Health Informatics

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Cognitive Informatics in Health and Biomedicine

Understanding and Modeling Health Behaviors

Springer

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To
Dr. Richard R. Cruess
With gratitude for his friendship and support,
which enabled and inspired the novel blend
of cognition and informatics that is reflected
in this volume.

Foreword

Architects and designers often look to the shortcuts that people take in the world around them to understand where points of friction might exist in the ways in which people are using their environment. Adept designers will then take their cues from users' real world behavior to create design solutions that are superior to previous iterations; that reduce friction in allowing users to engage in goal-directed behavior. For example, a well-worn dirt path across a grassy common area might suggest an ideal location for putting in a protected, paved walking trail. The resulting adaptation not only creates a solution that is superior in meeting the needs of individual users but also creates a design feature in the built environment that is supportive of community goals. Or to use another illustration, curb cuts—those graded ramps sloping down from sidewalks to the street—are not only useful as accommodations for people in wheelchairs but can benefit anyone pushing a stroller, hauling luggage, or steering a shopping cart (Hesse 1995).

As specialists in health informatics, I have argued, we can make some of the same improvements by looking to the information environment (Hesse 2005). Consider that as early as 1995 close to half of the discussion groups within the top ten Internet-based *Usenet* boards were dedicated to topics related to health and disease management (Rice and Katz 2001). In 1997, a Harris poll revealed that about half of World Wide Web users reported going online to search specifically for information related to health or medical topics (Rice and Katz 2001). In 2015, data from the National Cancer Institute's own Health Information National Trends Survey (HINTS) revealed that approximately 70% of the American public went to the Internet *first* to look for health and medical information, far outstripping the 14% who said that their physicians or healthcare providers were their first point of contact (Hesse et al. 2016). This trend, of looking first to the Internet to meet personal information needs but then following up with trusted healthcare providers to make sense of what they found online, was originally observed in the 2003 administration of HINTS but has been growing steadily over the past decade as more and more patients become accustomed to online searching (Hesse et al. 2010; Eysenbach 2007). In fact, the latest estimates from Google suggest that some two million searches per second on their websites worldwide can be attributed to health-related queries.

From these early digital shortcuts, it has become obvious that the public has been trying to go online to meet their health information needs; it was just well before healthcare systems were ready for them. Around the turn of the millennium, the information that government agencies and academic medical centers put on their public-facing websites may have been largely credible, but would have taken a college education or specialized medical training to interpret (Berland et al. 2001). Patient portals, which might have tailored information for individual needs, were few and far between in the days preceding the HITECH Act. For those who did have electronic communication capabilities, the billing codes often didn't exist to spend time online counseling patients (Kemper and Mettler 2002).

Now much has changed. The Meaningful Use incentives of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 have spurred a prodigious adoption of basic health information technology functionalities. Phase 2 of Meaningful Use incentives as well as the payment incentives authorized by the Medicare and CHIP Reauthorization Act (MACRA) of 2015 have placed a premium on creating platforms that would foster patient engagement in their own health and healthcare. In one report, a well-known integrated healthcare system showed a 27% reduction in costs from unnecessary office visits by offering virtual support to patients through secure messaging (Chen et al. 2009). Today, virtual consultations within that same system account for almost 50% of the communications recorded between patients and clinical staff (Garrido et al. 2016).

Nevertheless, in spite of these successes, many attempts at creating patient-centric health I.T. systems have simply failed. Users either fail to take advantage of the health-promoting functionalities available in these systems or else complain about the frustration of interacting with redundant or unwieldy interfaces. Why is that the case? What differentiates the uneven successes in providing informatics-mediated consumer support within the healthcare system from the relatively prodigious successes of online giants in other sectors? To begin with, healthcare is complex and many acknowledge that these are early days in the art of designing successful patient-facing technologies in medicine (Wachter 2015). Still, there is something else going on and the key may be in looking to the number of cognitive scientists who have made their way into the commercial I.T. fields. Even the Director of the National Institute of Mental Health announced his departure from government to join Google's life sciences team in 2015. Within the culture of Silicon Valley, understanding human cognition and then designing information technologies to do a better job at supporting basic cognitive processes has become the coin of the realm (Norman 2013).

This movement is part of what computer scientist Ben Shneiderman referred to as the "second wave" in computational technology (Shneiderman 2003). The first wave of computing, he argued, was focused on understanding what machines can do. The second wave was focused on understanding how the capabilities of computers could be harnessed, through tools and online services, to amplify what people do. Early research in medical informatics was a classic case in point. Early informatics engineering focused on recapitulating human expertise through rule-based expert systems. Current work, captured in the language of the HITECH Act, has been aimed at improving the performance of care teams and enhancing patient outcomes by error-proofing communications and refining support for decision-making. Authors of a 2009 report by the US-based National Research Council put it this way:

> *Success in achieving the vision of 21st century healthcare will require greater emphasis on providing cognitive support for health care providers and for patients and family caregivers on the part of computer science and health/biomedical informatics researchers.* (Stead and Lin 2009)

It is in this context that I have great enthusiasm for the content of *Cognitive Informatics in Health and Biomedicine: Understanding and Modeling Health Behaviors*. Understanding how electronic support structures can be the engine to power the twenty-first century healthcare and public health systems is both exciting and vital. It is exciting, in a Silicon Valley sense, to picture how cognitively supportive technologies might someday transform the worlds of health and medicine to function at a level on par with the transformational successes experienced in telecommunications, travel, finance, retail, and entertainment. It is vital, in a biomedical sense, to create a new environment for healthcare that is built on the predictive capacity of scientific evidence; that is applied preemptively to prevent or forestall disease; that is applied precisely and economically through the tailored application of therapeutics to the specific context of the individual; and that is participative, as it enables the co-creation of health outcomes between patients, their caregivers, and their healthcare teams.

The enlightening compendium to follow begins with an in-depth exploration of how health information technologies can be leveraged to support individuals' desires to live a healthier, disease-free lifestyle. It starts with a review of common health behavior theories and suggests how electronic functionalities can be molded around theoretical frameworks to bring the power of behavioral science into the design of consumer-facing applications. The emphasis on behavioral theory, and the use of evidence to refine applications built upon scientifically grounded thinking, differentiates the book's approach from the slapdash, intuitive approaches underlying many of the spurious "health apps" that often make their way, failingly (Jacobs et al. 2014), into the public marketplace. This rigorous adherence to what works in behavioral medicine is what will ultimately lead to consumer supports that offer true, reliable sustenance for long-lasting behavior change.

This same scientific approach, the book contends, can and should be applied across the full range of patient-system interactions. Several chapters in the book explore the context of behavioral support from the perspective of differing cultural perspectives; whether those perspectives can be culled from the commonsense understanding and folk traditions of popular culture, or the health beliefs endemic to specific countries or regions around the globe. From these chapters, a nuanced understanding of human knowledge can lead to educational materials that are linguistically superior for use across and within varying cultural contexts. Gaining better insight into the mental models of users can help health system designers anticipate errors and forestall misunderstandings (Hesse et al. 2011).

Similarly, the book takes on the challenge of designing health information technologies that can serve as a buttress against differing levels of health illiteracy. Much has been written about the issues surrounding health literacy in the twenty-first century (Nielsen-Bohlman et al. 2004). Unfortunately, much of that writing stems from a deficit model that places the blame for poor understanding on the part of the information receiver. Refreshingly, the authors in this book embrace the concept of "embedded cognition"—or the idea that literacy emerges from the interplay of knowledge in the head and knowledge in the world. From this perspective, much can be done in the design of user interfaces to make up for a lack of medical knowledge on the part of a patient or user. Embedded cognition is the reason why designers of GPS systems can steer drivers through both unfamiliar and well-known environments; knowledge is embedded within the tool to be leveraged as needed by the user. In this regard, designing a patient portal that presents complex laboratory values in a raw, unaided format is not only bad design, it is a type of information malpractice. It foists the risk of misunderstanding onto the patient. The authors within this compendium do a superlative job of laying out new approaches and new methodologies for designing systems that can be universally useful across levels of medical or technical knowledge.

Another intriguing characteristic of this compiled volume is the authors' insights into how the specialized features of information technologies can be adapted to meet the needs of individuals with cognitive deficits. Cognitive acuity, just like eyesight, tends to decline for most people as they age. With projections of an aging demographic cohort, it will be vital to create technologies that are supportive of individuals in spite of their declining short-term memories or gradually slowing responsiveness in executive function. To that end, some of the chapters in the book offer a perceptive blueprint for designing a smarter health environment through the use of cognitive assistive technologies. Innovations in wearable devices, mobile computing, ubiquitous sensing, and device-enabled reminders can all work together in giving an aging population the freedom of aging in place. Smart connections between these devices and the critical members of the patient's family and care networks can provide confidence that help is always just a wireless signal away. Even monitoring tools and continuous cognitive assessments can be embedded within assistive supports—smartphones, wearables, electronic card games—to provide prompt feedback in the event that cognitive decline may pose a threat to daily living.

From my estimation, the value of a text such as *Cognitive Informatics in Health and Biomedicine: Understanding and Modeling Health Behaviors* is its vital role in providing a framework for the design of a smart healthcare environment. This, I believe, is at the heart of the second revolution in informatics: not only to allow doctors to become better doctors but also to allow patients to become better patients. The days will soon be gone, I sincerely hope, when most patients are left to wander "frustrated and confused" (Arora et al. 2008) through the unfettered environs of the Internet, leaving unheeded digital trails from their efforts to seize control of their health or the health of a loved one. Rather, a new era is dawning when attentive designers can take notice of the digital paths patients are taking through the information environment and—armed with the tools of cognitive science—can create new architectures for channeling patients' capacities and efforts. This book, I hope, may serve as their blueprint.

Rockville, MD, USA
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Preface

My colleagues and I are pleased to present the next volume in my series of books published by Springer and dealing with cognitive informatics. With this third offering we bring together research in the fields of cognition, informatics, and personal health behaviors. The goal is to enhance our understanding of health promotion and disease prevention in our modern technological society and to investigate methods for bringing about individual behavioral changes that will support improved population health.

The seeds that support the coalescence of these disciplines have been germinating in my mind over many years. Early in my career at McGill University, I had the privilege of working in the area of medical education. I was fascinated with the topic of how the then new problem-based approach to medical education differed from the classical forms. There were two medical schools in Canada that provided natural test beds for my subsequent scientific investigations of cognition and education in the field of medicine. I had the honor of working closely with superb colleagues, such as Geoffrey Norman, Henk Smidth, Paul Feltovitch, Arthur Elstein, and Alan Lesgold, and benefitted from support by some most dedicated students, such as David Kaufman and Jose Arocha. As the director of Center for Medical Education in the faculty of Medicine at McGill, I was both gratified and excited to see the energy and insights generated through collaborative interactions with bright students and fellows.

Especially important in my pursuit of this work was the enthusiastic support of Dr. Richard Cruess, McGill's Dean of Medicine at the time. He was an extremely powerful force behind my continuing interest in the topic and my belief that we could gain great insight into the reasoning and decision-making processes of medical students and resident house staff by experimenting with different curricular formats and studying their impact from a cognitive perspective. These studies also enhanced our formal understanding of the role that the basic biomedical sciences play in supporting clinical practice. I am truly indebted to Dr. Cruess for his vision to support my research on the scientific foundations of medical education, which in turn led to opportunities to extend my work from the area of medicine to health more broadly and to explore a process-oriented approach to understanding health cognition.

Subsequently, beginning in 1987, my horizons were broadened through work with Tom Eisemon, also from McGill University. Together we investigated health-care decision-making, using the process-oriented approach to study both patients and clinicians in countries such as Kenya and Zimbabwe. This work allowed me, for the first time, to fully understand how deeply socio-cultural beliefs are grounded within a community and how important it is to gain a better understanding of these cultural values. It became clear that this was a prerequisite for achieving desired behavioral changes that would improve the health and care of individuals within a community.

With an award from *Shastri Indo-Canadian Institute*, I was able to extend our studies on health cognition and child nutrition to South India, together with Malathi Sivaramakrishnan. We learned quickly that most measurements of behavioral change by International Health Agencies based in South India were purely quantitative, with recommendations to improve child health through means that were not readily accepted within the cultural norm. Any behavioral changes (positive or negative) that occurred were qualitative in nature, alerting me to consider qualitative models of behavior change, which required me to learn this type of modeling by taking formal classes.

Armed with new methods and a stronger theoretical foundation, I led a study in Cali, Colombia, with Jose Arocha and Andre Kushniruk from my Center at McGill to study the impact of parasitic load on children's cognitive behavior. I was fortunate to receive funding for this study from the *James S. McDonnell Foundation,* whose President, John Bruer, immediately appreciated the potential of cognitive studies in health and behavioral change. I was not surprised to find that health behavioral changes are difficult to achieve, but it was disturbing to learn how culturally inappropriate the routine cognitive measurement tools were. After designing appropriate measurement tools for higher-order reasoning such as comprehension, problem solving, and decision-making, we were able to show cognitive behavior change. I found that each of these studies contributed something different to the building of cognitive models that served us well in subsequent studies of how to effect changes in health-related behavior.

Soon thereafter I became involved with the emerging field of biomedical informatics. Never a technologist myself, I still became convinced that my understanding of health cognition required us to gain experience with informatics issues and tools if we were to help to achieve successful behavioral changes. This was particularly timely, given that consumer use of health technology was becoming more widely adopted in the community. In addition, home-based patient care was also moving in the direction of technology-based care using such tools as smartphone apps and telemedicine links. These shifts led me to consider the importance of forming bridges and new research programs between the field of *cognitive informatics* (a term I coined to capture the intersection of biomedical informatics and cognitive science) and ongoing work on models of health behavior change.

Because there was limited literature that bridged the two fields, and most of what was written had come from my own research group, I felt that a book on the topic would highlight the research opportunities and accomplishments to date. I reached out to my longtime colleague José Arocha, who has a background in psychology and health cognition, as an ideal partner to work with me on this new volume on *Cognitive Informatics in Health and Biomedicine: Understanding and Modeling Health Behaviors.* I also extended an invitation to Jessica Ancker, who had impressed me during the years that we both worked in the Department of Biomedical Informatics at Columbia University. She has served as the third co-editor, offering insights from measurement and evaluation of patient behavior that have been valuable in providing balance and substance.

In designing this volume, we knew we wanted to convey how investigators in the area of health cognition have focused on the role of beliefs held by lay people in informing their health-related decisions and practices. Similarly, health educators and public health communicators are interested in how best to inform and educate people so that they are more responsive to health-related messages. The general public's understanding of health concepts has a bearing on consumer health decisions and behavior because such actions are based on one's conceptual understanding of health. These issues give individuals the power to derive predictions and explanations of a wide range of health-related phenomena, which can then be used in making decisions. At the same time, healthcare is moving toward a team effort, with patients as partners, which necessitates new sets of skills and knowledge. The emergence of e-health technologies has opened up new horizons for promoting increased self-reliance in patients. Although information technologies are now in widespread use throughout the world, there is often a disconnect between the scientific and technological knowledge underlying healthcare practices and the public beliefs, mental models, and cognitive representations of illness and disease. Misconceptions based on prior beliefs lead to miscommunication as well as to erroneous decisions about an individual's own health or the health of family members.

To optimize the utilization of health information and supporting technologies for the general public, we need to understand how people think and make decisions that affect their health and well-being. Research related to cognition and informatics has tended to focus on investigations of how the general public understand health information, assess risky behaviors, make healthcare decisions, and use health information technologies. Since the patient is the central entity of healthcare practice, the knowledge generated from this research is essential in improving biomedicine and healthcare. The purpose of this book is accordingly to present state-of-the-art research in this area. To meet our purpose, we have solicited a number of contributions from recognized researchers in the field. We were delighted that the chapter authors enthusiastically agreed to participate in the project. They have generally embraced the idea that such a volume is much needed.

The introductory chapter covers the main issues involved in the bridging of cognition, health behavior, and informatics, providing a landscape of the major issues in the entire discipline of cognitive health informatics. The rest of the book is organized thematically with chapters by representative scholars in the field who deal with these six themes:

- Introduction to the role of cognitive issues in health behaviors and the design of interventions
- Understanding public health beliefs

- Cognition and health behaviors
- Information technology and cognitive support
- Behavioral measures and interventions
- Future directions, with forward-looking views on the role of cognitive informatics in modeling and helping with health behaviors and behavior change

We intend this book to be of interest to researchers in biomedical informatics, public health, cognitive psychology, behavioral science, and health promotion and education. The work will also be useful to healthcare professionals, especially those who are in the primary-care sector. Additionally, we intend that the book will be useful in the education of healthcare workers who are studying consumer health information.

This book would not have been possible without support and collegial brainstorming with co-editors, Jose and Jessica, as well with my colleagues, David Kaufman, Thomas Kannampallil, and Ted Shortliffe. We spent hours communicating and providing timely input to the authors. Courtney Denton, from the *Center for Cognitive Studies in Medicine and Public Health* at the New York Academy of Medicine, provided much needed support in editing and keeping track of every chapter, the authors and their affiliations, as well as communications with our publishers. Her support was critical to our writing project.

I thank the Canadian International Development Agency (CIDA), USAID, UNICEF, and the James S. McDonnell Foundation for their generous support and for facilitating the wonderful and fruitful journey that I have enjoyed with my colleagues for the last three decades. I believe that this kind of work will become even more important as we introduce new and powerful technologies that will better support the general public as they seek to maintain healthy lifestyles. I trust that the lessons conveyed here will, in turn, support our ability to offer better care in clinics as well as in patients' homes.

New York, NY, USA Vimla L. Patel, Ph.D., D.Sc.
February 2017

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Part I

Introduction to the Role of Cognitive Issues in Health Behaviors and the Design of Interventions

Chapter 1
Cognitive Informatics and Behavior Change in the Health Care Domain

Vimla L. Patel, Jose F. Arocha, and Jessica S. Ancker

Abstract The fields of behavioral medicine and biomedical informatics, each with its own theories and methods, have been developing in parallel with little connection until recently. The convergence of research in these disciplines, cognitive informatics, provides enormous opportunities and challenges in addressing the prevention of public health problems and managing disease, as well as in maintaining healthy lifestyles. The limitations of such models in addressing digital health interventions are discussed within the context of cognitive models of behavior and methods of encouraging behavioral change.

Keywords Cognitive informatics • Behavioral theories • Health decision making • Cognitive design • Digital behavior change interventions

The fields of behavioral medicine and biomedical informatics, each with its own theories and methods, have been developing in parallel with little connection until recently. The convergence of research in these disciplines provides enormous opportunities and challenges in addressing the prevention of public health problems and managing disease, as well as in maintaining healthy lifestyles. An article by David Ahern and his colleagues (Ahern et al. 2016), published in a recent book on oncology informatics (Hesse et al. 2016), provides an excellent review of the current status of the merging of these two disciplines, which we summarize below.

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In recent decades, we have seen an explosion in the availability of health information resources. This can be attributed to the Internet coupled with the development of new information management and decision-support technologies. Technology has become a major mediator of behavioral change in our society. It can also provide feedback that allows developers to modify the technology that supports what we do, aimed at reducing the cognitive load that is required as we complete our tasks. The increasing pace of change in recent years is due in large part to the Internet and the use of cellular phones and other technological devices. People can now be in almost constant contact with each other, less dependent on face-to-face communication that occurred in fixed locations. Flexibility in communication has had a dramatic influence on the way that we transfer information, but we need to better understand how this can influence theories about behavioral change. What theories and models do we currently have about cognitive and psychological behaviors that would inform efforts to improve communication and information transfer during transitions in health care?

1.1 Behavioral-Psychological Models

Behavioral-psychosocial models of health behavior have been very helpful in explaining health behavior and how to motivate behavior change. Health behavior models are typically described as a group of psychosocial constructs (such as beliefs, intentions, or knowledge) linked together by relationships (such as causal relationships or associations), with the entire complex predicting an outcome of interest. Readers are referred to Chap. 2 in this volume (Laranjo et al. 2017) for a comprehensive review on behavioral models and outcomes.

An example of a well-validated behavioral model is the Health Belief Model (HBM), an influential theory that does a good job of predicting whether individuals will respond to a health threat by taking preventive or disease-control actions (Becker 1974; Glanz et al. 2008). Health decisions are influenced by *perceived severity* of the threat and the individual's *perceived susceptibility* to it, and the *perceived benefit* of a protective action, *perceived barriers* to action, and *perceived self-efficacy*, that is, the individual's confidence taking the action. Finally, the model recognizes *cues to action*, which are signals directing the individual's attention to their health or the health threat. The HBM and other health behavior models focus on these psychological constructs and their influence on decisions. Some of these constructs reflect perceptions (such as perceived susceptibility to disease). Other models include emotional components. The Extended Parallel Process Model (see Witte 1992; Witte 1998; Witte and Allen 2000 for examples) proposes that the perceived severity and susceptibility described in HBM, together stimulate *fear*, which is a key predictor of whether the individual will take protective action. Researchers and practitioners seeking to understand health decisions administer questionnaires or interviews to capture these constructs and link them to decisions. For example, for a Spanish-language mobile app for diabetes self-management, Burner and colleagues conducted interviews to show that the text messages are important not because they educated people about previously unknown diabetes facts, but because they served as cues to required action under the HBM (Burner et al. 2014).

However, these models also have limitations stemming from the fact that they do not address the cognitive processes by which individuals collect information, think about it, integrate it with their existing beliefs and knowledge, and act upon it.

As a simple example, the HBM and the Extended Parallel Process Model recognize that our decisions are influenced by our evaluation of the possible outcomes of the decisions—so, for example, whether we get a flu shot is influenced by our perception of the risk of flu and the effectiveness of the shot. But neither model acknowledges that the ability to collect information and assess risks is shaped by health literacy and health numeracy. Individuals with low health literacy may have limited ability to read and process information about the flu, whereas individuals with low health numeracy often develop exaggerated perceptions of risks (Ancker and Kaufman 2007). These cognitive factors shape all of the constructs, relationships, and processes in health behavior models. Failing to account for them can lead to intervention failures, such as when people are unlikely to act upon a flu promotion message designed to be “cue to action” if it is written at a high reading level full of medical jargon.

Another example can be found in electronic patient portals, which gives patients access to their medical records and have become increasingly common internationally. Unfortunately, it is also increasingly clear that portals are ill-suited to the cognitive needs of their patients. Britto and colleagues show that even though electronic patient portals contained potentially invaluable information about children’s health and healthcare, the parents have difficulty locating this information because of poor system usability (Britto et al. 2009). In our small ongoing usability project, we similarly found that only 2 out of 15 patients observed using the portal were able to successfully export their medical records to share with other doctors (Ali et al. 2016). From analysis of their think-aloud protocols (a well-known cognitive psychology method of data collection), it was evident that the visual design of the portal was not clear enough to help patients to construct a coherent schema (or mental model) of the portal. In part due to this problem, most patients could not develop a successful mental representation of the sequence of actions they would need to execute in the portal to accomplish the task (Patel and Kaufman 2013). However, interestingly, a number of patients developed creative and idiosyncratic solutions to accomplish the goal by exploiting other portal affordances. These solutions included cutting and pasting elements of the record into a word document, taking notes or even screenshots, or sharing their password.

These limitations of portals demonstrate the dangers of failing to consider the cognitive aspect of human behavior. If patients cannot access information and functions of the portal because of poor design, then it is unlikely the portal could successfully be used to deliver a theoretically-grounded behavior change intervention. When we recognize these limitations, we open the door to more powerful ways of thinking.

1.2 Cognitive-Psychological Models

Models of cognition reflect the generality of cognitive processes and they have not been developed specifically for the field of health. This generality supports the assumption that the cognitive architecture and processes are universal characteristics of the human mind, and are relevant to any given area or domain, either formal or informal. Models of cognition have also been used to account for various behaviors, such as those involved in decision making and problem solving. Thus, making use of a cognitive approach allows researchers and practitioners access to a breadth of scientific information that covers many different content areas and theories of cognitive processes beyond health and medicine.

Research in a variety of non-health and health-related areas (see Patel and Kaufman 2013; Patel and Kannampallil 2015; Patel et al. 2001 for a review) revealed the role that these cognitive processes play in problem solving and decision making, while stressing learning and performance as a function of domain knowledge. Knowledge, its content as well as its organization, has shown to be critical in a variety of tasks, including domains ranging from chess, to basic physics, to medicine and health (Patel et al. 2002, 2000a; Chi et al. 1988). Given the central role that knowledge plays in cognition, a basic assumption about research on health is that people, including the specialist as well as the non-specialist, intuitively interpret information in terms of their own prior beliefs, backgrounds and assumptions. Such intuitions are often in conflict with scientifically acceptable knowledge. Being aware of the discrepancies between intuitive models and scientific information is especially important in understanding the ways people assess health risk and, indeed, about risk in general. For instance, Arocha and Patel (1995) show that when dealing with information that is inconsistent with prior beliefs, people's interpretation of the said information is a function of their knowledge structure and organization, more than the amount of factual information. Similarly, a study (Patel et al. 2000b) that investigated the reasoning that mothers in rural South India employed to account for the cause and treatment of childhood malnutrition indicated that intuitive and traditional folk knowledge of Indian medicine mediated their health practices. Such knowledge was found to be story-like and was coherent with the mothers' causal explanations, suggesting globally coherent knowledge structures. Furthermore, when modern, scientific, medical knowledge was used, it remained compartmentalized and separate from the traditional knowledge, lacking the narrative structure and coherence of intuitive health knowledge. In addition, traditional knowledge continued to exert considerable influence on their reasoning.

The nature and organization of knowledge has implications for behavior change because any interventions can be matched to the familiarity with health domains that people have. Beliefs associated with coherent knowledge structures can be difficult to change if such knowledge is not taken into account; thus, rather than attempting to replace traditional knowledge, a more effective strategy could be to connect the new knowledge to the old knowledge while maintaining as much of the narrative nature and coherence of health knowledge structures as possible.

1.3 Conceptual Understanding and Health Care Decisions

Research in the health-related domain has suggested that having the knowledge alone is not enough for behavior change (for example, Sivaramakrishnan and Patel 1993; Chan and Chin 2017) and it is generally accepted that knowledge is a necessary, but not a sufficient condition for behavior change (Kenkel 1991). However, in the majority of the studies about behavior and knowledge, the latter is conceived as a collection of "facts" in people's memories. However, knowledge of "facts" is only one of the ways knowledge can be conceptualized. Indeed, there are different forms of knowledge that vary in terms of their degrees of depth. For instance, the knowledge possessed by the expert is of a different quality than that of the naïve or novice person as it goes much beyond the "factual" knowledge investigated in behavioral research. This has implications for designing tools for supporting communities with different levels of literacy.

The theory of conceptual change (Kaufman et al. 2013) posits that people's prior knowledge influences their beliefs and the generation of new beliefs, and that real understanding is required for true conceptual change, something which the simple accumulation of "facts" cannot produce (Kenkel 1991). Research suggests that a deep understanding of health concepts can lead to changes in health practices (Kenkel 1991; Vosniadu 2013). Also, investigation and assessment of conceptual change shows that underlying people's attempts to understand health concepts includes a variety of misconceptions that need to be identified and explicitly addressed in order to foster changes in making better decisions, and therefore better choices in health behaviors. Among the benefits of conceptual change is a kind of cognitive flexibility that allows a person to adapt knowledge to a variety of different contexts leading to a higher level of understanding (Donovan and Ward 2001). Such flexibility is a function of the in-depth nature of genuine conceptual understanding.

Finally, cognitive-psychological research that focuses on cognitive processes underlying decision making (role of memory, knowledge strategies and inferences) play a major role in determining how well any decision support systems deliver information that is received and processed, and action taken the way the designers intended them to. The deployment of electronic health record (EHR) systems in hospitals and through health care systems and healthcare clinics have contributed to the advancement of computer decision support at the point of care, and patient portals are being introduced such that physicians can engage patients so that they are more informed about their own delivery of healthcare. This also facilitates better communication between clinicians and patients in the decision making process. Recent mobile health technology (e.g. smart phones, iPad tablets, social networks), as a well as the use of sensor-based technology (e.g. wearable devices such as Fitbit, which uses physiological sensors, Bluetooth Beacon; radio frequency identifiers), has been used to communicate and monitor health-related behaviors. These mobile apps and other digital health care tools hold great promise as interventional methods to improve the health and wellbeing of an individual. The behavioral sciences, including cognitive sciences, offer ample evidence that we can leverage the principles from these sciences to advance the development and deployment of technological tools to provide efficient, effective and safe care to the patients.

1.4 Theories, Models and Frameworks

Behavioral change theories are attempts to explain why and how behaviors change. These theories cite environmental, personal, and behavioral characteristics as the major factors in behavioral determination. There are two major distinctions between the models of behavior and theories of change (Coulson et al. 1997). Whereas models of behavior are more diagnostic and geared towards understanding the psychological factors that explain or predict a specific behavior, theories of change are more process-oriented and are generally aimed at changing a given behavior. Thus, from this perspective, understanding and changing behavior are two separate but complementary lines of scientific investigation.

Theories have abstract and generalizable concepts with explanatory power, which specify relationships among constructs. Theories also follow a deductive system of logic for interpreting few empirical data that can either support the theory or provide evidence for its inadequacy. In contrast, conceptual frameworks share all the features of theories, except that they do not have explanatory power or follow a deductive system of logic (Patel and Groen 1993).

Theories of behavior change have been variable and tend to emphasize group-level generalization, although a theory is capable of generating individual behavioral patterns. A good theory will provide both group-level and individual-level generalizations. Digital behavior change interventions (DBCIs) are interventions that employ digital technologies to encourage and support behavior change that will promote and maintain health, through primary or secondary prevention and management of health problems. The readers are referred to a recent paper on Advancing Models and Theories for Digital Behavior Change Interventions (DBCIs) which provides an excellent account of limitations of behavior theories and future directions for research (see Yardley et al. 2016; Hekler et al. 2016). The authors argue that theories are key to personalization of DBCIs. Theories also facilitate health promotion by providing support in the "real world" to change-focused behaviors in specific contexts, and are used by individuals (Hekler et al. 2016). DBCIs use information about an individual to provide support in changing needs of the individual over time. Pagoto and Bennett (2013) argue for a critical role of behavioral and psychological science in advancing digital health and digital interventions. Furthermore, given the nature of expertise and limited funding resources, behavioral science researchers and industry that develop technological innovations cannot afford to work alone or in parallel to one another, but need to work in a team science approach with a multidisciplinary work.

1.5 Future Directions

We are in the midst of a transition from a focus on disease and its management to an effort to promote healthy lifestyles and activities that will help to stave off disease and provide a sense of wellbeing to individuals. This transition requires an increasing focus on cognitive aspects, not only in an individual's response to disease but in the way that they perceive and seek health. This suggests an increasing focus on cognitive design (design coupled to a way of thinking), which has implications both for an individual's response to disease and for their pursuit of health and its maintenance.

The multifaceted elements that underlie behavioral change imply that multidisciplinary collaborative research is needed. Basic principles from cognitive-behavioral and psychological sciences offer many opportunities to leverage cognitive informatics in developing behavioral support tools. Disparate theories and models of behavioral change can be reconciled with the creation of robust behavioral ontologies that allow the identification of how the general notions might apply to a specific individual. Current models of behavior focus on group-based outcomes, but with better development of strong theories, we will see a move towards addressing the evolution of personalized health, reflecting behavioral changes and their gradual or acute impact on the individual (Ahern et al. 2016; Yardley et al. 2016).

Technology is increasingly considered not to be separate from the healthcare team but, rather, to be a part of it. The resulting "intellectual partnership" can provide support in any patient-centered collaboration. The team must work together within the care system to ensure that the patient is not 'dropped' (Patel and Crook 2014). Although advances in communication technologies will enhance team effectiveness, we need to make sure that such influences are also scalable over time as teams increase in size or the number of patients that they manage.

