research.

Couples

Adults in a family are not only parents, but are also often part of a couple—a critically important subsystem that is often given little consideration in pediatric health care. The mutually interactive nature of couples is evident. For example, in a study of parents of children with cancer, marital adjustment was predicted not only by a parent's own affective functioning, but also by a spouse's marital satisfaction (Dahlquist, Czyzewski,

& Jones, 1996). Mothers and fathers have both common and distinct responses to child health conditions (Bakker, Van Loey, Van der Heijden, & Van Son, 2012; Wijnberg-Williams, Van de Wiel, Kamps, & Hoekstra-Weebers, 2014), and there is evidence that the discrepancies can affect disease management in diabetes (Lewandowski & Drotar, 2007; Sood et al., 2012). A frequent misperception is that marital separation and divorce are inevitable in the face of serious illness, despite compelling evidence to the contrary (e.g., Syse, Loge, & Lyngstad, 2010). Unfortunately, there is less information about the quality of couple relationships and the impact this quality may have on child outcomes (despite a broader family literature supporting the impact of marital relationships on children), and there is a notable lack of intervention studies in this area.

The Family

Research on the family as a whole is less common in pediatric psychology than is research examining the impact of dyad interactions (e.g., parent–child). Families are complex systems and can be difficult to define and characterize. For example, with regard to family structure, the strains associated with lone parenting are well known (Brown et al., 2008). However, there are many different types and structures of families, and illness-specific issues confronting these more diverse families have not often been addressed. For example, the family members who mobilize in a crisis; the family members who help assure that the family functions as routinely as possible; or the family members as defined by ethnic, religious, or other cultural parameters may vary and include caregivers other than parents (Fedele et al., 2014). Other factors known to place families at risk more generally, such as adolescent parents or families' struggles with socioeconomic difficulties, are also important. Consistent with the theme of adaptive adjustment in response to pediatric health conditions, Kazak (2006) has proposed the "pediatric psychosocial preventative health model" (PPPHM) to describe a triple-level risk stratified approach to summarizing level of family risk and resilience across various family-level factors (e.g., structure, resources, ongoing stressors). The PPPHM is adapted from a public health perspective: Families are conceptualized at "universal," "targeted," and "clinical" levels of need, based on their pattern of risks and resources, which can be assessed with the Psychosocial Assessment Tool (PAT; Kazak, Schneider, DiDonato, & Pai, 2015).

Some of the more consistent predictors of family adaptation include integration into a supportive social network, enough flexibility to balance the demands of the illness with other family needs and responsibilities, clear boundaries, effective communication, positive attributions, active coping, and encouragement of the development of individuals within the family (Kazak, 2006). Childhood illness challenges the ability of the family to function effectively, although most families are competent, adaptive, and able to cope and adjust over time (Long & Marsland, 2011).

Poorer family functioning (i.e., poorer task accomplishment, communication, affect management, interpersonal involvement, behavior control, role allocation, and cohesion) has been observed in some illness samples relative to groups without illness (e.g., Holmbeck, Coakley, Hommeyer, Shapera, & Westhoven, 2002; Janicke, Mitchell, & Stark, 2005). However, these findings are inconsistent across studies, suggesting that other factors moderate the findings. For example, among families with a child

with spina bifida, those with lower socioeconomic status (SES) evidenced less cohesion, more conflict, and more stressful life events than higher-SES families, suggesting how an exosystemic factor (i.e., SES) may shape a family's illness experience. Furthermore, early puberty was associated with higher levels of family conflict and lower levels of cohesion for well children, but not for those with spina bifida (Coakley, Holmbeck, Friedman, Greenley, & Thill, 2002), illustrating how normative developmental events may be experienced differently by families managing chronic illness. These kinds of developmental differences, their meanings for individuals and families, and similarities and differences across illnesses remain to be explored.

Some research suggests the potential for family-level variables to influence disease course and outcomes. For example, family risk (sociodemographic and life event changes) has been found to moderate the association between sleep and body mass index (Bagley & El-Sheikh, 2013). The associations among family variables in pediatric pain (e.g., parent pain histories, family interactional processes) are apparent (Fales, Essner, Harris, & Palermo, 2014; Sherman, Bruehl, Smith, & Walker, 2013). There is also a growing literature on the role that families play in adherence. If disease management responsibility is unclear, if parental oversight and monitoring are poor, or if there is family conflict, adherence to treatment regimens and outcomes suffer, including metabolic control in diabetes (Lewin et al., 2006), use of medications in inflammatory bowel disease (Reed-Knight, Lewis, & Blount, 2011), and responsibility for self-care responsibilities in spina bifida (Psihogios & Holmbeck, 2013). Furthermore, Fiese and Wamboldt (2000) describe family rituals—patterns of family behavior ranging from highly structured religious activities to daily household routines—as a mediating factor in asthma treatment adherence. Rituals may help families maintain disease-related treatment regimens by reducing anxiety, increasing predictability, or helping families adapt and apply effective problem solving to new demands.

The Illness and Treatment Microsystem

Characteristics of the illness, its treatment, and the setting in which treatment is provided form a critical microsystem in the development of children with chronic illness.

The Illness

Diseases and treatments differ vastly. Some conditions are highly visible (e.g., cerebral palsy, amputation); others, though significant, are not apparent to others. Illnesses also vary in severity, although this can be difficult to characterize. In general, illness severity is not associated with adjustment, although it may affect the demands placed on a child and family for treatment (Rodrigues & Patterson, 2007). There are also potential indirect effects; for example, disease severity may influence parental stress and health care utilization (Logan, Radcliffe, & Smith-Whitley, 2002). Subjective factors (e.g., what the patient and family believe about the illness and its treatment) are generally more powerful predictors of outcome than are typical "objective" measures of illness severity (e.g., physician ratings; Franck, McQuillan, Wray, Grocott, & Goldman, 2010). The lack of consistent associations between distress and more objective measures of illness severity emphasizes the importance of focusing on the subjective illness experience of children and their caregivers.

The Health Care System

Considering the interactions of families with often complex health care systems is essential in a social-ecological understanding of pediatric illness. Family members must first access and then join with the health care system, with the goal of establishing a collaborative and productive relationship over the course of the child's care. Understanding more about the potential problems in engagement and communication is important, at various levels. For example, Cohen and Wamboldt (2000) analyzed speech samples of parents of children with asthma and their asthma specialists talking about their perceptions of one another and their relationships. The researchers found relationship difficulties in 15–40% of these interactions. There are also many examples of how family-centered care is practiced in pediatrics (American Academy of Pediatrics, 2012), such as increasing involvement of families in the design of medical settings and assuring participant/stakeholder participation in the design of clinical care and in research initiatives. Evidence for the effect of family-centered care on outcomes has recently been obtained (Kuhlthau et al., 2011). However, more research into the best ways to deliver care at the interfaces between health care team members and children/families is needed. Models such as trauma-informed care (*www.healthcaretoolbox.org*) offer examples of how health care providers can practice in a manner that appreciates the many potentially traumatic aspects of health care and actively intervenes to reduce the likelihood of traumatic stress responses. Health care providers can also improve relations between families and the health care system by identifying tasks that are common to families and to staff; these include self-soothing in the face of stress, developing trust (in the relationships that must be formed to ensure optimal health care), and managing the inevitable conflicts that arise in modern health care (Kazak, Simms, & Rourke, 2002).

The School Microsystem

The second most common microsystem setting in which children spend time is the school. Given changes in health care delivery, increasing responsibility placed on communities for caring for children with health care needs (Power, DuPaul, Shapiro, & Kazak, 2003), and limited resources (e.g., school nurses), collaborations among families, schools, and health care systems are critically important. Integral to schools are peers—critical components of socialization for all children. Although peers are generally invisible in hospital and treatment settings, they are increasingly appreciated across patient groups from a broader social ecological perspective. For example, having a "reciprocal friendship" was associated with more adaptive emotional and social adjustment in youth seeking treatment for obesity (Reiter-Purtill, Ridel, Jordan, & Zeller, 2010). The social and peer implications for children whose conditions or treatments affect the central nervous system (see Holbein et al., 2014) remains an area ripe for a fuller understanding of how social factors relate systemically to outcomes (Hocking et al., 2015).

FAMILY/SYSTEMS INTERVENTIONS IN PEDIATRIC PSYCHOLOGY

Acknowledging these various microsystems and their influence on child development and adaptation to illness/injury is common in clinical contexts; however, systematically

assessing and conceptualizing the various interactions among these systems raise challenges for intervention research. Therefore, most interventions for children with pediatric illness have either focused on the child or included members of the family system without an explicit family/systems intervention framework.

In order to promote family/systems intervention research in child health, conceptual and methodological challenges must be addressed. Various "well-established" family assessment measures have been identified (Alderfer et al., 2008), and thus reliable and valid measures are available for family constructs relevant to pediatric health. Valuable suggestions have also been published regarding ways to ensure assessment quality, even when it is difficult to accurately identify and define the family (Hofferth & Casper, 2007). In addition, methods for integrating data from multiple family members and for nesting individuals within families and other systems are becoming more accessible (Atkins, 2005; Cook & Kenny, 2004; Deković & Buist, 2005).

Family-based interventions have been developed for children with a range of disorders, including asthma, cancer, cystic fibrosis, diabetes, HIV, obesity, recurrent abdominal pain, sickle cell disease, and traumatic brain injury (see Alderfer & Rourke, 2009, for an overview). Within these family interventions, there is a range of approaches, goals, and intended outcomes, but they all typically involve more than one family member. Such approaches may include and combine psychoeducation, disease training, skill building, clarification of expectations and roles, goal setting, and disease management routines. Interventions that specifically target multiple aspects of the family (i.e., emotional and organizational components, relationship skills, collaborative problem solving, communication), and that include attention to collaborations with the broader social contexts in which the child is embedded (e.g., school, health care system), have been labeled "systemic therapies" (Law, Fisher, Fales, Noel, & Eccleston, 2014).

Evidence for the superiority of family-based interventions to patient-only interventions is not overwhelming (Law et al., 2014; Martire, 2005); however, the literature base to date is thin. Randomized clinical trials have demonstrated the efficacy of various family-based interventions in, for example, improving asthma management and reducing hospitalizations among low-income children with asthma (Celano, Holsey, & Kobrynski, 2012); lowering posttraumatic stress symptoms within families of childhood cancer survivors (Kazak et al., 2004); and lessening pain among children with recurrent abdominal pain (Robins, Smith, Glutting, & Bishop, 2005). Most such interventions, however, have only been tested in a single study or a single population. Below, three examples of family/systems-based interventions with more substantial empirical evidence are provided to illustrate this clinical approach and area of investigation.

Behavioral family systems therapy (BFST) has been most often studied in the context of children with diabetes (Wysocki et al., 2000), but has been adapted for use with various childhood diseases (e.g., Quittner et al., 1998). This intervention involves (1) training in communication and problem-solving skills; (2) cognitive restructuring to address counterproductive beliefs, attributions, and assumptions held by family members regarding one another's behaviors; (3) systemic family therapy techniques to strengthen appropriate boundaries, roles, and relationships; and (4) rigorous disease management training (e.g., for diabetes, behavioral contracting around adherence, clinical algorithms for modifying insulin injections based upon blood glucose readings, and parents' simulating living with diabetes for 1 week). While some outcomes have been inconsistently demonstrated, randomized clinical trials of BFST have generally found

greater improvements in parent–teen relations, reductions in diabetes-specific conflict, improved treatment adherence (Wysocki et al., 2000), and improved metabolic control (Wysocki et al., 2006).

Comprehensive behavioral family lifestyle (CBFL) interventions have been utilized primarily to encourage modification in dietary intake and physical activity habits for families of overweight and obese children. Based upon behavioral strategies, these interventions incorporate parental modeling and monitoring, goal setting, problem solving, contingency management, and stimulus control, with the family as the critical agent of change. A meta-analysis identified 20 randomized clinical trials of CBFL interventions and found a statistically significant, albeit small, overall positive effect on child weight for these interventions when compared to passive (no treatment, educational interventions, treatment as usual) control groups (Janicke et al., 2014).

Multisystemic therapy is an intensive family-centered intervention delivered in the community (i.e., home, school, neighborhood) that targets risk factors for poor disease management across the individual, family, school, peer, health care, and community contexts. The interventions are individualized, but adhere to treatment principles that include improving self-management skills, providing caregivers with medical knowledge and training in parenting skills, enlisting the support of peers, improving school–family communication, and promoting a positive relationship between the family and health care team (Ellis et al., 2010). Even within clinical trials, therapy is continued until treatment goals are met, usually requiring one to three sessions per week for about 6 months (Ellis et al., 2010). Multisystemic therapy has been found to improve adherence and glycemic control (Ellis et al., 2012) and to decrease inpatient admissions and hospital costs (Ellis et al., 2005) for youth with poorly controlled diabetes. It has also been found to reduce viral load for poorly adherent youth with HIV (Letourneau et al., 2013) and to bolster family support for healthy eating and exercise, improve fat and fiber intake, and reduce body fat percentage and body mass index among obese African American adolescents (Ellis et al., 2010; Naar-King, Ellis, Kolmodin, Cunningham, & Secord, 2009).

SUMMARY AND CONCLUSIONS

Children facing health challenges live in systems, the most prominent of which are families, schools, and health care settings. More systemic conceptualizations of adaptation, and the development of interventions concordant with these systemic conceptualizations, have the potential to change not only children with illness, but also the broader contexts in which they grow and develop. As our conceptualizations of health and illness broaden within pediatric psychology, so can our reach.

As a first step toward this goal, it is important to ask multisystemic, interactional research questions. For example, how does the behavior among and between parents and staff members affect the child's coping ability in the procedural context? What impact do family patterns and the family's relationships with schools and community support systems have on an adolescent's diabetes management? How can the behavior of a disruptive pediatric inpatient be understood in terms of family and systemic factors that may be contributing to the behavior? These are questions that are easier asked than answered.

However, a few general recommendations can be made. First, assuring that multi-

disciplinary family and systems perspectives are integrated into all components of curricula—not only didactics, but supervised clinical experience—will expose more pediatric psychologists to these approaches. Second, pediatric psychologists can and should assume an optimistic and energetic approach to including all members of the family in their studies. At a minimum, psychologists should no longer tolerate generalizations made from mother-only data to represent the perspective of parents more broadly, but rather should consider how exclusion of fathers and other family members limits the knowledge contributed. Third, children do not seek health care in isolation from the broader contexts in which they live. Pediatric psychologists must identify better ways to account not just for family processes, but for the broader impact of peers, schools, culture/ethnicity, health care systems, and factors that affect access to care. In fact, a recent meta-analysis of health promotion interventions provides preliminary support for the contention that intervening at multiple systemic levels confers a greater impact (Cushing, Brannon, Suorsa, & Wilson, 2014). Addressing these issues will ultimately improve the ability of psychologists to provide clinical care to individual families, to consult with medical teams about family-focused treatment approaches, and to advocate more effectively for the inclusion of the needs of children and families in local and national health care policy.

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CHAPTER 44

Schools and Reintegration into Schools

George J. DuPaul, Thomas J. Power, and Edward S. Shapiro

Other than their homes, children and adolescents spend more time in school settings than in any other environment. In fact, the average student will spend at least 14,000 hours in school (assuming a 6-hour school day) from kindergarten through 12th grade. Schools are not only the major venues for acquisition and growth of academic skills; they also are primary settings for the development of appropriate social, emotional, and behavioral functioning. It is critical for pediatric psychologists to understand the educational system and the potential impact of physical health issues on students' school functioning, as well as the role schools can play in fostering healthy outcomes for all children.

The purpose of this chapter is to provide an overview of the K–12 educational system, with an emphasis on issues relevant to pediatric psychology. First, a brief description of systemic reform efforts over the past decade is provided. Next, the impact of pediatric illness on functioning in school settings is delineated. Interventions designed to improve school functioning are described, including monitoring medication, promoting treatment adherence, coping with stress and trauma, and facilitating reintegration into the school environment. Finally, school-based prevention and health promotion strategies that may have an impact on all children are detailed, including those related to nutrition education, physical fitness development, and violence prevention.