The complex nature of clinical care and health promotion can make it difficult to measure the influence of technological behavioral interventions. In most healthcare systems, situations change incrementally but non-linearly, with changes in focus due to multitasking and constant interruptions. Given that we are destined to function in such a world, and that the interventional technology itself is complex, any good design should attempt to tame complexity as much as possible, but learn to manage that which is untamable. As an example of why such complexity and its management is important, Donald Norman, in his book *Living with Complexity*, discusses two aspects of understanding that are considered pertinent for successful interventions (Norman 2010). These include understandability (i.e., once we understand the logic and underlying structure, many uncertain aspects make sense) and understanding (i.e., we must give enough time and effort in order to develop our own set of abilities and skills for understanding the structure). Models or approaches that fail to recognize such distinctions are doomed to fail; simplistic models fail to provide useful approaches for tackling such problems in real-world settings such as those that characterize the world of medicine and health (Kannampallil et al. 2011; Patel 2014).

This book accordingly acknowledges the complexity we have outlined and proposes a number of methods and examples for tackling real world problems in which simplistic solutions are certain to fail. The focus is on behavioral issues and the role of both technologies and cognitive theory in assuring that effective changes in behavior can be encouraged and measured.

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Chapter 2
Design and Implementation of Behavioral Informatics Interventions

Liliana Laranjo, Annie Lau, and Enrico Coiera

Abstract The growing burden of chronic disease is drawing unprecedented attention to the importance of optimizing lifestyle behaviors. Interventions to promote behavior change seem promising, but their full potential can be missed when they are not easily disseminated or accessible to a larger audience. The ability of technology to address these issues, as well as to facilitate the tailoring of interventions, has led to the growing popularity of the field of behavioral informatics (BI).

Behavioral informatics interventions are designed to support patients and healthy consumers in modifying behaviors to improve health, with the help of computers, the Internet, mobile phones, wireless devices, or social media, among other technologies. To date, BI interventions have been applied in several health domains, from the promotion of healthy lifestyle behaviors to mental health and chronic disease self-management.

The effectiveness and impact of BI interventions are largely dependent on their meaningful design, development, evaluation, and implementation. Key elements for success include: performing a comprehensive observation and framing of the particular behavioral challenge within context; recognizing the relevant behavior change theories, models and techniques; having a deep understanding of user characteristics and needs; involving users throughout design and development; and refining the design through user-centred evaluation.

Due to the rapid pace of technology development, the evaluation of interventions and translation of research to practice are met with particular challenges. Innovative methodologies and implementation strategies are increasingly required to bring to fruition the potential of BI interventions in delivering cost-effective, personalized interventions, with broad scalability.

Keywords Behavior • Behavioral informatics • Social media • Social networking site • Mobile health • Internet • Computer • Chronic disease • Lifestyle • Diet • Exercise • Smoking

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2.1 Introduction

Unhealthy lifestyle behaviors are a major contributor to the growing global burden of chronic diseases (Narayan et al. 2010; WHO—Department of Noncommunicable Disease Surveillance 2014). Sedentariness, poor diet, smoking, and alcohol misuse are known risk factors for cardiovascular disease and other chronic conditions, and are responsible for a great proportion of premature and preventable deaths, as well as rising healthcare costs, worldwide (WHO—Department of Noncommunicable Disease Surveillance 2014). Consequently, optimizing lifestyle behaviors is now recognized as a key challenge in both the prevention and management of chronic illnesses.

Behavioral informatics (BI), using health information technology (HIT) to facilitate behavior change, is becoming increasingly popular (Samoocha et al. 2010; Murray et al. 2005; Bull et al. 2005; Solomon et al. 2012). Apart from allowing the tailoring of interventions to individuals and groups, HIT may have additional advantages over traditional interventions. These include providing convenient and easy access to the intervention, facilitating access to real-time information and feedback, and reaching remote and larger audiences, using fewer resources.

Importantly, even small changes to health behaviors can lead to substantial public health improvements and cost-savings in health care, which makes the field of BI particularly promising. BI interventions have the potential to be highly cost-effective and scalable therapeutic options in the prevention and management of chronic conditions.

This chapter introduces the scientific field of behavioral informatics, describing several types of interventions that use technology to promote behavior change, as well as outlining the underlying behavior change theories, models and techniques. The process of designing, developing, evaluating and implementing these interventions will also be described, with a particular emphasis on innovative methodologies and implementation strategies that can be used to advance the field of evidence-based behavioral informatics.

2.2 Behavioral Informatics Interventions

2.2.1 Definition and Health Domains

Behavioral informatics (BI) interventions involve the use of technology, such as computers, the Internet, mobile phones, wireless devices, or social media, to facilitate behavior change and improve health (Coiera 2015; Kroeze et al. 2006; Shahab and McEwen 2009).

BI interventions address a specific behavior or set of behaviors, in a given health domain, for a certain population and setting. Consequently, three aspects are key in BI interventions: knowledge about the causal mechanisms and influencing factors of the behavior of interest, a deep understanding of the target population, and awareness of the context of the intervention. Evidence-based BI draws on existing knowledge regarding relevant behavior change theories, models and techniques, to deliver interventions that are appropriate for a particular behavior, audience and environment.

BI can support both patients and healthy consumers, having the potential to promote engagement and participation in care, and facilitating the better alignment of treatment choices with patients' preferences and values, through shared decision-making (Syrowatka et al. 2016). To date, BI interventions have been applied in several health domains, including primary prevention of chronic diseases and lifestyle improvement (e.g. healthy diet, fitness), substance abuse, mental health, and chronic disease management (e.g. asthma, type 2 diabetes, hypertension), with encouraging results (Murray et al. 2005; Webb et al. 2010; Pal et al. 2014) (Box 2.1).

Box 2.1 Summary of health domains addressed in behavioral informatics interventions

Primary prevention of chronic diseases and lifestyle improvement	The great majority of BI studies have focused on promoting physical activity, healthy diet habits, and weight loss (Laranjo et al. 2015; Chang et al. 2013; Neve et al. 2010; Fanning et al. 2012). For instance, meta-analyses of interventions involving mobile technologies in this health domain have shown significant improvements in weight loss and physical activity measures (e.g. step counts, duration of moderate to vigorous physical activity, accelerometer counts per minute, self-reported physical activity) (Fanning et al. 2012; Foster et al. 2013; Lyzwinski 2014).
Substance abuse and mental health	Smoking and alcohol misuse are also commonly addressed risk factors in BI interventions (Free et al. 2013; Whittaker et al. 2009), with the mode of delivery varying from computer and web-based (Saitz et al. 2004; Doumas and Andersen 2009) to text messaging and mobile applications (Suffoletto et al. 2012; Weitzel et al. 2007). Notably, BI for substance abuse offers relative anonymity and privacy, having been used to facilitate screening and assessment, provide brief interventions (Suffoletto et al. 2012), or deliver ongoing treatment and recovery support (Gustafson et al. 2011), through online support meetings, virtual sponsors, or recovery coaches (Cohn et al. 2011; Hester et al. 2013). BI is also being increasingly applied in mental health, for the prevention, screening, treatment and recovery support of mental health problems (Proudfoot 2013; Harrison et al. 2011). One example is the online delivery of cognitive behavioral therapy (CBT). CBT is an effective method used in the management and treatment of several mental health problems and behavioral issues, such as anxiety and depression. However, in-person CBT is time-consuming and resource-intensive. Research has shown that CBT can be delivered online with very positive results, having high adherence and effectiveness, as well as greater reach than traditional in-person CBT (Proudfoot et al. 2011; Andrews et al. 2010; Kiluk et al. 2011).

Chronic disease self-management	The use of technology to facilitate self-management has also been sharply increasing, with encouraging results (Murray et al. 2005; Bull et al. 2005; Solomon et al. 2012; Jackson et al. 2006; Cho et al. 2006; Costa et al. 2009; Lorig et al. 2010; Cotter et al. 2014; McMahon et al. 2005; Ralston et al. 2004). It is known that self-management support and behavior change programs can be effective in improving disease knowledge, self-management behaviors, symptom management, self-efficacy, and numerous clinical outcomes (Solomon et al. 2012; Newman et al. 2004; Lorig et al. 1999; Bodenheimer et al. 2002; Norris et al. 2001). BI has the potential to support patients with self-management activities, such as managing symptoms, doing the necessary treatments, making lifestyle changes and coping with the physical and psychosocial consequences of the condition. One important area where BI is supporting chronic disease patients is in medication adherence. Technology can be used in interventions across the continuum of non-adherence, from simplifying prescription refills, to facilitating monitoring (e.g. with pill-monitoring technology like electronic pill caps, smart blister packaging, and digital pills) (Krummenacher et al. 2011; Zeller et al. 2007), providing reminders (e.g. text messaging) (Thakkar et al. 2016), facilitating patient-provider communication, promoting shared decision-making, or delivering social support (Marsch et al. 2014).

2.2.2 *Mode of Delivery*

BI interventions may be delivered in a variety of ways, depending on the particular technological approach selected. A common feature enabled by technology is the ability to tailor (i.e. personalize) interventions and to promote an interactive exchange of information (Coiera 2015; Webb et al. 2010; van den Berg et al. 2007; Stevens et al. 2008). Tailoring can be used in interventions to provide feedback, facilitate action planning, provide behavioral goals, and enable social comparison, among others.

Notably, technology facilitates personalization based on the assessment of a number of variables, through the application of decision rules. At the simplest level, tailoring may be static, involving the design of intervention components targeting a specific characteristic of participants (e.g. delivery of different age-relevant educational content according to age group).

Apart from static one-time tailoring, technology also enables the delivery of dynamic tailoring using machine learning, based on data trends over time (e.g. data captured by an activity tracker or other sensors) (Marsch et al. 2014). Consequently, BI interventions can provide static or dynamic tailoring, or even both within the same intervention.

Interestingly, BI interventions involving tailoring strategies have been shown in several trials to be significantly more effective in improving behavior-related outcomes than the ones that do not involve tailoring, showing higher engagement and being perceived by participants as more personally relevant (Shahab and McEwen 2009; Marsch et al. 2014; Krebs et al. 2010; Lustria et al. 2013; Portnoy et al. 2008; Civljak et al. 2013).

Furthermore, BI interventions vary in their components and features according to the technology used in its delivery. To date, a great number of BI interventions involve the use of computers, the Internet, mobile phones, wireless devices, and/or social media. Additionally, some interventions commonly involve the utilization of more than one technology in their delivery (e.g. computer- and web-based interventions).

Computer-Based and Web-Based BI Interventions

Computers and the Internet obviate the need for in-person provision of interventions, reducing the resources and costs associated with their delivery, and therefore facilitating the dissemination of interventions to a wider audience, in a cost-effective manner. In particular, the Internet facilitates the implementation of interventions across geographic boundaries, greatly increasing their reach. Common features of computer and web-delivered interventions include progress-monitoring, goal setting, and the provision of links to educational resources and peer support (Lustria et al. 2009). Computer and web-based interventions have been developed in several health domains, from primary prevention, substance abuse and chronic disease self-management (Box 2.2).

Box 2.2 Examples of behavioral informatics interventions delivered by computer and/or the Internet

Computer	Computer-delivered and computer-tailored BI interventions have shown positive results in promoting dietary change and physical activity (Kroeze et al. 2006), as well as in improving other behaviors, such as tobacco use, substance use, and safer sexual behavior, among others (Krebs et al. 2010; Portnoy et al. 2008; Reed et al. 2012).
Web	Web-based interventions have been associated with improvements in health outcomes across a variety of medical conditions and patient populations (Webb et al. 2010; Neve et al. 2010; Lustria et al. 2013; Wantland et al. 2004), namely weight loss (Wieland et al. 2012), physical activity (Davies et al. 2012) and smoking cessation (Myung et al. 2009; Walters et al. 2006).
Computer and web	Computer-based and web-based systems combining health information with either social support, decision support, or behavior change support, have been shown effective in improving behavioral outcomes for chronic disease patients (Murray et al. 2005).

Social media

The use of social media in BI interventions is promising, as it facilitates addressing the social processes related to behavior change (Coiera 2015). Social media can provide access to a large community of peers, which may deliver support, information and access to helpful resources (Coiera 2015). Systematic reviews evaluating the effects of social media (e.g., blogs, discussion boards, wikis) on health behavior change (Williams et al. 2014), health promotion (Chou et al. 2013), and health communication (Moorhead et al. 2013) have shown promising results.

One particular type of social media tool that is gaining increasing attention is the social networking site(SNS). Social networking sites are web-based platforms that enable users to create their own personal profile and build a network of connections with other users (Boyd and Ellison 2007).

So far, SNSs used in behavior change interventions have primarily been Facebook (Foster et al. 2010; Napolitano et al. 2012; Cavallo et al. 2012; Valle et al. 2013; Bull et al. 2012; Young and Jaganath 2013; Mayer and Harrison 2012) and Twitter (Turner-McGrievy and Tate 2011). However, some studies are also using more specific SNSs, sometimes designed purposefully for research (Brindal et al. 2012; Graham et al. 2011; Centola 2010, 2011).

General SNSs like Facebook have several benefits for the implementation of health interventions, compared to health-specific SNSs (Cobb and Graham 2012; Bennett and Glasgow 2009). They have millions of regular users worldwide (Pew Research Center 2013; Facebook Newsroom 2014), potentially facilitating the recruitment of participants (Napolitano et al. 2012; Valle et al. 2013; Bull et al. 2012; Young and Jaganath 2013) and minimizing problems of retention and lack of adherence to interventions, by being easily incorporated in people's routines and habits (Jimison et al. 2008).

Importantly, most interventions that involve social media for health behavior change consist of other features in addition to the SNS (e.g. podcasts, mobile application, pedometer), making it difficult to determine the contribution to effectiveness of each particular component (Laranjo et al. 2015; Chang et al. 2013; Neve et al. 2010; Hamm et al. 2013; Eysenbach et al. 2004).

Mobile Health (mHealth)

Mobile health can be defined as "the use of mobile telecommunication technologies for the delivery of health care and in support of wellness" (Steinhubl et al. 2013), and it includes both mobile phone technologies and wireless devices (e.g. wearables, tracking/monitoring devices) (Box 2.3).

Mobile phones have several features that make them a promising tool for behavior change interventions: they are portable and ubiquitous—most people own a mobile phone that is always carried with them throughout their everyday activities; they are personal, making intervention tailoring possible; they are connected, being able to provide direct access to a wide range of external resources; and they are intelligent tools with increasing computational capacities (Fogg 2009).

Mobile devices are being used in BI interventions to provide access to self-monitoring resources, self-management tools, health information, prompts, and reminders, in real time and in the context of people's daily lives. Notably, there is evidence that the use of prompts, reminders, and proactive messaging improve behavioral outcomes in BI interventions (Krebs et al. 2010; Fry and Neff 2009).

Box 2.3 Examples of behavioral informatics interventions involving mobile technologies

SMS (Short Message Service)	SMS (i.e. text-messaging) uses standardized communication protocols, therefore working independently of the underlying hardware, which makes it a useful tool in disseminating BI interventions and reaching larger and more diverse audiences (Cole-Lewis and Kershaw 2010). SMS is most commonly used in BI to transmit educational content and to provide reminders or prompts (Thakkar et al. 2016). An interesting example of a SMS-only BI intervention is a smoking cessation program which delivered motivational messages and behavior change support through text messages, before and after the quit date, having shown significant improvements in abstinence rates at 6 months (Free et al. 2011).
Mobile applications	More recently, mobile applications (apps) have started to be incorporated in BI interventions for lifestyle improvement, chronic disease management and mental health. For instance, in the domain of chronic disease self-management, particularly in diabetes, a review of the use of apps has found that common features included decision support, data entry, and the delivery of alerts and reminders (El-Gayar et al. 2013). Overall, these apps for diabetes self-management were found to be able to support patients with tasks such as exercise, insulin and oral medication dosage, blood glucose testing, self-monitoring and diet (El-Gayar et al. 2013).

The ubiquity of mobile phones and their ability to reach individuals continuously in their natural environment is also contributing to a sharp growth in the field of "ecological momentary assessment" (EMA, i.e., the collection of participants' data in real-time) and "ecological momentary interventions" (i.e., the ability to trigger the delivery of interventions based on real-time data and on "just-in-time" assessments) (Marsch et al. 2014; Heron and Smyth 2010a, b; Riley et al. 2011;). EMA can involve the collection of self-reported data in response to prompts, but also the passive recording of information (e.g. messages sent, application usage) and the use of embedded sensors (e.g., accelerometers, video cameras, microphones, light sensors) to collect data and make inferences about the environment (e.g. location, time, weather, activity) (Burns et al. 2011). In the future, the data collected through mobile technologies may increasingly promote the design and delivery of highly-personalized, context-sensitive, and effective interventions.

2.2.3 Behavior Change Theories, Models and Techniques

BI interventions exist to address a specific behavior in a particular health domain, for a certain population and setting. Consequently, three key aspects should be at the basis of the design of a BI intervention: evidence about the causal mechanisms and influencing factors of that particular behavior, a deep understanding of the target population, and knowledge about the context of the intervention. Behavioral theories, models and techniques are useful in addressing these questions, bringing considerable value to the design and development of evidence-based BI interventions.

A theory, or model, of behavior change aims to explain or predict why and when a behavior does or does not occur, as well as its influencing factors (Michie et al. 2014). As each theory addresses different concepts of behavior change, it is not unusual for an intervention to be based on more than one theory or model (Glanz et al. 2008). More recently, interventions are increasingly being described in terms of the specific behavior change techniques involved (Abraham and Michie 2008). A behavior change technique (BCT) is an “observable, replicable and irreducible component” of a behavioral intervention designed to alter or redirect causal processes that regulate behavior (Michie et al. 2013). BCTs can be linked to existing theories and models, and arguably provide a more fine-grained approach to the design and evaluation of behavior change interventions (Abraham and Michie 2008; Michie et al. 2013).

Until now, the predominant theories used in behavior change interventions include the Health Belief Model, the Theory of Reasoned Action, Social Cognitive Theory, and the Transtheoretical Model of Change (Michie et al. 2014; Glanz et al. 2008; Prestwich et al. 2014). These theories are also among the most commonly cited as the basis for mobile (Riley et al. 2011) and Internet-based interventions (Webb et al. 2010; Marsch et al. 2014). More recently, the ‘Capability Opportunity Motivation—Behavior’ (COM-B) system and the ‘behavior change wheel’ (Michie et al. 2011a) were developed to provide a comprehensive model for the design and evaluation of behavior change interventions, based on the use of BCTs.

Health Belief Model

The Health Belief Model (HBM) contains several concepts that predict why people will take action to prevent, screen for, or manage health problems (Glanz et al. 2008). These concepts include ‘susceptibility’, ‘severity’, ‘benefits and barriers to a behavior’, cues to action’, and ‘self-efficacy’ (Table 2.1). According to the HBM, individuals are more likely to take preventive action when they believe the threat of a health risk is serious, when they appear personally susceptible, and when the gains of engaging in prevention are higher than the costs involved (Fig. 2.1) (Michie et al.

Table 2.1 Key concepts of the Health Belief Model

Concept	Definition	Possible application
Perceived susceptibility	Belief about the probability of experiencing a health risk or health problem	–Make perceived susceptibility more consistent with an individual's actual risk –Provide personalized risk prediction according to a person's characteristics
Perceived severity	Belief about how serious a condition and its consequences are	Specify consequences and inform about severity
Perceived benefits	Belief in efficacy of the advised action to reduce risk or severity of consequences	Define action to take and explain the positive effects to be expected
Perceived barriers	Belief about the tangible and psychological costs of the advised action	Identify and reduce perceived barriers (e.g. reassurance, correction of misinformation, incentives, assistance)
Self-efficacy	Confidence in one's ability to take action	–Provide training and guidance in performing recommended action –Give verbal reinforcement –Improve physical and emotional states –Demonstrate desired behaviors –Use progressive goal setting
Cues to action	Strategies to activate "readiness"	–Promote awareness –Provide how-to information –Use reminders

Adapted from: Glanz K et al. Health Behavior and Health Education; 2008 (Glanz et al. 2008)

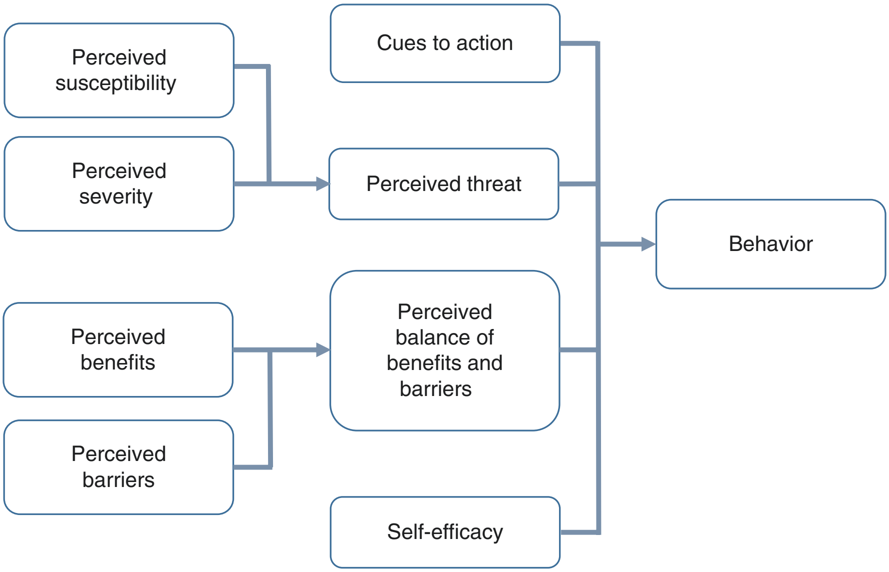

Fig. 2.1 Schematic representation of the Health Belief Model. Adapted from: Glanz K et al. Health Behavior and Health Education (Glanz et al. 2008); and Marsch L et al. Behavioral Healthcare and Technology: Using Science-Based Innovations to Transform Practice (Marsch et al. 2014)

2014). Behavior change interventions using the Health Belief Model tend to focus on perceptions of susceptibility (e.g. risk calculation and prediction), as well as on the benefits and barriers of engaging in a particular behavior or intervention (Glanz et al. 2008).

Since its development in the 1950s, the HBM has been widely used in behavioral interventions. Many theories have been developed since the HBM, rendering this model rather incomplete in explaining behavior change, but its contribution to intervention design continues to this date, mostly when screening behaviors are involved, and usually in combination with other theories or frameworks (Box 2.4) (Marsch et al. 2014; Mortimer et al. 2015).

Box 2.4 Example of the use of the Health Belief Model in a behavioral informatics intervention

The HBM has been used in a successful web-based intervention involving the use of a Personally Controlled Health Management System to promote sexual health screening. This system delivered educational content on aspects such as severity and perception of risk, provided indications regarding screening for Sexual Transmitted Infections (STI), and enabled the use of an online appointment booking system (Mortimer et al. 2015). Access to this intervention was associated with a significant increase in the proportion of participants undergoing STI screening, in a randomized controlled trial (Mortimer et al. 2015).

Theory of Reasoned Action and Theory of Planned Behavior

The Theory of Reasoned Action (TRA) and its subsequent revision as the Theory of Planned Behavior (TPB) assume that the best predictor of a behavior is the intention to perform that behavior (Fig. 2.2) (Glanz et al. 2008). On the other hand, the intention to engage in the behavior is the result of the individual's attitudes and subjective norms regarding that particular behavior, being also influenced by the degree to which the individual perceives he or she is able to perform it. TRA and TPB involve several concepts (Table 2.2) and are commonly used in interventions that target a set of beliefs (e.g. behavioral, normative or control beliefs) in order to affect attitudes, subjective norms or perceived control, with the final goal of changing intention and behavior (Glanz et al. 2008).

TRA and TPB have been applied to explain a variety of health behaviors, including exercise, substance abuse, sexual health behaviors, screening and preventive services (Box 2.5) (Albarracín et al. 2001).

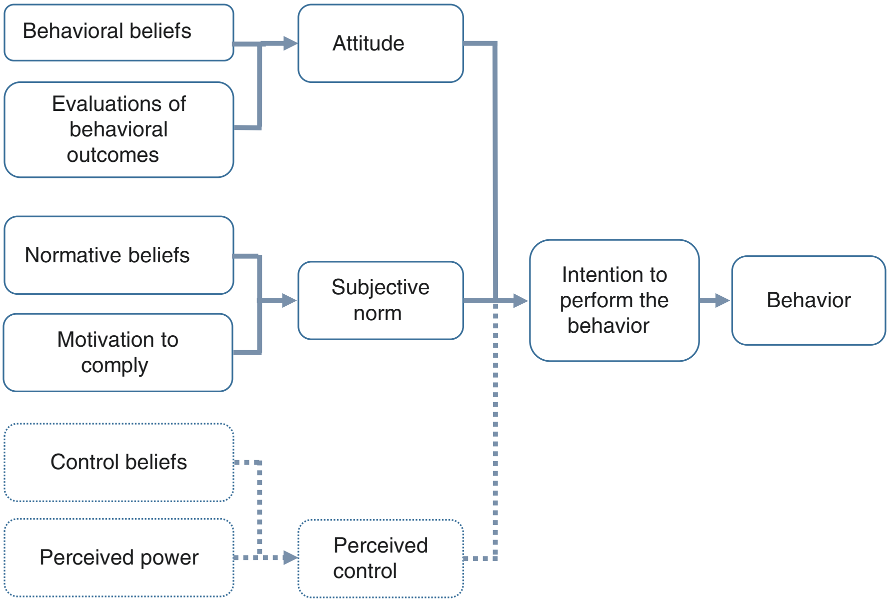

Fig. 2.2 Schematic representation of the Theory of Reasoned Action (excluding *dashed lines*) and Theory of Planned Behavior (entire figure). Adapted from: Glanz K et al. Health Behavior and Health Education (Glanz et al. 2008)

Table 2.2 Concepts in the theory of reasoned action and theory of planned behavior

Concept	Definition
Intention to perform the behavior	Perceived likelihood of performing a behavior or readiness to perform a behavior
Attitude	Overall affective evaluation of the behavior
Behavioral beliefs	Belief that a behavior is associated with certain outcomes
Evaluations of behavioral outcomes	Value attached to a behavioral outcome
Subjective norm	Belief about whether most people approve, disapprove or perform the behavior
Normative beliefs	Belief about whether other people approve, disapprove or perform the behavior
Motivation to comply	Motivation to do what other people desire
Perceived control	Overall measure of perceived control over the behavior
Control beliefs	Perceived likelihood of occurrence of a facilitating or constraining condition
Perceived power	Perceived effect of each condition in making a behavior difficult or easy to perform

Adapted from: Glanz K et al. Health Behavior and Health Education; 2008 (Glanz et al. 2008)

Box 2.5 Example of the use of the Theory of Planned Behavior in a behavioral informatics intervention

Suffoletto et al. developed an interactive text message (SMS) intervention based on the Theory of Planned Behavior, aiming at reducing binge drinking in young adults (Suffoletto et al. 2015). The intervention involved the use of SMS assessments and provision of feedback, with the intent of increasing awareness regarding weekend drinking intentions and behavior, as well as promoting goal-striving and goal-attainment toward reduced alcohol consumption. The intervention was shown to be more effective than standard-of-care (control group) in reducing binge drinking, in this population (Suffoletto et al. 2015).

Although the HBM, TRA, and TPB have been useful for developing numerous behavior change interventions, they have also been criticized for being incomplete models of behavior, focusing mostly on the cognitive aspects of behavior change, like behavioral intentions, and missing many social and environmental influencers of behavior (Marsch et al. 2014).

Social Cognitive Theory

Social Cognitive Theory (SCT) proposes that the environment, behavior, personal and cognitive factors are all interdependent elements (Fig. 2.3) (Michie et al. 2014; Glanz et al. 2008). SCT was first known as Social Learning Theory and focused on the behavioral learning principles of classical and operant conditioning. Subsequently, internal cognitive concepts such as self-efficacy were included, giving rise to SCT (Table 2.3) (Bandura 1986). In SCT, environmental factors influence individuals and groups, but individuals and groups can also influence their environments and regulate their own behavior (Glanz et al. 2008). Important concepts in SCT include: psychological determinants of behavior (outcome expectations, self-efficacy and collective efficacy), environmental determinants of behavior (incentive motivation and facilitation), observational learning, self-regulation, and moral disengagement (Table 2.3).

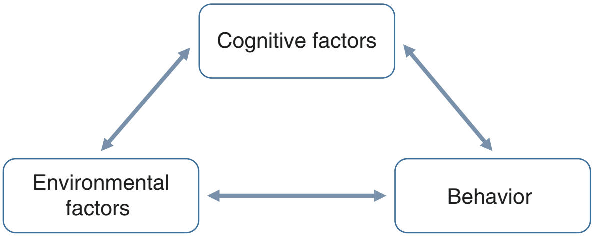

Fig. 2.3 Schematic representation of the Social Cognitive Theory

Table 2.3 Social Cognitive Theory concepts

Concepts		Definition
Psychological determinants of behavior	Outcome expectations	Beliefs about the probability and value of the consequences of behavior
	Self-efficacy	A person's belief in their own ability to perform a task when faced with several challenges
	Collective efficacy	Beliefs about the ability of a group to act in a certain way
Observational learning		Learning to perform new behaviors by exposure to interpersonal or media displays of that same behavior (e.g. peer modelling)
Environmental determinants of behavior	Incentive motivation	Use of rewards or punishments to modify behavior
	Facilitation	Providing tools, resources, or environmental changes that make new behaviors easier to perform
Self-regulation		Self-regulation, or controlling oneself, can be achieved in six ways: (1) self-monitoring and systematic observation of one's own behavior, (2) goal-setting, (3) feedback on performance quality and potential improvements, (4) self-reward, (5) self-instruction, and (6) social support from people who encourage one's efforts to exercise self-control
Moral disengagement		Disengagement of self-regulatory moral standards (thinking about harmful behaviors and harmed people in a way that makes the suffering acceptable)

Adapted from: Glanz K et al. Health Behavior and Health Education; 2008 (Glanz et al. 2008)

SCT has been commonly used in BI interventions. A meta-analysis of text-messaging interventions for health promotion (e.g. smoking cessation, physical activity, weight loss, sexual health) showed that 40% of theory-based studies mentioned the use of SCT (Head et al. 2013) (Box 2.6).

Box 2.6 Example of the use of Social Cognitive Theory in a behavioral informatics intervention

Voth et al. developed an intervention based on Social Cognitive Theory to promote physical activity, through the use of a mobile application and text-messaging. The mobile app was used to facilitate self-monitoring, and text messages were sent each week, targeting SCT components such as self-monitoring, verbal persuasion, performance accomplishment, and vicarious experience (Voth et al. 2016). At the end of the 8-week intervention, engagement in exercise bouts was significantly greater in the experimental condition as compared to the control group (Voth et al. 2016).

Table 2.4 Stages of change in the Transtheoretical Model

Stages of change	Description
Precontemplation	No intention to change within the next 6 months
Contemplation	Ambivalent or thinking about change
Preparation	Taking steps towards change
Action	Attempting the change
Maintenance	Having sustained the behavior change for more than 6 months and working to prevent relapse

Adapted from: Glanz K et al. Health Behavior and Health Education; 2008 (Glanz et al. 2008)

Transtheoretical Model of Behavior Change

According to the Transtheoretical Model (TTM), behavior change undergoes five sequential stages: pre-contemplation, contemplation, preparation, action, and maintenance (Table 2.4) (Michie et al. 2014; Glanz et al. 2008). In addition, there are ten 'processes of change' that are considered to be important in facilitating progress between the different stages, and two more variables that influence the change process: decisional balance (evaluating pros and cons of changing) and self-efficacy (Prochaska and Velicer 1997).