OVERVIEW OF SCHOOLS FROM A SYSTEMS PERSPECTIVE

As of 2011, approximately 54 million children and adolescents attended schools in the United States, with over 91% of these students attending public schools (U.S. Department of Education, 2013). The school population is projected to continue growing through at least 2023 (U.S. Department of Education, 2013). Furthermore, the student

population has become increasingly diverse over the past several decades. As of 2011, nonwhite students were predicted to be in the majority by 2014, and the largest minority was Hispanic, at 25.8% of the school population (U.S. Department of Education, 2013).

Educational Reform Efforts

Over the past two decades, four systemic reforms have played a major role in shaping efforts to improve achievement in schools. Recognizing the national need to improve the reading performance of all children in the earliest grades of school, the U.S. Congress enacted legislation known as the No Child Left Behind (NCLB) Act in 2001, setting the lofty goal that by 2014 all children would reach a minimal level of proficiency in reading by the end of third grade. To move schools toward this goal, programs such as Reading First and Early Reading First were established by the U.S. Department of Education to provide schools with the training, support, funding, and motivation to meet the high standards established by the NCLB Act. From a prevention perspective, schools focused on the prevention of future problems in reading by bolstering instruction within the core academic program, at the same time as providing needed remediation and intervention at the earliest point possible to those identified as potentially at risk for failure.

Currently, an effort is emerging in the U.S. Congress to completely revise the NCLB Act of 2001. Although this effort is just now developing, and it is too early to determine how the final law will look when (and if) enacted, revisions of the law are likely to offer states alternative methods to how they demonstrate accountability in delivering high-quality instructional programs. It is also expected that the law will require all schools to have some form of multi-tiered system of supports in place, to assure that all students who show early need for remediation are identified and provided with effective instructional intervention.

A second reform effort, which emerged in the last decade, was a focus on developing students whose skills upon graduating from high school made them college- and career-ready. Lead primarily by state directors of education in 2009, along with the support of the governors from 48 states, 2 territories, and the District of Columbia, the Common Core State Standards were developed to deepen and strengthen the educational competencies of students exiting public education systems. These standards represent instructional benchmarks for expected performance that are intended to ensure a standardized, common level of expected learning across all schools in the United States. As of 2016, 42 states along with four territories, the Department of Defense Education Activity, and the District of Columbia, had adopted the Common Core or a state-modified version of the Common Core (see *www.corestandards.org*).

Another major reform effort starting in 2004 was the reauthorization of the Individuals with Disabilities Education Act, now known as the Individuals with Disabilities Education Improvement Act (but still abbreviated as IDEA). This reauthorized law, which governs the decision-making process for identifying students in need of special education, included a particular provision related to the identification of specific learning disabilities that had the potential to fully change the conceptual basis on which learning disabilities were built. Historically, a "learning disability" was defined as unexpected underachievement: Students were considered to have a learning disability when there was evidence that their capacity for achievement was much greater than what they were actually displaying. The assumption was that the unexpected underachievement

was due to a difficulty with the neuropsychological processing of information, and that these children needed specific accommodations to the learning process that exceeded what could be provided within the general education system alone. Based upon these assumptions, the model for diagnosing a specific learning disability was to identify the discrepancy between a child's level of intellectual functioning and current achievement (Fletcher, Coulter, Reschly, & Vaughn, 2004). Unfortunately, research has shown that although the discrepancy model may have logical and conceptual soundness, it has not held up to empirical scrutiny (Fletcher et al., 2004).

As a function of the dissatisfaction with the discrepancy model of identification, "response to intervention" (RTI) was proposed as an alternative method to identify students with specific learning disabilities. According to the RTI model, a learning disability can be identified by a student's failure to respond adequately to effective, research-based interventions delivered within the context of the general education environment (Gersten & Dimino, 2006). Although the methodological details of RTI are too complex to describe in this chapter (see Kovaleski, VanDerHeyden, & Shapiro, 2013, for a more detailed description of the RTI approach), the essential concept is that if typical instruction results in adequate gains for most children, those who do not respond to this type of instruction, as well as instruction that is intensified and individualized to address specific needs, are viewed as "not responding to instruction" and therefore as potentially eligible for services under the classification "specific learning disability." Research efforts to evaluate the outcomes of RTI are just emerging, as a fully implemented RTI model requires at least 3–5 years for evidence of full impact. In those reports, RTI appears to be at least correlated with the reduction in the number of students identified as having learning disabilities over the past several years. Perhaps more importantly, the RTI model does appear to have reduced risks of academic failure—especially in early reading development, where the majority of RTI implementation has been taking place (e.g., Shapiro, Zigmond, Wallace, & Marston, 2011).

All of these reform efforts in schools reflect a clear recognition that academic success is linked to favorable developmental and health outcomes. The development of strong academic skills is known to diminish the presence of many emotional/behavioral difficulties in students (e.g., Lane, Barton-Arwood, Nelson, & Wehby, 2008), as well as to serve as a protective factor for many adolescent mental health concerns (Brindis, 2005). The connection among academic health, prevention, and overall wellness is clearly an area of substantial overlap between pediatric psychology and school psychology.

Public Health Perspective

The public health model is highly consonant with the mission of schools. Consistent with a public health framework, educational professionals have a responsibility to address the developmental needs of all students in the least restrictive, maximally inclusive settings, including children with specialized needs and those at risk, in addition to those performing competently in all domains. Within education, there is widespread recognition that health conditions, including mental health problems, can serve as obstacles to the development of academic competence. As such, strategies to promote health and to address disorders and risk, when they arise, are often required to promote the academic competence of all individuals (Adelman & Taylor, 2012).

A key component of public health models is a multi-tiered continuum of services that incorporates the aforementioned RTI process to identify students in need of special education. Although the structure of tiers may vary across public health models, most models include a universal tier applicable to all students, one or more targeted tiers for students at risk, and an intensive tier for students with identified impairing problems. Although the RTI framework in schools has been developed primarily to address children's instructional and behavioral needs, the model can be applied readily to address health issues with regard to their impact on children's academic and social competence (Power & Bradley-Klug, 2013). For example, universal prevention promotes the health of all students; targeted prevention is designed for children with health problems at risk for academic and social problems; and intensive prevention or intervention is designed for students with health conditions that are having a clear impact on academic performance (e.g., chronic illness resulting in frequent school absence and poor school performance).

IMPACT OF PEDIATRIC ILLNESS ON SCHOOL FUNCTIONING

Given that approximately 7% of the child population is reported by parents to experience some activity limitation due to a chronic health condition (Adams, Martinez, Vickerie, & Kirzinger, 2011), and that 4% of children missed 11 or more days of school in 2012 due to illness or injury (Bloom, Jones, & Freeman, 2013), it is not surprising that chronic illness may have a significant impact on academic, social, and behavioral functioning.

Academic Functioning

The educational achievement of children with chronic medical conditions may be compromised by direct effects of the conditions (e.g., impact of symptoms or treatment on central nervous system functioning) and/or the secondary consequences of the conditions (e.g., fatigue, stress, or frequent absences from school; Shapiro & Manz, 2004). The potential impact on educational achievement is characterized by substantial variability between and within conditions. Pinquart and Teubert (2012) conducted a meta-analysis of 954 studies (N = 104,867) that evaluated functional impairment in various chronic illness populations (e.g., asthma, cancer, diabetes). Students with chronic illness demonstrated significantly lower levels of academic (g = −0.53) functioning, relative to healthy peers or test norms. Deficits in academic functioning are particularly apparent for children who have chronic health conditions that affect the central nervous system, who receive treatment that impairs cognitive functioning, or who have a physical disability in addition to a chronic condition (Shapiro & Manz, 2004). Despite the risks for academic impairment, the impact of a chronic illness on educational functioning is variable across children, with most students functioning in the average range (e.g., McNelis, Johnson, Huberty, & Austin, 2005). Given the heterogeneity of academic outcomes in children with chronic medical conditions, it will be important for educational and health professionals to identify those children at greatest risk for educational impairment as a function of these conditions.

Behavioral Functioning

Children with chronic health conditions may be at risk for behavioral difficulties. although this risk appears minimal for most such conditions. In a comprehensive meta-analysis of 569 studies (N = 51,422), Pinquart and Shen (2011a) found that youth with physical illness were significantly more likely to exhibit internalizing (g = 0.47), externalizing (g = 0.22), and total behavior (g = 0.42) problems relative to healthy controls. Group differences were most apparent for parent ratings and weakest for adolescent self-report ratings. Although elevated levels of emotional/behavioral difficulties were found across almost all chronic illnesses, internalizing disorder symptoms were more prominent than externalizing disorder symptoms. The association between chronic physical illness and elevated symptoms of internalizing disorder is particularly concerning in the case of depression, which is associated with long-term impairment in many areas of functioning and could lead to suicidal ideation and behavior (Pinquart & Shen, 2011b). Thus systematic screening for depression, suicidal ideation, and psychological distress may be warranted for adolescents with chronic physical illness (Pinquart & Shen, 2011a).

Social Functioning

It is possible that chronic health conditions may interfere with children's opportunities for typical social development by limiting independence from parents, exposure to healthy peers, participation in peer activities (e.g., athletics), and/or development of self-efficacy in peer interactions (Schuman & La Greca, 1999). In their aforementioned meta-analysis, Pinquart and Teubert (2012) found that students with chronic illness demonstrated significantly lower levels of social functioning (g = −0.43), relative to healthy controls. The risk for social functioning deficits appears greatest for males, for children with more severe and disabling symptoms of chronic illness, for those with conditions that alter physical appearance, and for those who are submissive and/or restricted in their social activities (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000; Schuman & La Greca, 1999).

INTERVENTIONS TO IMPROVE SCHOOL FUNCTIONING

Given the potential impact of chronic health conditions on important areas of functioning, school-based interventions are often utilized, including medication, behavioral treatments, and cognitive-behavioral strategies. Four examples of important treatment directions are discussed here: monitoring medication effects, promoting treatment adherence, coping with stress and trauma, and facilitating school reintegration after hospitalization.

Monitoring Medication Effects

The behavioral, academic, social, and cognitive effects of medication can be evaluated through a variety of methods, including behavior rating scales; direct observations of classroom behavior; review of school archival data (e.g., completion and accuracy rates

on academic assignments); direct measures of academic performance (e.g., curriculum-based measurement); and, when necessary, cognitive tests (Power, DuPaul, Shapiro, & Kazak, 2003). Multiple models for school-based medication evaluation have been proposed (e.g., Power et al., 2003; Volpe, Heick, & Gureasko-Moore, 2005). For example, Volpe et al. (2005) have described a monitoring protocol that uses a behavioral problem-solving framework. The evaluation is conducted across several stages: (1) pretreatment assessment of acceptability and feasibility of monitoring methods; (2) problem identification to prioritize treatment target(s); (3) problem analysis to examine contextual factors (e.g., antecedent and consequent events) that may be influencing target behavior(s); and (4) treatment implementation, including assessment of multiple dosages (if possible), followed by identification of optimal dosage. The acceptability and feasibility of assessment methods are evaluated over time, and any adjustments to data gathering are based on feasibility and cost-efficiency. Medication effects are evaluated by using a single-subject research design, and findings are reported to the child's family and physician. If treatment with medication is implemented following an initial evaluation trial, then long-term effects should be assessed by periodically repeating data collection. For example, a child placed on medication across several school years might undergo an annual reevaluation of this treatment by assessing current and alternative dosages (possibly including no medication) at some point during the middle of the school year, after the student has adjusted to the new classroom and the teacher is familiar with the student's behavior.

Promoting Adherence

Interventions for many health conditions involve components that are applied in school. For example, children with asthma or attention-deficit/hyperactivity disorder (ADHD) are commonly prescribed medications to be taken while they are at school. Furthermore, medical interventions applied at home often have an effect on how children function in school. Because adherence with medical treatments can be highly variable across and within families, and because adherence generally is considered to be critical to effective care (La Greca & Mackey, 2009), interventions to improve adherence with medical interventions are important for promoting academic and social competence. Conceptualizations of approaches to optimize adherence have been grounded in an ecological model (Power et al., 2003). Adherence with medical interventions is highly influenced by dynamics within systems, particularly the family, school, and health care system. The challenge for health care professionals is to delineate the parameters of care to ensure evidence-based practice, and to offer options that acknowledge family preferences and school realities. Optimizing adherence also requires strong connections between and among systems (Leff, Hoffman, & Gullan, 2009).

Because treatment regimens can involve a series of steps or be relatively complex, adherence may be optimized by multicomponent, multimethod assessment and feedback (Rapoff, 2010). For example, measures for assessing adherence in school may include student self-report, teacher (and/or parent) report, direct observations, and products of treatment implementation (e.g., empty medication dispensers) (Leff et al., 2009).

Within the context of effectively functioning systems and strong intersystemic partnerships, there are cognitive-behavioral interventions that can be helpful in improving adherence (Power & DeRosa, 2012). Environmental modifications may be helpful in

preventing medical crises that can arise in school. For example, reduction of airborne allergens may help to prevent asthma attacks, and dietary changes can prevent significant blood sugar irregularities among children with Type 1 diabetes. Organizational strategies can be designed to modify contextual variables for situations in which nonadherence is likely to occur. Posting notes in children's notebooks, tailoring the medical regimen to meet children's preferences, and scheduling visits to the school nurse's office at times that are convenient for students are examples of organizational approaches. Reinforcement-based approaches have repeatedly been demonstrated to be effective components of treatment. For instance, points and stickers that can be exchanged for valuable school-based or home-based reinforcers have been shown to be helpful in improving adherence (La Greca & Mackey, 2009). Furthermore, giving performance feedback (i.e., providing feedback to intervention participants about implementation and outcomes) has been demonstrated to be effective in improving adherence with interventions in a range of settings, including schools (Solomon, Klein, & Politylo, 2012).

Enabling Students to Cope with Stress and Trauma

A majority of children in the United States experience one or more potentially traumatic events by the time they are 16 years of age (Copeland, Keeler, Angold, & Costello, 2007). Traumatic events may include community and school violence, physical and sexual abuse, neglect, medical trauma, injuries, natural disasters, and war-related experiences. Although traumatic events typically do not result in children's meeting full criteria for posttraumatic stress disorder, a substantial minority experience one or more symptoms of posttraumatic stress or depression. Parental responses to trauma appear to contribute to children's risk for experiencing traumatic stress; the link may be due in part to shared genetic risk and epigenetic influences (Koenen, Amstadter, & Nugent, 2009) and in part to parental modeling and reinforcement of traumatic stress symptoms (e.g., avoidance; Fisak & Grills-Taquechel, 2007). The risk of trauma and prolonged exposure to stress is especially high among children of lower socioeconomic status, who are disproportionately represented among racial and ethnic minority groups (Warnecke et al., 2008).

Given the high percentage of children who experience impairments related to trauma, experts have advocated for creating trauma-informed networks of support based in child-serving systems, including schools (Ko et al., 2008). Trauma-informed schools provide screening for trauma exposure; training in evidence-informed practices; resources for professionals; and continuity of care, including more intensive services when needed (see the National Child Traumatic Stress Network's Resources for School Personnel, *www.nctsn.org/resources/audiences/school-personnel*). Cognitive-behavioral intervention for trauma in schools is a highly promising, group-based intervention for children in middle and high school experiencing traumatic stress and emotional problems (Stein et al., 2003).

Facilitating School Integration/Reintegration

Children with chronic health conditions often have difficulty becoming integrated into school early in their education, as well as during transitions into middle school, high school, and young adulthood. Furthermore, school reintegration is typically a challenge

for students after periods of acute problems resulting in temporary removal from school. Approximately 20% of children with chronic medical conditions may be removed from school for an extended amount of time or for repeated brief time periods (Alderfer & Rourke, 2014). Absences may be due to medical issues (e.g., hospitalizations, medical appointments), parental concerns about the school's ability to meet medical needs (e.g., monitor symptoms, handle emergencies), or children's concerns regarding peer reactions (Alderfer & Rourke, 2014).

Comprehensive, multicomponent programs have been proposed to include the following components: (1) family support to maintain strong parent–child relationships and prepare the family for school reentry; (2) education of school staff regarding a child's illness/condition and effective school-based approaches to intervention; (3) peer education and support programs; and (4) sustained follow-up to monitor progress and adjust the educational plan as needed (Madan-Swain, Katz, & LaGory, 2004). For example, we (Power et al., 2003) have proposed a staged model that includes interventions to prepare systems for integration and to guide participants through an extended integration process. Step 1 focuses on efforts to strengthen the family; Step 2 involves preparing the family to partner with the school; Step 3 emphasizes preparing school professionals to partner with the family and health care system; and Step 4 focuses on engaging the family, school, and health care system in a conjoint process of planning and implementation, which is based on the principles of conjoint behavioral consultation (Sheridan & Kratochwill, 2008). Although intervention programs typically focus on intervention design and strategy implementation (Step 4), efforts to prepare systems for multisystemic collaboration (Steps 1–3) are essential for successful school adaptation. Step 4 is viewed as an ongoing, recursive process involving intervention design, implementation, progress monitoring, intervention modification, and continuing monitoring/fine-tuning of the intervention. The purposes of Step 4 are to identify and build upon a child's strengths and system resources, to anticipate and address challenges, and to solve problems when they arise.

Generally, the empirical support for school reintegration programs has lagged behind theoretical and conceptual models. Canter and Roberts (2012) conducted a comprehensive quantitative review of the school reintegration literature, and identified only 12 empirical studies published between 1983 and 2007. Large effect sizes were found for positive attitude change for teachers, as well as increases in teacher knowledge. Increases in peer knowledge and positive attitude change were in the medium range. School reentry programs were associated with small effects on children's self-worth and self-esteem. Conclusions based on this meta-analytic review are limited by the small number of studies. Canter and Roberts noted that it will be particularly important for future studies to examine the impact of school reintegration programs on educational outcomes (i.e., academic functioning) and to consider the possibility of iatrogenic effects (e.g., increased likelihood for children with chronic health conditions to be bullied).

SCHOOL-BASED PREVENTION AND HEALTH PROMOTION

Nutrition Education and Physical Fitness Development

Perhaps the major public health concern today involving children in the United States is pediatric overweight. Data from the fourth National Health and Nutrition Examina-

tion Survey show that 16.9% of U.S. children and adolescents are obese, and another 14.9% are overweight (Ogden, Carroll, Kit, & Flegal, 2014). Schools have attempted to implement programs to slow the alarming trend toward obesity by directly curbing the available food items for students (e.g., reducing high-sugar food in vending machines). Efforts to alter the knowledge and eating lifestyles of students have also been common (e.g., Blom-Hoffman, Kelleher, Power, & Leff, 2004). A consistent theme across studies is that altering behavior is much more difficult than improving knowledge. Certainly, this area remains a challenge and potential focus point for pediatric and school psychologists. Although impact on knowledge may be a precursor to behavior change, without improvement in behavior the risk factors for child overweight/obesity will remain very high and of substantial concern for the future health of our children.

Perhaps equally important to weight control and nutrition are efforts to improve overall physical wellness among students. In fact, physical fitness has been identified as a potential protective factor for adolescent health difficulties (Kirkcaldy, Shephard, & Siefen, 2002). Werch, Moore, DiClemente, Bledsoe, and Jobli (2005) describe the implementation of Project SPORT, which consisted of an in-person health behavior screen; a one-on-one consultation; a take-home fitness prescription targeting adolescent health-promoting behaviors and alcohol use risk and protective factors; and a flyer reinforcing key content provided during the consultation and mailed to the home. Project SPORT was compared to a minimal intervention involving two commercially available alcohol prevention and health promotion booklets given to students.

Project SPORT participants demonstrated significant positive effects at 3 months postintervention for alcohol consumption, alcohol initiation behaviors, alcohol use risk and protective factors, drug use behaviors, and exercise habits, and at 12 months for alcohol use risk and protective factors, cigarette use, and cigarette initiation. At 18 months postintervention, no significant effects were found for the full sample; however, among drug-using adolescents, students who participated in Project SPORT obtained significantly lower scores on measures of alcohol and marijuana use, relative to drug-using controls (Moore & Werch, 2009). Despite some dropoff in effect, the encouraging outcomes that cut across both substance abuse and physical wellness suggest that interventions such as Project SPORT may present viable opportunities to improve longer-term health outcomes for adolescents.

Violence/Aggression Prevention

Youth violence is a major public health problem in the United States and around the world. In a nationwide survey of high school students (Centers for Disease Control and Prevention [CDC], 2012), 33% reported being in a physical fight one or more times in the past month; 17% reported carrying a weapon on one or more days during the past month; and 8% reported being threatened or injured with a weapon in school during the past year. About 20% of high school students reported being bullied at school in the past year (CDC, 2012).

Efforts to reduce school violence have focused on understanding and preventing bullying. "Bullying" has been defined as repeated acts of aggression involving a power imbalance favoring the perpetrator (Olweus, 1993). Beyond physical acts of aggression, bullying may also occur through verbal intimidation and relational aggression (i.e.,

social exclusion or injuring the reputations of others; Leff, Waasdorp, & Crick, 2010). Substantial research has shown that bullying can have immediate as well as long-term health and psychological consequences for both bullies and their victims (Farrington, Loeber, Stallings, & Ttofi, 2011).

Early efforts to reduce violence in schools, which are still used in some schools, have emphasized the use of reactive, punitive strategies, such as increased security and the aggressive prosecution of offenders. More recent efforts have emphasized the need to prevent violence through whole-school approaches involving partnerships with families and the community, and emphasizing health promotion and development for all children and youth (Farrington & Ttofi, 2009). Although comprehensive programs to prevent school bullying have been implemented since the 1970s, research on the effectiveness of these efforts has been insufficient and generally lacking in rigor. Overall, the findings have been modest, indicating that improvements are more evident in youth's knowledge and attitudes than in their behavior (Merrell, Gueldner, Ross, & Isava, 2008).

A whole-school approach that involves all school professionals, as well as parents and community leaders, is widely regarded to be essential for the prevention of violence in schools. A commonly implemented whole-school approach is known as "positive behavioral interventions and supports" (PBIS). This model has been demonstrated to improve school organizational climate (Bradshaw, Koth, Thornton, & Leaf, 2009) and to reduce school suspensions and office discipline referrals (Bradshaw, Koth, Bevans, Ialongo, & Leaf, 2008), which are likely to be related to decreases in school violence. PBIS is a multi-tiered system that provides universal programming for all students, targeted strategies for those at risk, and intensive interventions for those with identified problems (Sugai & Horner, 2010).

As part of a whole-school framework, targeting unstructured areas of school where bullying is likely to happen (such as lunch areas, playgrounds, and hallways) by organizing activities and carefully monitoring behavior has been demonstrated to be an effective approach (Leff, Costigan, & Power, 2004). Furthermore, classroom-based approaches designed to prevent all forms of aggression by strengthening students' skills in conflict resolution, problem solving, and friendship making (e.g., Second Step; Frey, Nolen, Van Schoiack Edstrom, & Hirschstein, 2005) have been shown to be highly promising and are becoming widely disseminated.

The role of the bystander in bullying has become increasingly recognized. Bystanders can explicitly or implicitly support bullying, or they can attempt to discourage it. A recent meta-analysis of bully prevention programs demonstrated their effectiveness in changing the behavior of bystanders with regard to reducing antisocial actions (Polanin, Espelage, & Pigott, 2012).

Concern in schools about cyberbullying has increased significantly. A recent study found that 16% of high school students reported being bullied during the past year (CDC, 2012). In addition, approximately 14% of youth are perpetrators of electronic aggression (David-Ferdon & Hertz, 2009). The effects on victims of cyberbullying appear to be similar to those of in-person bullying (Ybarra, Diener-West, & Leaf, 2007). A disconcerting impact of cyberbullying is the potential for the anonymity of cyberspace to offer opportunities for increased levels of bullying. At present, programs to prevent and reduce cyberbullying are in their infancy; this topic has emerged as a highly important, albeit challenging, area of investigation.

CONCLUSIONS

Given the potential impact of chronic medical conditions and unhealthy behavior on academic, behavioral, and social functioning, schools are critical settings for health-related prevention and intervention efforts. Substantial progress has been made with respect to the identification of school-related deficits associated with chronic illness; however, further delineation of disease-specific risk factors and predictors of outcome is needed to aid prevention and intervention efforts. Systemic efforts at school reform also must be considered in addressing the needs of students with or at-risk for health difficulties. In particular, the adoption of a public health perspective in the context of the RTI model may be a particularly effective strategy for identifying and working with students whose health difficulties significantly affect school functioning. Pediatric and school psychologists can engage in both intervention (e.g., medication monitoring) and health promotion (e.g., violence prevention) activities at the individual, classroom, or schoolwide level. Empirical studies documenting effective strategies that change not only understanding and knowledge, but also key health-related behaviors, will be critical in promoting successful outcomes for all students who experience or are at risk for health difficulties.

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PART V

SPECIAL TOPICS

CHAPTER 45

Rural Pediatric Health

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The definition of "rural" varies, depending on the source. The U.S. Census Bureau (2014) defines "rural" as all population and territory falling outside urbanized areas with at least 2,500 people. The Office of Management and Budget (2013) defines counties as "metropolitan" (urban core population of 50,000 or more), "micropolitan" (urban core population of 10,000–49,999), or "nonmetropolitan/rural." The U.S. Department of Agriculture's Economic Research Service (ERS) system uses rural–urban codes to determine degree of rurality. Continuum codes separate county-level data into smaller residential groups, while commuting area codes account for population density, work-commuting patterns, and proximity to urban areas (ERS, 2013). The variability of classification schemes allows researchers and policy makers the flexibility to target populations with different levels of rurality and socioeconomic resources. However, the inconsistent definitions of "rural" also challenge efforts to conduct effective research on pediatric health risk among rural populations.

In 2010 an estimated 69.5 million Americans resided in rural areas (housing and territory outside urban areas), accounting for 19.3% of the total population and 18.5% of the child population (U.S. Census Bureau, 2014). Approximately 74% of children living in small rural areas (populations of 2,500–9,999) and 67% of children living in large rural areas (populations of 10,000–49,999) are white. In contrast, fewer than 10% of children living in small and large rural areas are black, while 9.4% and 15.5% of children living in small and large rural areas are Hispanic, respectively (U.S. Department of Health and Human Services [DHHS], 2011).

Rural children are at risk for poor psychosocial and physical health outcomes, with the greatest vulnerabilities among rural minority children. In the following section, we provide an overview of the status of pediatric health among rural children. Conditions and health behaviors for which there was sufficient research were included in our discus-

sion. However, despite evidence of greater morbidity and mortality compared to their urban counterparts, rural children remain an understudied population (U.S. DHHS, 2011; Singh, Azuine, Siahpush, & Kogan, 2012). Because of this paucity of research on rural health, a number of prominent pediatric health conditions are not discussed here.

PREVALENCE OF COMMON PEDIATRIC HEALTH/MENTAL HEALTH CONDITIONS AMONG RURAL YOUTH

Research on rural pediatric populations should be considered within the context of important methodological considerations. First, data on indicators of pediatric rural health are commonly derived from national surveys limited to parent-only reports, increasing the likelihood of response bias and inaccurate prevalence rate estimates. Second, rural children from racially/ethnically diverse backgrounds are unevenly distributed within and across regions; thus national estimates based on aggregate data likely do not accurately capture variability in health disparities among subgroups. Third, research on rural health is often population- and region-specific, thereby limiting the generalizability of findings.

Overweight and Obesity

Approximately 34.6% and 35.2% of children living in large and small rural areas, respectively, are overweight or obese (U.S. DHHS, 2011), compared to 31.8% of 2- to 19-year-olds nationally (Ogden, Carroll, Kit, & Flegal, 2014). Research on risk factors for overweight and obesity among rural children suggests that rural children are likely to engage in lower levels of physical activity and more hours of screen time, compared to urban youth (Lutfiyya, Lipsky, Wisdom-Behounek, & Inpanbutr-Martinkus, 2007). Higher rates of obesity-promoting behaviors among rural youth have been attributed to contextual characteristics of rural neighborhoods (e.g., lack of sidewalks, parks, and recreation centers) and socioeconomic characteristics (including minority status, lower socioeconomic status, lack of health insurance, and lower utilization of preventive care services) (U.S. DHHS, 2011; Lutfiyya et al., 2007).

Asthma

Asthma affects approximately 9.3% of U.S. children, with steadily increasing prevalence rates each year. Research suggests a lack of rural–urban differences in asthma prevalence; however, among rural youth, rates of asthma are significantly higher for youth living adjacent to metropolitan areas than for youth living in nonadjacent areas (Hendryx, Gurka, Ahern, & Putman, 2012). Rural children also demonstrate a greater risk for poor asthma-related health outcomes (even after controlling for race and income level), suggesting poorer illness management. For instance, rural youth living in Southern states are more likely to have moderate to severe asthma, have higher rates of asthma-related inpatient hospitalizations and emergency department visits, and have lower rates of outpatient visits, compared to their urban counterparts (Roy, McGinty, Hayes, & Zhang, 2010).

HIV and AIDS

An estimated 62,400 children and young adults (ages 13–24) are living with HIV and account for approximately 21% of all new cases (Centers for Disease Control and Prevention [CDC], 2015). HIV and AIDS remain more prevalent in metropolitan areas (Hall, Li, & McKenna, 2005), but rates of new HIV infection are increasing more rapidly in rural areas, especially among adolescents and young adults living in Southern states (Hall et al., 2005). Rural residents are less likely to be tested than urban residents, and more likely to be diagnosed later in the course of infection (Weis, Liese, Hussey, Gibson, & Duffus, 2010). However, HIV/AIDS mortality among adolescents and young adults is 5.6 times greater in urban than in rural areas (Singh et al., 2012). Discrepancies in identified rural–urban disparities in HIV/AIDS highlight the need for more research in this area.

Emotional and Behavioral Problems

An estimated 13–20% of children nationwide suffer from mental, emotional, and/or behavioral problems (O'Connell, Boat, & Warner, 2009). However, emotional and behavioral problems are estimated to affect approximately 20% of rural children, similar to the upper end of national estimates (Polaha, Dalton, & Allen, 2011). Despite similar rates of mental health problems among urban and rural children, rural children are more likely to have unmet mental health care needs (Leonardson, Ziller, Lamber, Race, & Yousefian, 2010).

Suicide

Suicide is the second leading cause of death of individuals ages 10–34 years (CDC, 2014). Research based on data from the World Health Organization mortality database suggests that U.S. rural residents aged 14–24 years have an 84% higher suicide mortality than their urbanized counterparts, even after controlling for socioeconomic indicators (Singh et al., 2012). These findings suggest that rural youth may be at greater risk for more severe and undertreated mental health problems.

Substance Use and Risky Sexual Behavior

Youth risk behavior research has focused largely on high-risk urban youth. However, a report from the National Center on Addiction and Substance Abuse found that eighth graders living in rural America were 104% more likely to use amphetamines, 83% more likely to use crack cocaine, twice as likely to smoke cigarettes, and five times more likely to use other types of tobacco than their peers living in large metropolitan areas (Foster, 2000). Rural males are more likely to engage in sexual intercourse and less likely to report using a condom, especially while under the influence of alcohol (Crosby, Yarber, Ding, Diclemente, & Dodge, 2000). However, other research suggests that after controlling for socioeconomic status and race/ethnicity, rural–urban differences for some health risk behaviors disappear (Levine & Coupey, 2003), underscoring the importance of considering the influence of sociodemographic factors on pediatric health.

Unintentional Injury

Unintentional injury is the leading cause of death among individuals ages 1–44 years old (CDC, 2014). Annually, approximately 9.2 million children visit an emergency department, and 12,175 children die from unintentional injury (Borse et al., 2008). Children living in rural areas are more likely to have injury-related emergency department visits (Owens et al., 2008) and primary care visits (Hambidge, Davidson, Gonzales, & Steiner, 2002), and are 2.3 times more likely than urban children to die from unintentional injuries (Singh et al., 2012). For example, compared to urban children, rural children are at higher risk of injury and death due to motor vehicle crashes (Kim, Ozegovic, & Voaklander, 2012), which may be associated with risk-taking behaviors (speeding, alcohol use) and limited access to pediatric trauma centers (Singh et al., 2012).