One main advantage of stage-based approaches such as the TTM, is that they facilitate the tailoring of interventions (Michie et al. 2014; Glanz et al. 2008). Interestingly, technology offers an efficient way to scale behavioral interventions using stage-based approaches, as it facilitates the personalization of interventions. In particular, the TTM has been the basis for numerous Web-based expert systems that tailor interventions to the stage of change (Webb et al. 2010). The majority of TTM-related interventions until date have focused on smoking cessation, diet, and exercise (Bridle et al. 2005) (Box 2.7).

Box 2.7 Examples of the use of the Transtheoretical Model in behavioral informatics interventions

One example of a behavioral informatics intervention based on the Transtheoretical model was developed for smoking cessation, involving the delivery of computer-tailored messages. In this intervention, tailoring variables were selected from a number of health behavior theories, including the Transtheoretical Model, the Health Belief Model, and Social Cognitive Theory (Strecher et al. 1994; Kreuter and Strecher 1996; Strecher 1999; Kreuter et al. 1999). Furthermore, an enhanced health risk appraisal program was developed to evaluate not only perceived health risks from smoking but also (a) perceived benefits and barriers to quitting as per the HBM, (b) readiness to quit as per TTM, and (c) relapse history as per the relapse prevention model. Then, tailored message feedback was developed based on assessments of these theoretically based constructs, resulting in over 4500 different combinations of messages (Kreuter and Strecher 1996).

Another example of a successful intervention was a text messaging program for smoking cessation that adjusted the frequency and content of messages based on stage of change of the Transtheoretical Model (Brendryen and Kraft 2008; Brendryen et al. 2008).

The COM-B Framework and the Behavior Change Wheel

The "Capability Opportunity Motivation—Behavior" (COM-B) system is a comprehensive framework that can be used to characterize and design behavior change interventions (Michie et al. 2014, 2011a). The COM-B system involves three main components: capability, opportunity, and motivation (Table 2.5).

According to the COM-B system, for any behavior to occur at a given moment, not only there must exist capability and opportunity to perform the behavior, but also the motivation to engage in the behavior must be greater than for any competing behaviors (Michie et al. 2014). Moreover, these components interact: motivation can be influenced by both opportunity and capability, which can in turn influence behavior; behavior can then have a feedback influence upon a person's opportunity, motivation and capability to perform the behavior again (Fig. 2.4) (Michie et al. 2014).

Based on the COM-B system, the 'behavior change wheel' (BCW) includes nine intervention functions (training, education, enablement, persuasion, incentivization, coercion, modelling, environmental structuring, and restriction) aimed at addressing one or more of the three COM-B components, as well as seven categories of policy that may facilitate the occurrence of these interventions (guidelines, environmental/social planning, communication/marketing, legislation, service provision, regulation, and fiscal measures) (Michie et al. 2011a). The nine intervention functions can be linked to the COM-B system's components and to one or more behavior change techniques, thus making this framework particularly useful as a comprehensive tool in characterizing and evaluating behavior change interventions (Michie et al. 2011a, 2009a).

The BCW has already been used to characterise interventions within the English Department of Health's 2010 tobacco control strategy and the National Institute of Health and Clinical Excellence's guidance on reducing obesity (Michie et al. 2011a), as well as to design BI interventions (Box 2.8) (Fulton et al. 2016).

Table 2.5 Components of the 'Capability Opportunity Motivation—Behavior' framework

Components	Sub-components	Definition and examples
Capability Psychological and physical capacity to engage in the activity concerned	Physical	Skill, strength and stamina
	Psychological	Knowledge and skills to perform the behavior, and the capacity to engage in the necessary thought processes such as comprehension and reasoning
Opportunity All the factors that are external to the individual, and which enable or prompt behavior	Physical	Physical opportunities created by the environment (e.g. time, financial resources, access, and cues)
	Social	Social opportunities created by the cultural environment
Motivation All the brain processes that influence one's behavior	Reflective	Planning, goal-setting, and other analytical decision-making, evaluations and plans
	Automatic	Habit, impulses and emotions that result from innate dispositions or associative learning

Adapted from: Michie et al. Implementation Science 2011 (Michie et al. 2011a)

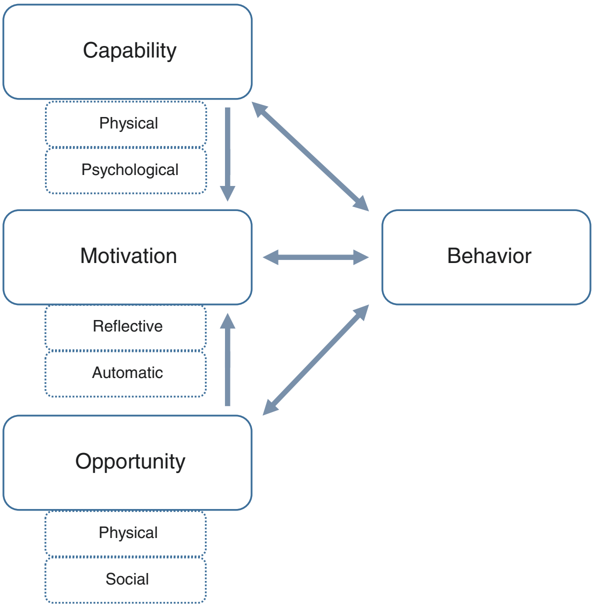

Fig. 2.4 The COM-B system. Components in this system can interact: motivation can be influenced by opportunity and capability, which can in turn influence behavior; behavior can have a feedback influence upon a person's opportunity, motivation and capability to perform the behavior again. Adapted from: Michie et al. Implementation Science 2011 (Michie et al. 2011a)

Box 2.8 Example of the use of the 'Capability Opportunity Motivation—Behavior' system

One interesting example of a BI intervention developed based on the BCW and COM-B system is the "StopApp", a mobile application aimed at increasing uptake and attendance at the National Health Service (NHS) 'Stop Smoking Services' (SSS) in the United Kingdom (Fulton et al. 2016). In a first phase, barriers and facilitators to people using SSS were explored and, in a second phase, a behavioral analysis was conducted based on the BCW framework, in order to identify relevant intervention functions, policy categories, and behavior change techniques. Finally, in phase 3, the acceptability of the app was tested. For this intervention, all the three components of the COM-B system were considered important to address, as the target audience was found to often lack 'Capability' (e.g. lack of knowledge about the benefits of SSS), 'Opportunity' (e.g. beliefs that SSS are hard to access), and 'Motivation' (e.g. lack of perceived personal benefit from SSS) (Fulton et al. 2016). This app is now intended to undergo evaluation of effectiveness in a randomized controlled trial, before being implemented and offered by the NHS in the United Kingdom.

The Behavior Change Technique Taxonomy

A behavior change technique (BCT) is an "observable, replicable and irreducible component" of a behavior change intervention (Michie et al. 2013). The BCT taxonomy was developed by Michie and colleagues to enable the systematic

Table 2.6 Behavior Change Technique Taxonomy: 93 Hierarchically-Clustered Techniques into 16 Groups

Grouping of BCTs	Examples of BCTs
1. Goals and planning	Goal-setting, problem solving, commitment
2. Feedback and monitoring	Feedback on behavior, self-monitoring of behavior
3. Social support	Emotional social support, practical social support
4. Shaping knowledge	Instruction on how to perform the behavior
5. Natural consequences	Information about health consequences, monitoring of emotional consequences
6. Comparison of behavior	Demonstration of the behavior, social comparison, information about others' approval
7. Associations	Prompts/cues, cue signalling reward, exposure, associative learning
8. Repetition and substitution	Behavioral practice/rehearsal, behavior substitution, habit formation, habit reversal, graded tasks
9. Comparison of outcomes	Credible source, pros and cons
10. Reward and threat	Material incentive/reward, social incentive/reward, future punishment
11. Regulation	Pharmacological support, reduce negative emotions
12. Antecedents	Restructuring the physical/social environment, avoidance/reducing exposure to cues for the behavior, distraction
13. Identity	Identification of self as role model, framing/reframing, valued self-identity, identity associated with changed behavior
14. Scheduled consequences	Behavior cost, punishment, remove reward, reduce reward frequency
15. Self-belief	Verbal persuasion about capability, mental rehearsal of successful performance, focus on past success, self-talk
16. Covert learning	Imaginary punishment/reward, vicarious consequences

Adapted from: Michie et al. (Michie et al. 2013)

identification and characterization of theory-based BCTs within interventions (Abraham and Michie 2008). This comprehensive taxonomy of 93 behavior change techniques, hierarchically clustered into 16 groups, provides a framework for the design and evaluation of behavior change interventions (Table 2.6) (Michie et al. 2013; Dusseldorp et al. 2014).

The BCT taxonomy facilitates the study of mechanisms of action in behavior change (Michie et al. 2008), as well as enables the evaluation of specific components in an intervention (Michie 2008). In turn, the possibility to identify the effective behavioral components of an intervention and the conditions under which they are effective, enhances the potential for efficiency, replicability, and fidelity of behavior change interventions (Michie et al. 2013). Notably, there is evidence that characterizing interventions by BCTs can be helpful in understanding which interventions are more or less effective (Michie et al. 2009a; West et al. 2010). Moreover, linking BCTs with theories of behavior change is enabling the investigation of mechanisms of action in several interventions, namely the domains of physical activity, healthy eating, and weight loss (Michie et al. 2009b; Dombrowski et al. 2012; Michie and Johnston 2012).

Effective BCTs have been identified for interventions promoting physical activity and healthy eating (Michie et al. 2009b), smoking cessation (West et al. 2010; Michie et al. 2011b, c), and safe drinking (Michie et al. 2012). Specifically, in dietary and physical activity interventions it has been shown that the overall effectiveness of an intervention can be increased by promoting social support, goal-setting, and self-monitoring (Box 2.9) (Dombrowski et al. 2012; Greaves et al. 2011).

Box 2.9 Examples of common behavior change techniques used in behavioral informatics interventions to promote physical activity, healthy diet, or weight loss

Self-monitoring	Self-monitoring is one of the most frequently used BCTs in BI interventions to promote weight loss, fitness or diet (Marsch et al. 2014). Evidence shows that the frequency of self-monitoring behaviors (e.g. recording dietary intake, physical activity and/or weight) is significantly associated with weight loss (Burke et al. 2011) and that self-monitoring is particularly effective in physical activity interventions (Dombrowski et al. 2012; Greaves et al. 2011), namely through the use of pedometers (Bravata et al. 2007). Technology offers great potential in facilitating self-monitoring in BI interventions, enabling the automated collection, analysis and display of data, and the frequent or continuous monitoring of several parameters (e.g. weight, body fat percentage, physical activity) (Marsch et al. 2014). Not only that, but technology also facilitates the provision of tailored feedback based on the parameters self-monitored, in the form of performance evaluation, motivational messages (feedback regarding progress), or normative feedback (e.g. delivering information on peer performances as a benchmark for improvement and as a social comparison technique) (Marsch et al. 2014; Lustria et al. 2009).
Goal-setting and action planning	Goal-setting and action planning are also frequently used BCTs in weight loss, dietary and fitness interventions. In some cases, technology is used to deliver automated pre-set or personalized goals (Van Genugten et al. 2012; Collins et al. 2012; Turner-McGrievy et al. 2009); in other cases, the intervention encourages and guides participants to define their own goals (Turner-McGrievy and Tate 2011; Van Genugten et al. 2012; Collins et al. 2012).
Social support	One BCT that is becoming increasingly common in BI weight loss interventions is the provision of social support with the help of technology, namely through discussion forums and online chats (Tate and Wing 2001), or through social networking sites (Laranjo et al. 2015; Turner-McGrievy and Tate 2011; Brindal et al. 2012).

2.2.4 *Design, Development, Evaluation and Implementation Aspects*

The effectiveness and impact of behavioral informatics interventions are largely dependent on their meaningful design, development, evaluation, and implementation. Key elements for success include careful observation and framing of the particular behavior in context, understanding user characteristics and needs, involving users from the beginning of the project, and applying user-centred evaluation to constantly refine the design, in an iterative process (LUMA Institute 2012; ISO 9241-210 2010).

Early in the design phase of a BI intervention, it is very important to achieve a good understanding of individuals in the target population, to ensure that the intervention is acceptable and appropriate for them, at a personal, cognitive, and sociocultural level. Furthermore, understanding the cognitive needs of users in interface design helps build better interaction experiences for users, as well as more effective and engaging systems (Patel et al. 2014).

Notably, certain target populations require special considerations, as is the case with the elderly. Senior individuals may have difficulty reading text on small mobile phone screens, lack the dexterity to manage small buttons or touchscreens in mobile phones, or have difficulty with hearing. Designing successful BI interventions for the elderly requires that all their physical limitations are taken into account, as well as their needs and preferences.

Also crucial is to consider potential competing demands of the patient/consumer and enable a seamless integration of the intervention with the tasks of daily life (Valdez et al. 2014). A well-integrated intervention will more likely be adopted and maintained throughout time, as opposed to one that is seen as an extra burden for users.

Designing and developing a BI intervention should also involve careful consideration of the necessary aspects to ensure intervention fidelity, i.e., the extent to which the intervention is delivered as it was originally intended. Fidelity is related to the methodological strategies used to monitor and enhance the reliability and validity of behavioral interventions, including study design aspects, treatment delivery and receipt, and actual implementation of behavioral skills or cognitive strategies at the appropriate time and setting in daily life (Bellg et al. 2004; Shaw et al. 2014; Eapen and Peterson 2015). One benefit of technology is that it allows for automation in the delivery of the intervention, enabling close similarity between treatments that were experimentally tested and the treatment that is delivered to individuals in the real-world (Marsch et al. 2014). This ‘built-in fidelity’ is an important advantage of BI interventions, when compared to traditional face-to-face interventions.

The development and evaluation of an informatics system or intervention are generally interrelated and concurrent processes (Coiera 2015). An iterative approach to system development, including several phases of formative evaluation, testing and stakeholder input, is an efficient way to reveal flaws and problems at an early stage of development, when correcting them is less expensive. Technologies may undergo many formative rounds to shape design, before undergoing summative evaluation to evaluate its efficacy (Coiera 2015).

The rapid pace of technology development poses some challenges in evaluating BI interventions, as the technology may become obsolete by the time of completion of a research study like a randomized controlled trial(RCT) (Riley et al. 2013). Therefore, flexible and innovative strategies are increasingly essential in the design, development, evaluation and implementation of BI interventions. The RCT, considered the gold-standard for evaluation of effectiveness of an intervention, typically requires considerable time and resources to be conducted. However, social media, mobile and Internet technologies may increasingly facilitate the implementation of these studies, by accelerating recruitment or enabling the trial to be conducted remotely in its entirety.

A common challenge in evaluating BI interventions is that these usually involve multiple components bundled together, which makes it difficult to attribute causation to any specific component or feature. A component can be considered any aspect of the intervention that may be reasonably separated for investigation, including: the content of the intervention; modes of delivery; the dose or intensity of the intervention; the number and types of behavior change techniques utilized; or tactics used to promote compliance, adherence, and long-term use (Marsch et al. 2014). The relative contribution and effectiveness of these components and their combinations is often unclear.

Consequently, design and evaluation efforts where intervention components are assessed separately are increasingly important. For instance, modular software development may be helpful for this purpose, enabling the isolation of intervention components in software modules, and allowing for each module to be easily added or removed from the system (Marsch et al. 2014).

Additionally, a useful set of methods has been recently developed to help evaluate intervention components—the Multiphase Optimization Strategy (MOST) (Collins et al. 2007). MOST helps answer two important questions for the development of behavioral informatics interventions: (a) which combination of intervention components produces the optimal outcome; and (b) in which sequence should those components be combined. MOST involves the use of randomized experiments with (full or fractional) factorial designs to test separate components of an intervention (Collins et al. 2009, 2004; Rivera et al. 2007), which may be chosen based on information from previous pilot studies (Collins et al. 2007; Resnicow et al. 2010). Subsequently, sequential multiple assignment randomized trials (SMART) can be helpful in determining the optimal temporal sequence of intervention components (Marsch et al. 2014; Collins et al. 2007; Murphy 2005). Methods involving MOST and SMART have the potential to facilitate determining not only which components to include in an intervention, but also their ideal 'dose', timing, frequency and optimal sequence throughout time (Marsch et al. 2014) (Box 2.10).

Box 2.10 Example of the use of the Multiphase Optimization Strategy to develop a BI intervention

A study protocol by Pellegrini et al. explored the use of MOST to develop a smartphone weight loss intervention (Pellegrini et al. 2014). Their experiment (Opt-IN trial) aims to randomize participants to one of 16 conditions in a fractional factorial design involving five intervention components: treatment intensity (12 vs. 24 coaching calls), reports sent to primary care physician (yes or no), text messaging (yes or no), meal replacement recommendations (yes or no), and training of a participant's self-selected support buddy (yes or no) (Pellegrini et al. 2014). During the 6-month intervention, participants will monitor weight, diet, and physical activity on the Opt-IN smartphone application. The Opt-In trial is one of the first studies to use the MOST framework to develop a BI intervention.

Finally, implementation of an effective BI intervention will be dependent on its adoption and sustained use. Implementation research may be helpful at this stage, enabling the understanding of possible facilitators and barriers to the adoption, use and dissemination of a particular BI intervention (Marsch et al. 2014; Chambers et al. 2016; Eccles and Mittman 2006; Fisher et al. 2016; Damschroder et al. 2009). Interestingly, the stage model of behavioral intervention development, suggested by the National Institutes of Health, is an iterative, recursive model of development that promotes continuous improvement upon efficacious behavioral interventions, by boosting their potency, broadening their impact, and enhancing their portability, "implementability" and "community friendliness" (Marsch et al. 2014; Onken et al. 2014). Another framework frequently used to guide this process is the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework (Bennett and Glasgow 2009).

Importantly, three key aspects should always be at the basis of any research process in BI informatics, from design and development to evaluation and implementation: (1) evidence about the causal mechanisms and influencing factors of a particular behavior; (2) deep understanding of the target population; and (3) knowledge about the specific context. In the end, discovering what works in changing a particular behavior, for whom, and in what context, is the main aim of evidence-based behavioral informatics.

2.3 Conclusion

There is growing interest in the field of behavioral informatics. The use of technology to deliver behavior change interventions has numerous advantages, from higher accessibility, broad scalability and reach, to the ability to deliver an interactive, adaptive and personalized intervention, with high fidelity.

At the same time, the rapid pace of technological development is challenging researchers to use more innovative strategies in the design, development, evaluation, and implementation of behavioral informatics interventions. Importantly, three key aspects should always be at the basis of the research process: evidence about the causal mechanisms and influencing factors of a particular behavior, a deep understanding of the target population, and knowledge about the specific context. In the end, discovering what works in changing a particular behavior, for whom, and in what context, is the main aim of evidence-based behavioral informatics.

Discussion Questions

1. How can we ensure that the field of behavioral informatics is increasingly evidence-based?
2. How might technology contribute to advance the science of behavior change?
3. What might be done to prevent the widening of disparities due to the digital divide when designing, developing, evaluating and implementing behavioral informatics interventions?

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Part II
Understanding Public Health Beliefs

Chapter 3
Making Sense of Health Problems: Folk Cognition and Healthcare Decisions

Jose F. Arocha and Vimla L. Patel

Abstract In this chapter we present research on the roles that traditional and folk knowledge play in comprehension and use of health concepts in making health related decisions. The studies were conducted with children and mothers in several less developed countries of Africa, Asia and South America. Issues relevant to personal healthcare, such as the abilities for following health-related instructions, conceptualizations of causal mechanisms of disease, traditional beliefs and practices of family planning, and the assessment of health related cognitive activities are the focus of the chapter. We discuss these issues in the context of the relation between folk beliefs and modern biomedical knowledge. We also present some thoughts on ways to advance in our understanding of health cognition in relation to health beliefs and behavioral outcomes for further research, and the potential benefits that such understanding can provide for more adequate health promotion intervention efforts.

Keywords Folk beliefs • Traditional health knowledge • Biomedical knowledge • Comprehension • Conceptual understanding • Decision making

3.1 Introduction

We live in an increasingly globalized world community. Over the last decades, millions of people have moved from their countries of origin, mostly in the South, to reside elsewhere. According to a report published by the United Nations Department of Economic and Social Affairs and the Organization for Economic Cooperation

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and Development (UN-Department of Economic and Social Affairs/Organisation for Economic Cooperation and Development 2013) in 2013 there were over 230 million migrants in the world, of which seven out of ten lived in the developed countries. Close to 46 million migrants resided in the United States alone at the time the report was published, 9.8 million in Germany, 7.8 in the United Kingdom, 7.5 in France and a similar number in Canada, while Australia and Spain got 6.5 million immigrants each. Most of these migrants originated in the less developed world, usually the war-torn regions.

While becoming more multicultural and culturally-enriched, the influx of immigrants into the new countries may also pose some challenges. The health care system is at the forefront of some of those challenges. Immigrants bring with them various cultural perspectives, which reflect in their languages, manners of relating to health care professionals, health beliefs, and expectations. It is not uncommon for these immigrants to bring their traditional forms of health care, including home remedies, treatments, and even different conceptions about health and disease. Addressing the current challenge of promoting better health and health care for our multicultural society, health professionals in the developed world need to acquire an understanding of what those beliefs are and how they impact health care decisions.

To develop satisfactory adherence to treatments and fostering health, patients would benefit from possessing some modern health knowledge of their illnesses, such that they are in a position to make informed decisions about their health care (Kenkel 1991). However, it is not trivial to achieve this, since just "adding" modern biomedical information to traditional, popular knowledge, does not work (Patel et al. 2000). At the same time, as the health care system imposes patients with increasing responsibilities for their health, it becomes important for practitioners to have some appreciation of patients' views on their illnesses, since these may have consequences for effective decisions, overall recovery, and for maintaining a healthy life style.

Research (Garro 1994; Holmstrom and Rosenqvist 2005; Zhang and Verhoef 2002) has shown the public possess models of illness that are different from the disease models of health care professionals (Meyer et al. 1985; Leventhal et al. 2011), where the former are supported by evidence from their personal knowledge, life histories and cultural influences; while the latter are supported by scientific evidence from biomedical science and pathology. Both parties have the aim of restoring normal health, but the paths chosen by patients and health care providers are different, e.g., restoring a normal life style vs. restoring normal physiology (Patel et al. 2002a). This disparity between loosely connected experiential evidence people bring to the clinical encounter and the causal, scientific knowledge of health care providers may be responsible, at least partly, for the failure of many patients to adhere to, and maintain provider-prescribed treatments, or even to make use of suggested preventive measures and behaviors by healthy people (Jin et al. 2008).

The purpose of this chapter is to summarize our own research carried out over the last 24 years on health and folk cognition. This research covers studies conducted with the indigenous populations and ethnic minorities in several countries, with particular focus on traditional beliefs and practices in parts of the less developed regions of the world. In the rest of the chapter, we begin with a description of how the study of folk cognition has been conducted, which situates the series of studies that follow. Then, we describe studies conducted in Kenya, Zimbabwe, and Colombia with women (mothers) and school children as participants, including issues involved in the coordination, or lack thereof, of informally acquired folk beliefs when confronted with conflicting evidence.

3.2 The Socio-cultural Context in Folk Cognition

In cognitive theoretical frameworks, it was traditionally assumed that cognitive activity could be investigated by examining individual cognition separate from the social and cultural contexts where cognition takes place. Many researchers have studied, and continue to study, human cognition in artificial, experimentally controlled contexts, with little similitude with people's everyday world. For example, studies on human memory have made use of meaningless stimulus materials, e.g., nonsense syllables or abstract pictures, to understand basic memory processes. Although this research has been of much significance in advancing our knowledge of basic human cognition, the assumption is that the cultural and social milieus are not an essential component of cognition, and are seen as factors that while affecting cognitive activity are external to it (Verhaeghen et al. 2008). In fact, some studies show that there are general strategies that are common to all human beings, where social-educational influences play a secondary role (Patel et al. 1990a). In contrast, research conducted in natural environments, e.g., schools, communities, find it difficult to unravel cognitive processes from the local, cultural, and social contexts where people live (Greeno 1997). For instance, studies on memory "in the wild" (Verhaeghen et al. 2008) show that contrary to laboratory research showing dramatic decline in memory with age, older people in their natural environment make use of social artifacts and motivational forces to maintain a high level of competence. This has led to the hypothesis is that people's natural environment is constitutive of their everyday cognitive activity. In this view, although important for understanding cognitive activity such as decision making, laboratory research is less relevant to investigating culturally-embedded cognition (Arocha and Patel 2008; Kahneman and Klein 2009; Klein 2008).

Nowhere is the influence of socio-cultural factors more important than in the investigation of folk cognition. When people move from their countries of origin to start a new life in other, sometimes alien places, investigating culturally embedded cognition may be necessary to understand the specific knowledge and strategies, and supporting features that make migrants' adapt, or fail to adapt, to their new environments (Patel et al. 2000).

3.3 Social and Cultural Influences on Healthcare Practices in Less-Developed Countries

In the modern world, biomedicine and clinical science serve to support the reasoning, decision making, and clinical practices used in medical settings by health care professionals (Patel et al. 2000). Biomedical knowledge supports clinical practice by providing explanations of specific diseases while clinical practice serves to identify and categorize patients' signs and symptoms into diagnoses or to suggest the appropriate course of action (Patel et al. 2000).

In the folk health domains, traditional beliefs and practices are socially acquired through informal interactions between patients and their "care givers," being these a mother taking care of her child, or a shaman providing traditional medicines to a woman who is ill. For instance, studies of Indian mothers' health-related knowledge (Sivaramakrishnan and Patel 1993) show that their understandings of childhood problems are supported by the social practices and local customs within their communities. Some of these beliefs and practices have been codified into elaborate systems of indigenous folk medicine, such as Ayurveda and Siddha in India (Sivaramakrishnan and Patel 1993; Sivaramakrishnan et al. 1998). The knowledge structures (specifically-organized structures in memory) used by mothers to treat their children (take action), are not taken simply from these codified systems, but are more "opportunistic" where knowledge of traditional medicine is combined with common, everyday, community practices under specific situations (i.e., situational variables) (Patel et al. 2000). Such knowledge-practice relations change when the conditions of applicability change. For instance, a study was conducted of unschooled and schooled Indian mothers' reasoning about childhood disease in rural South India and Canada (Sivaramakrishnan et al. 1998), where they were shown a series of pictures of children with major forms of malnutrition. The results showed that the nature of information used to justify the problem changed depending on the current environment. Furthermore, although the schooled mothers used biomedical knowledge in their interpretation of the problem, only biomedical concepts while, while the reasoning to connect the concepts to make decisions were shown to be borrowed from well-understood, traditional knowledge. In these mothers the knowledge of biomedicine was very superficial, with little understanding of the underlying mechanisms. Such opportunistic use of knowledge has been similarly shown in adolescents reasoning about HIV (Keselman et al. 2004).

To provide examples of our research on folk cognition, we center our attention on three cognitive activities: Interpretation of instructions found on oral rehydration therapy packages for the management of diarrheal diseases in children; comprehension and reasoning during health problem solving children in rural Colombia, and sexual beliefs and contraception practices by rural women in rural Zimbabwe.

3.3.1 Making Sense of Health Related Problems in Local Contexts

Mothers' Interpreting Instructions for Oral Rehydration Therapy for Children: Kenya

A number of studies were conducted in Kenya and Ethiopia that addressed how the nature of the underlying knowledge that the lay public have about illnesses—whether indigenous or school-based—impacts their ability to follow instructions for treatment.

Commercial oral rehydration therapy (ORT) solutions have been widely available in Kenya through the health care system, and are often used to prevent infant and child mortality due to dehydration. Studies by Patel and her colleagues (Patel et al. 1990a; Eisemon et al. 1992; Eisemon et al. 1987) examined the interpretation of instructions for the use of ORT by Maasai mothers living in rural and urban Kenya. ORT solutions consist of water, salt, and sugar mixed together in specific proportions optimal for providing hydration to children who are dehydrated, commonly due to diarrhea. Although with proper instructions, the solution can be prepared at home, one of the more common commercial ORT solutions was used, which is available over-the-counter in Kenya. Preparation instructions were given in a narrative accompanied by a pictorial sequence. These were translated from English to Maa, the language of communication used by the Masaai (Eisemon et al. 1992).

For our task, we analyzed procedural knowledge and skills required in processing textual and graphical information, when using the commercially available medicine, and then followed the mothers in their homes as they used the instructions to prepare their own mixture for the children. Pharmaceutical instructions on commercial products, such as ORT packages, can be used as a test of various strategies involved in basic, daily life literacy, as the misuse of such products permeates all cultures and is a demonstration of functional illiteracy (Eisemon et al. 1992)

A group of 40 literate English speaking Maasai mothers living in villages and trading centers in the Kajiado district of South-central Kenya participated in the

Table 3.1 Instructions for administering the solution as printed on the commercial ORT package

Replaces Body Water and Body Salts Lost During Diarrhea	
How to Use ORT Solution (for children up to 5 years old)	
1.	Fill tumbler with water up to mark (300 ml)
2.	Add all powder from sachet
3.	Stir
4.	Give 2 or 3 tumblers during the first 4–6 h
5.	Give 2 or 3 more tumblers over next 18–24 h
6.	Give 2 or more tumblers in the following 24 h
7.	Do not give more than 6 tumblers in 24 h
Important	
8.	Always use as instructed unless otherwise directed by your doctor
9.	Give slowly to prevent vomiting during treatment
10.	Use clean spoon to give mixture to small babies
11.	If baby is thirsty between drinks of mixture, give plain boiled and cooled water
12.	Begin normal feeding again as soon as possible
13.	***Warning:*** See a doctor whenever diarrhea is severe or if it has not stopped in 2 days

Instructional Science, Comprehending instructions for using pharmaceutical products in rural Kenya, vol. 19, 1990, p.75. VL Patel , TO Eisemon , JF Arocha (© Kluwer Academic Publishers. Dordrecht-Printed in the Netherlands). With permission of Springer

study (Patel et al. 1990a). Eighteen of those women had 6 or more years of education and their ages ranged from 19 to 35 years with a mean age of 25 years. The ORT package used in the study contained a series of instructions for administering the solution to a child, accompanied by pictures each with a description. The text and pictures formed a sequence showing the steps necessary to prepare and dispense the solution to the child. Table 3.1 (Patel et al. 1990a) presents the written directions for administering the solution to a child (notice that the intervals for the administration of the solution were irregular).

Together, the text-plus-pictures on the ORT package delivered the following information:

(a) The specific amount of water to be used for the solution.
(b) The water should be boiled and cooled.
(c) Only one package of the sugar-salt mixture should be used each time the solution is prepared.
(d) The whole content of the package should be used each time the solution is prepared.
(e) Once the solution is put in water, it should be completely dissolved.
(f) The solution is to be administrated slowly to the child in a specified amount, sitting the child upright.

The mothers' task was to verbally describe the text-picture sequence to prepare and administer the solution to a child with severe diarrhea. Their verbalizations were recorded, transcribed, and analyzed to identify the mothers' understanding of the procedures using semantic analysis of their responses.

The results showed that all mothers found it difficult to follow the procedures, since the instructions were not culturally sensitive, e.g., asking mothers to boil a given amount of water, when they never heat a measured amount. Because of the ambiguous and complicated nature of the instructions, the mothers ignored the text and used their intuitions or their personal knowledge to interpret instructions by following the pictures. When the mothers were asked to use the procedure for administering the solution to a child, 12 women remembered the sequence of administration but failed to process the quantitative information regarding the dosage and the timing of administration, except for one of the procedural steps, namely "give slowly to the baby", which was remembered by 98% of the mothers. Part of the mothers' difficulty was more likely the result of the administration instructions themselves containing complex sentences, with embedded concepts, which are known to make challenging text interpretations (Patel et al. 2001). An excerpt of a verbal protocol shown below is representative of many of the mothers' verbalizations:

> *"You boil the water, you let it cool. You pour it into a container which you will use. Then you pour powder into the container you are using. And then you stir it. Then you give to the baby slowly."*

Thus, when reading the instructions, the mothers focused their attention on the pictures rather than on the written descriptions. On occasion, the reliance on the pictures led to inaccurate interpretations. For example, because the sequence of pictures illustrated the administration of the solution to a small child held in her arms by a woman, one of the participating mothers thought that the ORT solution was only to be given to babies (Eisemon et al. 1992). Overall, none of the participants recalled all instructions related to the administration of the ORT solution. A major problem with the text interpretation—which generated ambiguity for the mothers when they fell back on their prior knowledge and beliefs—was the non-uniformity of application procedure, as shown in steps 4–7 on Table 3.1.