DETERMINANTS OF HEALTH OUTCOMES

The available research suggests rural–urban differences in children's emotional and physical health. Compared to urban youth, rural youth are at greater risk for some chronic conditions (U.S. DHHS, 2011; Hall et al., 2005), are likely to be diagnosed later in the course of illness (Hall et al., 2005), are more likely to experience greater illness severity (Roy et al., 2010), and are at greater risk of preventable death (Singh et al., 2012). In this part of the chapter, we consider the effects of socioeconomic inequities on service access; the impact of the profound health care provider shortage in rural communities on the availability of services; and, finally, the role of cultural beliefs on the acceptability of available services and health care use (Jameson & Blank, 2007).

Socioeconomic Disadvantage

Urban youth are recognized as a population disproportionately affected by poverty; however, recent prevalence rates suggest that rural children are the fastest-growing U.S. population entering poverty. Since 2000, 1.3 million rural children have entered poverty, and in 2012 rural children accounted for approximately 38% and 57% of all children living in poverty and high-poverty areas (30% or more of children living in poverty), respectively (Anne E. Casey Foundation, 2014). Compared to 21.6% of urban children, 26.2% of rural children live below the federal poverty level (ERS, 2015). Furthermore, racial and ethnic health disparities are exacerbated among rural communities. For example, among urban children, 16.9% of white, 32.5% of Hispanic, 32.2% of American Indian/Alaskan Native, and 37.9% of black children live in poverty. Among rural children, poverty affects 22.1% of white children, compared to 36.0% of Hispanic, 44.1% of American Indian/Alaskan Native, and 51.8% of black children (ERS, 2015). Poverty among rural children may have particularly detrimental implications for child health and well-being, given socioeconomic and contextual barriers that may exacerbate health disparities (ERS, 2015).

National initiatives under Medicaid, the Children's Health Insurance Program, and the Patient Protection and Affordable Care Act have successfully increased children's access to health care insurance. In 2014, an estimated 94.5% of U.S. children (<18 years old) had health care insurance, representing an 8.4% increase since 1997 (Cohen

& Martinez, 2015). However, compared to urban children, rural children are more likely to be uninsured (Alker & Chester, 2014) and to have unmet health care needs despite insurance (Leonardson et al., 2010). Among the insured, rural children are more likely to have public health insurance than are urban children (36–38% vs. 24%) (U.S. DHHS, 2011). Public insurance is generally associated with greater access to services and lower rates of unmet needs, compared to no insurance or private insurance (Leonardson et al., 2010). However, rural children with public health insurance are less likely to access preventive health care (U.S. DHHS, 2011) and 20% more likely to have unmet health care needs than urban children (Leonardson et al., 2010). To shed more light on the inequities of health care among rural children, we next discuss the role of persistent health professional shortages in rural areas, as well as unique challenges associated with the acceptability of services among rural residents.

Health Professional Shortage Areas and Rural Health Care

In 2010, 34%, 23%, and 25% of nonmetropolitan counties were designated "health professional shortage areas" (HPSAs) for primary care, dental care, and mental health, respectively (U.S. DHHS, 2011), with the most profound shortages in more sparsely populated areas (Allison & Manski, 2007). Fewer than 12% of graduating health care professionals enter rural practice. These providers are more likely to be generalists, especially family medicine practitioners (22.6%), and less likely to be specialists such as pediatricians (9.1%) or psychiatrists (8.7%). Despite a persistent and growing need, the increase in new providers entering rural practice over a 10-year period was less than 2% (Chen, Fordyce, Andes, & Hart, 2010).

Health professional shortages may increase travel distances and decrease the timeliness of receiving needed services. Furthermore, the limited availability of mental health providers increases the burden placed on alternative service systems, especially primary care providers and schools (Polaha et al., 2011), which often lack the resources for adequate treatment of mental and behavioral health concerns (Steele et al., 2012). Parents in rural Appalachia report commonly seeking treatment for child psychosocial concerns from pediatricians (63%) and less often from counselors/therapists (24%) (Polaha et al., 2011). Data from the Great Smoky Mountains Study (Farmer, Burns, Phillips, Angold, & Costello, 2003) showed that children diagnosed with a psychiatric condition or a functional impairment most frequently received mental health services through their schools (50%), followed by their primary care providers (30%) and, to a lesser extent, mental health professionals (15%). Fewer than half of the children who initially received psychological services through school or primary care also received treatment from specialty mental health providers.

Limited research suggests that rural children rely more heavily than urban children on school-based programs for mental health care (Wade et al., 2008). However, the broader issues associated with shortages of mental health providers in rural communities trickle down to school systems. For instance, compared to schools in more densely populated areas, rural schools often face greater barriers to effectively implementing and sustaining school-based mental health services, due to inadequate funding and difficulty in recruiting and retaining qualified mental health professionals (Edwards & Sullivan, 2014). As a consequence, rural school-based mental health providers often lack the training to address more complex behavioral and mental health concerns.

In a recent survey of rural primary care physicians from Canada, most providers reported inadequate knowledge and training to manage mental health problems (Steele et al., 2012). Rural physicians were less likely to treat mood disorders such as anxiety and depression; more likely to diagnose externalizing behaviors, especially attention-deficit/hyperactivity disorder (ADHD) (Steele et al., 2012); and more likely to prescribe psychotropic medications for behavioral concerns than to refer patients to a psychologist (Cooper, Valleley, Polaha, Begeny, & Evans, 2006). This is consistent with research documenting higher rates of ADHD and use of psychotropic medications among rural compared to urban children (Anderson, Neuwirth, Lenardson, & Hartley, 2013).

Acceptability of Services

Taken together, socioeconomic inequalities and HPSAs contribute to higher rates of unmet health care needs among rural children, especially children from ethnically/racially diverse backgrounds, those living in deeper poverty, and children in more sparsely populated areas. Despite national initiatives to increase health care coverage among children, population dispersion has created barriers to educating rural residents about health care options for children (Alker & Chester, 2014). Research also suggests that conservative cultural and political beliefs, which are more common among rural communities, may also increase mental health care stigma and create barriers to treatment initiation. Dense social networks may increase concerns about privacy and social stigma, and reduce families' willingness to participate in treatment (Lim & Janicke, 2013).

INNOVATIVE METHODS OF TREATMENT DELIVERY

To address treatment barriers, innovative methods of delivery have been developed and tested, including school-based programs, community-based programs, telehealth, and (to a lesser extent) integrated care. Some of these programs are reviewed next.

School-Based Behavioral and Emotional Health Programs

Given the increased accessibility and convenience of schools, effective and sustainable models of school-based behavioral health programs offer one avenue for addressing rural health disparities. However, school-based programs to address rural pediatric health concerns are few and have generally been limited to obesity prevention. One such program, the Winning with Wellness program, has been pilot-tested in both elementary and middle schools in rural Appalachia. The program was based on the coordinated school health model, and development was informed through a community-based participatory research approach. School personnel delivered the intervention, which targeted healthy lifestyle behaviors. Although there was no significant effect of treatment on change in children's body mass index (BMI) *z*-scores (Schetzina et al., 2009; Dalton, Schetzina, & Conway-Williams, 2014), mixed evidence suggested some improvements in health behaviors. After 7 months, elementary school children demonstrated signifi-

cant improvements in their dietary intake and physical activity (Schetzina et al., 2009), with continued improvements 4 years later (Schetzina et al., 2011). In contrast, there were no significant changes in diet or activity among middle school children after 9 months (Dalton et al., 2014).

The school-linked Mental Health Program in rural central Florida provides an example of an innovative program focused on addressing mental health concerns among rural children. Empirically supported interventions are provided by licensed psychologists, psychology graduate students, and postdoctoral psychology interns from the University of Florida. Families are school-referred and treated either in the schools or in community outpatient clinics, depending on the families' preference (Evans, Radunovich, Cornette, Wiens, & Roy, 2008). Over a period of approximately 4.5 years, oppositional behavioral problems (26.1%) and depressive symptoms (22.9%) were the most common concerns among the 168 children and families treated. Rates of treatment completion were similar among families treated in the schools or in community clinics, with approximately 45% of all children either successfully completing or maximizing treatment benefits. These findings support the feasibility of delivering empirically supported interventions in established rural settings.

Treatment Dissemination and Implementation in Communities

Previous research has highlighted the need to increase the dissemination and reach of evidence-based interventions to real-world settings where underserved populations live (Jameson & Blank, 2007). Project STORY provides one example of the effective translation and dissemination of a behavioral pediatric weight management program to a real-world rural setting (Janicke et al., 2008). The intervention was delivered through Cooperative Extension Service offices within participating rural communities. In this randomized controlled trial, child–parent dyads were randomly assigned to a behavioral family intervention, a behavioral parent-only intervention, or a wait-list control condition. Compared to children whose families were assigned to the wait-list control group, children of families in the two behavioral intervention groups had significantly lower BMI *z*-scores at 4 and 10 months. Cost analysis found lower cost per child for the behavioral parent-only intervention than for the behavioral family intervention (Janicke et al., 2009). This type of cost analysis is becoming increasingly important for determining the potential sustainability of interventions in real-world settings with limited resources.

Telehealth and Integrated Care in Rural Pediatric Psychology

In recent years, there has been a growing interest in telehealth services to increase access to health care in rural communities. Telehealth-based treatments have been effectively implemented in the assessment, consultation, and treatment of a range of pediatric conditions, including sleep problems (Witmans et al., 2008), complex feeding disorders (Clawson et al., 2007), and obesity (Davis, Sampilo, Gallagher, Landrum, & Malone, 2013). Telehealth has been effectively used to deliver individual, group, and multidisciplinary treatments and has been associated with high levels of patient (Clawson et al., 2007; Marcin et al., 2004; Witmans et al., 2008) and provider (Marcin et al., 2004)

satisfaction, as well as with reduced patient burden of expense and time for travel (Witmans et al., 2008).

To date, however, much of the research on telehealth-facilitated mental and behavioral health services has been limited to grant-funded pilot studies, and very few studies have focused specifically on rural pediatric populations. Davis et al. (2013) have conducted one of the few randomized controlled trials of a telehealth intervention to improve pediatric health. Fifty-eight rural children with overweight or obesity (BMI ≥ 85th percentile) and their families were randomly assigned to one of two treatments: an 8-month (eight weekly sessions, followed by monthly sessions) family-based behavioral group intervention delivered via telemedicine, or a one-time structured physician visit guided by a written list of pediatric obesity topics. At 8 months posttreatment, there were no significant differences between groups; both groups improved on measures of child BMI, dietary intake, and physical activity.

There is compelling evidence for the integration of behavioral health services into primary health care, both for improved access and cost-effectiveness (Kolko, 2015). However, again, research on models of integrated practice in rural communities is limited. Davis et al. (2013) provide one example of a "minimal intervention" that could be implemented in a primary care setting to address some pediatric weight concerns. This approach may also improve provider self-efficacy to address other behavioral health problems.

CURRENT STATUS OF RESEARCH AND FUTURE RESEARCH DIRECTIONS

Rural pediatric populations continue to be understudied. To date, much of the research has consisted of large national surveys based on aggregate data, qualitative studies, and small pilot intervention studies with restricted populations and inadequate controls. Randomized controlled trials are rare in this population (Davis et al., 2013; Janicke et al., 2008), and few examples of translation and dissemination intervention studies exist (Janicke et al., 2008). More research, based on more rigorous designs, is needed. Further investigations into the long-term feasibility, cost-effectiveness, and sustainability of innovative approaches to treatment, including telehealth services, are also warranted.

To move this field forward, we will also need to address the multifaceted challenges unique to conducting research and addressing pediatric health concerns in rural communities, including population dispersion, socioeconomic constraints, and barriers to research participation. For instance, efforts are needed to increase access to treatment among families living in sparsely populated areas, distal to other institutional supports (e.g., universities). Innovative approaches are needed to increase the feasibility of implementing and sustaining telehealth interventions within the context of underfunded rural health care centers with limited access to essential resources (e.g., technological infrastructures, software, hardware). Efforts are also needed to address the inconsistent reimbursement of telehealth services, which may tax already strained financial infrastructures and decrease feasibility (Van Allen, Davis, & Lassen, 2011). Efforts will also be needed to decrease barriers to engaging rural residents in research, including distrust of research and researchers, concerns about retaining privacy, social stigma of mental health care, and limited access to transportation and technology (Lim & Janicke, 2013).

SUMMARY

There is growing evidence of rural–urban disparities in pediatric health. Rural children are at greater risk than urban children for poor health outcomes, and they experience greater barriers to timely and quality care. Research on rural pediatric health remains sparse, with research on many prominent pediatric health conditions (e.g., diabetes, cancers) lacking in the current body of literature. Socioeconomic characteristics have been inconsistently considered across studies, providing an incomplete picture of pediatric health outcomes among the most vulnerable populations—rural children from racially/ethnically diverse backgrounds. Continued efforts are needed to improve reach and accessibility to high-quality services through innovative methods such as school-based programs, telehealth, translational and dissemination research, and integrated care. However, culturally sensitive approaches will be equally important to treatment development and implementation, especially approaches that strengthen community acceptance of and confidence in behavioral health approaches to improving pediatric health outcomes among rural children.

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CHAPTER 46

International Developments in Pediatric Psychology

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> International research and practice in pediatric psychology provide an opportunity to learn about children's health and illness and to share strategies for health promotion and illness prevention across international boundaries. There are many common aspects to children's health, ranging from biomedical concerns, such as infectious diseases, chronic illnesses, and disabilities, to psychosocial concerns, such as child abuse and neglect. However, contextual and cultural differences are associated with the understanding and interpretation of child health and illnesses across the world. With increasing globalization and the resultant intermingling of cultures, there is much to be gained from a more culturally sensitive approach to the issues of children's health and illness.
>
> —Black, Eiser, and Krishnakumar (2000, p. 363)

These words, published in 2000 in the *Journal of Pediatric Psychology* (*JPP*) special issue on international research and practice, are of utmost relevance today. We live in a world where international collaborations are growing rapidly across subfields of psychology (Kliegl & Bates, 2011). Technological advances enable us to become informed about and make contact with individuals from around the world almost instantaneously. Furthermore, prevalent throughout the world are concerns about maternal and child health, and about the treatment and prevention of diseases and conditions in youth that contribute to adult morbidity and mortality (World Health Organization [WHO], 2014). Accordingly, international communication and collaboration should be important aspects of research and practice in pediatric psychology.

Many of the diseases and conditions that are of interest to pediatric psychologists in

the United States and Canada are also international concerns.[1] The U.S. Department of Health and Human Services maintains an Office of Global Affairs website with specific information on a global health strategy and concerns (*www.hhs.gov/about/agencies/oga/about-oga/why-hhs-works-globally/hhs-global-strategy/index.html*) that highlights international health topics, including noncommunicable diseases (e.g., cancer, diabetes, asthma, cardiovascular disease), communicable diseases (e.g., HIV/AIDS, influenza), and key issues in maternal and child health (e.g., cervical cancer, birth defects, vaccine-preventable diseases). In particular, chronic noncommunicable diseases are identified as the leading causes of death and disability in the world (*www.hhs.gov/sites/default/files/hhs-global-strategy.pdf*); *such diseases also are frequent* foci of the research and practice activities of pediatric psychologists. In fact, virtually all of the topics covered in Part III of this *Handbook* are of great interest from an international health perspective.

An even broader concept than international health is that of "global health," which has been defined as an area of "research and practice that places a priority on improving health and achieving equity in health for all people worldwide" (Koplan et al., 2009, p. 1995). Global health often emphasizes problems with a political or economic impact that extends beyond national borders (e.g., an Ebola outbreak; Macfarlane, Jacobs, & Kaaya, 2008). Although global health issues are often problems of low-income countries (e.g., infectious diseases, nutritional causes of disease), increasing numbers of child health problems are shared by low- and high-income countries around the world (WHO, 2014). For example, half of the top 20 causes of premature death worldwide are noncommunicable chronic diseases or injuries, which are also leading causes of death in the United States (Centers for Disease Control and Prevention [CDC], 2011, 2014). In addition, the problem of childhood obesity is of high concern in the United States and other industrialized countries (CDC, 2014; Olds, Tomkinson, Ferrar, & Maher, 2010; Stamatakis, Zaninotto, Falaschetti, Mindell, & Head, 2010), and it also has been identified as a critical global health problem (Lobstein, Bau, & Uauy, 2004; Wang & Lim, 2012; Wang & Lobstein, 2006). Recent statistics indicate that nearly 7% of the world's children under age 5 years are overweight or obese (WHO, 2014).

What does this all mean for pediatric psychologists? We believe that there are many opportunities for pediatric psychologists to share their research and practice knowledge with others and to learn from the expertise of others in similar and different cultures. There also are opportunities for pediatric psychologists to collaborate on global health issues that could affect the health of millions of children, youth, and families around the world.

This chapter describes some of the ways pediatric psychologists (in the United States and abroad) can become more internationally savvy and increase their involvement in and awareness of international collaborative efforts. Below, we first describe international organizations, meetings, and journals that can be starting points for networking and broadening pediatric psychologists' understanding of child health issues. Second, we describe some of the international efforts of the Society of Pediatric Psychology (SPP)

[1]This chapter defines "international" as "outside the United States and Canada." Although the United States and Canada have distinct cultures and health care models, there is a long history of exchanges between the two nations, one shared language, and collaborations between our major professional organizations (e.g., the American Psychological Association and the Canadian Psychological Association). Thus, in this chapter, we focus on activities outside these two North American countries.

and its journal. Third, we highlight several contextual issues that affect international activities in pediatric psychology, and we discuss some of the training and credentialing issues that affect pediatric psychologists outside the United States and Canada. We end the chapter with several conclusions and recommendations for facilitating international activities.

In preparing this chapter, we attempted to go beyond our own experiences and professional networks in order to learn more about the international activities of current SPP members. To do so, we prepared a brief online survey distributed via the SPP listserv in February 2015. Although this was not a scientific survey, we received responses from 116 SPP members, which were informative about their international activities. These survey responses contributed to the examples of international activities described in the chapter.

PEDIATRIC PSYCHOLOGY AROUND THE WORLD: INTERNATIONAL CONFERENCES AND JOURNALS

There are multiple ways that pediatric psychologists can become more involved in international projects and collaborations. Attending and presenting at international meetings constitute one common way of learning about clinical and research activities related to pediatric psychology and becoming acquainted with individuals who share similar interests. Reading articles in and submitting manuscripts to international journals in the areas of health, behavioral medicine, and child development can also be useful. Both kinds of activities provide opportunities to network and connect with international colleagues.

As we learned from our survey of SPP members, there are many diverse conferences that pediatric psychologists attend, and some key international journals that publish research of interest to pediatric psychologists.[2] In general, there are multiple broad-based meetings and journals that focus on topics of considerable interest to pediatric psychologists. Furthermore, depending on the area of expertise (e.g., diabetes, trauma, pain, oncology, cystic fibrosis, HIV/AIDS), many "topic-specific" meetings and journals could be of interest.

International Societies and Their Conferences

A key organization is the International Society of Behavioral Medicine (ISBM) (*www.isbm.info*), established over 25 years ago. ISBM is composed of many smaller "societies of behavioral medicine" from countries across the world (e.g., in Europe, Asia, and South America). Both SPP and Division 38 (Health Psychology) of the American Psychological Association (APA) are "affiliate members" of ISBM. ISBM sponsors the biennial International Congress of Behavioral Medicine, hosted by one of the member behavioral medicine societies (all presentations are in English). This is a reasonably sized meeting (about 700 attendees), with special programming for early-career psychologists (e.g.,

[2]For a detailed listing of key international societies, see Appendix A on the SPP website (*www.societyofpediatricpsychology.org/node/691*). International peer-reviewed journals also appear online in Appendix B (*www.springer.com/medicine/journal/12529*).

speed mentoring), and it is excellent for networking. Although the meeting content often focuses on adult rather than child health issues, greater involvement by pediatric psychologists would help to strengthen the pediatric offerings. The ISBM website lists other international meetings of interest to those in the health psychology field.

Another well-established broad-based international society is the International Association of Applied Psychology (*www.iaapsy.org*), founded in 1920. It is the largest international organization of psychology that is based on individual memberships. Its conferences (with about 2,500 attendees), held every 4 years, often have programming relevant to child health psychology and are much like international versions of APA meetings.

A relatively recent and potentially exciting international development is the Paediatric Psychology Network UK (PPN-UK) (*www.bps.org.uk/networks-and-communities/member-microsite/dcp-faculty-children-young-people-and-their-families/paediatric-psychology-network*), which was founded in 2000 as part of the Division of Clinical Psychology within the British Psychological Society (*www.bps.org.uk*). Its aim is to promote professional practice, research, and training in pediatric psychology, and it has an active listserv, to which pediatric psychologists worldwide can subscribe. This listserv is an excellent way to learn about some of the research and practice issues encountered by pediatric psychologists in the United Kingdom and Europe. In joint collaboration with the Paediatric Psychology Network in the Netherlands, the PPN-UK now has twice sponsored the International Conference in Paediatric Psychology in Europe. The conference has welcomed submissions from both clinicians and researchers, and has covered a broad range of topics of interest to pediatric psychologists, such as neuropsychology, neonatology, congenital heart disease, medical procedures, sleep, Type 1 diabetes, pediatric cancer, pediatric quality of life, asthma, and delayed puberty. The intent is to sponsor biennial meetings.

In addition, there are many international societies that focus on specific areas of health and hold regular meetings, such as the International Society of Paediatric Oncology (*www.siop-online.org*), the International Association for the Study of Pain (*www.iasp-pain.org*), and the International Society for Pediatric and Adolescent Diabetes (*www.ispad.org*). Similarly, there are also European organizations with a specific health focus, including the European Burn Association (*http://euroburn.org*), the European Cystic Fibrosis Society (*www.ecfs.eu*), and the European Health Psychology Society (*www.ehps.net*). (See Appendix A at *www.societyofpediatricpsychology.org/node/691*)

These scientific societies and their meetings can provide a forum for networking and learning about pediatric psychology throughout the world. Given the diversity of professional societies with child health interests, it is possible for pediatric psychologists to identify and target specific organizations that match their particular areas of expertise.

International Journals

Several broad-based, peer-reviewed international journals publish research relevant to child health and illness. For example, ISBM publishes the *International Journal of Behavioral Medicine,* which presents "original research and integrative reviews on interactions among behavioral, psychosocial, environmental, genetic and biomedical factors relevant to health and illness." Other broad-based journals include *Health Psychology*

Review, International Journal of Child and Adolescent Health, and the *Journal of Psychosomatic Research* (see Appendix B at *www.springer.com/medicine/journal/12529*).

There are also many journals that are population-specific. That is, many, if not most, subspecialties in pediatrics and medicine have international journals that publish pediatric psychology papers. Examples include *Diabetes Research and Clinical Practice, Injury Prevention, Journal of Cystic Fibrosis, International Journal of Pediatric Obesity, International Journal of Behavioral Nutrition and Physical Activity,* and *Psycho-Oncology.*

These international journals provide excellent information about child health research and practice in other countries, and can provide a global perspective on important pediatric issues (obesity, diabetes, etc.). We strongly encourage pediatric psychologists to keep abreast of international developments in their areas of interest or expertise. International journals also are important sources for identifying potential international collaborators.

INTERNATIONAL ACTIVITIES OF THE SPP

In many respects, the membership of SPP (Division 54 of APA), the sponsor of this *Handbook,* is fairly "U.S.-centric." Of the 1,773 members of SPP in 2014, fewer than 5% (n = 82) came from countries outside the U.S., and the largest group of non-U.S. members came from Canada (45% of the SPP international members). Individuals from the United Kingdom and Europe (especially Portugal, the Netherlands, and Belgium) accounted for another 41% of SPP's international members, with Australia/New Zealand (7%) and the Middle East and Asia (6%) accounting for the rest. Yet pediatric psychology is represented throughout the world, and SPP is making concerted efforts to broaden its scope and connect with pediatric psychologists worldwide.

For example, SPP has a long-standing interest in increasing the international visibility of SPP and recruiting international members for the society (Black et al., 2000; Wallander, 1996). Over 20 years ago, SPP initiated a Task Force on International Developments in Pediatric Psychology that evolved into the standing SPP International Committee. The committee's mission includes increasing international membership in the SPP and increasing pediatric psychology research in the developed world as well as in low-/middle-income countries (L. Simons, International Committee Chair, personal communication, March 23, 2015). Through the work of this committee, SPP has identified international speakers for its annual meeting, the SPP Annual Conference, and has established international travel awards to help support the attendance of international colleagues at the meeting. These activities provide opportunities for U.S. and Canadian psychologists to establish connections with pediatric colleagues from other parts of the world, and for international scholars to learn more about activities in North America.

SPP has encouraged greater international visibility for pediatric psychology research through its primary scientific journal, *JPP,* which is widely known around the world. *JPP* has always been open to and published papers from international authors. Moreover, for at least the past 20 years international colleagues have served on the *JPP* Editorial Board, and in 1998 the first Associate Editor of *JPP* from outside North America (Christine Eiser) was appointed.

In regard to *JPP* publications from international first authors, Wallander (1996) noted that there were only two such papers published from 1986 to 1990 and two to three such articles per year through the early 1990s, amounting to roughly 3.6% of the papers published in *JPP* at that time. The major countries represented were Australia, the Netherlands, Sweden, Israel, the United Kingdom, and New Zealand (Wallander, 1996). In contrast, our own review of papers published in *JPP* during 2013 and 2014 revealed that 15% had an author from outside North America. These authors were from the United Kingdom, Europe (the Netherlands, Germany, Belgium, Norway, Portugal, Hungary, France), and other countries, including Israel, China, and Korea. Furthermore, it is interesting to note that our informal survey of SPP members identified pediatric psychologists working in a broader range of countries and world regions than is reflected in *JPP* authorships—including, for example, India, Central and South America, and Africa. The increasing representation of international authors for papers published in *JPP* parallels the trajectories for other prominent psychology journals (Kliegl & Bates, 2011).

It is possible that publication outlets may be selected differently outside North America. To use psycho-oncology as an example, between 1986 and 2000 pediatric psycho-oncology researchers in Europe and Australia were significantly more likely to publish their work in medical journals (90% of the studies) than their U.S. counterparts (45% in medical journals, 30% in psychological/psychiatric journals, and 25% in *JPP* specifically) (Last, Grootenhuis, & Eiser, 2005). (We are unaware of any comparable data for other content areas of pediatric psychology.)

This greater focus on publishing in medical journals for international pediatric psychologists may reflect their professional positions. For example, in many countries (especially in Europe and Australia), the number of pediatric psychology specialists is relatively small, and they are likely to be embedded within medical health care teams (e.g., teams for oncology, cystic fibrosis, diabetes, etc.); these individuals may not be as well connected to other psychology colleagues. The greater focus on medical journals for publication may also be intended to promote psychological-mindedness and skills in other health care professionals and to influence psychological practices in medical teams (J. Young, personal communication, October 8, 2015).

CONTEXTUAL AND OTHER ISSUES PERTINENT TO INTERNATIONAL COLLABORATIONS AND ACTIVITIES

A number of contextual issues may influence the development and pursuit of international collaborations in pediatric psychology. We discuss several such issues below.

Teamwork and Service Delivery Issues

Contextual issues may help to push pediatric psychologists' professional networks to become increasingly culturally diverse and international in focus. One such issue is the growing emphasis on team science and interdisciplinary collaboration, both at the National Institutes of Health and in private organizations (Bennett, Gadlin, & Levine-Finley, 2010). In academic settings, particularly research-intensive institutions, meeting and interacting with others nationally and internationally are often critical to academic

success, sometimes with explicit expectations for doing so. At some point, most pediatric psychologists will meet international scholars doing similar or related work. These may be individuals whose work is known through publications or who are embedded in professional networks or teams. In addition, because people around the world read pediatric psychology journals, international professionals may reach out to discuss common interests with U.S. and Canadian pediatric psychologists.

Another contextual issue pertains to the diversity of patients seen in health care settings. For pediatric psychologists who provide services or conduct research in U.S. health care settings, an appreciation of diverse cultures and languages may be essential. There has long been a subset of families from around the world seeking medical treatment for their children in the United States, and this trend has accelerated in recent years, with most major children's hospitals now having a program or department for patients from other countries. Specifically, about 800,000 patients are estimated to come to the United States every year for medical care, often for treatment of complex conditions (*www.patientsbeyondborders.com/united-states*). In this way, pediatric psychologists practicing in hospitals where international patients are admitted will have exposure to patients and families from other countries and cultures. Many of these families have complex psychosocial needs, exacerbated by language and cultural barriers that can further complicate psychosocial concerns (e.g., Hilliard, Ernst, Gray, Saeed, & Cortina, 2012). Many children's hospitals are now forming specific relationships with hospitals in other parts of the world. These clinical collaborations also provide opportunities for pediatric psychologists to expand their practice with international patients, and to develop connections and relationships with health care providers at the patients' home institutions.

A related contextual issue is that U.S. health care settings also provide treatment for immigrants and foreign citizens from many diverse cultures, so that the cultural competence of the U.S. health care system has become critically important. U.S. residents speak over 300 different languages, and more than 30 million individuals speak a language other than English at home (Smith & Gonzales, 2000). At the same time, interventions to enhance the cultural competence of health care systems have been scant (Anderson et al., 2003). There is a clear need for pediatric psychologists and other health care providers to develop cultural awareness and competence even when they are providing care in U.S. health care settings.

Professional Issues, Training, and Service Delivery

Personal relationships are key components of successful international collaborations. Reaching out to colleagues from other countries, and arranging visits from these colleagues, are important ways to develop productive collaborations. In our experience, pediatric psychologists in other countries are often eager to visit the United States and are appreciative when a warm welcome is extended for them to visit. The host will often need to complete groundwork for the visit to assure that the experience will be structured and worthwhile, and that all needed visas and clearances are obtained. However, the visitors may have access to funds to allow them to travel and to cover their living expenses. As these relationships develop, reciprocal visits or ongoing plans for strengthening these professional relationships often emerge.

International colleagues (often physicians) also visit North American institutions,

sometimes for a semester or year. These visits are often good opportunities to learn about relevant work in other parts of the world. These visiting scholars are often eager to learn about innovations that they can take home with them, and they can be helpful in connecting pediatric psychologists with those with shared interests at their home institutions.

In particular, collaborations with colleagues across European countries are common for pediatric psychologists. Psychologists in the United Kingdom, the Netherlands, and Germany have been working in pediatric settings since the 1970s or 1980s (L. Goldbeck, personal communication, November 8, 2014; M. Grootenhuis, personal communication, November 9, 2014; K. Jacobs, personal communication, November 10, 2014).

However, a few distinctions between the North American and European systems are important (and some of these points may apply to countries outside Europe). First, psychologists in Europe (and other parts of the world) may not identify as "pediatric psychologists," or if they do, they may use different terminology to describe their professional positions. For example, in the United Kingdom and Australia, they may be referred to as "clinical psychologists," "consultation–liaison clinical psychologists," or simply "psychologists," even though we might consider them to be pediatric psychologists on the basis of their work.

Second, the academic structure in Europe is different. Doctoral degrees are less common than in North America, and psychologists with master's degrees deliver much of the clinical care. Doctoral students often are experienced psychologists who have decided to pursue a doctoral degree to conduct research and teach. Indeed, to be a professor in a European institution is to have achieved a very highly regarded stature, and there are relatively few professors in any academic institution (although there are other positions with titles such as "senior lecturer" and "reader"). As Wallander (1996) noted, training is more centralized under a smaller number of professors and is focused on research. European universities generally expect a series of three to four published papers that form a body of work for a dissertation—another difference from North American standards.

A third issue concerns differences in the structure and delivery of health care, some of which are striking. Many European countries provide nationalized health care that is free at the point of delivery, typically available to all, and paid for by taxation (either individually or occupationally). Due to the "single-provider" context, many countries also have established national registries and databases, which can facilitate health care research and practice. In addition, social differences across societies exist, such as more liberal policies for extended time off from work with a sick child, and coverage of more out-of-pocket expenses than in the United States.

Finally, it may be obvious that language issues are important when collaborations outside English-speaking countries are being considered. Fortunately, many people around the world speak English. Nevertheless, miscommunications in written and spoken English can cause confusion and should be anticipated; sufficient time should be allowed to clarify communications or to edit written materials that will be used in the United States and abroad.