Use of folk, traditional knowledge to interpret information under conditions of complexity, ambiguity and uncertainty are further illustrated by another study. The selected labels consisted of two over-the-counter medications for children: One label for the administration of cough syrup and another for the use of anti-pyretic drops (Patel et al. 2002b). The participants for these studies were English-Canadian, East-Indian, and Greek mothers. In these studies all participants had difficulty in the dosage and pace of delivering the medications, but for apparently different reasons: In the ORT solution study the main problem was the result of irregular timing of solution administration. In the cough syrup case, the complexity of the instructions was the main obstacle for calculating the dosages, and in the antipyretic drops case the problem appeared to be in a mismatch between the instructions and the intuitive model that the participants possessed based on prior experience.

Our studies also show that when two types of knowledge are added without conceptual restructuring, then it results in knowledge fragmentation. A study was conducted to assess schooled (n = 40) and formally unschooled (n = 20) mothers' conceptual understanding and causal knowledge of diarrheal disease in Kenya. The mothers' mean age was 30 years. Unschooled mothers attributed the cause of diarrhea to several sources, such as the person doing something wrong, the heat, and the child's teething. The treatment modality included the use of purgatives and herbal medicines, and to stop feeding the child. Some of these behaviors lead to further dehydration or malnutrition, while others, such as the use of herbal medicine may help the child. These mothers' explanations had a teleological nature and used only traditional knowledge (e.g., bad spirits heating the body, which need to be removed by using herbal medicines that cool the "heated" body).

In contrast to the unschooled mothers, all schooled mothers attributed the illness to dirt or dirty things that contain "germs", such as the child drinking unboiled water, while also on occasion mentioning change of season and coughing as the primary causes. Their preferred treatments included giving the child an ORT solution, or fluids; while traditional treatments, such as herbal medicines or purgatives, were seldom mentioned.

Apart from their causal explanations, schooled and unschooled mothers also differed in terms of how the explanations were structured. The schooled mothers generated explanations where modern medical knowledge was used together with traditional knowledge, which led to their explanations not being coherent, consisting of isolated pieces of information invoked to account for specific ailments (Patel et al. 1988). The schooled mothers' accounts of the diarrheal disease were disjointed because they possessed two different beliefs systems, namely, traditional Maasai health beliefs and the biomedical models of disease, and they were unable to make them congruent, resulting in fragmentary explanations composed of beliefs from the two incoherent systems. In contrast, the unschooled mothers, possessing only the traditional knowledge, showed more coherent accounts because of the lack of interference from modern health knowledge (Patel et al. 1988).

Well-integrated knowledge promotes consistency in people's interpretation of health and disease, which has implications for how we make decisions about our health. Simple addition of new knowledge to what is previously known generates fragmentary mental models and to make effective decisions, conceptual consistency is needed. It may be valuable to design interventions that aim at finding points of contact between the beliefs that the general public already possesses and the new scientifically based knowledge that is to be taught. This way, individuals, mothers in our case, can generate new conceptual structures that make sense to the them. Therefore, not only gaining knowledge is important but it is equally necessary that these conceptual structures be organized in a consistent and coherent fashion.

Children's Comprehension and Problems Solving: Colombia and India

Cognitive theory has provided a number of important insights and findings regarding the cognitive processes and the knowledge structures that underlie performance. Among these, those underlying comprehension and problem solving are probably the most wide-ranging and important for understanding health behaviors and belief systems. Comprehension is a ubiquitous component process of any cognitive activity (Kintsch 1998). Two aspects of comprehension had major consequences for health cognition in Colombia and India, especially in dealing with everyday functional tasks. First, comprehension processes involving procedural knowledge for following good health practices, especially preventive ones. Second, comprehension involving conceptual knowledge for succeeding in many everyday tasks, particularly those involving critical thinking. The nature of knowledge organization can be used as an indicator of comprehension and also of problem solving as the way knowledge is organized determines how it is retrieved and used.

Research in higher-order cognition involves investigating complex cognitive processes and structures that are the basis of many different abilities. Cognitive research has uncovered some of these processes and structures, which are of crucial relevance to education and health promotion of good health behaviors. In an early paper, Glaser and colleagues (Glaser et al. 1987) proposed eight dimensions that underlie the attainment of cognitive achievement: (1) knowledge organization and structure; (2) depth of problem representation; (3) quality of mental models; (4) efficiency of procedures; (5) automaticity to reduce attentional demands; (6) proceduralized knowledge; (7) procedures for conceptual change; and (8) metacognitive skills. All these dimensions are important for the development of a child's capacity for learning, comprehension, and problem solving and are required for successful scholastic achievement. However, tools designed to assess these dimensions are not available to address communities where concrete learning from everyday tasks (usually informally acquired) is more a norm than abstract, formally learned tasks. To investigate how formal and informal knowledge relate to each other, four sets of age and culturally-sensitive tasks were designed to assess the following constructs: (1) knowledge organization; (2) comprehension of picture sequences; (3) depth of representation; and (4) coordination of hypotheses and evidence.

The tasks were given to two groups of rural children in the Pacific coast of Colombia and in Southern India. The Colombian children were selected from grades 3 (8–11 years), 4 (10–13 years), and 5 (12–14 years). Six children from each grade were selected for giving the whole set of tasks, balancing gender, in a pretest-posttest design. The sample from India consisted of younger children, with ages ranging from 4 through 8 years.

Knowledge organization is often investigated using tasks in which participants walk through the task while verbalizing, and the generated protocols are recorded (Arocha and Patel 2008; Arocha et al. 2005). These generated protocols typically contain large amounts of data and are labor intensive to analyze. There are, however, knowledge elicitation techniques, such as the concept-grouping task, which do not require obtaining verbal protocols. The concept-grouping task requires participants to organize concepts—which can be a series of pictures or words—that belong together in a way that made sense to them (Strauss et al. 2006). The result is a structure that represents the way the concepts are held together in memory. Each structure from the child can then be compared to that of a reference model (Patel et al. 1986, 1990b) constructed from the knowledge of an expert in the field, a schoolteacher, or a scientific health knowledge, which serves as comparison to the child's concept organization. Children's knowledge is then assessed to the extent that their concept organization is similar to, or different from, the reference model.

We used a card sorting task (Strauss et al. 2006), which is one of the easiest methods of knowledge elicitation and can be used for evaluating younger children's knowledge easier than using other methods. The cards presented to the children had various terms, such as "Alive being", "vertebrate" and "invertebrate" "cold blood" and "warm blood", "water," "earth," and "air," and various animals (e.g., bird, dog, fish) which could be represented as warm vs. cold blood and living in different habitats. The concepts, when placed in the correct order should form a hierarchical organization.

In the Colombian sample, on average, third grade children generated the largest number of clusters (8), whereas fourth grade children generated the least (4). The difference in the number of clusters between grade 4 and grade 5 was only of one cluster, something of little or no significance. The difference in the number of clusters between grade 3 and grade 5, however, was 4; the former generating twice as many clusters. As noted above, the number of clusters is an indication of the coherence of the children's representation. Younger children showed more fragmented representations, pointing to a developmental trend in the ability to form coherent accounts of information. Assuming similar levels of knowledge in all the children (there is no reason to believe that the children differed in this regard as far as their familiarity with each of the concepts, as all the children were very familiar with the things and events referred to by the concepts) about the items clustered, there seemed to be a difference in terms of the degree of coherence in their mental representation of such familiar concepts.

Comprehension of Sequences

In the card sorting task a child was presented with a thematic set of pictures or words in a random order and asked to organize them. However, the types of processes that can be studied with this simple task are manifold, including procedural knowledge. Comprehending sequences may require different kinds of procedural sequences, including, temporal, causal, and logical sequencing. The tasks used described routine activities (e.g., a child helping a mother to change a baby's diaper) and the hygiene practices relevant to that activity, or a sequence of disease transmission. One task used in the study was designed to assess the children's ability to organize information that followed some temporal order. Our tasks were based on material that was taught in school, e.g., the sequence of transmission of parasitic diseases; or those with which they were informally familiar, such as the preparation of an ORT solution.

In the Indian sample, the sequence of preparing the ORT solution was correctly ordered by all the female and only two of the five male children. All, except two of the Colombian children were able to order the steps correctly, probably given they older age. Consider the following examples of two children of different ages (12 and 8 years old) presented below.

The correct order as presented to the children was as follows:

1. Get a litre of water
2. Boil the water
3. Pour the water into a clean tumbler

4. Mix one spoonful of sugar
5. Mix half teaspoonful of salt
6. Stir mixture thoroughly
7. Pour mixture in a clean glass
8. Drink the mixture slowly

In contrast, consider the sequence of steps by a grade 6 child (12 year old):

1. You put water to boil in a big pail
2. Then you boil it
3. You pour the water in a bottle to measure it
4. You pour it into a pail and let it cool
5. You pour four spoons of sugar and one spoon of salt
6. And then it becomes the solution

Figure 3.1 gives a representative example of a sequential ordering by 8-year old child #3 (grade 3). A correct ordering is represented as straight line. Any deviation from the straight line indicates a failure to order sequence correctly. The child remembered six steps, out of the eight, of which only the last step was placed in the correct order, i.e., drinking the mixture. Instead of the correct sequential order from 1 through 8, the sequence for this child was steps 6,3,4–5,1,2,8. Notice that the child skips step

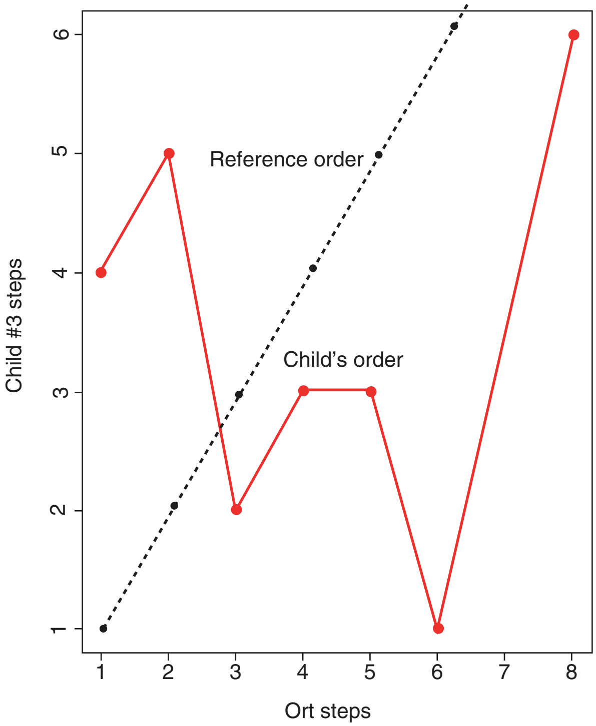

Fig. 3.1 Sequence of steps for the preparation of ORT solution given by child #3 (8 years old). The *filled* (*red*) *line* indicates the sequence of steps provided by the child. The *dashed line* represents the reference (correct) ordering of the steps

7 (“Pour mixture in a clean glass”). Overall, the children diverged more from the linear sequence in the intermediate steps, than at the beginning or ends of the sequence.

A failure to correctly order the sequence of steps may reflect lack of experience in preparing the home-made ORT solutions in their daily life. Although all children were familiar with boiling water (it is regularly done in their homes) and with ORT solutions, (the packaged ORT is widely available in the community), they seldom perform the sequence of steps involved in the task. While recalling the sequence order, they missed some of the details. For instance, they all failed to mention the word “liter”, using instead terms such as “pail” or bottle, something with which the children were more familiar. This suggests that the children used items available in their local context. Another possibility is that the children did not have a deep understanding of the reasons underlying the use of ORT, which is a reasonable assumption, given the children’s ages and school levels. In this light, depth of knowledge representation may be necessary for effective health behaviors.

Depth of Knowledge Representation

Expertise research in various domains has provided evidence that a fundamental characteristic of experts is that they possess a typically deeper, more principled understanding of a given topic than novices (Larkin et al. 1980). The depth of their representation not only allows experts to understand better a given problem, but also

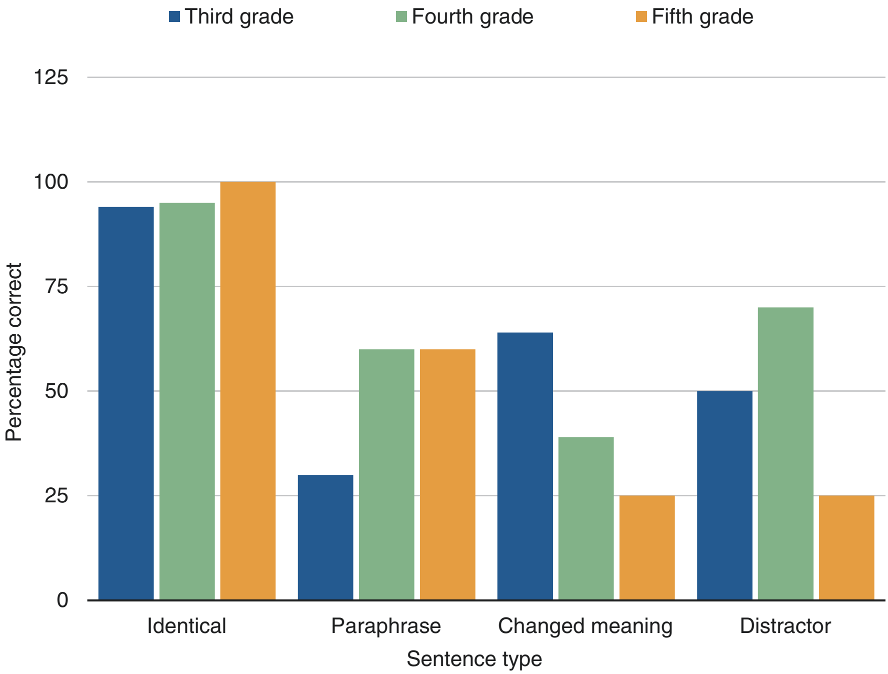

Fig. 3.2 Depth of knowledge representation as assessed with the sentence verification task by grade level

to respond in more adaptive ways to the situational context. Having a surface, unprincipled, representation of a problem limits one's ability to understand and to act in effective ways as making health care decisions.

The sentence verification task (Coney 1988; Royer et al. 1987), was used which consist of giving the children a problem to read after they were asked to identify test sentences (identical, paraphrase, irrelevant, and contradictory) and say whether they related to the problem or not. All children regardless of age or school level were able to identify the identical sentence, but failed in the paraphrases, which suggests they understood the problem at the surface level. This is supported by the high level of mis-identification of changed meaning sentences, although there was a trend to decrease such mis-identification with increasing schooling (See Fig. 3.2).

As suggested before, having a deep understanding of a domain maybe necessary for effective health behaviors. The lack of knowledge at the level of the mechanisms of action underlying a health problem results in not being able to identify the key concepts of an issue, while focusing some attention on nonessential aspects. As learning progresses, acquisition of deeper knowledge may increase, thus facilitating problem solving. It has been known for decades the role that deep, expert-like knowledge plays in comprehension and problem solving (Chi et al. 1988, 1981).

Children's Reasoning About Theory and Evidence

The ability to reason with evidence is an important component of the success in many school and out-of-school tasks, including tasks related to health behavior. It requires some abstract reasoning and ability to question one's own prior beliefs. Traditional classroom instruction, however, is carried out without acknowledging both the human tendency to see the world through prior beliefs and the difficulty of reasoning abstractly. Both of these aspects of human cognition should be taken into consideration for assessment to be successful.

Let us work through examples of children providing an explanation for the cause of a disease. The starting hypothesis was that dirty water is known to cause disease, which all children knew about. The picture set presented to them was designed to contradict this hypothesis. The test consisted of pictures of animals (a frog, a snail, a fly, commonly found in the testing environment) believed to be responsible for the transmission of diarrheal disease. Each of the pictures of the animals was associated with pictures of sick or healthy children. For instance, the frog was matched only with a picture of healthy children while the snail was matched with only with a picture of sick children, and the water was matched to both. The starting hypothesis for the test we used was that dirty, unboiled, water causes disease. All the children knew of the possible effects of drinking unboiled, dirty water, as there was a cholera epidemic in the community several months before the testing was done. Although all children maintained the starting hypothesis that dirty water causes disease, after examining the evidence, they generated other hypotheses. The causal agent, based on the cards, was the fly (in Colombia) and the snail (in India) because of the children's familiarity with these animals.

The children first were asked to identify the causal factor responsible for the sickness and then to provide a reason for their response based on the sequence of pictures presented to them. Although 41% of the Colombian children were correct in identifying the fly as the cause of the children's disease (since the fly was consistently matched to sick children only), all children changed their initial hypothesis to include at least one of the animals. Most of their reasons for supporting their responses, however, were based on prior beliefs and prior experiences (86%), rather than on the consideration of the evidence alone (6%).

Let us look at a dialogue between the experimenter (E) and one Colombian child (C) from third grade.

C: *Dirty water causes headaches, fever, and stomach pain.*
E: (After having explained the task to the child): *Can you tell me what caused the children to get sick?*
C: *Oh, what is this? I do not understand… what are you asking me?*
(Experimenter repeats the question)
C: *The water with the frog made the children to get sick.*
E: *Why do you think that the frog made the children sick?*
C: *Because animals have infections and pollute the water.*
E: *What about the fly? Does it not cause disease?*
C: *No, the fly does not cause disease, because I once drank water with a fly in it and I did not get sick. I just took the fly out and drank it.*

Similar illustrations of children giving reasons based on prior probabilities and experience was evident in other protocols, as seen in the following example in which a fourth grade child gave reasons from her prior direct experience with flies. The initial hypothesis is expressed as follows by the child:

S: *The dirty water causes disease. It makes me vomit and it gives me diarrhea.*

After the experimenter had explained the task to the child she was asked about the cause of the children's sickness:

C: *The children got sick because they drank the water with the frog and the fly in it.*
E: *Why did the frog and the fly cause the children to get sick?*
C: *Because the water gets polluted by the frog and the fly. If the children had drunk water with only the fly, they would not have gotten sick, but they drank water with the frog and got sick.*
E: *So, what's the main cause of the children getting sick?*
C: *I think that the main cause is the frog.*

Although some children were able to generate the correct answer based on the evidence alone, their reasoning was almost exclusively based on their prior experiences and beliefs.

Now, let us look at a response given by a fifth grade child who generated the correct response as the cause of the sickness, but also generated evidence-based reasons for her selection:

E: *What do you think caused the disease?*
C: *The cause is the fly.*

E: *Why?*
C: *Because they are dirty and make people sick.*
E: *What about the water?*
C: *The water maybe… no, because here (pointing to a picture), they drank dirty water and the children did not get sick… When the fly is in the picture, then the children are sick.*
E: *Do you think that there is something else that may cause the children's sickness?*
C: *No.*
E: *How about the frog?*
C: *No, because the frog is here* (pointing to a picture) *and they did not get sick, and whenever there is a fly, they are sick, … but if there is no fly, they are not sick.*

These selected excerpts from the participants' protocols are provided to show that evidence-based reasons by a child in a higher level of schooling. However, most children had a great deal of difficulty separating their pre-conceived ideas from what the evidence on the pictures said. Since concluding the correct response may be supported by the wrong reasons, this task could be used effectively to tap the underlying processes rather than the children's overt response.

In summary, this section presented a series of tasks, which can be used to assess people's health knowledge, problem solving, and reasoning in a relatively manageable way. As of now, these tasks remain a proof of concept, but further development may result in a battery of assessment tools that can be applied more generally to appraise the knowledge and comprehension components of health literacy.

Zimbabwe: Women's Beliefs and Reasoning About Contraception: Making Sense of Something Makes No Sense Outside Culture (Percival and Patel 1993)

It is well known that cultural beliefs exert a strong influence on the adoption of modern health practices. Cultural variations must be taken into consideration during interactions between the health care professional and the immigrant patient in health care settings. Explanations and perceptions of the community and local traditional health practitioners are necessary to conceptualize the definition of health within the context of cultural beliefs and practices. In particular, the role of folk beliefs in the adoption and continued usage of modern contraception by women in rural Zimbabwe was explored (Percival and Patel 1993). Twenty-three Ndebele women (ages between 22 and 47) and three female traditional healers were interviewed to elicit information regarding family planning. All interviews were audiotaped and subsequently transcribed for analysis.

The women had various levels of formal education, ranging from no schooling (n = 6) to post-secondary education (n = 1), with most women having reached elementary (n = 8) and secondary education (n = 8). All women, regardless of education, were familiar and used modern contraception, while only the sole woman with post-secondary education reported not having used traditional methods.

Traditional and modern health practitioners are available and are consulted about health issues. Whereas modern healthcare is based on the biomedical model, traditional healers have a more holistic approach to health and illness, which allows them to play the roles of medical, social, and spiritual advisors. In the traditional belief system, the cause of illness frequently involves spiritual factors, such as the introduction of germs into an individual's body by someone possessed by an evil spirit (Gelfand et al. 1985). The more holistic nature of traditional healing practice made it very appealing to the women, especially in cases where the use of modern methods (e.g., the pill) resulted in unwanted side-effects (e.g., excessive vaginal discharge), as revealed in an verbal exchange between the interviewer (I) and a woman participant (W) (Percival and Patel 1993):

I: *So these ladies were already on contraceptives?*
W: *Yes, most of them would come for herbs. The people who have herbs are people who have too many side effects of contraceptives.* (p. 262)

Similarly, the women resorted to traditional methods in cases where spiritual issues were involved. In such cases, traditional methods of family planning were used involving the symbolic use of local herbs, as described in the next excerpt by a female healer (W):

I: *And what's another one? Which ones do you use, and do they work?*
W: *Yes, there is another herb. It is short plant, almost like that. You cut it into four equal pieces. While it is still wet, you bind it around the woman.*
I: *Her waist?*
W: *Her waist. And it dries on her. As it dries, the womb will not have any conception.* (p. 261–262)

The family planning methods used were thought to protect the woman from getting pregnant by following a ritual whose effect could be ended by doing the same procedure but in a reverse order. Despite the typically symbolic nature of the traditional healing practice, the healers combined it with some modern knowledge of biomedicine. For instance, they possessed some knowledge of the female reproductive system or attributed a disease to the introduction of germs (e.g., a bacteria) into the body by an evil spirit. The extent of combination of modern and traditional beliefs was not clear from the women's protocols, but as research has shown most often the knowledge structures arising from different sources result in fragmentary systems of beliefs and opportunistic use of such knowledge (Patel et al. 2000; Sivaramakrishnan et al. 1998). For instance, the hypothesized causation of a disease determined the women's selection of health practitioner (de Zoysa et al. 1984). Traditional healers would be consulted if the illness was perceived to be primarily caused by social and spiritual factors, whereas the modern medical system was used when the illness was thought to involve a "physical" cause.

In summary, the women in the study relied on the traditional health practitioners for guidance in family planning, as their approach to healing was more holistic. The belief systems could also be used to explain some of the side-effects experienced by women who use modern contraceptive methods, such as the pill. Given that their traditional beliefs were well grounded within the women's everyday environment, the introduction of anything new is likely to be very difficult unless the new system is somehow related to the traditional system. A detailed understanding of traditional beliefs and practices may be necessary to design health education that will promote effective behavioral change.

3.4 Conclusion

This chapter illustrated the role that traditional beliefs and knowledge play in understanding health, illnesses and health practices. In many cases described, we show evidence that separately traditional health or biological knowledge underlies and probably supports health beliefs. Traditional knowledge, however, seems to be less used as a function of education, as demonstrated by schooled mothers in Kenya and the older children in Colombia. Although the nature and extent of traditional knowledge may vary between cultures, there are also some commonalities. Regardless of age, traditional knowledge seems to be present even in educated people who are familiar with modern biomedical knowledge. When this latter kind of knowledge is present in people's knowledge "systems", it does not completely replace the traditional beliefs but act as "add-ons" which may have a secondary role in explaining illness, but also may interfere with the use of biomedical knowledge. The difference in explanatory coherence between formally unschooled and schooled mothers supports such a conclusion. In some cases, such as the women in rural Zimbabwe, modern biomedical knowledge can be used alongside with traditional knowledge to provide apparently consistent beliefs, which are most used to generate explanations when modern biomedical knowledge is absent.

Changing health behaviors is always difficult and particularly so, when dealing with people who make decisions about their healthcare based on folk and culturally grounded knowledge. Confronting people with evidence that contradicts their experience-based hypotheses does not necessarily lead to belief change. One reason is that the relation between the nature of evidence and the considered hypothesis about a disease or illness is not tightly coupled, but loosely connected via associations, which change from situation to situation (the opportunistic nature of folk knowledge). The inconsistent nature of evidence-theory relationship makes it difficult to make recommendations for health promotion and prevention purposes. This makes it important for researchers to understand folk knowledge and the role it plays in making decisions before conducting any interventions.

Scientific knowledge provides the best explanation of health and illness and, we may argue, mastering it should lead to behavioral change. However, when deeply entrenched beliefs are unresponsive to evidence, the challenge of designing interventions is made more demanding of deeply understanding folk beliefs. Even if scientific and traditional knowledge are partially coextensive, because of their added-on nature, one needs to clearly delineate their boundaries. Having ways to link scientific and traditional knowledge may make individuals more aware of their distinctions and similarities. It can also bring scientific biomedical knowledge to the forefront, which could be the beginning of a process of knowledge reorganization leading to behavioral change.

Traditional knowledge has existed in all societies. In “The formation of the scientific spirit” (Bachelard 2002) French philosopher Gaston Bachelard described many instances of how traditional knowledge was used by seventeenth and eighteenth Century European scientists to make sense of phenomena for which they lacked a scientific explanation, combining everyday notions with religious and ideological ideas. The lay reasoning revealed in this chapter by children and adults presents similarities to those of early scientists: They are ideas all based on cultural and local experience with people’s everyday environment. Given the time it has taken for science to rid of folk knowledge, interventions that attempt to replace traditional knowledge with biomedical knowledge are not likely to succeed. Folk knowledge is often so entrenched in people’s minds that attempting to teach this knowledge will not replace traditional beliefs. The challenge is to “break” the barriers that separate one knowledge type from the other to find points of contact between them that can be used to anchor modern biomedical knowledge.

The ever increasing availability of information technologies at a global level is likely to change some of the traditional beliefs people possess of health and disease as they continue to be more exposed to scientific knowledge. We know that to effect such changes more is necessary than standard health promotion and education programs. One starting place to move beyond these programs is to use emerging technologies for the delivery of personalized information (Hawkins et al. 2008; Kreuter et al. 2005), which if adapted to specific cultural and individual characteristics of the people receiving the information, may lead to behavioral change. It needs to be stressed, though, that simply using information technology may not be enough. Its use should be supported by a disciplined approach that delves into the specific cognitive processes underlying belief and behavior change to uncover their nature. The success of cognitive technologies may rely on having a deep comprehension of the fundamental factors on which belief and behavior change depend. Developing tools along the suggestions made a few decades ago by Robert Glaser et al. (1987) could be a first step in uncovering the knowledge structures and the specific cognitive processes underlying people’s understanding and use of health concepts in decision making.

Discussion Questions

1. Research shows that when traditional and modern health concepts are both a part of a person’s mental model, they remain separate and are used in an opportunistic manner to solve health related problems. Can you think of two or three consequences of these models for health?
2. Some paper-based experimental tasks have been used in research to assess children’s higher-level cognitive functions in multicultural environment, such as assessment of depth of understanding. Given that most children have access to games and tools, how can we capitalize on these to automatically assess cognitive functions in these environments?

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Chapter 4
Toward a Framework for Understanding Embodied Health Literacy

Jose F. Arocha and Laurie Hoffman-Goetz

> *The first principle is that you must not fool yourself, and you are the easiest person to fool*
>
> —*Richard P. Feynman, Cargo Cult Science, 1974*

> *Much of the fascination of statistics lies embedded in our gut feeling—and never trust a gut feeling—that abstract measures summarizing large tables of data must express something more real and fundamental than the data themselves*
>
> —*Stephen Jay Gould, The Mismeasure of Man, 1981*

Abstract This chapter addresses issues regarding the conceptualization of health literacy and its measurement from an embodied cognitive perspective. We also present a critical analysis of some aspects of health literacy research, while calling for a realist approach to the design of cognitive assessments that addresses the various abilities underlying health literacy and numeracy, which may better represent the actual processes involved in the comprehension of health information. While health information is ubiquitous in modern society, it is often not easily comprehensible given the literacy abilities of the general population. Health information and health literacy have been researched in isolation of each other, when in actuality, they are two faces of the same coin. It is important to investigate them together, but current assessments treat them separately using tools that do not take into account the complexity of the process of health information understanding. Furthermore, these two components are studied by means of abstract, variable-based models that often obscure the embodied nature of health information and its understanding. Although most researchers in these fields are aware of the limitations of the models and current tools to investigate health information and literacy, an embodied approach to health literacy is still needed to complement the traditional variable-based approach. The process of comprehension of health information is complex, requiring investigation

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at the microlevel to uncover its component processes. An embodied approach, however, would benefit from a realist philosophy that may serve to provide an epistemological framework for guiding research.

Keywords Health literacy • Health numeracy • Assessment • Embodied cognition • Realism • Methodological aspects

4.1 Introduction

The term "health information" is typically used in two different senses: either the personal information about patients held in patient records, which is protected by security and privacy processes; or the information about health and illness that appears on mass media, such as newspapers, magazines, pamphlets, and the Internet. This latter kind of health information is a ubiquitous component of our daily life. We find mass media very frequently giving information about the latest cases of illness, being infectious diseases, such as Chikungunya, or chronic diseases, such as cancer. Similarly, public health organizations produce and distribute pamphlets about disease prevention and care among frontline medical and health professionals to be given to patients, with the expectation that they would be able to understand the information given. A great deal of this information contains technical terms and numerical information that may be difficult to understand by the common folk or even the journalists who write it. Furthermore, despite its wide availability in newspapers, magazines, and on the Internet, this information is oftentimes not accurate, giving misleading or even wrong information (Peters et al. 2016; McClure et al. 2016; Pires et al. 2015). How can patients and the general public be able to understand health information when much of this information is difficult and sometimes even inaccurate?

Understanding such information has become more pressing in recent times. The health care system has changed from a "paternalistic" model, where the physician makes the health decisions for the patient and simply tells the patient what to do; to a "patient-centered" model, where the patients themselves in consultation with the doctor make treatment and prevention decisions regarding their health. This model imposes increasing demands on the patients to take responsibility for their own health, and taking responsibility requires a more literate and numerically-skilled patient. In particular, given the ubiquity of prose and numeric health information and their importance for comprehension of many daily tasks (e.g., reading prescribed instructions, assessing medical risks) it has become more necessary for the common folk to understand numbers within health prose messages and interpret and use them appropriately and effectively.

Unfortunately, a great deal of research (Hannon and Daneman 2009; Hoppe et al. 2013; Thomson and Hoffman-Goetz 2011; Downs et al. 2008; Donelle et al. 2008; Vail et al. 2008; Reyna et al. 2009; Davis et al. 2006; Friedman and Hoffman-Goetz 2007) has shown that many people have problems understanding much basic health and numerical information, especially when numbers are embedded in a health prose context (Reyna et al. 2009; Golbeck et al. 2011; Gatobu et al. 2016; Donelle et al. 2009). If we take into account the general low levels of literacy in the general population, then the problems become even worse. It has been estimated that ninety million US adults (Nielsen-Bohlman et al. 2004) and 48% of Canadians aged 16 years and over have low literacy (ABC Canada Literacy Foundation 2005). Although literacy and health literacy are not the same (Hoffman-Goetz et al. 2014), we can only assume that the spread of low health literacy in the population follows the same pattern as those for basic literacy.

Health literacy is a multifaceted issue and its conceptual counterpart is polysemous, involving different aspects at various levels from the individual to the social, all of which need to be attended to, to gain a better understanding of its dimensions (Hoffman-Goetz et al. 2014). In this light, research in health literacy and numeracy is needed in at least two different directions. To fully understand health literacy and numeracy research should be done "outwardly" by aiming to account for the contextual, cultural, and societal factors involved; or "inwardly" by identifying and describing the component processes underlying the individual cognitive abilities that are part of health literacy and numeracy. As acknowledged by Reyna and colleagues (2009), researchers need to go beyond the individual to include the local and sociocultural contexts and artifacts used to comprehend and use health information (Hoffman-Goetz et al. 2014) (see Chap. 11). Likewise, health numeracy can be investigated by aiming at understanding individuals' knowledge and cognitive and behavioral skills necessary for comprehending, reasoning about, and using information related to health. The present chapter limits its scope to the second of these aims, while addressing some methodological problems underlying academic health literacy and numeracy research.

Before we enter into our main analysis, we would like to acknowledge that health literacy as a public health issue is well served by the numerous models and programs developed for increasing the public's health literacy, and in the end, effecting health behavior change. Furthermore, many of these models and programs have proven to be beneficial for understanding and generating effective interventions aimed at improving health literacy, especially of the more vulnerable populations. Our aim is not to question the value of health literacy research but to offer some suggestions for increasing our understanding of people's abilities to comprehend investigation of health information. We intended to do this on three flanks: first, by proposing that investigation of health information and health literacy are two sides of the same coin, since assessing the quality of information cannot be separated from the person who is reading and using such information; second, by emphasizing some methodological aspects of research that have been questioned in recent years and point to the relevant literature. Third, by suggesting the need for generating assessment tasks that look at more specific aspects of comprehension, a process that is essential for understanding what health literacy involves from the cognitive viewpoint.

Health literacy is a complex concept involving a large collection of individual skills and knowledge types which are immerse in the local, health-care specific, and the broader sociocultural contexts. A full understanding of health literacy, to the extent that this is possible, necessitates an investigation of all relevant factors. The referent of this chapter is limited to only a small portion of health literacy, i.e., the process of comprehension. Also, the tools that have been developed to assess health literacy, whatever their limitations, are typically used as screening instruments for the identification of individuals who lack the knowledge and skills needed to successfully navigate and make use of the health care system. They are also used in the assessment of health literacy interventions. That, in our view, these tools need improvement in no way detract from their usefulness as practical screening and assessment devices for public health purposes.

4.2 Health Literacy as Discourse Comprehension

In the year 1996, Alan Sokal, a physics professor at New York University submitted a hoax paper to a post-modern social science journal. The paper was written in such a way that it imitated the language and structure typical of the papers submitted to that and similar journals, but whose content was not supposed to mean anything. Indeed, the paper was a parody of the type of discourse typically found in post-modern social science journals (Sokal and Bricmont 1998). However, the reviewers of the article, as well as the editors of the journal, appearing to make sense of such Jabberwocky, accepted the paper for publication, and finally published it (Sokal 1996). Although the Sokal story became a source of heavy discussions and disagreements among scholars about the quality of the scholarly review process and the limits to academic honesty (Sokal 2000), it also serves to highlight the complex web of factors involved in someone's making sense of information, i.e., the reading comprehension process. How were the reviewers and the editors of the journal able to make sense of a text that was nonsense, as acknowledged of by its own author?

Meaning is a property symbols, such as words, and it is composed of sense (i.e., their content, as in "bachelor" is a "non-married male") and reference (i.e., the object which a concept is about, such as the reference of "married" is any person who is in the legal and/or religious sanctioned union with another person known as "marriage")—see Bunge (1974); however, without a reader symbols are just a bunch of squiggles on a piece of paper. The process of interpretation and the construction of "meaning" involves then and interaction between the person and the text. When conceived in this way, to make sense of textual information, knowledge is required, although such knowledge needs not be relevant to the text, as it is demonstrated by the seminal studies of Bransford and Johnson (1972) and more dramatically the Sokal hoax (Sokal 2000).

What became known as the "Sokal affair" highlighted issues that cognitive researchers already knew about: That the process of comprehension involves a complex interaction between the information that is communicated and the knowledge, and prior experiences of the reader or user of that information. That is, interpreting and understanding a piece of text is not only a function of the text properties (e.g., the words chosen, the length of the sentences), but they involve an interaction between text with its intended meaning and the reader's experiences and background knowledge. As an illustration, consider the classic studies of Bransford and Johnson (1972), showing that even though a text may appear simple to comprehend, it can be often a difficult task to do so. Branford and Johnson presented readers with passages where the overall meaning of the text was not obvious, involving sentences like these: "If the balloons popped, the sound wouldn't be able to carry since everything would be too far away from the correct floor. A closed window would also prevent the sound from carrying, since most buildings tend to be well insulated…" (p. 719). Although each of the words in this text can be understood by any competent speaker of English, without having a context for the text itself, the interpretation task becomes extremely difficult; even impossible when considered in light of its intended meaning.

What does all this have to do with health literacy and numeracy? The answer is that, as will be shown below, although health literacy/numeracy have been defined in such a way that includes the ability to understand health information, the tools available for researching and assessing the difficulty of health information, as well as the ability to understand it, are based on the consideration of the text or the reader in isolation, rather than as a complex interactional process between the two.

4.3 Readability and Comprehensibility of Health Information

In order to be used successfully, health information has to be comprehensible by the people to whom the information is delivered. Research has shown (Berland et al. 2001; Brigo et al. 2015; Cherla et al. 2012; Friedman et al. 2004), though, that health information for the general public is complex, containing many technical words and jargon that most people may find unfamiliar. This poses a problem for the delivery of information to the target populations, especially the most vulnerable groups, such as the poor and the elderly, who are known to have the most difficulty understanding health information (Gatobu et al. 2016; Smith 2014; Kobayashi et al. 2016; Kirk et al. 2012; Serper et al. 2014; Delazer et al. 2013).

Readability has been defined in many different ways. For instance Flesch (1948) equates the term to "comprehension difficulty," which highlights the role of the reader, rather than the properties of the texts. In turn, McLaughlin (1969), has defined readability as an assessment of "the relationship between two variables, which in this case are a measure of the difficulty experienced by people reading a given text, and a measure of the linguistic characteristics of that text" (p. 640). Taken these two definitions together, readability seems to mean two concepts rather than one, with different referents: the text and the reader (experienced comprehension difficulty).

However, the readability of health information has been assessed mostly with the use of instruments designed to give an indication of the difficulty of a corpus of text in isolation, often presented as the school-grade level needed to fully understand the said information. Readability assessment tools have been used extensively in health research. A quick search for the term "readability" in the title of articles one of the authors conducted recently (June 30, 2016) resulted in 20,511 on JSTOR and 599 hits on PubMed. Most of these assessment instruments are based on formulas that compute a value based on surface features of the text, such as word length (e.g., the number of syllables in a word) under the assumption that word length and sentence length are indicators of text difficulty and abstraction (Flesch 1948).

The most widely used tests to assess the degree of difficulty of health information are the Flesch-Kincaid and its related test the Flesch Reading Ease, the Gunning Fog index, and the Simple Measure of Gobbledygook (SMOG). These tests vary in terms of the factors they consider for assessment. The Flesch-Kincaid/Flesch Reading Ease is based on the number of syllables, words and sentences in a text passage. Using a formula, the test provides a score indicating the grade level needed to read the text. The Gunning Fog is computed from the number of words and sentences in a sample of 100-word text passage by using a six-step process involving counting, addition, multiplication, and division. Finally, the SMOG involves computing the number of syllables in multi-syllable words of a sample of thirty sentences. What these formulas give is a number that is supposed to provide a numerically precise indicator of the difficulty of a text corpus, but without considering other properties of the text (e.g., text cohesion) or the knowledge and experiences that the readers bring to the act of reading. Given that these tools are restricted to identifying surface features of texts up to the sentence level, they are easy to compute and offer a reasonable but limited indicator of text difficulty, which can be used as a research and diagnostic tool to help in adapting text passages to the assumed comprehension levels of the readers.

4.4 Other Factors Involved in Text Difficulty

Despite the wide use of readability assessment tools and some researchers' acknowledgement of their limitations (Friedman et al. 2006), they have been the target of scathing criticism most often outside the health domains (Meade and Smyth 1991; Zamanian and Heydari 2012; Kazemek 1984; McConnell 1983; Wray and Janan 2013; Leroy et al. 2008). For instance, consistent with the view from the discourse comprehension field, Kazemek (1984) provides a conceptual analysis, concluding that readability tests …"ultimately fail because they are based upon a mistaken understanding of the reading process. Meaning does not lie solely in the text; rather, meaning is a result of the reader-text interaction" (p. 249), as it has been shown in reading comprehension research (Kintsch 1998; Kintsch 2005).

As the most widely used formulas are based on surface features of the text, there is a great deal of room for improvement or at least for developing complementing instruments that take into account other features of texts, aside from word and sentence length. Some aspects of the text that are ignored when assessing health information with readability assessment tools are familiarity (Leroy and Kauchak 2014), text coherence (Leroy et al. 2013) and propositional density (Kintsch and Keenan 1973). The last two aspects refer to the degree of semantic linkages between propositions in a text, and the degree of semantic complexity. These two text aspects have been investigated using propositional analysis (Kintsch 1998; Frederiksen 1975). Propositional analysis is a discourse-analytic method, which is applied to connected discourse and has ample applicability to the study of discourse processes. It has been used for analyzing health text information into its constituent idea units (Arocha et al. 2005).

Coherence and propositional density appear to be independent indicators of text difficulty, whose effect may not show in standard readability tests. Ta-Min et al. (2007) made a comparison between the coherence of text information about breast, prostate, and colorectal cancer available on the Internet with readability measures of the same information. They also looked at the semantic aspects of the text by using propositional density (Coughlin and Patel 1987), a measure of the underlying complexity of text; and discourse coherence of a text, both of which are based on the comprehension theory of Walter Kintsch (1998). The results revealed that semantic aspects of texts are independent of the degree of surface text readability, thus assessing two very different properties of the texts. Furthermore, the readability tests used gave inconsistent results leading to the conclusion that if these tests are to be used it is probably beneficial to make use of more than two instruments. In contrast, the two semantic measures gave consistent results, where higher coherence was related to higher propositional density. In another study, Tulsieram et al. (2016) conducted an investigation of readability and coherence of the information on the human papilloma virus (HPV) available on the official Web pages of Health Ministries in seven Canadian Provinces. The results showed that the readability of HPV information was estimated to be understandable by about 60% of the population (i.e., parents and their pre-adolescent children); but in terms of the coherence, as measured by Latent Semantic Analysis (Foltz et al. 1998; Landauer et al. 2013) the study showed that most of the texts were not likely appropriate for the target population. Also, Flaherty et al. (2015) conducted a review of published definitions of consumer health informatics and evaluated them using five quality assessment criteria and measures of similarity. In particular, the propositional density and the degree of similarity between the definitions were assessed, showing that although the degree of complexity as assessed by propositional density varied, their similarity was consistent between all definitions. These two different assessments can have applicability to determine the degree of comprehension by comparing the text analyzed with the verbal reports given by the readers of the information.

Lastly, in a series of studies, Leroy and colleagues (Leroy and Kauchak 2014; Leroy et al. 2013; Leroy et al. 2010) investigated various aspects of health information that make it difficult to understand, such as sentence structure (e.g., passive vs. active), function-word density, and word familiarity. Familiarity, as determined by word frequency found in two large word corpuses (Google web corpus and the Moby word II list), was researched by Leroy and Kauchak (2014, 2016). In their studies with people's evaluations of 275 words, they showed a weak but stronger association between word familiarity and actual text difficulty ($r = 0.219$, $p = 0.001$) than between the latter and word length ($r = -0.075$, $p = 0.107$).

Overall the studies serve to highlight properties of textual information, such as word familiarity, semantic complexity, and text coherence that may be important for comprehension aside from the surface linguistic features investigated through the use of readability measures.

4.5 What Is Health Literacy?

Having dealt with some of the issues involved in the assessment of health information as a piece of discourse, we now turn to the overall concept of health literacy, which includes numerical information. There exist several expanded models and definitions of health literacy (Hoffman-Goetz et al. 2014; Botash et al. 2005; Altin et al. 2014; Sørensen et al. 2012). A commonly cited definition (Ratzan and Parker 2006) is the extent to which "individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions" (p. 713).

Aside from the lack of precision and vagueness of this definition (e.g., What capacities are those? What does it mean to say that a decision is "appropriate"? How can we test if a decision is appropriate?), what the definition makes it clear is that health literacy is a property of the individual person. A propositional analysis (Kintsch 1998; Frederiksen 1975), as shown in Table 4.1, can serve to specify more precisely the components of such definition. The analysis allows us to clearly see that health literacy involves three cognitive-behavioral processes (obtaining, processing, and understanding) applied to both health information and services with the goal of making health decisions that are appropriate.

If health literacy is conceived as a property of individual persons, then what needs to be uncovered are what those capacities might be. Several health literacy

Table 4.1 Propositional analysis of a definition of health literacy

Proposition	Predicate	Arguments
1.0	IDENT:	[Health literacy], [1.1–1.9];
1.1	have (POSS:)	[PAT: individual, OBJ: capacity], [1.2–1.4];
1.2	PROC: obtain	THM:[1.5, 1.6];
1.3	PROC: process	THM:[1.5, 1.6];
1.4	PROC: understand	THM:[1.5, 1.6];
1.5	information	THM: health, ATT: basic;
1.6	services	(THM: health, ATT:basic);
1.7	need	PAT:[1.2–1.4], [1.8];
1.8	GOAL: make	[1.9];
1.9	decision	THM: health, ATT: appropriate;

and numeracy researchers have proposed the need to elucidate and investigate the component processes involved in health literacy and numeracy (Baker 2006; Golbeck et al. 2005a; Muñoz et al. 2015), something which can only be done within a nomological network (Bunge 2014) in order to rigorously identify the relations between such component processes.

4.6 The Scope of Health Literacy and Numeracy Assessment

A number of tools have been developed to assess health literacy and numeracy (Altin et al. 2014; Jordan et al. 2011). The National Library of Medicine-funded project, *Health Literacy ToolShed* (http://healthliteracy.bu.edu), for instance, lists and describes 113 domain-general and domain-specific instruments that are used to assess different aspects of health literacy in several languages, from comprehension to information seeking, to communication, to numeracy. Of the total, there are 56 instruments that have items devoted to the assessment of health numeracy and 98 whose target population is adults, 18 years of age or older.

Probably the most widely used tests in English are the REALM (Murphy et al. 1993); the TOFHLA (Parker et al. 1995) and its most commonly used short version, the S-TOFHLA (Baker et al. 1999); and the Newest Vital Sign (Weiss et al. 2005). The REALM tests a patient's pronunciation of lists of medical terms. The S-TOFHLA was designed to test reading ability in the health context, and consists of 36 prose and 4 numeracy items, with a total weighed score of 100. The 36-item prose component of the test is designed as a cloze procedure while the four questions of the numeracy component are used to assess understanding of instructions on a prescription bottle, ability to determine correct blood sugar and identifying time of appointment on a card. Conventionally, the test is used to categorize test-takers into three levels of health literacy: inadequate (0–53), marginal (54–66), and adequate (67–100). The Newest Vital Sign (NVS) was designed to test patients' ability to read an ice-cream nutrition label and answer six questions that assess health literacy and numeracy skills. Four of the questions require numeric manipulation while the other two call for prose comprehension. As with the S-TOFHLA, the NVS is used to place readers into the categories of high likelihood of limited literacy (scores 0–1), possibility of limited literacy (scores 2–3), and adequate literacy (scores 4–6).

Other various tests have been designed to specifically assess numeracy, among which we find the Numeracy Scale (Lipkus et al. 2001), a 10-item questionnaire that includes three general numeracy items and seven items in the context of health decision making; the recently developed General Health Numeracy Test (Osborn et al. 2013) a test of health numeracy with two versions of 21 and 6 items; the Subjective Numeracy Scale (Fagerlin et al. 2007; Zikmund-Fisher et al. 2007a), which is used to assess people's subjective estimate of their numeracy level; and the Numeracy Understanding in Medicine Instrument, or NUMi (Schapira et al. 2012), a 20-item test of health numeracy

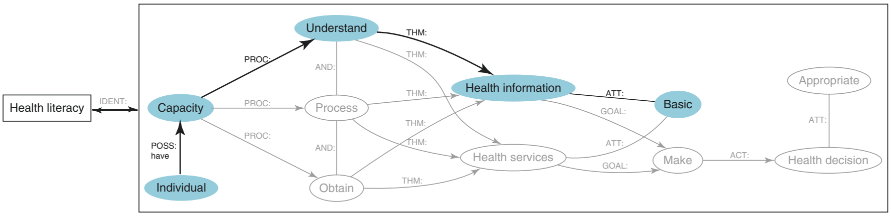

Fig. 4.1 Schematic representation of the definition of health literacy. Nodes represent concepts and links represent relations between concepts. *Filled nodes* indicate the aspects of health literacy that more often are taken into account by assessment tools, such as the NVS and the S-TOFLHA

that serves to assess several domains, such as understanding of basic numeracy and percentages, ability to read charts, and to interpret nutrition labels, among others.

Considering the definition of health literacy presented in Table 4.1 and the tests used to assess the construct, it is easy to see that there is a gap between what the definition says health literacy is and what is assessed through many of the instruments, such as the TOFHLA or the NVS. Figure 4.1 shows the aspects that appear to be assessed using these tools and what these tools leave out, based on the definition in Table 4.1. As is the case with the vast majority research on health literacy, including validation studies, claims are made regarding the measurement of different abilities, predicated on standards of success that have come under scrutiny in recent years. The next section deals summarily with issues of measurement, pointing out to the relevant literature and the more general problem of testing hypotheses in the behavioral health sciences.

4.7 Measurement and Hypothesis Testing: Some Methodological Issues

Health literacy and numeracy scientists often make reference to "measurement" and "measuring instruments" without mentioning (or probably with a lack of awareness of) the hard conceptual and practical problems posed by measurement, both as a concept and as an empirical procedure (Berka 1983; Borsboom 2005; Bunge 1995; Michell 1999). Although sometimes researchers acknowledged some difficulties in current measures (Nutbeam 2009), more of often than not, they appear to assume that measurement is straightforward and unproblematic. We find many papers on measurement and measurement scales devoted to the development and testing of different types of instruments or tools for measuring health literacy and numeracy "constructs" (Baker 2006; Fagerlin et al. 2007; Morrison et al. 2014; O'Connor et al. 2014; Pleasant et al. 2011; Smith 2007; Stonbraker et al. 2015).

The apparent unproblematic nature of measurement in health literacy and numeracy research stems from the definition of measurement, proposed by S. S. Stevens over 70 years ago (Stevens 1935, 1946), which has been traditionally used and accepted by the vast majority of behavioral and cognitive health researchers. Influenced by the positivist-operationalist philosophy of science popular at the time, Stevens (1946) proposed that measurement consisted of "assigning numerals to objects or events according to rules" (p. 677).

Such operational view of measurement has been strongly criticized for not being consistent with measurement as practiced in the natural sciences, such as physics, chemistry, and biology (Berka 1983; Borsboom 2005; Michell 1999), to the point of questioning even the possibility of measurement in the behavioral sciences (Trendler 2009). By defining measurement this way, Stevens bypassed the requirements for including the properties, units, dimensions, and the necessary theoretical knowledge to effect measurement. For instance, by accepting Steven's definition, one has to also accept what is called "nominal measurement scale" which is contrary to the intuitive notion that assigning numerals as labels does not constitute measurement at all.

The idea that in order for measurement to exist a quantitative property has to be first established (Michell 1997, 2003), is simply ignored in health literacy measurement. If there is a "quantitative imperative" (Michell 2003) for measurement to take place and research in health literacy and numeracy ignore this imperative, then measurement becomes a kind of qualitative assessment because the actual numbers in such measurements are devoid of any mathematical quality (Bunge 1973, 1995). Furthermore, any measurement requires an instrument whose values vary as the objective property being measured varies, establishing a lawful functional relation between the degrees of the property and the instrument degree indicators. Such known lawful relation necessitates a unit of measurement and some dimension along which measurement takes place, something which is not very frequently considered in the assessment of health literacy. Indeed, many assessment instruments are validated by what in his classic paper on the philosophy and methodology of the soft areas of psychology, Paul Meehl (1978) called *stepwise low validation*: the reliance 'on one investigation to "validate" a particular instrument and some other study to validate another instrument, and then we correlate the two instruments and claim to have validated the substantive theory' (p. 823), which led Meehl to conclude that the procedure "is about as close to a [scientific] nothing as you can get without intending to" (p. 823).

That is, in many cases, the validity of a new measurement instrument is predicated on purely empirical grounds; e.g., on its correlation with another older instrument and then, if the correlation is statistically significant, the new test is considered validated. However, as stressed by Borsboom (2005), empirical correlation is insufficient to determine the validity of a test. The relation between a test and the property it measures is causal, not correlational, since the instrument indicator varies as a result of changes in the property being measured. This places the burden of health literacy measurement on the elucidation of the actual, embodied processes involved in making sense of health information, some of which will be described later.

An assumption in the behavioral health sciences is that a high degree of correlation between variables suggest that a real connection is involved, such that as the correlation approaches 1, the dependence between the variables (e.g., causal) becomes stronger. Although this assumption may work at the population level, there is a class of system for which the assumption does not hold. These are purposive systems that live in a negative feedback relation with its environment, of which humans are a classic example (Powers 1998, 2008). It can be demonstrated that for such systems causally connected variables can have correlations of zero whereas relatively high correlations may not be factually related at all (Kennaway 2013; Powers 1978).

Another issue is that, despite their aggregate nature, measurement instruments are typically used to assess individuals' health literacy levels, a practice which is consistent with most of the standard definitions of the term emphasizing individual capacities and skills. The problem is that population measures cannot be used to predict individual performance. For instance, consider the following examples: (1) assuming a binary classification, to categorize an individual reliably on 42.6% of the cases with 95% confidence necessitates a correlation of 0.90 (Kennaway 1998); (2) for any particular individual, to guess the sign of a score with a 95% confidence the correlation between independent and dependent variables must be 0.99; (3) it is theoretically possible that while a correlation in the population is positive, the within-individual correlation be negative (Powers 1990). Given that most correlations in behavioral health sciences are often 0.30 or thereabouts, one has to expect much more difficulty in predicting an individual's performance on a typical test.

Another methodological issue with health literacy and numeracy measurement is the introduction of "subjective measures." That is, tests that are not actual measures of health literacy and numeracy, but are about people's perceptions of their literacy levels (Fagerlin et al. 2007; Dolan et al. 2016; McNaughton et al. 2015; Zikmund-Fisher et al. 2007b; Kiechle et al. 2015). The justification for the use of these tools is predicated on the assumption that such perceptions are indicators of actual health literacy and numeracy. Even though subjective and objective measures of numeracy are correlated, the correlations are typically low. For instance, it has been found (McNaughton et al. 2015) that a short version of the Subjective Numeracy Scale (SNS) significantly correlated with the Wide Range Achievement Test ($\rho = 0.57$) with the S-TOFHLA test of health literacy ($\rho = 0.35$), and with education ($\rho = 0.41$). Another study by Fagerlin et al. (2007) showed correlations ranging from 0.63 to 0.68 between the SNS and other indicators of numeracy. A more recent study (Ramirez-Zohfeld et al. 2015) with 402 older adults showed a correlation of $\rho = 0.69$ between the S-TOFHLA and the NVS for the whole multiethnic population investigated. In these cases, for subjective assessment to be used as an indicator of actual numeric skill, what must be demonstrated is that a lawful relation exist between the subjective assessments and the results of the objective tests (Borsboom 2005). The same way that meteorologists do not measure the weather by distributing questionnaires to the people of a region and asking them to complete them, it is hard to justify the claim that the so called subjective measures of health numeracy actually measure the said ability.

A further issue is that, in all of these cases, the validity of health literacy and numeracy tests are based on statistical significance. A difficulty with using statistical significance as a criterion is that research has shown that those measures such as *p*-values and confidence intervals present many challenges that make them inadvisable for the testing of scientific hypotheses (Trafimow and Marks 2015). First, despite its universal use in hypothesis testing, the *p*-value has been shown to be a very confusing standard. The confusing nature of such criterion has become evident in studies where students, psychology professors, and even statisticians fail to provide a correct interpretation of what a *p-value* means (Poitevineau and Lecoutre 2001; Lecoutre et al. 2003; Haller and Krauss 2002). Incorrect interpretations of the *p*-value abound. For instance, the Numeracy Understanding in Medicine instrument, or NUMi (Schapira et al. 2012) includes an item that states that a statistically significant result at $p < 0.05$ indicates the probability that the result is due to chance. Although the item is supposed to test for the ability to interpret study results (the meaning of a *p-value*), the question itself contains a basic misunderstanding. The meaning of the *p*-value as the "probability that this finding is due to chance" (p. 863) as the question states is incorrect. The reason why the statement in the item is incorrect is simply that the tested hypothesis, i.e., the null hypothesis, already assumes that the data are due to chance (Lambdin 2012). A *p*-value simply refers to the probability of obtaining a result like the one observed or a more extreme one given that chance alone is acting (Acree 1978; Gigerenzer et al. 2004; Gigerenzer 2004; Gliner et al. 2002; Rozeboom 1960; Waller 2004; Berger and Sellke 1987; Hubbard and Lindsay 2008). In other words, regardless of the value of *p,* statistically significant or not, the research findings are assumed to be the result of chance.

Second, *p*-values can lead dubious conclusions. As an illustration, consider for instance, the Pearson product-moment correlation of 0.43 shown in Fig. 4.2. With an $n = 500$ observations, the correlation is statistically significant ($t = 10.429$, $df = 498$, *p*-value <0.00000000000001), showing that there is an association between the two variables. In much of health behavioral research, such a result would lead to a very positive statement regarding the correlation (e.g., "highly significant"). However, although a trend is visible in the scatterplot as a whole, there is also a great deal of variation in the scores. If we were to ask, how accurately the dependent variable matches the independent variable (Grice 2011; Grice et al. 2012), we would find that despite the "highly significant result", only about 32% of the dependent variable scores conform to the independent variable. That is, only 158 of the 500 observations would fit the *independent variable* ⇒ *dependent variable* model. In a recent study (Gatobu et al. 2016), where we investigated the effects of education on a basic numeracy task, it was found that while the differences between the education levels was highly significant ($p = 0.000000024$), only 56% of the study participants were accurately classified in terms of education level. That is, the hypothesis that an increased in education level was associated by an increase in numeric ability only applied to just over 50% of the study participants. Can such a result, which is barely above chance level, lead one to postulate any actually significant relation?

A final issue that can be considered problematic focuses on the nature of the models proposed to account for health literacy. The rationale for the criticism is as follows: In the more developed sciences, reality is studied "embodied" in the system whose properties are investigated. For instance, research on the process of digestion is tied to the actual organisms who are characterized by digestive systems. In other words, natural kinds—that is, collections of entities defined by a law—are

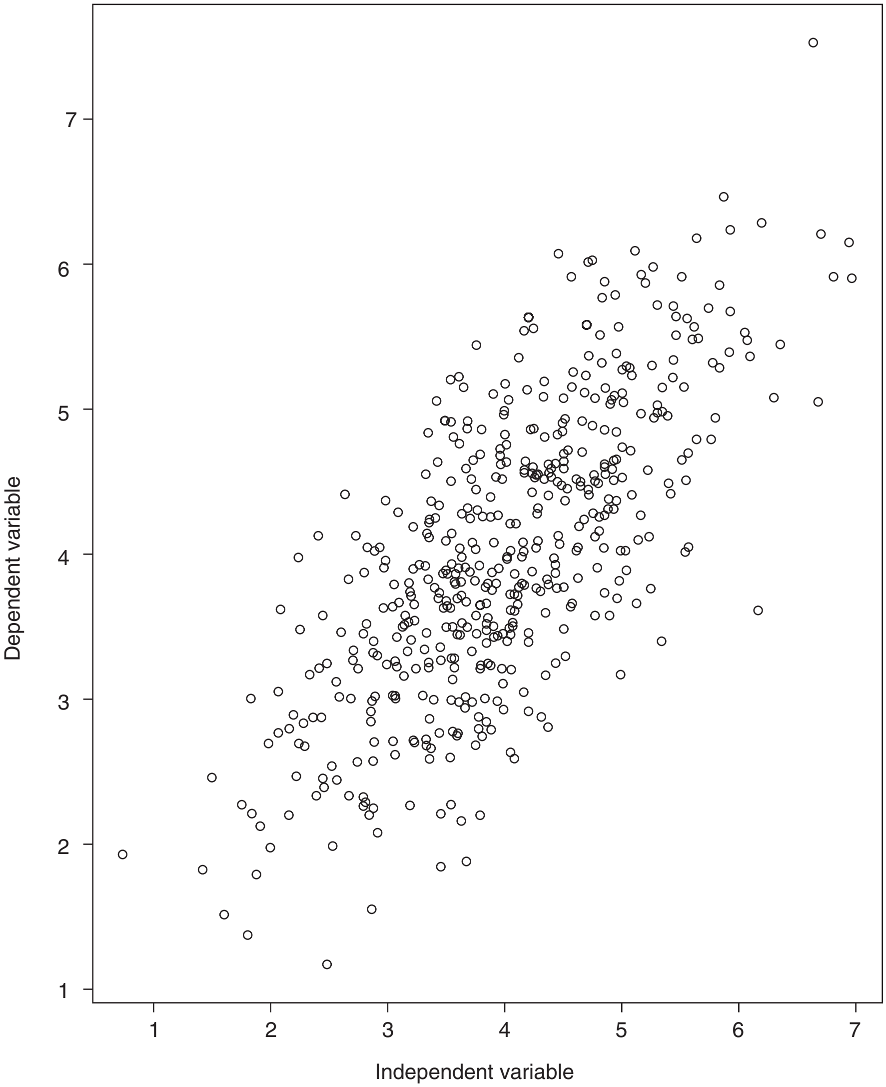

Fig. 4.2 Scatterplot showing a highly significant Pearson product-moment correlation of 0.43 between independent and dependent variables randomly generated (n = 500)

selected for investigation in which the researched processes exist. Scientific investigations cannot be carried out only abstractly. It is unfortunate that in the health behavioral sciences, many processes are separated from its material foundation and studied as if they were abstract functions. Thus the notion of natural kinds as the object of scientific inquiry does not seem to enter in developing such abstract models. Health literacy and numeracy are often considered in this way and models of health literacy and numeracy are represented without consideration of their real embodiments. For instance, many variable-based models depict “constructs” and relations between them, where different levels of reality are included without representing their natural boundaries or their ontological levels. Examples of abstract models and frameworks of health literacy and health numeracy have been provided by Baker (2006), Schapira and colleagues (2008), and Golbeck et al. (2005b), among others.

Abstract, variable-based, models are the most commonly used in the behavioral health sciences and are developed in part because the standard for modeling relies on statistical abstractions to generate tests of hypotheses and predictions (in actuality, “postdictions”, since in the vast majority of the cases, the predictions are “made” after the data have been collected and analyzed). It is usually difficult by looking at variable-based models to determine the natural kind in which health literacy takes place (occurs). Although health literacy and numeracy like any process of scientific inquiry are embodied in real entities (Carreiras et al. 2015; Vogel et al. 2016), their representation and investigation as statistical variables appear to researchers as the real thing, when in reality they are constructions that erase the boundaries of the material reality where such processes exist. Instead, a call for embodiment (Ghane and Sweeny 2013) would focus the researchers’ attention on the specific component processes underlying health literacy and numeracy (Moeller et al. 2012).