Although there are many benefits of international activities, a potential obstacle is cost. Although email and internet-based teleconferencing (e.g., Skype, FaceTime, Google Hangout) have facilitated collaborations, it is still important to have face-to-

face meetings, and also to visit other locations in order to learn about and appreciate international venues. Some institutions and funding agencies may not provide or allow support for international travel; others may encourage it, particularly when developing international collaborations and focusing on global health are priorities. Our informal survey of SPP members suggested that funding for international collaborations may be available from internal funds at one's home institution; such funding may come from one's department, global health programs, fellowships, international societies, and a range of governmental research agencies.

Developing Infrastructure

Infrastructure to support international collaborations is helpful in fostering working relationships with psychologists from other countries, while also offering the potential for significant advances in pediatric psychology and research. In the area of childhood cancer survivorship research, for example, Last et al. (2005) presented data to make the point that looking at differences in the United States and Canada will provide a richer understanding of outcomes than relying on only one part of the world.

In regard to developing infrastructure, there has been a "pediatric psychosocial group" within the International Society for Pediatric Oncology for a number of years, but only recently has the group obtained official recognition. This recognition includes programming time on the official program for the annual conference, as well as registration fees that are comfortable for nonphysician attendees. In addition, the psychosocial group holds a 1-day preconference meeting. This structure has fostered cohesiveness among psychologists working in pediatric cancer around the world. It does necessitate the investment and persistence of a leadership team of individuals committed to maintaining its listserv and disseminating relevant information. However, this type of "interest group" might serve as a model for developing infrastructure in other key areas of pediatric psychology.

CONCLUSIONS AND RECOMMENDATIONS

This chapter has provided information on the importance of international collaboration, contextual issues that influence collaborations, and some general strategies for becoming involved in or more knowledgeable about international activities. Here we offer a few additional recommendations for how individual pediatric psychologists and SPP as an organization might increase international involvement and scope.

Individual Strategies

Forging individual relationships with other professionals (psychologists and other health care providers) is an essential aspect of developing international collaborations. In this regard, learning more about international activities, enhancing the visibility and accessibility of one's work, and networking with others are important activities, as discussed both above and below. These strategies are applicable to individuals at all levels of training (e.g., students, postdoctoral fellows, professionals).

Several learning activities can promote international awareness. One strategy is to

subscribe to listservs for organizations that focus on pediatric or child health, general health, or a specific area of interest (diabetes, asthma, trauma, cancer, etc.). Listservs announce conferences and special issues of journals, and also provide information about the research and practice issues that concern pediatric psychologists worldwide. Another strategy is periodically checking the websites of international societies (described earlier in the chapter) or of major organizations that focus on global health, such as the World Health Organization (*www.who.int/en*) or the U.S. government Office of Global Affairs (*www.globalhealth.gov*), for updates and recent developments. The website Psychology Resources around the World (*http://resources.iupsys.net/iupsys/index.php/pra*), which was developed by the International Union of Psychological Science, also is a comprehensive "go-to source" for international activities in psychology.

Enhancing one's professional visibility can help foster international connections. For example, it can be useful to establish a professional webpage and a presence on scientific (e.g., ResearchGate.net, Academia.edu) or professional (e.g., LinkedIn.com) social media sites. These sites can be used to follow international research, disseminate eprints and other materials, and form affinity groups and joint projects. In addition, submitting manuscripts for publication in international journals can enhance one's international visibility. It is also useful to cite relevant work by international authors to bring readers' attention to a broader knowledge base.

Other ideas for networking and collaboration include attending international meetings or, if funds are limited, attending an international meeting that occurs in the United States. Presenting a poster facilitates connecting with others who have similar interests. It is useful to identify and contact individuals in advance, with a plan to connect during a conference, and with further follow-up afterward. Further networking strategies include identifying potential colleagues to contact via postings on relevant social media sites (as noted above) and reading articles in international psychological and medical journals related to one's area of interest or expertise. It is helpful to reach out to others and include international colleagues when submitting a conference proposal, planning an edited book, or organizing a meeting. In general, creating a mutual project can be a very productive way to establish collaboration.

Strategies for SPP as an Organization

SPP's International Committee has long-term goals to increase international collaboration among society members, such as by establishing a network of partner pediatric psychology organizations across the world. Some additional ideas for enhancing collaborations and expanding the international reach of SPP are offered below.

With respect to conferences, one idea could be to hold the SPP Annual Conference in an international venue every few years, in conjunction with other established pediatric or international health groups. In particular, a joint meeting with the Pediatric Psychology Network in Europe, or a meeting in conjunction with one of the many international behavioral medicine conferences, may be useful. In planning SPP meetings, international colleagues could be invited to speak about their work; these colleagues should include speakers beyond northern Europe and Australia, if possible. For example, articles in *JPP* have come from countries such as Israel, China, and Korea, and the respondents in our informal survey reported colleagues from India, Central and South America, and Africa. Annual SPP meetings might routinely have programming

and social events (e.g., an opening "social hour and poster session") that highlight international work and collaborations.

In regard to SPP publications, articles that highlight pediatric psychology work abroad might be invited for *Progress Notes* (the SPP newsletter), *JPP,* and *Clinical Practice in Pediatric Psychology*. It could be interesting and informative to feature a key international or global issue (e.g., obesity, asthma/respiratory problems, diabetes, health risk behaviors) in the SPP journals or newsletter, inviting diverse national and international pediatric psychologists to contribute to the issue.

Finally, efforts could be made to highlight international conferences and journals on the SPP website. Links to the organizations mentioned in this chapter are posted in the Appendices on the SPP website (see footnote 2).

Final Words

International collaboration is a welcome new topic for the *Handbook,* given the number and importance of global issues facing health care professionals today, and the rather long history of successful international collaboration and involvement by pediatric psychologists. We encourage pediatric psychologists to become involved in international activities in their relevant specialties, and we anticipate ongoing growth in the breadth of resources available to facilitate this work.

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CHAPTER 47

Transition in Pediatric Psychology

Adolescents and Young Adults

Katie A. Devine, Maureen Monaghan, and Lisa A. Schwartz

Approximately 750,000 adolescents and young adults (AYAs) with special health care needs (SHCN) transfer from pediatric to adult health care each year (Scal & Ireland, 2005). This transition occurs in the context of a larger developmental transition from adolescence to young adulthood, referred to as "emerging adulthood"—a term intended to capture the growth and associated instability in education, employment, supportive relationships, and personal responsibility common between the ages of 18 and 25 (Arnett, 2000). For AYAs with SHCN, the transfer to adult medical care is just one of many developmental tasks (e.g., pursuing academic and career goals, forming intimate relationships, moving away from the family home, assuming financial independence).

Poor planning and inadequate preparation for adult health care can have harmful medical effects for AYAs with SHCN, including increased morbidity and mortality, as well as disengagement from medical care (Pai & Ostendorf, 2011; Van Walleghem, Macdonald, & Dean, 2008). The promotion of readiness to transfer to adult medical care has become a focus of clinical practice and research in recent decades for AYAs with and without SHCN. In 2011, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians, and the American College of Physicians jointly published a clinical algorithm based on expert consensus of best practices in health care transition for youth with and without SHCN (AAP, American Academy of Family Physicians, & American College of Physicians, Transitions Clinical Report Authoring Group, 2011). Systematic application of the algorithm's tenets has successfully advanced the transition process in primary care (McManus et al., 2015). Yet the majority of AYAs with SHCN do not receive adequate preparation for adult health care (McManus et al., 2013). There is also inadequate attention to theoretical frameworks to

guide clinical and research practices in transition (Betz et al., 2014; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011).

This chapter presents an overview of the transition process and key considerations for transition for youth, families, and providers. Embedded within this transition between health care systems is the transition of responsibility for disease management from caregiver responsibility to shared responsibility with young adults or primary responsibility by the young adults.

THE PROCESS OF HEALTH CARE TRANSITION

The process of health care transition includes the time leading up to the departure from child-centered health care systems to the engagement in adult-oriented health care systems, and encompasses planning for and executing this move. The goal of health care transition is to promote optimal functioning through access to high-quality, developmentally appropriate health care services that continue uninterrupted from adolescence to adulthood (Rosen, Blum, Britto, Sawyer, & Siegel, 2003). "Health care transfer" refers to the discrete move from the pediatric to the adult care system. It is just one aspect of the transition process, but the subsequent uptake of care in the adult medical system is often used as a measure of success for the process.

Given the importance of successful transition, specialty care practice organizations have offered expert consensus statements on health care transition procedures and policies, including the recent clinical algorithm offering specific steps toward integrating transition care for all AYAs (AAP et al., 2011; Peters, Laffel, & American Diabetes Association Transitions Working Group, 2011; Sable et al., 2011). Key elements of these consensus statements include initiating discussions about transition policy and planning in early adolescence (ages 12–13); developing and routinely assessing skills associated with transition readiness; evaluating and modifying an individualized transition plan with youth and parents; recognizing unique psychosocial and developmental concerns and behaviors present in AYA patients; and moving to an adult model of medical care between ages 18 and 21 as developmentally appropriate. Aligned with these consensus statements, Got Transition/Center for Health Care Transition offers resources and tools for health care providers, patients, and families to improve the transition process (*www.gottransition.org*). Transition efforts are most successful when they are planned and coordinated, include multiple stakeholders (patient, family, health care providers), occur in a developmentally appropriate setting, promote gradual advancement of autonomy, and are tailored to individual and family needs (AAP et al., 2011).

Preparation for transfer to adult medical care includes two dynamic, reciprocal processes: evaluating transition readiness, and developing and implementing transition plans. "Transition readiness" broadly refers to the degree to which AYAs and supportive partners (e.g., parents) are able and willing to initiate and progress through the transition process. It may be operationalized differently for different populations. Although no consensus definition exists, assessment of transition readiness may include evaluation of skills, ability, knowledge, motivation, and resources related to transition (Betz & Telfair, 2007; Sawicki et al., 2011; Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004). Ideally, transition readiness is assessed at repeated intervals to track progress and can be used to predict outcomes in adult medical care, such as attendance

or self-management skills (Schwartz et al., 2013). Transition plans detail key goals that should be accomplished before the transfer to adult medical care, and describe how to meet these goals. These plans should include developmental milestones relevant for all AYAs, as well as patient-specific intervention targets across multiple systems. The combination of assessment and transition planning/intervention should facilitate an increase in transition readiness over time and lead to successful transfer from the pediatric to the adult health care system (Schwartz et al., 2013).

KEY CONSIDERATIONS FOR TRANSITION

To date, clinical algorithms and recommended guidelines on transition readiness and transition planning have been atheoretical (Betz et al., 2014). Although age, discrete skills (e.g., refilling a prescription), and knowledge (e.g., identifying signs of an adverse reaction, listing current medications) are typically used as indicators of transition readiness, essential components of transition readiness are not well defined, and research has not yet linked transition readiness skills with outcomes in adult medical care. Broader social-ecological correlates of transition readiness have received comparably little attention. One notable exception is the Social-ecological Model of AYA Readiness to Transition (SMART; Schwartz et al., 2011).

SMART emphasizes multiple factors, stakeholders, and systems, and their reciprocal relationships in influencing the readiness for and likelihood of success in transfer to adult-oriented care (see Figure 47.1; Schwartz et al., 2013). It considers indicators of transition readiness beyond patient-centered variables, and distinguishes between variables more or less amenable to change. A mixed-methods study of patients with childhood cancer, parents, and providers supported the validity of SMART in terms of the relevance of transition readiness components and its multisystemic focus (Schwartz et al., 2011, 2013). Evidence supporting key considerations for transition at the individual, family, and health care system levels is described below.

Individual

Certain preexisting factors that are considered less modifiable, such as sociodemographic characteristics and access to care, serve as facilitators of and barriers to successful transition to adult health care. There is evidence of racial and ethnic disparities in the transition to adult health care for AYAs with SHCN (Lotstein, Kuo, Strickland, & Tait, 2010; Stollon et al., 2015). A recent national survey of AYAs with SHCN showed that female gender, non-Hispanic white race, higher family income, and insurance coverage were associated with youth's meeting the transition outcomes of discussing transition with providers and being encouraged to take responsibility for their health care needs (McManus et al., 2013). Youth whose conditions adversely affect their activities, and those who have emotional, behavioral, or developmental conditions, are less likely to meet these transition outcomes (McManus et al., 2013). Cognitive delays or deficits may limit AYAs' abilities to take independent responsibility for their own care, and some youth may require ongoing assistance in decision making and disease management (Herzer, Goebel, & Cortina, 2010). It is especially important to include parents or other stable caregivers in the transition planning for these youth.

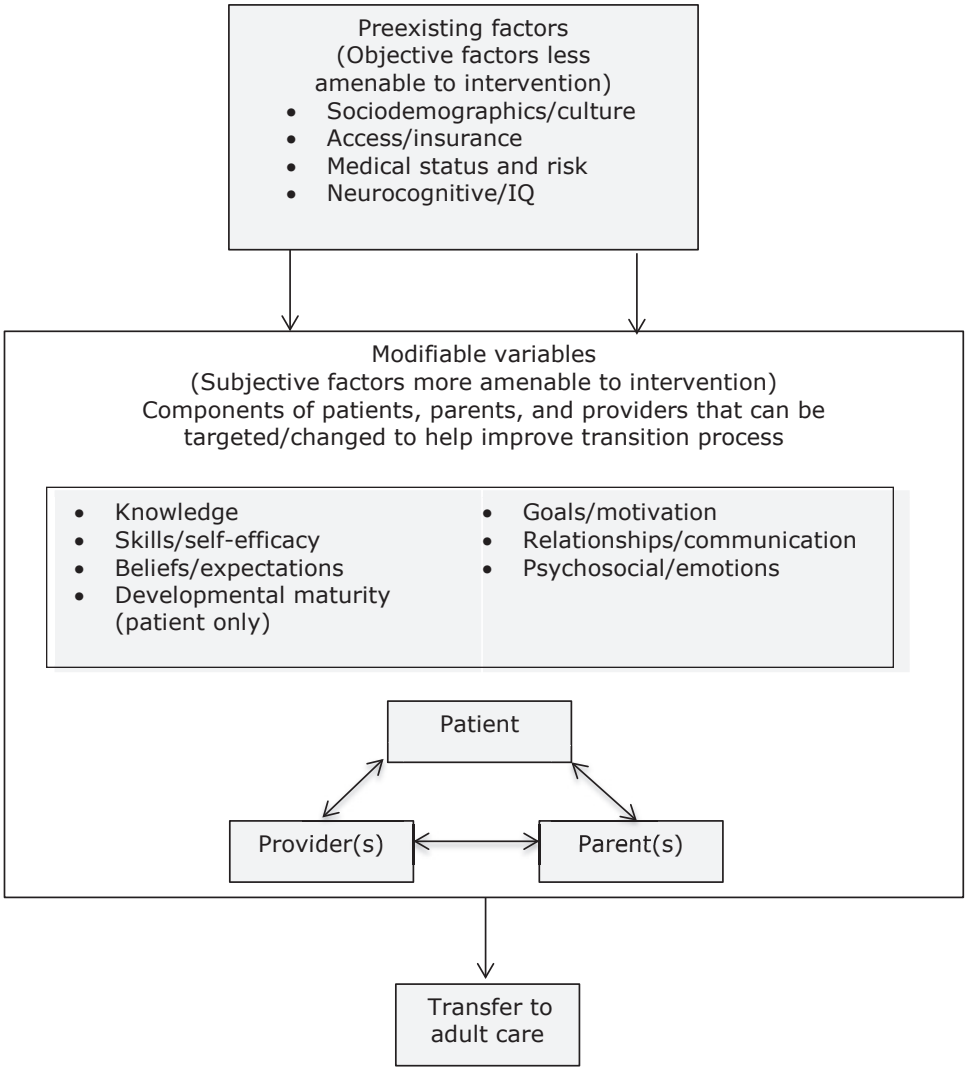

FIGURE 47.1. Social-ecological model of AYA readiness for transition (SMART). From "Stakeholder validation of a model of readiness for transition to adult care" by L. A. Schwartz, L. D. Brumley, L. K. Tuchman, L. P. Barakat, W. L. Hobbie, J. P. Ginsburg, . . . J. A. Deatrick, 2013, *JAMA Pediatrics, 167,* p. 940. Copyright © 2013 American Medical Association. Reproduced with permission. All rights reserved.