In health literacy research, several frameworks have been developed of various processes, mostly linking health literacy to factors that either affect (e.g., socioeconomic factors) or are affected by health literacy (e.g., use of health services). For instance, Schapira and colleagues (2008) generated a conceptual framework (p. 508) of health numeracy that identifies some of the components of health numeracy (e.g., primary numeric skills) and other relevant factors obtained from a series of focus groups of older adults. Similarly, Baker (2006) developed a conceptual model (p. 879) depicting the relations that exist between individual capacities, oral and print health literacy and health outcomes. Another framework is the health literacy skills developed by Squiers et al. (2012) which attempts to bring together and summarize other frameworks published in the literature (Baker 2006; Paasche-Orlow and Wolf 2007; Manganello 2008).

Although these frameworks and models are useful in identifying hypothesized health literacy-relevant concepts and relations between them, they typically do not explicate causal mechanisms underlying the various levels of health literacy in a manner that the frameworks can lead to precise testable models. A way to move beyond frameworks is to develop explicit models. These models can take various forms, but what is common to all of them is that the causes and the effects are explicitly expressed in the form of propositions, rather than concepts. Such form of expression can be seen in modeling techniques such as system dynamics, agent-based models, iconic-integrated models (Grice 2011), or Boudon-Coleman diagrams (Bunge 1996), all of which encourage the researcher to place the processes and events to be modeled within the embodied biological, psychological, and social worlds.

4.8 Pushing the Boundaries: Toward Embodied Cognitive Assessment

As was pointed out in the introduction, research on health literacy and numeracy can move outward to uncover the local and broader contextual aspects of health literacy (Hoffman-Goetz et al. 2014), as presented in Chap. 11, or it can move inward to elucidate its cognitive component processes. Cognitive research, especially the study of comprehension processes, can shed a light on ideas for generating new forms assessment that take into account the characteristics of the cognitive system and its limitations.

Although knowledge has been recognized as an important aspect of individual health literacy, there are several aspects to knowledge (e.g., vocabulary, conceptual). One important component is the way knowledge is organized in a person's mind. The ability to organize knowledge in a coherent manner is a characteristic of experts in any domain. For instance, research has demonstrated that an expert's knowledge is highly interconnected, forming a system of closely linked concepts (Chi et al. 1981; Patel et al. 1994). By comparison, the knowledge possessed by a novice is typically fragmented and lacking in relations among concepts (Arocha and Patel 1995). The ability to organize concepts is also an important indicator of successful comprehension. Although knowledge acquisition constitutes a goal of education, assessment tools that are traditionally employed do not typically evaluate the organization of knowledge, but rather whether the test subjects possess a given piece of knowledge or not. It has been shown that sometimes people possess the concepts required for comprehension, but lack the organizing principles that give coherence to their understandings. Tasks can be designed that make use of methods from cognitive science to address the depth of knowledge about health and health services a person may possess. Current cognitive research has employed, in great detail, categorization and clustering tasks to investigate the use of knowledge organization and coherence. Such tasks, for instance, have been used to investigate children's intuitive knowledge of tropical infectious diseases in Colombia and India (Sivaramakrishnan et al. 1998).

Another aspect of comprehension involves the changes in knowledge representation as a person becomes more knowledgeable of a domain. Expertise research in various domains has provided evidence that a fundamental characteristic of expertise is that experts possess a typically deeper, more principled understanding of a given topic than novices. Earlier research (Arocha and Patel 1995; Patel et al. 2001) has shown that as expertise within a domain increases, so does the level of representation of problems and situations. More expert subjects in physics, for instance, represent physical aspects of the world in terms of deep features rather than surface features, which less expert and novices use (Chi et al. 1981). The degree to which stimulus materials are categorized or represented is an indicator of the depth of knowledge. The depth of their representation not only allows experts to understand better a given text or problem, but also to respond in more adaptive ways to the environment. Having a surface, unprincipled, representation of a text or problem limits one's ability to understand and to act in effective ways. Despite the importance of having deep representations in learning and performance, most current assessment tests tend to evaluate people's comprehension by using questions and items that capture only the surface representations of factual information (see Chap. 6).

An example of a cognitive task that can be used for assessment consists of a tool for evaluating depth of representation, which has been used in cognitive psychology for a variety of research endeavors, is the sentence verification paradigm. The task consists of giving the subjects a text to read after which a set of test sentences are presented to them. The set of test sentences contains a sentence that is identical to one presented in the text (i.e., a sentence that expresses the same meaning with the same words used in the text); a sentence that is a paraphrase (i.e., a sentence that expresses the same meaning but whose surface presentation differs from the one used in the text); a test sentence that contradicts a sentence in the text (i.e., a sentence that closely resembles the original sentence but whose meaning is opposite); and finally, a distractor sentence about the same general topic, but with no relation to the text itself (i.e., a sentence that expresses a content closely related to the text as a whole but whose meaning is not included in the text). The subjects are asked to verify if each sentence recounts something from the text. It is important to make the contradictory sentence match the original sentence as closely as possible in terms of its appearance (using the same words whenever possible) making sure, however, to change one or two words so that its meaning is altered. Typically, this involves modifying the sentence such that it has an opposite meaning to the original sentence. Such technique can be expanded to study gist comprehension by presenting whole paragraphs followed by the gist verification paradigm.

Another example of a theory-based task addresses the ability to follow sequences, which is an important part of many health related behaviors such as taking medications in a particular order or schedule. Health education should promote the ability to comprehend and follow sequences, be these causal, temporal, or logical. One of the hypotheses implicit in various tasks involving the comprehension of sequences is that it assesses cognitive components that are critical for carrying out appropriate actions in the world. For instance, understanding the sequence of the transmission of infection is fundamental to avoiding infection. This hypothesis is based on the fact that comprehension is a fundamental process which serves as the basis for successful problem solving. Indeed, some of the more basic aspects of successful problem solving seem to develop as a consequence of comprehension. The importance of sequence comprehension is manifest in a variety of contexts. For instance, for a patient to follow instructions, he or she has to be able to understand the sequence of steps required to carry out a task; similarly, to avoid becoming infected, the person must be able to understand the causality of infection, which implies a temporal sequence between cause and effect. To investigate comprehension of sequences, a task has been used which consists of presenting a thematic set of pictures in random order and asking the study participant to order them. The types of processes that can be studied with this simple task are manifold. Comprehending sequences may require different kinds of knowledge, including, temporal, causal, and logical sequencing. The latter demands more abstract capabilities than the former, since it requires the subject to keep in mind the whole task (in order to see how the steps are logically related), while the former requires the subject to maintain in memory only the previous and the current steps to understand the underlying process.

The generation of process-specific tasks to tap into particular component processes in health literacy and numeracy is a step forward in the development of an embodied approach to health literacy that could serve to, at least, complement the more standard abstract, variable-based approach to scientific inquiry. Instead of using general tests to assess health literacy and numeracy validated through correlations an embodied approach serves to clarify the actual dynamics underlying the tasks of making sense of health information.

Discussion Questions

1. Health literacy refers to a complex collection of processes and skills. Most measuring instruments focus on some aspects of health literacy. Can you think of a battery of tests that could be used to assess all aspects of health literacy? How would they look like?
2. Health numeracy is considered by some researchers as part of health literacy. Are they the same? Do they involve the same processes? Investigate the extent to which they are similar or different.
3. This chapter presents a critique of some methodological problems of current research on health literacy. Do you agree with such criticisms? Can you think of alternative methods for testing hypotheses regarding health literacy?

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Chapter 5
Models of Health Beliefs in South India: Impact on Managing Childhood Nutritional Illnesses

Malathi Sivaramakrishnan and Vimla L. Patel

Abstract In several societies, culture-specific models of health co-exist with modern science-based medicine, and influence the way people manage their health. When people from such communities immigrate elsewhere, they often continue to retain their traditional health beliefs and practices. If national health programs are not inclusive of this phenomenon, then they are likely to fail in reaching their goals of healthcare for all. This chapter begins by tracing the beliefs and treatments in healthcare systems prevalent in different regions around the world. In the Indian subcontinent community, systems of traditional codified medicine such as Ayurveda and Siddha continue to influence peoples' health related decisions. The chapter continues with descriptions of the findings from case studies conducted in the region of south India on mothers' reasoning about childhood malnutrition, which is one of the major problems influencing child health. The relevance of the findings are then contextualized within a larger framework of understanding human health behavior, planning appropriate theory based interventions, including the use of technological support.

Keywords Health beliefs • Cognitive-cultural models • Knowledge restructuring • Conceptual understanding • Childhood nutritional diseases

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5.1 Global Ethnic Diversity and the Challenges for Health Care

Various countries today have embraced multiculturalism. For example, in the United States, according to the 2010 census data, 16% of the total population are identified as Hispanic, 73% white, 13% African American, 0.9% American Indian and Alaska native, 5% Asian, and 0.2% Native Hawaiian and other Pacific islanders (Humes et al. 2011). Each community has its own set of beliefs and traditions on health which have evolved over many centuries and are usually handed down through generations. Immigrant populations are at different levels of acculturation when they migrate to a foreign land. Traditional cultural beliefs are often retained even after migration and influence the community's health related decisions (Mukherjea et al. 2013). An entirely biomedicine-centric system of healthcare may not therefore deliver the desired outcomes for people who believe in different traditional systems of healthcare. Over time, this results in an ever widening gap between discovery of better health care strategies on one hand and their adoption by populations at large on the other.

5.1.1 Models of Health Beliefs in Different Cultures

Literature provides ample evidence across communities of culturally customized health practices that influence peoples' understanding of disease causality, prevention and treatment. Anthropologists associate such alternate frameworks of knowledge to the existence in societies of indigenous, traditional and often codified models of health and illness along with modern biomedicine. They talk about dominant theories, namely personalistic, naturalistic and biomedical, that underlie such practices (Carteret 2012). The personalistic system of beliefs deals with the influence of supernatural forces and treatment involves the use of rituals and symbolism. In the naturalistic system, an individual is said to be closely tied to the universe and emphasis is on achieving harmony and balance with the universe. The biomedical model focuses on understanding the mechanisms underlying disease causation based on theories of current science.

An example of the personalistic system of beliefs can be seen in rural Nigerian culture in which blindness is most commonly thought to be due to supernatural forces and is said to happen when a "wicked person" points a finger at someone's eye (*won naka si loju*) by wearing a ring (kind of charm) which is clearly visible. When the victim sees it, he/she starts showing signs of a staring gaze and develops inability to see. Use of herbs and rituals are the major treatments given by traditional healers (Ashaye et al. 2006). Traditional Chinese medicine typically represents a naturalistic system of belief and practices. A human is considered to be a part of the universe as well as a complete cosmic entity. All things are said to be made up of five elements—gold, wood, water, fire and earth. Both the human (with his/her body, soul and spirit) and the surroundings are considered to be made up of well-balanced *yin* and *yang* forces that are complementary to each other, resulting in *qi* energy. Any imbalance in the two forces or in the *qi* energy results in an illness.

For example, whenever *yin* is higher than *yang*, it causes body rash and fever, and whenever *yang* is higher, it causes colds and cough. (Chew et al. 2011) All disease symptoms are viewed in terms of two opposite categories of hot/cold (*han/re*), dark/bright (*yin/yang*), weak/strong (*xu/shi*) and exterior/interior (superficial/internal). These concepts extend to food and health as well. Disease prevention is considered more important than treatment. Foods with properties of *han* (for example wheat, vegetables), *re* (mutton, ginger), *wen* (in between *han* and *re*) (rice, beans) and *bu* (dates) (to be used with *wen* to prevent nutrient insufficiency) are identified. These foods could produce different effects on the body. For example, *han* food causes diarrhea (and is therefore used to treat constipation) and *re* food causes constipation (and is therefore used to treat diarrhea). *Han* food is cooked with *re* food to neutralize it (for example vegetables cooked with ginger). Nourishing the body and nourishing the mind are both considered important (Zhi-chien 1993).

Similar concepts of bodily imbalances as causative factors for disease are evident in Tibetan (Yoeli-Tlalim 2010) as well as in the Philippine cultures (Abad et al. 2014).

5.2 Culture and Related Health Behavior in India

5.2.1 Traditional Medicine in India

Traditional medicine in India can be classified into (1) Traditional medicine with a structured codified body of knowledge either in the form of scriptures or pharmacopoeias such as Ayurveda, Siddha and Unani medicine, (2) non codified traditional medicine or folk medicine acquired through verbal communication from previous generations (forefathers) and often based on trial and error self-experimentation with no written documentation, (3) spiritual medicine based on spiritual/religious beliefs and practiced by local experts, and (4) related forms of health knowledge, such as yoga (Upadhya et al. 2014).

While Ayurvedic medicine that originated over three millennia ago with its literature in Sanskrit and other regional languages (Payyaappallimana and Venkatasubramanian 2016) is practiced all over India, Siddha medicine with its origin in BC 10,000 to BC 4000 is prevalent in Tamil Nadu (southern India) (National Institute of Siddha. National Institute of Siddha [Internet]. Tamil Nadu, India: National Institute of Siddha 2016). Siddha is a Tamil word derived from Siddhi, meaning attaining perfection in life or heavenly bliss. Transcribes of this tradition on palm leaf manuscripts that are available even now serve as a repository of this ancient knowledge. Both the Ayurveda and Siddha medical theories are based on the concept that the individual is a microcosm of the universe. All material in the universe including the human body and food are composed of five basic elements called the *pancha mahabhootas* namely earth (*prithvi* in Ayurveda or *mann* in Siddha), water (*apya/neer*), fire (*teja/thee*), air (*vayu/katru*) and space (*akash/veli*). These correspond to the five basic senses of smell, taste, sight, touch and hearing. For ease of understanding of physiological and pathological aspects, the five elements are grouped into three humors or *doshas* called *vata or vatam* (a combination of space and air), *pitta or pittam* (fire) and *kapha or kapham* (water and earth). All pathological conditions are considered to be the outcome of an imbalance of these three humors, and diseases are labelled as *vatha*, *pitha* or *kapha* diseases, based on the preponderant humor. For example, common problems of the digestive system are considered to be *pitha* related and most respiratory diseases are *kapha* related. The concept of restoring balance of humors is the fundamental basis of therapy in both Siddha and Ayurveda practices. For example, if *vata* is weak, then drugs preponderant in *vata* are administered to restore the balance. On the other hand, if *vata* is dominant, then drugs that possess the opposite properties (those of *prithvi* or earth) are selected and given (Rao and Veluchamy 1983).

Traditional Indian medicine focusses more on preventive aspects of disease rather than curative. Three important therapeutic aspects of this holistic medical science include, *oushadha* (drugs and therapies), *ahara* (diet) and *vihara* (practices). Among these *ahara* is a key determinant of health and disease, and a proper diet (*pathya*) is one that keeps an individual healthy, helps maintain normal body functions, nourishes the mind and intellect, corrects imbalances in the body, prevents the onset of disease, and has therapeutic value (Srikanth et al. 2015; Masram et al. 2014). Food consists of six basic tastes and each taste has a pre-dominance of a particular element of the *panchamahabhootas.* For example, *madhura* (sweet) is linked to *prithvi* (earth) and *apya* (water). Each food therefore has a *dosha* aggravating or a *dosha* pacifying effect on the human body.

According to Siddha medicine “food itself is medicine” and drugs used by the Siddha physicians include *thaavaram* (herbal products), *thaatu* (metal & minerals) and *jangamam* (animal products) (National Institute of Siddha. National Institute of Siddha [Internet]. Tamil Nadu, India: National Institute of Siddha 2016). Pediatric disease management in Siddha medicine varies with the age of the child. For infants up to 3 months of age only leafy extracts are administered either orally (by applying on the mother’s breast so that the child receives it through breast feeding) or by cutaneous application (over the anterior fontanelle). Medicinal herbs are also used in the bath water. Up to 1 year of age the child is considered vulnerable to the influence of birds and humans who can cast an evil eye, and the treatment is given by tantric practices, which are practiced in rural areas even now. For the older children, selected combinations of herbs (barks, roots, etc.) and also ingredients of mineral or animal origin, are given to improve digestion, regulate the bowel and control the disease by stabilizing the vitiated *dosha* (Krishnamoorthy 1983).

5.2.2 Influence of Traditional Medicine on Health Beliefs Regarding Childhood Illnesses in India

According to traditional Indian medicine, the maintenance of life depends on the digestion, absorption and assimilation of food and this in turn depends on the *Agni* (translated into bioenergy) present in the stomach and intestine (Agrawal et al. 2010). Traditional prevention and also treatment of most childhood ailments accompanies attempts at improving digestion. For example, in a study by Benakappa and Shivamurthy (Benakappa and Shivamurthy 2012), data on diet during illness for infants revealed that the caregivers either stopped or decreased the frequency of both breast and supplementary feeding since the child cannot digest food during illness. For the older children, there were several dietary restrictions during illness that had bearings on the traditional concepts of hot/cold foods and hot/cold diseases. For example, in respiratory illness, the preferred foods were *idli* (a steamed preparation made with rice and lentil), rice and bread, and the to be avoided foods were, spicy, oily and those that are considered as cold (yoghurt, buttermilk, bananas, lemon and other citrus fruits). Sixty percent of the caregivers avoided cold food during fever. “Hot” foods were considered as those that produce heat in the body such as chicken, eggplant, lamb, jaggery, fish, papaya and beetroot. Herbal home remedies like *Tulsi* (*Ocimum sanctum*), ginger, cloves, pepper, honey, turmeric and garlic were used during a cold. Dietary beliefs in mothers was the result of influence of elders in the family. Beliefs related to hot/cold foods was also observed among some of the biomedical practitioners (referred to as “doctors” by the participants in the study).

Care of new-born children by mothers in the Mangalore taluk of India, revealed several practices that have bearings on traditional East Indian medical concepts. The most frequently observed practices were the massaging of the baby with oil before giving bath, exposing the baby to *dhopam* (herbal smoke) after bath, oral administration of garlic, ginger and other herbal leafs (in liquid form) to improve digestion, exposing the baby to sunlight to treat jaundice, applying a *kaajal* (traditional eye cosmetic from home-made soot) spot on the baby’s face to prevent evil eye and use of black thread/black bangles on the baby’s wrist or ankle to prevent evil eye (Reshma and Sujatha 2014). While practices such as the use of herbs to improve digestion, oil massage before bath and exposing the child to the fumes of a *dhopam* created by the burning of a substance called *sambrani* (translated into benzoin resin) may prove to be beneficial to the child, other practices such as application of *kaajal* on the face to avoid evil eye may cause harm. Traditional *kaajal* used to be made with herbs that are considered beneficial to the eye. However, modern mothers use the commercially available *kaajal*, which are made from chemicals and as such do not have the medicinal value. Similarly management of jaundice by only exposing the child to sunlight, which may be a necessary but not a sufficient condition to treat jaundice, may delay the much needed medical treatment.

Most of these studies from literature provide descriptive data on the influence of traditional medical models on peoples’ beliefs about disease causation and treatment. They do not provide any remedial suggestions, which require detailed analysis of the nature of knowledge an individual acquires through cultural influences, and the impact of such knowledge on his/her practices. In our studies presented in this chapter, we used theories and methods developed within cognitive psychology that serve as powerful tools to characterize peoples’ knowledge structures to better understand their relationship to behaviors, and to make specific recommendations.

5.3 Study Design

5.3.1 Demographics of Study Population

The study was conducted in Madurai, which is one of the districts of Tamil Nadu in southern India. The study population was drawn from rural areas in and around (40–80 km) the town of Madurai, with a high incidence of childhood malnutrition (identified after consultation with the pediatricians at the Government Rajaji hospital in Madurai). Most of the houses are made of mud with a thatched roof. The primary occupation for most men and women in these villages is subsistence farming of rice, vegetables and animal stock (goats, cows, pigs and poultry). A day typically starts at 4:30 to 5:00 a.m., where the men and women work in the fields until about 2:00 to 3:00 p.m., and then the rest of the day is spent at home with their families. Several generations of people in each family live under the same roof, and when the parents are at work, the younger children are taken care of by the elders and the older children in the family. The women folk, particularly the older women, make all decisions regarding the child feeding and general care. Tamil is the spoken language.

The rural areas are connected to Madurai town by public transportation. There are public schools in all the villages that the children attend. The villagers have access to modern biomedicine (locally referred to as "*English medicine*") through health clinics in nearby towns and hospitals in Madurai. All the villages also have access to at least one of the government-run nutrition programs in the vicinity. Supplementary nutrition, nutrition education and basic healthcare was being provided at the nutrition centres. Formally trained traditional medicine practitioners (Siddha and Ayurveda physicians) as well as untrained traditional practitioners (folk healers and mid wives) are available both in the villages and in nearby towns. Although the government hospital facilities could be used by the villagers, the treatment in private clinics in the vicinity was rated as expensive. Transportation costs are another issue of concern. Thus, for most common ailments, people use home remedies and if needed, they consult the local folk healers and the doctors attached to the nutrition centres during one of their visits to the villages. Visits to the health clinics and hospitals are made only for ailments that are severe and not manageable locally.

5.3.2 Health Domain in Focus

Malnutrition among children under the age of 5 years is a major public health problem in India and an issue of great concern for the health authorities. It starts at conception itself because of maternal malnutrition and about 22% of the children are born with low birth weight (<2500 g or 5.5 lbs) as compared to less than 10% in developed countries (NIN [National Institute of Nutrition] 2011). A recent review that compiled data on malnutrition among under five children in India from several studies conducted during the period 1999–2015 (Sahu et al. 2015) reported incidence of underweight ranging from 39 to 75%, stunting from 15.4 to 74% and wasting from 10.6 to 42.3% in different parts of the country.

The studies presented in this chapter, therefore focus on mothers' reasoning about appropriate diet for children and the cause and treatment of two important childhood nutritional problems: chronic and acute protein energy malnutrition, and vitamin A deficiency.

5.3.3 Data Collection

Data was collected from a total sample of 108 mothers randomly selected from the list of mothers enrolled in the nutrition centres in the selected rural areas, and also those who consented to being a participant in the study. Eighty percent of the participants came from the households where the men were either agricultural or non-agricultural laborers. The rest of the household heads were rickshaw drivers, truck drivers or small shop-keepers. The participants were all from low socio-economic group. The mothers' ages ranged from 18 to 41 years and the total number of children in each family ranged from 1 to 6. Seventy percent of the children under the age of five showed mild to moderate malnutrition (Grade I and II) and around 10% showed severe malnutrition (Grade III), as per the health cards used for growth monitoring at the nutrition centres.

The mothers were interviewed individually in their homes by the first author, who is a nutritional scientist, and a native of Tamil Nadu, and thus, well versed with the local language (Tamil) and culture. Background information was collected on the mothers' ages, education, number of children, ages of children and occupation of the household head. Data was collected on the mothers' reasoning about the cause and treatment of PEM, both *chronic*, as characterized by height and weight retardation and *acute*, as characterized by symptoms of Marasmus and Kwashiorkor, and vitamin A deficiency. Pictures of children showing the most prominent symptoms of the nutritional problems along with a verbal description of the symptoms were used to elicit data from the mothers. The child with marasmus showed symptoms of extreme wasting of subcutaneous fat and muscle. The child with kwashiorkor showed symptoms of apathy, generalized edema, enlarged abdomen, skin changes (dry, flaky, peeling skin) and hair changes (thin dry hair on the head). For vitamin A deficiency pictures of the eye were used showing symptomatic changes in the conjunctiva (dry, dull, wrinkled with greyish patches) and cornea (dry, dull and opaque). Symptoms of night blindness and chronic PEM (principally height weight retardation) were only verbally explained. The mothers were then given a specific task to explain (1) how and why she thought the conditions were caused and (2) how would she treat them. Based on their responses, we probed with further questions to obtain detailed information on their thoughts behind the decisions. Similar information was obtained from registered traditional practitioners (Siddha and Ayurveda physicians), the traditional practitioners in the villages and from the medical officers attached to the nutrition programs. All the interviews were audiotaped and later transcribed, and translated into English for analysis.

5.3.4 Data Analysis

For quantitative data analysis, the responses were categorized and the frequency of occurrence of the responses was calculated as a function of mothers with varying levels of formal education. The qualitative analysis of the participants' generated explanation protocols was done using the techniques of discourse analysis with the methods successfully used by the second author in her studies, which are described elsewhere (Patel et al. 1988; Patel and Groen 1986). In summary, the method of natural language representation (propositional and semantic analysis) was used to generate representations of the participants' explanations (Van Dijk et al. 1983; Kintsch 1974). Propositions and the relations among propositions were represented in the form of semantic network structures. A proposition is defined as a sematic unit in the form of a triplet in which two concepts or nodes are joined together by a labelled relation or link (Arocha et al. 2005). For example in the proposition "indigestion causes diarrhea", the two concepts of "indigestion" and "diarrhea" are linked by a causal relation. Links labelled CAU: (cause) are the strongest since the statement of the relationship is explicit and precise. In the proposition "for symptoms of kwashiorkor give tonics", the two concepts of "symptoms of kwashiorkor" and "give tonics" are linked by an "if-then" relation labelled as COND: (conditional). Conditional links are not as strong as the causal links since they could arise from a number of actual relations subsumed under conditional such as, is- caused- by and is-evidence-for. The other relations used in the semantic networks were EQUIV (equivalent in value of a specific property), IDENT (identity), TEM: ORD: (temporal sequence of events), RSLT (result of a specified action) and PRT (part/whole relation). Semantic networks were generated individually for each explanation protocol for each of the presented problems.

The biomedical reference model [based on (Patel and Groen 1986)] was developed from the protocols of the medical officers and pediatricians attached to the nutrition centres and with the help of textbooks on nutrition. Likewise, the traditional model was drawn from the protocols of the registered traditional Siddha/Ayurveda practitioners, protocols of the other traditional practitioners and from traditional medical texts. A description of the basic principles of the traditional model has been presented earlier under Sect. 5.2 of this chapter. In the biomedical model, the focus is on disease rather than on illness. The nutritional problems are explained in terms of the underlying biomedical and physiological abnormalities. Concepts generated in the mothers' protocols were compared with the two reference models for similarity in concepts, node-link structures and for the interpretation of these structures within each of the two theoretical frameworks. The responses of mothers with varying levels of formal education were compared to examine the effect of formal education on the mothers' reasoning about childhood nutritional problems. The participants were assigned a score of one for each of the biomedical and traditional concepts identified in their protocols. The total biomedical and the traditional scores were calculated and used as dependent variables in our analysis. A multivariate analysis of variance test was performed using the two theories and the level of formal education (no schooling, primary schooling and secondary schooling) as the independent variables.

5.4 Impact of Traditional and Biomedical Models on Mothers' Conceptualization of Childhood Nutritional Problems in South India

5.4.1 Concept of Appropriate Diet for the Child

Foods associated with three childhood illnesses of *thokam, mandham* and *perali* (considered together because of their close association) and *karpan,* were strictly avoided in the child's diet by a large percentage of mothers in the study, irrespective of the years of formal education. This kind of practice about food selection for children appears to have a bearing on traditional Indian medicine with a focus on disease prevention more than therapy.

Thokam was described by the mothers in the study as a condition characterized by abdominal distension, vomiting, diarrhea and feeling of faintness in the child. It was considered to be caused by articles of food such as meat pieces, fruits and vegetables with skin such as grapes, eggplant and jackfruit and also by the intake of non-food items such as paper or hair. Such substances were considered to be getting stuck in the *kodal* (intestine) of the child resulting in the symptoms of *thokam* (Fig. 5.1). All such foods were thus avoided in the child's diet.

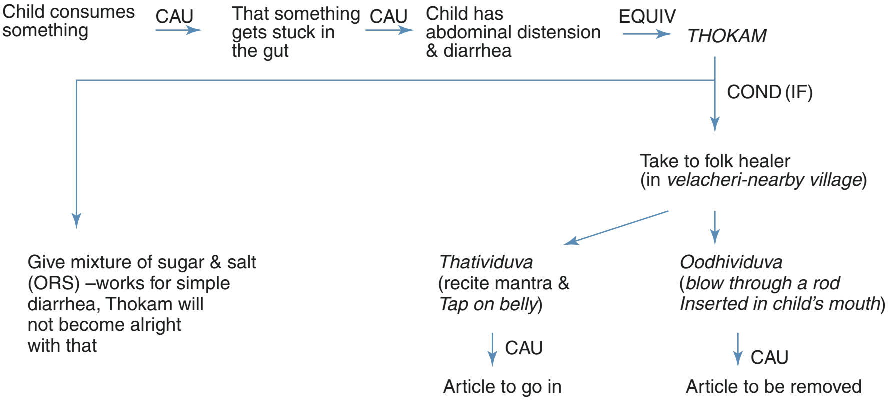

Fig. 5.1 Explanation and semantic representation of the protocol for the concept of *Thokam* by a mother (#1) with a primary school education

In the result presented in Fig. 5.1, the mother is aware of the use of sugar and salt mixture (ORS) for treatment of diarrhea. However, according to the mother, treatment of *thokam* is not effective with ORS and she recommended taking the child to a folk healer who can either make the material stuck in the intestine to go in (by tapping on the belly and chanting *mantras*) or remove the same (by a rod inserted into the child's mouth). Similar treatment strategies were seen in the protocols of other 18 mothers in the study, including 6 mothers with secondary level schooling. Some mothers (e.g. Mother #2) also mentioned the oral administration of herbal extracts or application of herbal paste on the child's stomach by the folk healers to induce diarrhea to treat *thokam*.

Response of mother #2 (mother with secondary schooling): *There is an old lady who gives a leaf juice, enchants God's name and applies something on the stomach of the child. After coming home the child will have diarrhea. Then we give black coffee and sangellai juice (a herbal remedy).*

The herbal purgative treatment was followed by the administration of black coffee and herbal remedies (*sangellai* juice) to stop the diarrhea after the primary problem was handled.

The digestive and anti-emetic properties of other substances such as lemon (*Citrus aurantifolia*) and *omam* (*Trachyspermum ammi*) used by the mothers in the study have been documented in Siddha medical literature (Rao and Veluchamy 1983). Such herbal remedies if followed with adequate concern for hygiene and sanitation may benefit the child with problems of the gastro intestinal tract. However, folk practices of treating the condition of diarrhea using purgative herbs as evident from the protocol of mothers (#2) may prove detrimental to the child already prone to dehydration. Folk treatments such as the introduction of a rod into the child's mouth (Fig. 5.1) may prove to be a source of infection in the already sick child.

This concept of *thokam* in south India is very similar to the folk ailment called *empacho* in Mexico. *Empacho* characterized by diarrhea, abdominal distention, abdominal pain, fever, nausea and vomiting is said to be caused by excessive eating or inability to digest fruits with peels and legumes. Treatment often involves a massage of the abdominal area and the use of medicinal plants as purgatives (Campos-Navarro and Coronado 2008). Folk healers also link the condition to a ball of hair or something else that blocks the gut because of evil spirits and they use magical cures and procedures such as sucking on the belly (Werner 1990).