There are also many potentially modifiable characteristics to consider. Patients' knowledge of their condition is a prerequisite to self-care; patients must understand what is required to take care of their health as they shift from parent-guided management of care to self-management of care (Sawicki et al., 2011; Schwartz et al., 2011). Knowledge and self-management skills are the most common factors included in measures of transition readiness, suggesting a consensus regarding these issues as key contributors (Schwartz et al., 2014). More empirical data are needed, but knowledge and

self-management beliefs have been associated with transition readiness and plans for transfer to adult care (Gilleland, Amaral, Mee, & Blount, 2012; Sawicki, Kelemen, & Weitzman, 2014).

The patients' beliefs, attitudes, and expectations about the transition process and about adult health care are expected to influence transition. Beliefs that medical care should be with an adult provider are associated with successful transfer (Reid et al., 2004). Encouraging patients to identify positive aspects of transition is expected to facilitate successful transition (Lugasi, Achille, & Stevenson, 2011). Other individual factors to consider include patients' goals for the transition process (Reiss, Gibson, & Walker, 2005) and general psychological functioning as well as emotions specific to transition (Lugasi et al., 2011; Schwartz et al., 2011; Tuchman, Slap, & Britto, 2008). Finally, patients' developmental maturity influences their perceptions of transition readiness, as well as parents' and providers' perceptions of readiness (Kaufman, 2006; Peter, Forke, Ginsburg, & Schwarz, 2009; Schwartz et al., 2013). It is important to note that this transition co-occurs with other big developmental changes for patients, and that some patients report feeling overwhelmed by the simultaneous transitions (Tuchman et al., 2008).

Family

Developmentally appropriate AYA–parent relationships, frequent communication about the transition process, and adequate family resources can facilitate a successful transition to adult medical care. Autonomy in health care typically develops later than autonomy in other developmental areas, and it is recommended that this critical transition of health responsibility occur gradually (Beacham & Deatrick, 2013). It is misleading to equate the transition to adult-oriented health care with young adults' independently managing their chronic medical conditions with no assistance from others. In tandem with preparing for the transfer to adult heath care, parents and caregivers must shift from provision of direct support or monitoring for daily activities to provision of emotional support or discrete support for infrequent events, such as refilling prescriptions or managing acute complications (Hanna, Weaver, Stump, Guthrie, & Oruche, 2014; Hilliard et al., 2014). In other words, parents change roles from "CEOs" of daily health management in childhood, to "managers" in middle childhood/early adolescence, to "supervisors" in adolescence, and finally to "consultants" in young adulthood (Bell et al., 2008). Parents ideally start modeling and assigning responsibility for health-related skills early in adolescence, to allow adequate opportunities for practice (Reiss et al., 2005).

Family characteristics and available support should be considered in assessing the transition process. Parental goals, values, or priorities that do not align with those of the young adult or health care team may hinder the transition process. Young adults typically report lower levels of conflict with parents than adolescents; however, greater parent–child conflict may arise during times of transition, and this may lead to increased difficulties with disease care (Hanna et al., 2014). Parents sometimes have difficulty decreasing their involvement in daily tasks (Sonneveld, Strating, van Staa, & Nieboer, 2013). Just as underinvolved parents can hinder a successful transition to adult care by removing supports abruptly or offering little guidance, overinvolved parents can hinder a successful transition by decreasing youth motivation for assuming responsibility for

health care (Huang et al., 2011). Proximity also influences family relationships supporting transition to adult care; young adults who live independently report decreased parental involvement in daily health care, but still rely on parents for tangible support (e.g., scheduling appointments; Hanna et al., 2014). Similar to the individual qualities of young adults, adequate parental psychosocial functioning, knowledge, and skills are key considerations for transition. Assessment of family resources, communication, and attitudes toward health care transition can assist with transition planning and contribute to successful transition outcomes.

Provider/Health Care System

Relationship and communication issues are commonly cited as barriers to transition, including patients' and parents' concerns about ending the relationship with a trusted pediatric provider, apprehension at having to "start over" with an adult provider, and worry that the adult provider does not have adequate knowledge of the pediatric-onset condition (Reiss et al., 2005; Schwartz et al., 2013; Tuchman et al., 2008). Physicians may also be reluctant to transfer the care of their pediatric patients to adult providers (Reiss et al., 2005).

Patients and families perceive fundamental differences between the pediatric and adult health care systems (Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005). Pediatric care is family-based and often includes access to a multidisciplinary team (Pacaud, Yale, Stephure, Trussell, & Davies, 2005). Youth and their parents, particularly those with illnesses diagnosed at birth or early in childhood, typically have a long-standing relationship with one health care team whose members are knowledgeable about their unique medical, personal, and social histories (Peters et al., 2011). In contrast, discontinuity in health care providers is common in adult health care (Dovey-Pearce et al., 2005). The patient caseload exponentially increases, with adult providers caring for up to 5–10 times the number of patients as pediatric providers do (Bell et al., 2008). Clinic visits may be shorter and tend to focus on objective medical indicators and physical symptoms (e.g., weight, blood pressure, hemoglobin A_{1c}) while minimizing psychosocial needs (Geddes, McGeough, & Frier, 2005; Peters et al., 2011). Patients may not be prepared for this shift in treatment style when moving to adult health care (Lotstein et al., 2009; Tuchman et al., 2008). Furthermore, there is a lack of adult-oriented physicians with optimal experience and competence to care for young adults with SHCN that are historically considered childhood diseases but require lifelong care (e.g., cystic fibrosis, autism spectrum disorder; Patel & O'Hare, 2010). Recommendations to improve the transition process at the health system level include increased medical education specific to AYA issues and health care transition (Sharma, O'Hare, Antonelli, & Sawicki, 2014). Got Transition (see *www.gottransition.org*) provides resources and checklists enabling pediatric and adult health care providers and practices to use a quality improvement approach to implement the six core elements of transition (from adopting a transition policy to completing the transfer of care) and measure progress.

Financial barriers to successful transition of health care include the cost of health care, gaps in insurance coverage, and changes in reimbursement for services that may make it more difficult for patients to obtain services (Okumura, Hersh, Hilton, & Lotstein, 2013). The implementation of the Affordable Care Act has resulted in increased numbers of young adults with insurance coverage through enrollment on their parents'

plans or individual plans; it should also benefit AYAs with chronic conditions through Medicaid expansion in some states, and through elimination of lifetime benefit caps and preexisting coverage clauses (Blumenthal & Collins, 2014). Furthermore, although the AAP has suggested strategies for billing for transition care services within existing services and established billing codes (AAP et al., 2011), reform in payment for transition care services is needed to promote adoption of clinical recommendations by pediatric and adult practices (McManus et al., 2013). Got Transition offers a specific resource for providers for coding and reimbursement of transition services.

INTERVENTIONS TO PROMOTE TRANSITION READINESS AND IMPROVE THE TRANSITION PROCESS

In the area of health care transition, intervention development and testing are in their infancy. Some programs have taken a quality improvement approach to changing the transition process at the level of the health care system (e.g., McManus et al., 2015; Okumura et al., 2014), while other programs have focused on improving the transition readiness of individual patients and families (e.g., Mackie et al., 2014). Ultimately, a multilevel/systems approach guided by theory to address individual, family, and health care system factors may be needed for optimal results, but this remains to be tested.

A recent report from the Agency for Healthcare Research and Quality identified 25 studies evaluating transition programs (McPheeters et al., 2014). Most interventions were conducted with AYAs with diabetes or solid organ transplants. Common components of these interventions were the employment of a transition coordinator, implementation of a specialized transition clinic, education, and self-management skill building (McPheeters et al., 2014). Several programs included the use of technology for patient education and reminders; technology-based interventions may be particularly relevant for AYAs, who tend to be daily users of technology (Huang et al., 2014). Although some programs demonstrated improved adult clinic attendance, medication adherence, clinical outcomes, or patient satisfaction, evidence is generally lacking regarding the success of these programs (McPheeters et al., 2014).

Current limitations of the literature include a lack of consensus regarding definitions of transition readiness and successful transition outcomes, as well as a lack of validated measures of transition readiness (Schwartz et al., 2014). Evaluating the transfer from pediatric to adult care requires prospective longitudinal follow-up, but many transition programs have not been in existence long enough to have adequate numbers of AYAs who have reached the age of transfer. Furthermore, young adults are highly mobile and can access care in many settings. Research on outcomes in adult health care systems may overestimate health, as studies may be missing the most at-risk young adults who are not connected with traditional or specialty adult medical care. Many studies also lack a valid control group or rely on self-reported data, which may be biased, as participants are aware of their intervention allocation. The lack of guiding theoretical frameworks has made it difficult to identify the essential components of transition readiness and determine targets for intervention. Future intervention research would benefit from incorporating a theoretical framework, such as SMART or the model developed by the Health Care Transition Research Consortium (Betz et al., 2014); determining how indi-

vidual, family, and health care factors influence the effectiveness of interventions; evaluating the importance of tailored versus generic approaches to transition; and examining the cost-effectiveness of transition programs. Researchers should also consider strategies for optimizing multicomponent behavioral interventions, such as using factorial designs to determine the efficacy of individual components or using a sequential, multiple assignment, randomized trial to determine sequencing of components (Collins, Nahum-Shani, & Almirall, 2014).

IMPLICATIONS FOR PEDIATRIC PSYCHOLOGISTS

Pediatric psychologists are perfectly poised to improve the transition process through the systematic evaluation of transition readiness over time and through the development and evaluation of interventions with patients, families, and providers. Psychologists working with AYAs can support the inclusion of transition services in routine clinical care. Transition readiness assessment should not be limited to a checklist of skills or milestones at each visit. Rather, components such as skills, knowledge, expectations, motivation, and goals associated with health care transition should be assessed and revisited throughout adolescence. The development and administration of such assessments will require the skills of psychologists and other members of multidisciplinary care teams. Pediatric psychologists can also contribute to readiness for adult health care by increasing disease self-management and self-efficacy, improving patient–family–provider communication, and establishing and monitoring mutual goals for transition among stakeholders. Health care providers may require assistance in ending long-standing relationships with pediatric patients in a therapeutic way that helps to initiate positive relationships with adult providers (Reiss et al., 2005). Pediatric psychologists can also educate and train pediatric and adult medical providers to better understand and meet the needs of patients and families during the transition from pediatric to adult health care.

There are great opportunities for pediatric psychologists to improve the evidence base for best practices in transition care. Much of the research thus far has been qualitative, at least partly due to a lack of agreement about successful transition outcomes and inadequate measurement of factors associated with transition outcomes. Possible transition outcomes include attendance at adult appointments; patient, parent, and physician satisfaction with transition; disease-specific medical adherence; patient quality of life; and cost of medical care (McPheeters et al., 2014). Whereas transfer to adult care is a discrete event that can be measured by appointment attendance, measuring the success of integration into the adult health care system is more complex and requires lengthier follow-up. Furthermore, although there are several promising generic and disease-specific measures of transition readiness, none have demonstrated predictive validity, indicating that further work on available assessment tools is needed (for a review, see Schwartz et al., 2014). Longitudinal evaluation across the transition process is needed to determine the best indicators of when to initiate transfer to adult care and whether particular aspects of interventions are more effective at different points in the transition process. Future work will need to identify whether certain programs work better for individuals with particular characteristics or illnesses. Pediatric psychologists can also contribute to needed policy changes by enhancing communication and partnerships between pediatric and adult provider systems, and by advocating for financial reforms

to pay for transition care costs on both pediatric and adult provider sides (McManus et al., 2013).

CONCLUSIONS

The transition from pediatric to adult health care is an emerging area of focus for clinicians and researchers. Advances in transition care have been hindered by methodological limitations and the lack of consensus regarding definitions of transition readiness and transition outcomes. Clinical algorithms (e.g., AAP et al., 2011) and theories (e.g., SMART; Schwartz et al., 2011) have been proposed and moderately tested to inform evidence-based practices and guide research. However, more rigorous research is needed to determine optimal targets of intervention and best practices related to transition care that yield positive posttransfer health and psychosocial outcomes. Pediatric psychologists are well prepared to develop and evaluate theory-based transition care interventions and assessment tools to support AYAs and their families as they make the transition into adult care.

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CHAPTER 48

Disorders/Differences of Sex Development

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Western societies are increasingly at ease with men and women who cross conventional societal boundaries in their choice of appearances, careers, and sexual partners. When it comes to biological sex, however, societies lack the framework, legal or otherwise, to accommodate anatomies that challenge the binary male–female distinction (Ainsworth, 2015). Yet variations in the genetic or hormonal determinants of somatic sex development can result in a newborn with characteristics that do not fit neatly into either the male or female category—in other words, a child born with a disorder (or difference) of sex development (DSD). DSD is an umbrella term (used as both singular and plural), referring to "congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical" (Lee, Houk, Ahmed, Hughes, & the Participants in the International Consensus Conference on Intersex, 2006, p. e488). DSD do not necessarily imply ambiguity in the appearance of the genitals, but can present with a wide range of genital phenotypes, depending on the syndrome and its expression (Achermann & Hughes, 2011). Although the majority of children born with DSD are identified soon after birth because of visible genital differences or health concerns (such as salt-wasting crises in congenital adrenal hyperplasia [CAH]), the condition may not be detected until childhood (or later) when an inguinal hernia is identified, a girl never begins menstruation, or an adult experiences fertility problems. In the aggregate, DSD have an estimated incidence of as high as 0.018–1.7% of live births (Sax, 2002).

WHAT ARE DSD?

Typical Sex Determination and Differentiation

DSD reflect deviations from typical sex determination and/or sex differentiation (Achermann & Hughes, 2011). Five weeks after conception, human embryos are identical and

have the potential to form either male or female anatomy. At 6 weeks, sex chromosomes (XX or XY) guide the bipotential gonads to develop into testes or ovaries (i.e., "sex determination"). Under the influence of the *SRY* gene on the Y chromosome, testes develop; without *SRY,* ovaries develop.

Testes produce androgens (testosterone [T] and its metabolite, dihydrotestosterone [DHT]) and anti-Müllerian hormone (AMH), responsible for differentiation of the internal ducts and external genitals (i.e., "sex differentiation"). AMH causes regression of the Müllerian ducts (precursors of the uterus, cervix, fallopian tubes, upper vaginal canal). Androgens differentiate the Wolffian ducts (precursors of the vasa deferentia, seminal vesicles, prostate gland, epididymides). T and DHT also promote growth of the genital tubercle and glans penis; fusion of the urogenital folds and swellings form the shaft of the penis and the scrotum.

In the case that ovaries develop, the associated absence of AMH, T, and DHT results in differentiation of the Müllerian structures: The genital tubercle develops into the clitoris, and the urogenital folds and swellings form the labia minora and majora. Sex hormones come into play once more at puberty, triggering development of the secondary sexual characteristics (e.g., breasts, facial hair). Animations of the process of sex development—from sex chromosomes through puberty—can be viewed at *www.accordalliance.org* ("Learn about DSD" menu).

DSD Classification and Terminology

The DSD classification system is based on the number and visual appearance of the chromosomes in cells (or karyotype). People typically have 46 chromosomes, arranged in 23 chromosome pairs, including one pair of sex chromosomes (XX or XY). "Sex chromosome DSD" encompasses differences in the typical number of sex chromosomes, such as Klinefelter syndrome (KS; 47,XXY and variants) and Turner syndrome (TS; 45,X and variants), or cases when an individual has more than one cell population with a different chromosomal makeup—that is, mosaicism (e.g., 45,X/46,XY mixed gonadal dysgenesis). Individuals with these variable karyotypes may have gonads containing both ovarian and testicular tissue (ovotesticular DSD). More commonly, the gonads have developed atypically (gonadal dysgenesis). For example, boys/men with KS present with a typical male body appearance, but the testes are small and dysfunctional. In TS, physical appearance is that of a typical female, but the ovaries are underdeveloped and, if functioning at all, rapidly lose that capacity. In both syndromes, gonadal maldevelopment is associated with infertility and low levels of sex hormones.