Mandham and perali: Green diarrhea caused by indigestion was identified as a condition called *mandham* and *perali* in the child. It was said to be caused by the consumption of articles of food such as mango, jackfruit or guava by the young child. An example of the reasoning by a mother with elementary level schooling (Fig. 5.2) indicates the use of traditional herbs for treatment, and dietary avoidance of the causative foods. The biomedical treatment using ORS, according to the mother, works only for some children. This mother also recommends dietary restrictions for the lactating mother. *Mandham* is recognized in Siddha literature as febrile gastro-intestinal illnesses that affect infants and children under three. The word itself means retarded digestive energy. *Poduthalai* leaves and *omam* recommended by the mother are both documented in Siddha literature as digestive aids. For example,

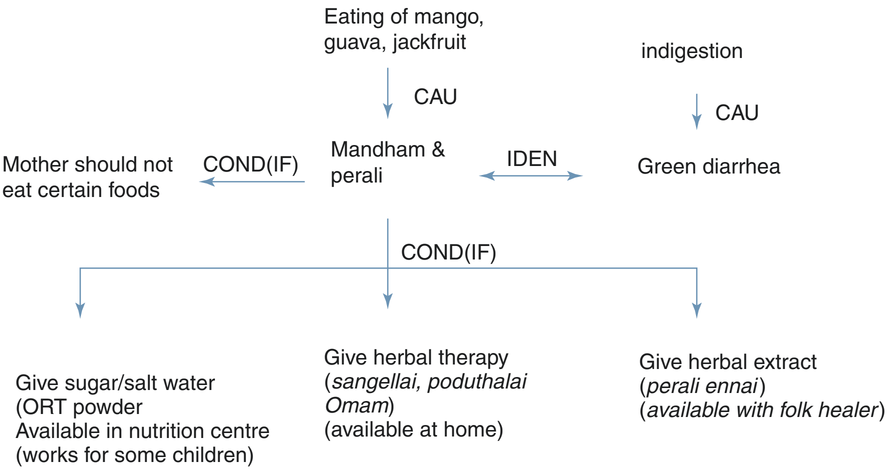

Fig. 5.2 Explanation and semantic representation of the protocol for the concepts of *mandham* and *perali* in the child of a mother (#4) with a primary school education

Poduthalai has astringent, antibacterial and anti-amoebic properties (Rao and Veluchamy 1983). *Perali* ennai, mentioned by the mother is made by local folk healers by boiling several such roots and leaves and extracting the oil from them as evident from the protocol of a local mid-wife (Mother #5).

Response of mother #5***:*** *We make this oil from a lot of leaves, roots, medicines, etc. We buy all this from the local market. We boil all these things, filter and keep the oil read**y.***

> *Subject's (#4) response to what foods should be avoided in the child's diet: Mango, guava and jackfruit cause mandham and perali. Perali is green diarrhea due to indigestion. For this, some people who don't know that it is perali go to remove thokam. Others give salt and sugar water (ORT powder) which we get at the nutrition centre. Salt sugar water works for some children. For perali give herbs (sangellai, podudhalai, omam, etc.). We get all this here. We also get an oil called perali ennai in Mathur (next village). The mother should not eat brinjal (egg plant), some lentils, fish, meat and dried fish. Otherwise the child will have problems.* (Sivaramakrishnan and Patel 1993a, p. 111)

Karpan: *Karpan* was identified as a skin condition in the child caused by the consumption of foods such as eggplant and certain varieties of lentils which were thus avoided in the child's diet. *Karpan* is recognized in Siddha medicine as an allergic skin condition caused by the consumption of rotten food among children usually between the ages of 1 and 3 years. However, the practice of avoiding all potentially *karpan* causing foods from the diets of all children may contribute to inadequate dietary diversity which is one of the major underlying causes of nutritional deficiencies.

5.4.2 Concepts of Causation and Treatment of Chronic PEM and Marasmus

These two conditions are being discussed together because of the similarities in the mothers' concepts for their causation and treatment. According to the biomedical model, dietary insufficiency of both calories and protein in the child's diet is the principle cause for PEM. A predominance of caloric insufficiency surfaces as extreme wasting of muscle and fat, a condition labelled as Marasmus (referred to as *nonjan* by the local physicians). Both the biomedical and the traditional Siddha model recognize the importance of maternal malnutrition prior to and/or during pregnancy as an important determinant of the child's pre and postnatal development. Considerable importance is given to the food given to the expectant mother. As a traditional custom in south Indian societies, relatives and friends invite the mother for a feast of all her favorite food, and also give nourishing food as a gift whenever they visit her.

Too little and/or improper food was identified as the major causative factor for chronic PEM (Table 5.1), more so among the mothers with higher levels of formal education. They also recommended treatment with giving more food. However, the cultural concept of *therai* dominated the mothers reasoning about cause and treatment of Marasmus in the child. Traditional concepts of *therai* and *kanai* that featured in the mothers' explanations of causality and treatment for both chronic PEM and Marasmus are detailed below.

Therai: Siddha medicine identifies a common pediatric problem called *thodam (dosham)* that is caused by "touching" by hand, by bodily contact or by casting an evil eye. *Therai thodam* is said to be caused by the airy touch of a kind of toad called *therai* which is often spotted in the local fields. Clinical symptoms of this condition identified are dyspnea, refusal of feeds, dryness and emaciation of the body, narrowing of eyes, folding of limbs on the trunk, abdominal distension, loss of hearing and shrieking voice (Krishnamoorthy 1983). According to the mothers, the condition of *therai* occurs at birth if the pregnant mother comes in contact with the *therai* directly or consumes any food which has been in contact with the *therai*. For example, a soft interior and a distinct odour and taste in coconut was said to be the result of contact with a *therai* and the coconut was identified as a *therai* coconut (Fig. 5.3). The condition was said to occur because contact with the *therai* was considered to be draining out all the *rasam* (nutrients) from the foetus such that the child was born like the *therai* (very thin like the marasmic child). Folk treatment involved the tying of a live *therai* often sold enclosed in small leather bags onto the child's stomach. The explanation given was that as the *therai* dries up the *rasam* (nutrient) returns to the child and the child gradually gets the strength back (Fig. 5.3). The treatment of *thodam (dosham)* in Siddha practice involves the administration of a fatty extract of herbs and leaves which are proven to have anti-bacterial and anti-viral effects. The practice of tying a live *therai* on the child as stated by the mothers may on the other hand prove to be infective and harm the child. Although the importance of giving nourishing food to the *therai* child was

Table 5.1 Number (%) of occurrence of concepts among mothers with no schooling (group A), primary or elementary schooling (group B), secondary schooling (group C) and elders in the community (group D)

Nutritional deficiency	Concepts	Group A	Group B	Group C	Group D
Chronic PEM					
Causality	Too little and/or improper food	18(69)	24(83)	27(84)	8(38)
	THERAI	3(12)	4(14)	0(0)	0(0)
	KANAI	0(0)	0(0)	0(0)	6(29)
Treatment	Food	18(69)	24(83)	27(84)	8(38)
Marasmus					
Casuality	*THERAI*	11(42)	20(69)	9(28)	9(43)
	Less food	9(35)	3(10)	10(31)	5(24)
	Maternal malnutrition	4(15)	5(17)	4(13)	3(14)
	Worms	2(8)	3(10)	7(22)	3(14)
	Lack of immunization	2(8)	4(14)	8(25)	0(0)
	KANAI	3(12)	0(0)	0(0)	4(19)
Treatment	Tying *therai*	8(31)	16(55)	5(16)	9(43)
	Food	8(31)	3(10)	15(47)	5(24)
	Tonic/doctor	9(35)	13(45)	8(25)	0(0)
	Can't do anything	0(0)	5(17)	0(0)	2(10)
Kwashiorkor					
Casuality	*SAVALAI*	5(19)	7(24)	10(31)	1(5)
	Less food	1(4)	2(7)	6(19)	4(19)
	Too much food	5(19)	4(14)	4(13)	5(24)
	Mud eating	8(31)	11(38)	7(22)	6(29)
	SOKAI	3(12)	10(34)	9(28)	6(29)
	Indigestion	8(31)	3(10)	6(19)	7(33)
Treatment	With food	5(19)	5(17)	3(9)	2(10)
	Consultation of doctor	6(23)	6(21)	7(22)	6(29)
	With digestives	6(23)	3(10)	3(9)	5(24)
Vitamin A deficiency					
Causes	Less food	3(12)	3(10)	16(50)	1(5)
	Heat	6(23)	5(17)	1(3)	4(19)
	God's doing	4(15)	8(28)	5(16)	2(10)
Treatment	Food	6(23)	6(21)	20(62)	5(24)
	Doctor	13(50)	17(59)	14(44)	9(43)
	Oil bath	7(27)	16(55)	9(28)	11(52)
	Breast milk/castor oil	4(15)	5(17)	4(13)	5(24)
	KANMALAR	1(4)	8(28)	3(9)	4(19)
	NANDIYARVATTAI	2(8)	3(10)	3(9)	9(43)
	Goat hen *PITTU*	8(31)	2(7)	0(0)	6(29)

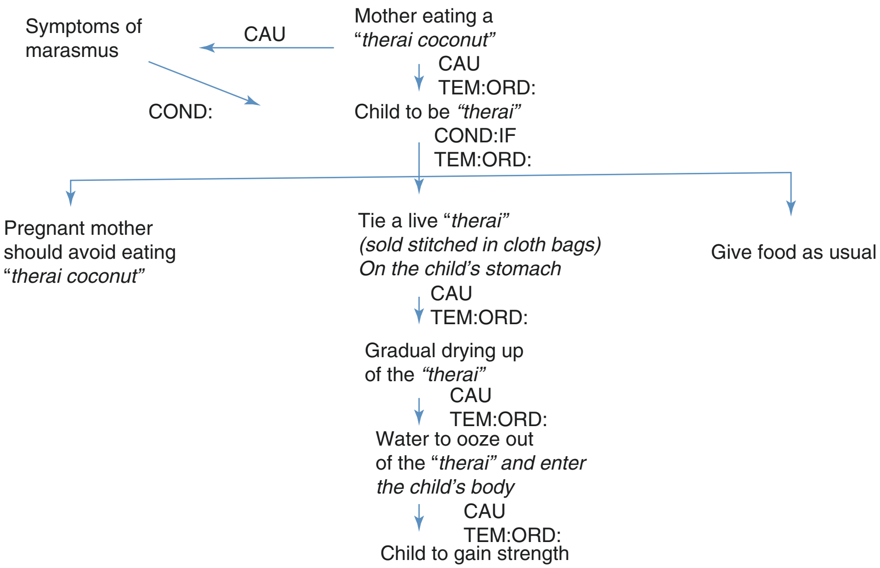

Fig. 5.3 Explanation and semantic representation of the protocol for the cause and treatment of marasmus in the child by an elderly lady (#6)

recognized by the mothers, the first line of treatment appeared to be the tying of a *therai*. This would delay the rehabilitation of the child with the much needed immediate dietetic supplementation.

> *Subject's response to symptoms of Marasmus: This is because the mother has eaten "therai coconut", then the child has "therai". The pregnant mother should not eat such coconuts. For treatment, tie a live therai onto the child's stomach. As water oozes out of the therai, the child will gain strength. The therai will die and as the therai dries up the water enters the child's body and he gains strength. It is stitched in a cloth bag and sold. Tie it around the child's stomach and hang it from his shoulder. Give food as usual.* (Sivaramakrishnan 1991, p. 79)

Kanai**:** Both chronic PEM characterized by height weight retardation and marasmus were associated with excess body heat resulting in a condition referred to as *kanai kachal* (a feverish condition in which the child remains slightly warm and fails to gain weight). Wheezing and cough were identified as additional symptoms by several mothers. For treatment the mothers recommended the administration of a locally available *kanai ennai* (ennai refers to an oil) prepared by extracting the oil from selected leaves and roots. This oil was given to the child at night so that the child has a complete bowel movement in the morning which removes all the excess body heat causing the *kanai kachal*. This line of treatment has a strong bearing on the concept of *kanai* in siddha literature which refers to primary complex (childhood

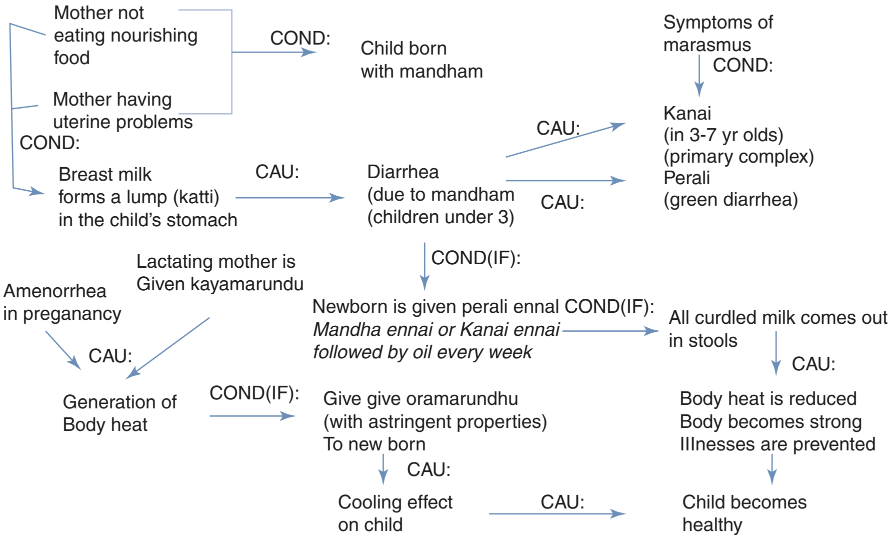

Fig. 5.4 Semantic representation of the explanation protocol for the concepts of mandham, perali and kanai by Siddha physician

tuberculosis), a disease still prevalent among children in India. The disease is characterized by irritability, lack of appetite, stunted growth, fever and muscular wasting. Treatment in Siddha medicine involves the administration of Neem (*Azadirachta indica*) oil, since the active compounds in Neem (Nimbidin, Azadiractin and nimbinin) have antibacterial activity (Campos-Navarro and Coronado 2008). Excessive body heat is identified as the root cause for all problems of childhood such as *mandham*, *perali* and *kanai* according to the Siddha physicians in the study (Fig. 5.4). The administration of herbal medicines called *kayamarundu (marundu* means medicine in Tamil) to the lactating mother is considered to be generating body heat both in the mother and in the breast fed child. To counter this the newborn is given an *oramarundu* which has cooling properties, so that the body heat is reduced, the body gets strength and all illnesses which arise in the child after 6 months of age are prevented.

While the mothers' reasoning about growth retardation in the child due to excessive body heat (*kanai kachal*) and treatment by use of laxative oils (*kanai ennai)* seems to be based on Siddha concepts, this first line of treatment shifts the focus away from the need for providing nourishing food. The identification of every case of marasmus as *Kanai* and treatment by the administration of a laxative oil without the consultation of a physician may harm the already malnourished child. Moreover, the study also identified other harmful lay practices such as the application of cow dung on the back of the child so that the body heat (*kanai*) shows up as thorns which can be eliminated, after which a bath was given to the child to remove the excess body heat.

R. *Shows a picture of a child suffering from marasmus.*
S. *This is a type of 'kanai.' Child gets it while inside the mothers womb. If the mother does not eat nourishing food, or if she has some uterine disorder, child is born like this. When the child has milk, it forms a lump (katti) and the child has diarrhea. This is called 'mandham', the stage before kanai in children below 3 years of age. In 3–7 year olds, it becomes kanai which is called 'primary complex, in modern terminology.' 'Perali' is green diarrhea due to mandham. To cure mandham in Siddha vaidyam (medicine), to the new born give various oils such as 'mandha ennai', 'kanai ennai', and 'perali ennai'. By giving this all the curdled milk in the stomach comes out in motions. After that every week they give oil (different types each day). All the curled milk and milk lumps formed while inside the uterus come out. Body gets strength, body heat is reduced and all the illnesses which come after 6 months of age are prevented. For the lactating mother, the mid-wives give a herbal medicine called 'kayamarundu'. This gives body heat (because of lack of menstration in the mother for 10 months, the body becomes very cool) and the mothers milk becomes good. The child then remains healthy. The mothers then give the child a herbal medicine called 'oramarundhu' which is cooling, and has astringint properties. This is given because the mothers during lactation eat 'kayamarundu' which is hot*. (Sivaramakrishnan 1991, p. 79)

Response of mother (#7) with no schooling for the cause and treatment of height weight retardation in the child*: It is due to Kanai (heat), so the child does not grow. Body is kanai, we have to remove the kanai. At home we apply cow dung on the back of the child. The Kanai shows up like thorns. Pluck them and give bath with hot water—do this once a month for 3 months. That would reduce the body heat. If the child does not gain weight, remains thin, and hair becomes discoloured than we do this.*

Cow dung is culturally used as a cleansing agent for several purposes. However, application of cow dung on the back of the child may prove detrimental by causing infection in the previously malnourished child.

Concepts of maternal malnutrition, less food, lack of immunization and worm infections were also linked to the causality of marasmus, and treatment with food, supplements (tonics) and consultation of the physician were identified (Table 5.1). While this exemplifies the influence of biomedical knowledge among the mothers particularly among mothers with more exposure to formal education, causal explanations and treatment strategies are still rooted in traditional beliefs. For example, worm infection in the child was attributed to the addition of more sugar in milk. For treatment, the mother recommended the administration of crushed neem leaves (*vepaellai*) so that the increased bitterness would help eliminate the worms. Neem has proven anti-helminthic action according to Siddha literature (Lakshmi et al. 2015). More than 50% of the mothers in the study recommended the use of either neem oil and/or castor oil (an established laxative in traditional Indian medicine) for treatment of worm infections in the child.

5.4.3 Concepts of Causation and Treatment of Kwashiorkor

Kwashiorkor in the child characterized by symptoms of apathy, generalized edema, skin changes (dry flaky skin), hair changes (dry and thin hair), liver enlargement and abdominal distension, results when the child is abruptly weaned from the breast to a high carbohydrate low protein diet. In the Indian context, the condition has been identified by the local physicians as *savalai* and the child is referred to as a *savalai* child. According to the local physician both delayed weaning and wrong weaning foods (only rice gruel) due to poverty and lack of knowledge of healthy local weaning foods is the underlying cause for *savalai*.

The biomedical concept of *savalai* does appear in the protocol of mothers, more so in those with higher levels of formal education (Table 5.1). However, relatively smaller percentage of mothers were able to link the condition to a dietary deficiency of food. Only 2% of the mothers were able to specify that the condition is due to the dietary lack of protein *(puradha sathu* in local terminology). While the mothers do associate the condition with weaning due to another pregnancy, the causal explanation provided is that the older child who now misses mother's milk is overfed, the excess food is not digested resulting in diarrhea and growth failure (Fig. 5.5).

> *Subject's response to symptoms of Kwashiorkar: This child is savalai. It happens because the mother becomes pregnant again. The child misses mother's milk. But we keep giving food and so the stomach becomes big. This child cannot say that it is full. But the food is not digested well and the child keeps having diarrhea and so it will not grow well. Give tonics.* (Sivaramakrishnan and Patel 1993b, p. 949)

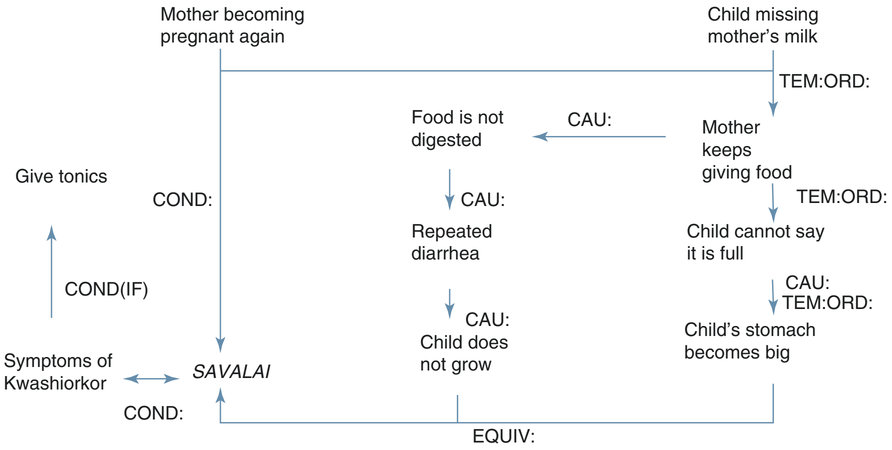

Fig. 5.5 Explanation and semantic representation of the protocol for the cause and treatment of Kwashiorkor in the child by a mother (#8) with a secondary school education

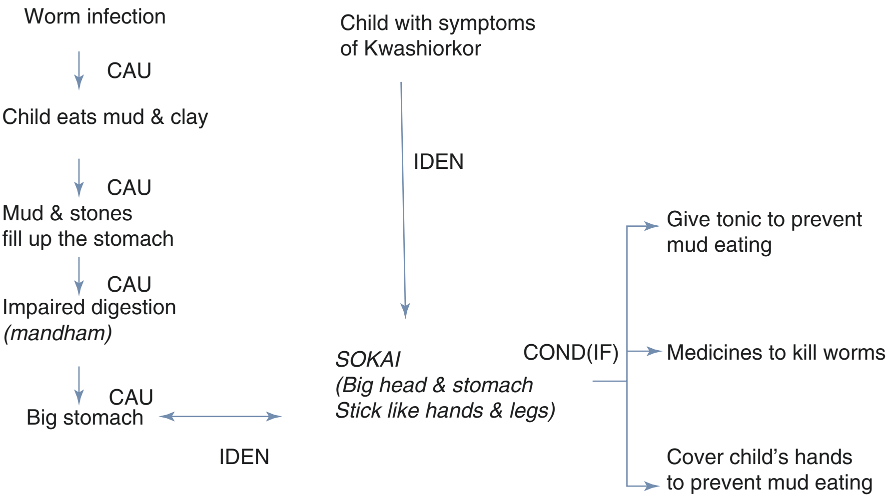

Fig. 5.6 Explanation and semantic representation of the protocol for the cause and treatment of Kwashiorkor in the child by of a mother (#9) with a secondary school education

For treatment, the mother recommends supplements (tonics). Concepts of mud eating and *sokai* were however the most frequently mentioned causative factors for kwashiorkor in the child. Pica or clay eating is a well-recognized condition in the biomedical model in which the child tends to eat non-food items such as mud or clay. The likely explanations are (1) emotional factors due to abrupt weaning and resultant maternal deprivation (2) hunger (3) attempts at exploring the outside world. Pica often results in worm infections causing discomfort, indigestion, weakness and abdominal bloating. The mothers' causal explanations however reveal the phenomenon of lay interpretations of biomedical concepts. According to the mothers (Fig. 5.6) worm infections in the child cause mud/clay eating. The mud or clay fills up the stomach, causes the stomach to swell up, drains the nourishment and causes indigestion and *mandham* (described earlier), all of which results in the head and stomach being big and the hands and legs being thin, symptoms typically seen in a child with kwashiorkor. Treatment focusses on medicines to kill the worms or attempts at prevention of mud eating (covering hands or administration of tonics).

> *Subject's response to symptoms of Kwashiorkar: Child is Sokai, only head and stomach are big and hands and legs will be like stick. It is because the child eats mud and clay and so the stomach swells up. Mud and stones fill up the stomach and so digestion is impaired and the stomach is mandham and big. There is a tonic which prevents the child from eating mud. Child has worms which make the child eat mud. Give medicines to kill the worms or cover child's hands with a cover.* (Sivaramakrishnan and Patel 1993b, p. 946)

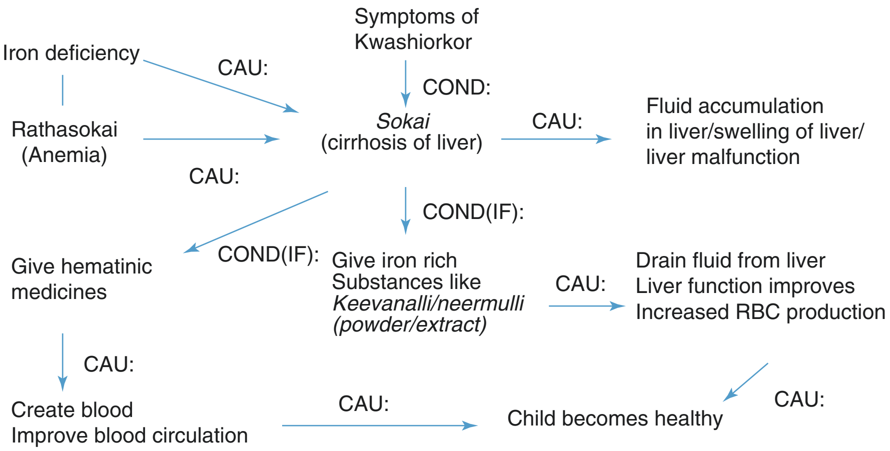

Fig. 5.7 Semantic representation of the protocol for the cause and treatment of Kwashiorkor by a Siddha Physician

The interpretation of Kwashiorkor as *sokai* by the mothers in the study seems to parallel the understanding of traditional Siddha physicians (Fig. 5.7). The symptoms of enlarged abdomen in Kwashiorkor have been identified as *sokai* or cirrhosis of the liver which is said to be caused by deficiency of iron resulting in *rathasokai* (anemia) which then causes *sokai*. The symptoms mentioned include the accumulation of fluid in the liver, liver enlargement and liver malfunction. For treatment, the physician recommends the use of herbs such as *keevanalli or neermulli* which are both iron rich (thus help in blood formation) and also act as a diuretic (thus help in draining out the fluid from the liver and help improve liver function).

> *This is "sokai" or cirrhosis of liver. Fluid accumulates in the liver, which swells up and does not function well. This happens because of less iron. First there is "rathasokai" (anemia) or deficiency of blood which then turns into sokai. We give iron rich food substances such as "keevanalli", "neermulli" etc. in powder form or as an extract. These extracts can drain the fluid in the liver so that the liver functions and produces RBCs. We also give hematinic medicines that create blood. Substances like keevanalli and neermulli remove fluid, stomach swelling is removed, blood circulation improves and the child becomes healthy.* (Sivaramakrishnan and Patel 1993b, p. 947)

Sometimes diseases with different causes and treatment requirements may present similar symptoms. For example, the abdominal distension caused by protein deficiency in Kwashiorkor could also be the result of a liver problem. Symptomatic interpretation without accompanying pathological data can often lead to a wrong line of diagnosis and treatment.

Other treatment strategies for Kwashiorkor recommended by the mothers' parallels their understanding of causation (Table 5.1). Besides food and medical intervention, the mothers' mention the need for administration of digestive herbs similar to those discussed for *mandham*, *perali* and *thokam*. The state of protein deficiency in Kwashiorkor often results in decreased secretion of digestive enzymes, impaired digestion and absorption. While the administration of digestive herbs may therefore help stimulate digestion and be beneficial for the child's health, the lack of understanding of kwashiorkor as a condition of nutrient (predominantly protein) deficiency by the mothers in the study is an issue of concern for nutrition education.

5.4.4 Concepts of Causation and Treatment of Vitamin A Deficiency

According to the biomedical model, Vitamin A deficiency is characterized by an inability to adapt to dim light (night blindness), conjunctival dryness (xeropthalmia), white/greyish patches in the conjunctiva (Bitot spots) due to heaping up of desquamated, keratinized epithelial cells and ultimately keratomalacia in which the cornea becomes ulcerated and softened often leading to blindness. Whitish patches in the cornea are also a clinical manifestation of cataract, a condition that occurs with aging. Night blindness was rightly identified as *malaikan* (the bio medical term in Tamil) by in the mothers in the study. However, Bitot spots were identified as *pu viyundiruku* (literally translated as white flowers fallen in the eye) which is a symptomatic interpretation and could be the result of either a vitamin A deficiency or cataract in the elderly.

The major cause of vitamin A deficiency in the child is a dietary lack of vitamin A rich foods. Treatment involves supplementation with Vitamin A and intake of vitamin A rich foods. Clearly, less food (in general and not specifically Vitamin A rich food) was identified as a cause by 50% of the mothers with increased formal education (secondary schooling) in the study and treatment with food and/or consultation of physician was recommended. However, the most commonly recognized cause by the others in the study was body heat or God's will. Treatment strategies therefore focused on attempts to lower body heat (giving of oil bath to the child and application of breast milk/castor oil on the eye) and offerings to a God (*kanmalar*—which is a silver replica of the eye offered to a God). The giving of oil bath to the child (every alternate day for younger children and once a week or once in two weeks for older children) is a common practice in this community. Even the days for oil bath were picked based on the gender of the child (Fridays for the girl child and Saturday/Sunday for the boy child). The procedure for oil bath involved the application of an oil (usually sesame oil) all over the child's body which is allowed to soak in for about 5 min and then washed off. *Ennai kataradhu* was another common practice in which either sesame oil alone or a combination of oils were poured into the child's eye and allowed to soak in. These treatments were considered to reduce the body heat and their use paralleled the mothers' understanding of eye conditions as something caused by excess body heat. The use of medicated oil baths (using oils prepared with herbs) and the localized application of oil in the eye using breast milk as a vehicle are established prophylactic and therapeutic practices for eye conditions according to Siddha medicine (Saroja and Veluchamy 1983). The importance of diet in therapy was recommended more by mothers with higher levels of formal education and the foods recommended for inclusion in the diet were greens and carrots (for their cooling effect) and meat. *Karimalai* was considered a special kind of night blindness that responds only to meat. Elders and mothers with no schooling recommended feeding of hen/goat *pittu* (liver) to the pregnant woman and the child with *malaikan* (the bitter tasting *pittu was* removed from the fowl at home and swallowed by keeping it inside a sweet banana). This traditional practice is not being followed by the educated mothers (Table 5.1). Both biomedicine and Siddha medicine recognize the importance of liver as an important source of vitamin A. Such cultural practices need to be reinforced along with adequate knowledge of hygiene to prevent any co-occurrences of infections in the malnourished child. Another traditional practice recommended particularly by the elders in the community was the application in the eye of an extract of *nandiyarvattai* flowers (Tabernae montana coronaria). Extracts of this flower are considered as a local anodyne agent (analgesic) and recommendations are made in Siddha medicine for its juice to be extracted and applied as eye drops (Glanz and Bishop 2010). While this practice can be encouraged, the inherent dangers of contamination and likelihood of eye infections need to be recognized. Mention was made by the mothers of the need to collect clean flowers (plucked by the priest from the plants grown in the temple as the ones outside may have been eaten by street animals like goat, cow, etc.) and the number of flowers to be used was said to be governed by specific rules.

5.5 Summary of the Study Results

5.5.1 Nature of Prevailing Traditional Knowledge

As evident from the above study results, the mothers' reasoning about both appropriate food for the child as well as the cause and treatment of common childhood nutritional problems, appears to be grounded in traditional theory of health and disease. Several concepts identified in the mothers' protocols such as *thokam, mandham, perali, therai and sokai* bear resemblance to similar concepts and their interpretations within the system of traditional Siddha medicine prevalent in parts of Tamil Nadu, south India, where the study was conducted.

In order to understand the mothers' reasoning and problem solving strategies, they were presented with the relevant data (the symptoms of the childhood nutritional problems) in a pictorial as well as in the form of a verbal description of the most important presenting symptoms. In all cases, the mothers responded by providing a diagnosis of the problem (data driven hypothesis) and then proceeded to confirm their hypothesis by providing often detailed causal mechanisms for the presenting symptoms. In doing so, the mothers' demonstrate the use of forward reasoning (data driven reasoning) which is characteristic of experts in any domain who draw upon their highly developed knowledge base in problem solving situations (Arocha et al. 2005). Traditional knowledge in the mothers thus appears to be "expert knowledge" rather than "naïve knowledge". This kind of expertise evident in the mothers, particularly in those with no/minimal formal education is what is referred to as "cultural expertise". Such knowledge is culturally defined, socially acquired and constantly re-in forced by practice. There is an element of adequacy and confidence attached to such a knowledge base which makes it hard to be replaced with alternate biomedical knowledge.

The treatment strategies suggested by the mothers' parallels their understanding of the cause. For example, body heat is understood to be the cause for the changes in the eye and therefore oil baths that reduce the body heat are suggested for treatment. Similarly, Marasmus is believed to be caused by the *therai* falling on the pregnant mother and sucking all the nourishment from the foetus and so for treatment the mothers' recommend the tying of the *therai* on the child so that the nourishment that was drained out is returned back to the child. The entire knowledge structure is in the form of a story with an ordered sequence of events supported by strong causal mechanisms. "Naïve knowledge" regarding childhood nutrition among the mothers in rural Tamil Nadu is not piecemeal and fragmented but appears to be having a "story like" and coherent structure. Such a belief structure that is supported by notions of causality is often resistant to change.