"46,XY DSD" stem from disorders of testis development, disorders of androgen synthesis or action, and other conditions. The somatic phenotype can range from subtle variations, such as in uncomplicated subcoronal hypospadias (in which the urinary meatus appears just below the glans, rather than at the tip of the penis), to more significant atypicality, such as in complete androgen insensitivity syndrome (in which a person with XY chromosomes is completely insensitive to the action of androgens, resulting in female-typical external genitalia).

Finally, "46,XX DSD" can result from disorders of ovary development, disorders of androgen synthesis, or other conditions, including exposure to exogenous androgens during sensitive periods of sex development. CAH (mentioned earlier), a treatable but potentially life-threatening condition, is the most common cause of ambiguous genitalia

in 46,XX newborns. Mutations of genes for enzymes mediating adrenal gland steroidogenesis result in insufficient cortisol and aldosterone production, and excessive androgen production in CAH (Speiser et al., 2010). Across all three DSD categories, DSD can present with a wide range of genital (internal and external) phenotypes, depending on the syndrome and its expression (Achermann & Hughes, 2011). For additional information about nomenclature and current classification of DSD, see Lee et al. (2006).

Reactions to Terminology

Until relatively recently, the diagnostic terms "hermaphroditism" and "intersex" were used to describe medical conditions associated with atypical somatic sex development. Recognizing major genetic discoveries, and acknowledging that the older terminology was vague, confusing, and potentially stigmatizing, the North American and European professional societies for pediatric endocrinology abandoned previous diagnostic labels in favor of "disorders of sex development" in 2006 (Lee et al., 2006). Recent surveys, scientific meeting proceedings, and published literature suggest that the new terminology has enjoyed broad acceptance by medical and research communities (Davies, Knight, Savage, Brown, & Malone, 2011; Pasterski, Prentice, & Hughes, 2010). In contrast, some people born with DSD and their advocates reject this terminology and propose alternative terms—including "differences of sex development," "divergence of sex development," or, again, "intersex"—due to concerns that the word "disorder" fosters stigma and contributes to providers' insisting on risky and potentially harmful surgical "normalization" procedures (Davis, 2013; Feder, 2014; Reis, 2007). Some are strongly opposed to what they experience as the unnecessary pathologization of their atypical bodies and the perceived damaging consequences associated with current clinical management strategies (Davis, 2013; Feder, 2014; Karkazis, 2008). Clinicians, meanwhile, generally prefer "disorder" over "difference" (and its variants), out of concern that speaking of somatic sex atypicality as if it always involves benign variation may lead parents, patients, or even some health care providers to ignore serious health risks that accompany specific DSD if left unattended—including the risk of gonadal tumors and the varied consequences of hypogonadism (Achermann & Hughes, 2011).

Issues of identity further complicate the choice of terminology. Some people with DSD have adopted "intersex" as an identity, rather than as a term for a medical condition. Others do not wish to be defined by their biological histories or want to distance themselves (or their children with DSD) from any words that may imply atypical gender or sexuality.[1] Although those born with DSD may identify with lesbian, gay, bisexual, transgender (LGBT) or other gender-nonconforming communities, many view themselves as "cisgender" (i.e., accepting the boy/man or girl/woman category in which they were reared from birth). While making it convenient to identify societal subgroups facing what may be perceived as comparable forms of discrimination, the increasingly common addition of I (for "intersex") to the acronym LGBT fosters perceptions that

[1]A person's sex anatomy may not always be congruent with the gender with which the person identifies (sex vs. gender). One's internal experience of gender identity may not necessarily be congruent with one's behavioral expression of gender (gender role). Gender expression inconsistent with one's anatomy (gender nonconformity) does not necessarily indicate an individual's experience of affective distress as a result of that discrepancy (gender dysphoria).

these groups are homogeneous and that people subsumed by the acronym have parallel (or even identical) health care needs and concerns, which does not reflect clinical reality (Hollenbach, Eckstrand, & Dreger, 2014; Mazur, Colsman, & Sandberg, 2007).

CLINICAL MANAGEMENT OF DSD

From the 1950s to early 1990s, recommendations regarding gender assignment in DSD were guided by the "optimal gender policy," which considered multiple aspects of outcome, most prominently the potential for complete sexual functioning (Zucker, 1999). This approach was predicated on two assumptions: (1) "Gender identity" (i.e., identification of self as either girl/woman or boy/man) is not firmly established at birth, but rather is the outcome of gender rearing; and (2) stable gender identity and positive psychological adaptation require genital appearance to match assigned gender, which often calls for reconstructive genital surgery (Zucker, 1999). The optimal gender policy called for "uncompromising adherence to the [gender assignment] decision" (Money, Hampson, & Hampson, 1957, p. 334); this guidance has frequently been misinterpreted to imply that details of the condition need to be kept secret, so that patients and parents remain insulated from shock and avoid uncertainty about early decisions (Creighton & Minto, 2001). These assumptions contributed to the practice of genital surgery in childhood, which is increasingly questioned (Creighton, Chernausek, Romao, Ransley, & Salle, 2012).

Any approach designed to shield patients from medical information can be viewed as reflecting a kind of paternalism discouraged in modern health care delivery. Moreover, aspects of this approach have been shown to foster negative psychological reactions (Alderson, Madill, & Balen, 2004), further contributing to a climate of stigma and shame surrounding DSD and their management (Chase, 1998; Preves, 2003). Some adults who received the earlier type of care, and their advocates, publicly denounced the damaging effects of repeated insensitive genital examinations and/or genital surgeries (all of which were performed without their consent) on sexual sensation and psychosocial well-being (Creighton, Minto, & Steele, 2001; Crouch, Minto, Liao, Woodhouse, & Creighton, 2004). Such grievances substantially influenced the medical community, culminating in advocacy representatives' participating in a DSD Consensus Conference to review clinical management practices and helping shape the published Consensus Statement (Lee et al., 2006). The Consensus Statement on clinical management emphasized an interdisciplinary approach, including, in particular, mental health care providers' offering immediate psychosocial support to families in distress (Crissman et al., 2011; Pasterski, Mastroyannopoulou, Wright, Zucker, & Hughes, 2014).

PSYCHOSOCIAL FACTORS

Understanding Parents' Reactions to DSD

Of all influences on psychosocial adaptation to consider, effects of a child's DSD on parents should be prioritized (Wisniewski & Sandberg, 2015). Pediatric chronic conditions in general exert a significant burden on parent and family functioning, including possible social isolation, anxiety, and depressive symptoms (Cousino & Hazen, 2013).

However, some influences on psychosocial health of the parents may be relatively unique to DSD. Virtually absent community awareness of DSD means that many parents have never heard of DSD prior to learning of their child's condition, whether at birth or later. The process of sex determination and sex differentiation is complex, and the understanding that "we all start out the same," with the potential to develop either a male or female anatomic phenotype, is not common. Instead, notions of the immutability of sex generally represent the status quo, except for vague recollections about Hermaphroditus from mythology or tabloid television and magazine stories about people born with both sets of sex organs. The result of this limited understanding can be confusion and intense anxiety over a child's DSD diagnosis and treatment options. And it should be underscored that except in discrete syndromes associated with DSD (e.g., salt-wasting CAH), the child's immediate physical health is not in jeopardy. Instead, the anxiety derives from the perceived stigma associated with atypical sex development. The parents' desire to escape what is experienced as socially threatening to both the child and family may bias them toward decisions promising immediate relief (e.g., early genital surgery). Mothers of children with atypical genitalia who have received genitoplasty indeed report less stress than mothers whose children did not receive early surgery (Fedele et al., 2010). However, these decisions may be associated with subsequent regret, because of natural diminution of anxiety with time and the likelihood that parents will be exposed to information suggesting that the adult cosmetic and functional results of early surgery can be less than expected (Köhler et al., 2012; Thyen, Lux, Jurgensen, Hiort, & Köhler, 2014; van der Zwan et al., 2013).

Confounding the decision-making process of parents of newborns or young children with DSD are the often unspoken anxieties about the child's future development, including stability of gender identity and ultimate (hetero)sexual orientation. Unless providers explicitly separate these issues, parents could easily conclude that early surgery will "fix" everything (Reis, 2013). Clinicians should explicitly check for misunderstandings during the decision-making process, so that parents base their decision on the demonstrated benefit of the proposed intervention rather than on simple optimism (Tamar-Mattis, Baratz, Baratz Dalke, & Karkazis, 2013).

It is important to emphasize the need for parents' decisions for their child's care to be in line with personal values, as what constitutes the "right" decision or the "best" medical or surgical treatment for a child with DSD is frequently not obvious. For example, identification of the genetic variant responsible for the DSD is frequently not determinate of the treatment plan— neither gender assignment nor decisions regarding surgery (Cohen-Kettenis, 2005; Houk & Lee, 2010; Mazur, 2005). DSD-specific educational materials are currently in development, with the intent to better inform decisions such as gender assignment, genital surgery, sharing information about the child's condition with others, and parental preferences regarding common clinical procedures (e.g., genital exams and medical photography) (Siminoff & Sandberg, 2015; Wisniewski, Chernausek, & Kropp, 2012).

Early and ongoing discussions with parents are required to address concerns they may have, such as fears about having anyone outside a trusted circle of family and friends view the child's genitals during diaper changes, bathing, and dressing, or the need to inform the child about the condition to promote the child's autonomy (Hullmann, Fedele, Wolfe-Christensen, Mullins, & Wisniewski, 2011; Wisniewski & Sandberg, 2015). Families and patients require not only clear information about DSD, but

sometimes intensive input to empower them to address challenges successfully as these arise (Brain et al., 2010; Sandberg & Mazur, 2014). It is also accepted that those living with chronic conditions, and their caregivers, can benefit from opportunities for networking with those similarly affected (Baratz, Sharp, & Sandberg, 2014; Doull, O'Connor, Welch, Tugwell, & Wells George, 2005). Strategies to help patients and caregivers overcome their initial inhibitions to share experiences with others who have "been there" represent a high priority.

Role of Pediatric Psychologists

Pediatric psychologists are well qualified to provide clinical service in DSD, given their specialized knowledge and skills in working with families and youth with medical issues, their background in empirically validated treatments, and their experience in team consultation. A psychologist is strategically positioned to act as an advocate and point of contact for a patient and family, and to coordinate contact with other members of the team (Brain et al., 2010; Sandberg & Mazur, 2014). Close communication and coordination among team members and the family can facilitate optimal timing of medical interventions and education of the patient—for example, determining the age to begin delivering information to the patient about the potential need for lifelong hormone replacement therapy or the likelihood of infertility.

In a survey of European DSD clinical management practices following the Consensus Statement, the majority of medical sites reported providing mental health services to patients and families (92% and 82% offering access to a psychologist or psychiatrist, respectively) (Pasterski et al., 2010). However, services appeared to be commonly delivered on a consultation basis only; psychologists regularly attended DSD clinics and were routinely involved in patient/family care at only 17% of sites. Access issues may also contribute to the mismatch between patients' and families' psychosocial needs and mental health service utilization. Provider expertise in DSD is typically located at select academic children's hospitals. Geographic distance, together with insurance coverage (especially in the United States) that excludes the specialized mental health component of comprehensive DSD services, can often contribute to fragmented care (Chadwick, Smyth, & Liao, 2014).

FUTURE DIRECTIONS AND CHALLENGES

Interdisciplinary DSD teams are increasingly common at children's hospitals located in academic medical centers; nevertheless, the skills of otherwise qualified subspecialists to attend optimally to the needs of these patients and their families require development and integration. Recent initiatives—including electronic learning portals and electronic consultations for expert advice (Drop, Mure, Wood, El-Ghoneimi, & Ahmed, 2012), and the emergence of national and international networks of DSD health care and research teams (Sandberg, Callens, & Wisniewski, 2015)—should prove valuable, as educational curricula for the training of providers in addressing the unique challenges of DSD clinical management do not yet exist (Hollenbach et al., 2014).

Families affected by DSD continue to have limited access to expert mental health services. In the United States, referrals to professional mental health providers still fre-

quently occur only at moments of crisis rather than as an integrated component of regular care, despite the recognition that DSD carries an increased risk of psychosocial stress that can easily interfere with balanced decision making. Peer support in DSD is relatively new, and much can potentially be learned from studies examining the relationship between patient support groups' characteristics and their benefits in other medical conditions. Health care providers' awareness of and attitudes toward these groups can influence the degree to which families value such support (Baratz et al., 2014). Research is warranted to examine factors that either encourage or discourage referrals to patient support groups by health care providers, intrafamily characteristics that predict involvement, and the skills and values developed through contact with such groups that promote resilience in patients and families.

Additional research is needed to (1) ascertain psychosocial factors that affect, and are affected by, DSD and its clinical management; and (2) assess the effects of psychological counseling/education and targeted interventions promoting competence and efficacy in affected families. In this context, qualitative research studies (e.g., Crissman et al., 2011) are extremely important in informing understanding of patients' and parents' perspectives. There is also value in investigating the preferences of health care providers for varying outcomes guiding the recommendations (Schweizer, Brunner, Schützmann, Schönbucher, & Richter-Appelt, 2009).

Optimizing psychosocial services for patients and families also requires that we fill substantial gaps in our understanding of the factors interacting to influence health-related quality-of-life outcomes in DSD. Much remains to be learned about social adjustment, mental health, and quality of life of children and their families affected by DSD (Sandberg & Mazur, 2014; Stout, Litvak, Robbins, & Sandberg, 2010). A broadened clinical and research agenda is warranted, in part to respond to justifiable criticism by former patients and advocates that poor psychosocial and sexual outcomes may be less a function of atypical sex hormone exposure or surgical procedures than the consequence of complex interactions among multiple experiences (e.g., medical decision making, experience of DSD as stigmatizing and associated feelings of secrecy and shame, parental mental health or marital problems that predate a child's birth, etc.) that modulate the outcomes within and across developmental stages (Wisniewski & Sandberg, 2015). The DSD field has not adopted theory or research strategies derived from developmental psychology (typical or atypical) or pediatric psychology that account for both biological predispositions and social environment in shaping outcomes (Rose, Holmbeck, Coakley, & Franks, 2004; Wallander, Thompson, Alriksson-Schmidt, & Roberts, 2003), including risk and resilience factors, cognitive appraisals, and coping processes. To date, no studies of interventions to reduce the experience of stigma or parental distress have been conducted. Given the proven benefits of cognitive-behavioral approaches in reducing psychological distress and promoting self-efficacy, we are exploring the possibility of extending their reach to DSD.

SUMMARY AND CONCLUSIONS

DSD are congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical; they can, but do not necessarily, imply ambiguity in genital

appearance or uncertainty about gender of rearing. Most conditions classified as DSD do not predict given levels of general physical health or quality of life across the lifespan, and in general do not constitute medical emergencies. Although DSD can be associated with life-threatening conditions (e.g., salt-wasting CAH), most are not. As such, there is time for psychologists to assess and address psychosocial concerns, and to assist family members in becoming fully informed members of their child's team engaged in shared decision making.

The most serious morbidity associated with DSD is believed to be the emotional and social consequences of being born with atypical body sex and its clinical management. Salient factors challenging positive adaptation of parents of newborns with DSD, and patients as they grow older, include the presence of atypical genitalia; associated decisions regarding gender of rearing (and the possibility that gender reassignment may follow); discordance between sex chromosomes and gender of rearing; ongoing controversies regarding the risks and benefits of early genital surgery; and perceptions of stigma, with the accompanying shame and secrecy. Valuable resources (with links to support groups) can be found at *www.accordalliance.org* and *www.dsdfamilies.org*. Among the highest priorities for research in DSD is the process of shared decision making (Siminoff & Sandberg, 2014). Pediatric psychologists have the opportunity to uncover evidence and develop strategies that will better inform providers, parents, and maturing patients of the predictable psychosocial challenges of DSD and ways these can be adaptively addressed, taking into account the changing needs and priorities of affected individuals across the lifespan.

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Author Index

Note: *f* following a page number indicates a figure; *t* indicates a table.

G

H

M

N

O

S

T

Subject Index

Note: *f* following a page number indicates a figure; *t* indicates a table.

B

D

E