5.5.2 Knowledge Restructuring with Formal Education

The effect of exposure to formal education on the mothers' knowledge structure was assessed by comparing the occurrences of traditional and biomedical concepts in the protocols of mothers with varying levels of schooling. The total number of traditional concepts (referred to as the traditional score) and the total number of biomedical concepts (the biomedical score) in their explanations were calculated. It was seen that traditional concepts were used more by mothers with no schooling or with primary level schooling than by mothers with secondary level schooling (traditional score of 4.0, 4.9 and 2.9 respectively). On the other hand, biomedical concepts were used more frequently by mothers with secondary level schooling rather than those with primary level schooling or no schooling (biomedical score of 8.9, 6.4 and 6.0 respectively). Thus, although with formal education, increased biomedical concepts are being used in the explanation, knowledge and practice of traditional belief persisted even after 10 years of formal schooling.

Semantic analysis of the explanation protocols for all of the problem scenarios presented do not indicate any evidence for a major change in underlying theory which would signify a strong restructuring of knowledge. For example, in Fig. 5.5, the mother with secondary level schooling identifies the symptoms of kwashiorkor as *Savalai* (the biomedical term) and recommends tonics for the child, but her explanations are based on concepts related to indigestion (the focus in traditional medicine). What seems to be happening with formal education is the addition of a few concepts and relations from the biomedical theories to the already well-structured and coherent traditional knowledge base. This is suggestive of a weak restructuring of knowledge even after several years of exposure to formal science. A likely explanation for this is the very nature of the traditional knowledge prevailing among the mothers as described earlier.

5.5.3 Implications of the Findings for Improved Instructional Strategies That Would Have Positive Impacts on Child Health

The traditional system of Indian medicine that appears to be providing a coherent framework of indigenous knowledge of health beliefs and practices among the mothers in the study is based on sound principles of ancient Siddha medicine. The mothers are also drawing upon biomedical concepts to which they are exposed through formal education and through nutrition education in the local nutrition centres. What emerges appears to be a socially acquired composite model of nutrition knowledge which is best suited, according to the mothers, to solve the everyday problems of childhood nutrition. The aim of health education should therefore not lie in changing in the underlying theory completely and bringing about a strong restructuring of knowledge, but in strengthening the existing theoretical model based on sound principles of current bio medical knowledge. There are several aspects of the traditional knowledge that are beneficial for the child's health. For example, the mothers' recommendations for the administration of hen/goat *pittu* (liver) and the juice of the flower *nandiyarvattai* for vitamin A deficiency and the herbal treatments recommended for diarrhea in the child have documentations in Siddha medical literature. Such practices need to be identified, refined and re-enforced. At the same time there are aspects of the mothers' traditional knowledge that are potentially harmful to the child which need to be replaced with sound biomedical concepts. For example, the folk practice of tying a live *therai* on a child suffering from Marasmus, blowing through a tube inserted into the child's mouth in order to cure diarrhea thought to be caused by *thokam*, treatment with purgative herbs without diagnosing the cause of the problem or the application of cow dung on the child's back to remove body heat or *kanai* can prove detrimental to the health of the child already weakened by malnutrition. Such weak conditional links (where conditions are sufficient but not necessary for action to occur) can be identified and manipulated by formal education.

Traditional concepts were being supported by strong causal mechanisms which made their understanding more coherent and thus resistant to change. On the other hand, the biomedical explanations provided, were naïve, suggesting a poor understanding of the biomedical concepts. For example although the subject matter taught in schools as well as the teaching material used in the nutrition centres relate symptoms of kwashiorkor to a deficiency of *puradha sathu* (or protein), only two mothers could identify this link.

The findings have implications in the planning of effective educational strategies. Biomedical concepts should not be presented in isolation but within the context of prevailing traditional knowledge. For example the concepts of *thokam, mandham* and *perali,* which are all linked to different forms of diarrhea with strong causal mechanisms should be built into the educational material for diarrhea. Similarly concepts of *therai* and *kanai* that dominate the mothers' reasoning about protein energy malnutrition in the child should be an integral part of the educational material for the same. Furthermore, biomedical information, like the prevailing traditional knowledge must be supported by underlying causal explanations so that it presents a complete coherent story linking the cause, symptoms and treatment.

As Werner points out "if we can use what is best in modern medicine, together with what is best in traditional healing, the combination may be better than either one alone" (Campos-Navarro and Coronado 2008).

5.5.4 Models of Health Behavior to Inform Interventions

Studies presented in this chapter substantiate the fact that in societies where culture-specific practices of traditional healthcare exist, achieving the integration of biomedical practices is a challenge. Although the focus of this chapter has been on the management of childhood nutritional problems in India, the concepts which surfaced have global relevance to all areas of healthcare. Over the years, several theories have emerged that serve as a basis for understanding human behavior and for the design, implementation and evaluation of health behavior interventions. In the area of healthcare, the Health Behavior Model (HBM) has been the most relevant and widely used conceptual framework for understanding human behavior (Orji et al. 2012). This model, which was developed in the 1950s and underwent subsequent modifications, is based on the guiding principle that peoples' beliefs about their health predict their behavior, and this behavior can be assessed by the perception of several different variables. However, even this model has failed to explain the complexities of human health behavior, and hence, efforts have constantly been made by researchers to add newer and more predictive variables to the existing model (Holden and Karsh 2010). Our studies add a new dimension to these efforts at understanding of peoples' health beliefs and behavior. It is apparent that in today's global, multicultural societies, peoples' traditional culture-based healthcare knowledge needs to be built into any theory that tries to understand and predict health behavior.

The nature of the lay reasoning models are shaped by cultural belief systems as well as by formal education. This mix of formal and informal knowledge is supposed to provide better understanding of health issues, but it can also give rise to misconceptions, biases, and faulty reasoning. Research in this context is about understanding how knowledge can support reasoning and justify action in varied cognitive tasks under different conditions. We find that the two types of knowledge used by our mothers do not integrate, but rather, an opportunistic composite model for making decisions is developed.

It is interesting to note that different conceptual structures are acquired through different means and they appear to remain apart even when situations may require their integration. It is very possible that as people increase their knowledge of both conceptual systems, they interfere with one another, rather than integrate. We attempted to explain this situation in one of our earlier papers, where we said, "This creates a situation of opportunism in terms of the concepts people use to explain a given phenomenon, by utilizing any concept that at the time may fit into the situation better, without concern for the internal consistency of the explanation" (Patel et al. 2000).

In our qualitative studies, we show that knowledge structures used in making decisions about children's health are linked together with tightly connected causal links as well as loosely connected associative or conditional links. The former links are difficult to break, but the latter form are easily intercepted. If we can qualitatively show any phenomena to be consistent in a large population, then the use of carefully monitored intervention, based on qualitative studies, would be more likely to be a successful model for intervention.

Discussion Questions

1. Explain why it is difficult to predict health behavior based on peoples' beliefs?
2. Describe some possible ways to intervene to improve child health based on your understanding of how mothers think and treat their children for childhood diseases?
3. How do you think modern technologies can assist in providing information access and decision support?

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Glossary

Local dialect	**English/Botanical**
Agni	**Bioenergy**
Ahara	**Diet**
Akash/Veli	**Space**
Apya/Neer	**Water**
Dhopam	**Herbal smoke**
Dosha	**Humor**
Ennai	**Oil**
Ennai kataradhu	**Application of oil in the eye**
Idli	**Traditional steamed preparation using rice and lentil**

Jangamam	**Animal products**
Kachal	**Fever**
Kanai kachal	**Primary complex**
Kanmalar	**Silver replica of the eye**
Kapha/Kapham	**One of the three humors (water + earth)**
Karimalai	**Night blindness responding to meat**
Karpan	**A skin condition**
Kayamarundu	**A herbal preparation**
Keevanalli	**A herb**
Kodal	**Intestine**
Kaajal	**Traditional eye cosmetic**
Malaikan	**Night blindness**
Mandham	**Gastro-intestinal problems in children**
Mantras	**Sacred words**
Nadiyarvattai	*Tabernae Montana Coronaria*
Neermulli	**A herb**
Nonjan	**Local terminology for child with marasmus**
Omam	*Trachyspermum ammi*
Oramarundhu	**A herbal preparation**
Oushadha	**Drugs and therapies**
Panchamahabhootas	**The five gross elements of the universe**
Perali	**Green diarrhoea in children**
Perali ennai	**Oil extracted from herbs**
Pitha/pitham	**One of the three humors (fire)**
Poduthalai	*Lippia nodiflora*
Prithvi/Mann	**Earth**
Puradhasathu	**Protein nourishment**
Pu viyundiruku	**Local terminology for Bitot spots**
Pathya	**Proper diet**
Rasam	**Nutrients**
Rathasokai	**Local terminology for Anemia**
Sangellai	**A herb**
Savalai	**Local terminology for child with symptoms of Kwashiorkor**
Sokai	**Cirrhosis of the liver**
Sambrani	**Benzoin resin**
Teja/Thee	**Fire**
Therai	**A kind of toad/A condition in children in which child resembles a kind of toad**
Therai coconut	**Coconut with a soft interior and a distinct odour.**
Thodam/dosham	**Effect of touch/effect of evil spirit**
Thokam	**Condition caused by something obstructing the intestine**
Thaavaram	**Herbal products**
Thaatu	**Metals and minerals**

Tulsi	*Ocimum sanctum*
Vayu/katru	**Air**
Vata/vatam	**One of the three humors (space + air)**
Vepaellai	**Neem leaves**
Vihara	**Practices**

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Part III
Cognition and Health Behaviors

Chapter 6
Health Information Literacy as a Tool for Addressing Adolescent Behaviors, Knowledge, Skills, and Academic Trajectories

Alla Keselman

Abstract Health education and information outreach programs, implemented through in-school and afterschool settings, can positively impact adolescent functioning at a variety of levels. This chapter reviews research connecting health knowledge to health behavior and outcomes, while claiming that personal health is only one desirable outcome of health education. Viewing health as situated in a community context and largely determined by social and cultural factors, the chapter discusses the impact of scientifically sound, socially oriented health education on leadership, informed citizenship, community advocacy, and career interests. It also addresses the role of technology and health informatics in delivering effective health education by providing quality content as well as tools for adolescents' creative endeavors. Finally, the chapter reviews four broad-impact health information projects at the National Library of Medicine (NLM) targeting adolescents in primarily minority, low-income communities.

Keywords Adolescents • Health education • Health information literacy • Science education • Health literacy

6.1 Introduction

One of the objectives of health informatics is to help lay individuals—patients and consumers—understand health and disease, make healthy lifestyle choices and interact with the healthcare system. Health informatics shares these objectives with health education, which suggests a potential for a synergy between the field of

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health informatics and schools, where most health education takes place. However, taking advantage of this potential requires understanding where and how heath education is conducted in formal and informal (e.g., afterschool clubs) school settings. It also requires understanding the complex relationship between health information and various cognitive, social, and behavioral outcomes. This chapter describes some identity dilemmas of school health education, reviews literature about the impact of health knowledge on reasoning and behaviors, considers limitations of the literature, presents four National Library of Medicine programs supporting adolescent development through health information literacy, and proposes directions for investigating meaningful integration of information technology into delivering health education to adolescents. Based on our review of theory and practice, we suggest expanding the scope of health information initiatives from aiming to impact personal health to raising understanding of health as a social variable and promoting community and civic engagement. We also suggest that harnessing the power of technology can further the reach and extend the scope of health information outreach and health education for adolescents.

6.2 Two Facets of Health Education in the US School System

In the US schools, health education is currently laden with several dilemmas that pertain to its setting, content breadth, and content depth/orientation. With respect to the setting, health-related content is taught under the auspices of two related disciplines, health and science. Each discipline is associated with a different philosophy, learning goals, and instructional methods, which have different implications for the depth and breadth of what is taught. At the present, little connection exists between the two.

As a discipline, school health education is most concerned with promoting health and wellness. Health education classroom curriculum is often locally determined, although nationwide standards, the *National Health Education Standards*, created by a committee that includes several national associations, including American Public Health Association and American School Health Association, do exist (Centers for Disease Control and Prevention 2011). The emphasis is usually on health issues that are relevant to adolescents (e.g., mental health, nutrition) and on understanding risks, engaging in preventative behaviors, building communication skills, and developing self-efficacy. While knowing relevant health-related statistics, risk factors, and preventive measures is emphasized, understanding the underlying complex biological mechanisms of health and disease is not. The stress is on explicating behaviors that help prevent disease and maintain wellness, with the underlying belief that such knowledge translates into healthier lifestyle choices and outcomes.

Unlike health, science as a school discipline is not concerned with behavior change. However, many of its domains, particularly biology, provide foundational background knowledge for understanding health and disease. The science classroom is where students learn about cellular and pathophysiological processes that underlie disease mechanisms. Subjects other than biology also provide an opportunity for building health connections. For example, studying about the electromagnetic wave spectrum in physics is relevant to understanding issues around X-ray safety (Zeyer et al. 2015). The science classroom's emphasis on in-depth understanding and critical thinking makes it a potentially good place for fostering critical health literacy, which involves dealing with complex health issues, reviewing health information from different, sometimes conflicting, sources, and evaluating evidence. Unfortunately, until recently, science classroom made few connections to health functioning in daily life (Zeyer et al. 2015). The situation is changing gradually, partly with the advancement of *Science for All* movement, which stresses making science relevant to future scientists and non-scientists alike (Jenkins 2000), and partly with the adoption of the *Next Generation Science Standards (NGSS)* that emphasize conceptual connectedness of ideas (NGSS 2013).

6.3 Impact of Health Information on "Real World" Indicators

Health information professionals interested in targeting adolescents may choose either of the above settings, as well as informal settings such as an afterschool clubs, museums, or community organizations. However, in order to design effective programs, they need to pose clear program objectives related to the expected impact of health information provision. Traditionally, the objective of information programs is to impart knowledge, with the expectation that individuals will apply that knowledge to produce positive outcomes. When it comes to health information, the positive outcomes are usually health behaviors and health indicators. Producing such outcomes entails answering some questions. What is the value of providing health information of different degrees of depth and complexity? What is the relationship between health information and "real life" behavior change? Can health information affect outcomes other than understanding and personal health behaviors? The next sections review some of the relevant research, as well as the limitations in current knowledge.

6.3.1 Information-to-Behaviors Pathways as Depicted in Health Behavior Change Models

The pathway from health information to behavior is complex. For example, while information about the dangers of tobacco has been in the public domain for at least 50 years, many Americans continue to smoke (Centers for Disease Control and Prevention 2016). Different theories of health behavior change underscore different levels of factors underlying the change, from personal, to family and community, and to society at large. They also stress the complex, multifaceted, interactive nature of these factors. As such, these theories collectively stress that while health knowledge, obtained via health information, is an important prerequisite, it is not a sufficient driver of change (Mackey et al. 2016). A number of influential theories of health behavior, including Levental and colleagues (1992), Bandura's social cognitive theory (1986), and Ajzen's (1991) theory of planned behavior present health knowledge as a predictor or mediator of health behavior change. Similarly, Passche-Orlow and Wolf (2007) posit is as a mediator of health outcomes in their health literacy model. Reflecting the role ascribed to information in underlying theories and models, public health and behavior change interventions usually provide some background information, but do not focus on imparting deep understanding of biological mechanisms. With rare exceptions, they also do not isolate the impact of knowledge/understanding while assessing impact of interventions.

6.3.2 Knowledge-Behaviors-Outcomes Implications of Health Literacy Research

Some indirect evidence of the impact of knowledge on health behaviors and outcomes comes from the field of health literacy research. Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker 2000). The definition, however, is not formulated as a set of component skills, so there is no unequivocal way to express the relationship between health literacy and health knowledge. On the one hand, some background knowledge of health, disease, and the healthcare system can be seen as a necessary foundation for obtaining and understanding additional "basic health information." If we make this assumption, then health literacy can be seen as a proxy of health knowledge. In this case, demonstrating a relationship between health literacy and health behaviors and outcomes provides indirect evidence that health knowledge is also positively associated with those behaviors and outcomes. On the other hand, health knowledge can be conceptualized as an outcome, rather than a component of health literacy. If we hold this assumption, then demonstrating that health literacy is associated with both health knowledge AND health behaviors/outcomes provides support to the connection between health knowledge and behaviors/outcomes.

In most research studies health literacy is measured via tests that are not grounded in a theory that would relate it to specific cognitive components, such as health knowledge, numeracy, or ability to interpret different visual representations of quantitative information. The two health literacy measures that are most frequently used in research and clinical settings are Rapid Estimate of Adult Literacy in Medicine (REALM), and Short Test of Health Literacy in Adults (S-TOFHLA) (Davis et al. 1993; Baker et al. 1999). REALM requires that the test-taker read aloud a list of health-related words of increasing complexity. In S-TOFHLA, the test-taker reads short passages adapted from real healthcare texts, filling in missing words by selecting each from four multiple choice options. While many newer tests attempt to develop more authentic information tasks typically involved in engaging with healthcare (Altin et al. 2014), S-TOFHLA's and REALM's brevity and ease of administration are responsible for their persistent prevalence. As a result, we have no evidence-based way to determine whether health literacy is a proxy or a possible predictor of health knowledge, and need to investigate both possibilities.

A number of studies demonstrate that health literacy, as measured by standard health literacy instruments, is positively associated with health knowledge. In a meta-analysis of chronic disease self-management skills, Mackey et al. (2016) found that low health literacy, as measured by standardized tests such as S-TOFHLA and REALM, is consistently associated with poor disease knowledge, as measured by disease-specific knowledge questionnaires, in a range of disease categories. Knowledge, in these surveys, was measured via straightforward factual questions, the answering of which did not require understanding biological mechanisms. For example, participants in Mancuso and Rincon's (2006) study had to know that "breathing problems are dangerous" and "people with asthma should exercise." The meta-analysis also identified a relationship between low health literacy and incorrect beliefs about health and diseases. While the meta-analysis does not include a definition of beliefs, examples of beliefs involve views that are likely to be grounded in the understanding of the underlying mechanisms (e.g., whether chronic disease medications work better if not taken all the time).

With regard to the relationship between health literacy and health behaviors/outcomes, a number of studies document such associations. For example, Baker et al. (2002) showed that older adults with poor health literacy undergo more hospitalizations. Kalichman and Rompa (2000) demonstrated that among HIV-positive individuals, lower health literacy is associated with higher viral loads and lower CD4 cell counts (an indicator of weakened immune system). Meta-analyses, however, suggest that the picture is rather complex. For example, upon reviewing research on health literacy and diabetes, Bailey et al. (2014) conclude that health literacy is positively associated with treatment adherence, self-care and reduction in diabetes complications. Others, however, point out to a number of studies that fail to document such relationships, concluding that the association between health literacy and factors such as adherence is weak and mixed (Geboers et al. 2015), or that the effect sizes, while statistically significant, are small (Zhang et al. 2014).

Overall, health literacy research provides evidence-based support to the view, expressed in health behavior change models, that while health knowledge is not sufficient for health behavioral changes, it is a component or mediator of this change. Moreover, while interventions based on health behavior change models focus on supporting variables other than knowledge, health literacy research points to the importance of providing health information. However, neither of these two areas of public health addresses the question of what constitutes necessary and sufficient actionable health knowledge.

6.3.3 The Cognitive Perspective on Actionable Health Knowledge

Before devising interventions for teaching health to adolescents and finding the right environment to implement them, we need to determine what concepts are important and at what level of detail they should be taught. The field that traditionally pays profound attention to the content and structure of individuals' knowledge is cognitive science. In particular, it distinguishes between different kinds of knowledge, such as factual, procedural, and conceptual knowledge (Keselman et al. 2004). One can think of factual knowledge as simple knowledge that something is true, such as knowing that some diseases are contagious. Procedural knowledge is knowledge of steps needed to carry out an action, such as knowing that proper handwashing involves 20 seconds of scrubbing with soap. Finally, conceptual knowledge is represented by a reasonably deep, well-connected, flexible model that can be used for solving problems and generating new knowledge (Keselman et al. 2004). An example of such a model is understanding that contagious diseases are caused by microorganisms that are transferred from one individual to another, and that different microorganisms differ in their ability to survive in various conditions. Such conceptual understanding is seen as more desirable than mere factual knowledge, because of its ability to support critical thinking in in response to novel questions. For example, a person with some conceptual understanding of contagion is more likely to judge correctly that depression is not contagious than a person merely knowing that some diseases are contagious and others are not.

While traditional health education and public health campaigns do not usually discuss different kinds of knowledge, the kinds they are most likely to target are factual and procedural. In contrast, science education is a setting concerned with imparting conceptual knowledge, or deep, connected understanding of scientific concepts and mechanisms. For example, a high school health class is likely to approach teaching about immunization by imparting procedural and factual knowledge. Health students will learn about immunization-related reduction in preventable diseases, recommended vaccination schedules, frequency and severity of possible side effects, and steps for getting vaccinated. In contrast, students in a high school anatomy and physiology class learn about the structure and function of different bodily organs and systems, focusing on both cellular-level and systems-level processes. Science education does not address procedural health knowledge, so it is unlikely to include any mention of things like recommended schedules. The students, however, will learn about the structure and lifecycle of viruses and the body's immune response, which are foundational to understanding how vaccines work. Is this understanding connected to health behaviors? While traditional public health/behavior change approaches view depth of knowledge as largely irrelevant, studies in cognition and education depict a number of situations when it matters. These situations typically involve evaluating information from discrepant sources, navigating multiple information streams, and resolving scientifically-based and folk/cultural beliefs.

A number of such studies suggest that possessing a collection of accurate, but superficial and fragmented facts cannot replace an earlier, less accurate, but well-connected and/or culturally embedded system of naïve beliefs and misconceptions. For example, in a study of adolescents' reasoning about HIV, Keselman et al. (2004) presented middle and high school students with an HIV information web page, allegedly created by a group of teens learning web design. The design explicitly emphasized that the information site was not created or vetted by health professionals. The site depicted several vignettes with myths about HIV. One stated that it was possible to rid one's body of HIV during an early stage of infection via urine and sweat and suggested exercising, drinking, and spending time in the heat as a self-treatment measure. When asked to evaluate the vignette, a number of participants saw it as plausible, despite having been told in numerous school health education classes and events that HIV was incurable. Yet, during interviews, students without biological knowledge came up with analogies, folk beliefs, and personal experiences that, to them, suggested possibility of an exception to the rule. For example, some participants referred to the idea of "flushing one's system" and thus ridding it of diseases.

Depth of conceptual knowledge or the lack of it played a role in the students' tendency to accept the vignettes. The authors characterized participants' HIV knowledge into three models: naïve, intermediate, and advanced. Model assignment was done on the basis of understanding of the underlying biological principles and processes of HIV (e.g., viral use of host cells for reproduction). The naïve model involved knowing that HIV is a sexually transmitted infection, but without any understanding the biology of its transmission or progression, apart from the fact that it "gets into the body" and makes one sick. The intermediate model involved understanding that HIV is a biological entity, which enters with bodily fluids and affects the immune system. The advanced model involved knowing that HIV is a virus that entered T-cells of the immune system and destroyed them by taking over their reproductive mechanism. The study found that while a number of students with naïve and intermediate models of HIV knowledge accepted the inaccurate statements in the vignettes as possible, none of the students with advanced models did. This happened because students at the advanced level of understanding used qualitatively different reasoning patterns, and were able to pinpoint and confront inaccuracy on the cellular level. The other knowledge models did not provide a robust foundation for such reasoning.

Other cognitive studies similarly suggest that superficial knowledge does not provide a robust basis for reasoning with multiple information streams (e.g., naïve childhood views, traditional beliefs, sensational claims). For example, Sivaramakrishnan and Patel (1993) found that formally educated Indian-Canadian mothers simultaneously held two very different health belief systems. One of these systems is grounded in formal biological concepts received through the educational system. The other is a traditional holistic North Indian system of health beliefs that views illnesses in terms of imbalance of humors, or four basic substances of the human body. When asked to discuss childhood nutritional deficiencies, these mothers used standard biomedical terminology, but interpreted disease causality and suggested treatments that corresponded to the traditional holistic system.

In another, recent, study, Zeyer and Sidler (2015) presented young Swiss student teachers in the age group targeted by HPV vaccination guidelines with a vaccination flyer that is often promoted in Swiss schools. The flyer contained information about prevalence and severity of cervical cancer and HPV vaccine's effectiveness and safety information commonly included in health promotion materials. The study found that reviewing the flyer did not affect the participants' negative or ambivalent view of HPV vaccination. Moreover, negative or ambivalent views of vaccination were often connected to misconceptions that could not be addressed by provision of superficial facts and required an in-depth discussion of the biological foundation. For example, one common misconception involved a concern that the attenuated (weakened) virus in the vaccine could somehow revert to its active virulent form and cause cervical cancer.

The cognitive studies connecting biological knowledge and reasoning about health are not conducted with patients and do not measure health behaviors and outcomes. They, however, present a plausible pathway from insufficient conceptual understanding to information behaviors and decisions. For example, mothers who interpret childhood diseases in terms of an imbalance of forces may be more likely to forego evidence-based treatments in favor of traditional remedies. Similarly, young women who believe that HPV vaccine may cause cervical cancer may choose to avoid vaccination for that reason. Keselman and colleagues also demonstrated that insufficient conceptual knowledge may be associated with suboptimal information behaviors. For example, superficial knowledge of health facts may prevent individuals from navigating to relevant health information on the Web (Keselman et al. 2008), understanding objectives/potential relevance of clinical trials, and interpreting doctors' notes (Keselman and Smith 2012).

The studies described above suggest that conceptual knowledge provides a more robust basis for reasoning about health in real-life situations than knowledge of isolated facts. This implies that foundational health-related knowledge taught in science classes may be beneficial to health education. Yet, actually reaping the benefit may be contingent upon making the connection explicit and meaningful, or the potentially relevant scientific knowledge may lie dormant. As an illustration of this, Keselman et al. (2015a) asked two groups of 3rd and 4th year undergraduate college students, biology majors and students who never took science courses for science majors, to agree or disagree with frequently held, but often inaccurate, health beliefs and explain their judgments. They found that for all but one belief, biology majors did not differ from non-majors in the accuracy of their assessment. Demonstrating how formal biology education can be divorced from everyday reasoning, students from both groups were equally likely to agree or disagree that it was impossible to contract a sexually transmitted disease from a toilet seat or that humans only used 10% of their brain. The study also found a small, but significant association between advanced-level biological reasoning and accuracy in evaluating the beliefs, supporting previous findings that biological reasoning is useful when employed in daily life. At the same time, in another study, Keselman et al. (2007) demonstrated that a biology-based HIV education curriculum taught in a middle school science classroom improved adolescents' ability to dismiss plausible HIV myths as inaccurate. The curriculum explicitly connected HIV to the learning units about microorganisms and bodily systems.

6.4 Benefits of Health Education Beyond Personal Health

So far, we have focused on health information and knowledge as they pertain to functioning of isolated individuals. Yet, both science education and health practices exist in society. Their success often depends on social factors, and their outcomes have an effect beyond the individual. In the field of science education, the prevalent philosophy is that it is essential to deliver quality science education to all students regardless of their future careers. This is grounded in the belief that scientific knowledge is essential for informed citizenship (Zeyer and Dillon 2014). In discussing the content of scientific knowledge that is essential to civic life and, therefore, should be taught in schools, Fensham (2012) pointed out that the most pressing socio-scientific concerns of the twenty-first century can be categorized into two large themes, environment and health. Indeed, lists of key scientific challenges and opportunities compiled by major professional organizations (e.g., US National Research Council, American Association for the Advancement of Science, The Gates Foundation) include issues such as mediating the impact of climate change on societies, controlling infectious diseases, improving nutrition and childhood vaccination, and addressing drug resistance (Fensham 2012). While scientific research and practice relevant to these issues are carried out by highly trained professionals, the policy agenda and priorities are affected by informed citizens.

The support of citizens is essential to reduction of social determinants of health disparities, mitigation of climate change and its accompanying health effects, ethical implementation of cutting-edge biotechnologies, and more. In order for education to contribute to informed citizenship, it needs to provide reasonably deep conceptual knowledge that is practically and culturally grounded and explicitly linked to social action. Science and health education for informed citizenship also need to incorporate teaching communication, leadership, and advocacy skills, essential to knowledge application. They should also emphasize community connectedness, inspiring students' motivation to become advocates.

If social perspective is important to health education for informed citizenship, it is also important to health practices and outcomes within communities. Most health behavior models recognize the importance of culture and social support in individual health behaviors and outcomes (Passche-Orlow and Wolf 2007). Recognizing this, many health information outreach and behavior change initiatives target families and communities, rather than individuals. This is reflected in the popularity of train-the-trainer approach and peer mediation in health information outreach (Warner et al. 2005).

6.5 Actual and Potential Role of Technology

Health information and health information programs—in schools, libraries, clinics, and community centers—precede health information technology. Despite contemporary proliferation of technology, it is entirely possible today to deliver an excellent health information program without employing technology. At the same time, in the era of the Internet, social media, and widespread mobile devices, a very large proportion of lay health information seeking, learning, exchanging, and discussing occurs online. Information technology provides means for increasing reach and reducing cost of health information delivery, as well as expanding its scope and innovating the delivery.

6.5.1 Technology as a Facilitator of Quality Information Delivery

To serve as a foundation of meaningful actionable knowledge, health information needs to be accurate, reliable, age-appropriate, engaging, and relevant. In the past, locating and obtaining information resources meeting these requirements could be a formidable challenge for educators. Today, the difficulty is greatly reduced by availability of free quality online information resources. Many federal, educational, and other organizations develop web information materials that aim to deliver health information to adolescents. For example, the National Library of Medicine (NLM) maintains a number of web health information portals, such as GeneEd (https://geneed.nlm.nih.gov/index.php, a genetics information resource for grades 9–12) and Environmental Health Student Portal (http://kidsenvirohealth.nlm.nih.gov/, an online collection of materials for grades 6–8, linking the environment and human health). These resources are specifically designed to support classroom teachers and extracurricular instructors interested in delivering health information by taking away the burden of searching, collecting, and organizing information. The materials included in the portals target building strong conceptual knowledge foundation, as well as providing actionable information for prevention and action. NLM's original and linked resources include a diversity of formats, ranging from traditional informational sites to interactive games and engaging animations. In addition, many general consumer health resources, such as NLM's MedlinePlus consumer health information portal (https://www.nlm.nih.gov/medlineplus/) can be used effectively in health information programs for adolescents.

6.5.2 Technology as a Valuable Skill

While technology-enhanced information access helps youths learn health content, placing them in a position of information consumers, it can also provide the added benefit of giving them an opportunity to be information creators. Creating health information constitutes active, process-based learning, resulting in better retention and understanding (Freeman et al. 2014). Additionally, it equips adolescents with valuable twenty-first century skills and has the potential of integrating health education with technology and art education. The value of learning computer programming and design has been underscored by leaders in diverse human endeavors, including the US President Barack Obama and the inventor of Facebook Mark Zuckerberg. In addition, Common Core education standards, voluntarily adopted by 42 states, emphasize the importance of integrating instruction across subject areas (National Governors Association Center for Best Practices and Council of Chief State School Officers 2010). Health provides a meaningful, engaging domain for developing design and technology skills, even for students who may not be initially interested in technology. Moreover, many current digital design tools allow users to create nearly professional level animations, games, websites, videos, and dynamic presentation after a relatively short learning period (Ahmed et al. 2015).

6.6 NLM Health Information Programs for Adolescents

As part of its mission to reduce health disparities and improve outcome through promoting health literacy, National Library of Medicine has been conducting quality health information outreach programs for different population groups, including adolescents. Each program incorporates some of characteristics of high-impact initiatives, discussed throughout this chapter (e.g., emphasis on communication and leadership skills, use of technology as a creative medium). The remaining part of the chapter describes four of these initiatives.

6.6.1 Med High Peer Tutor MedlinePlus Project

The primary objective of the program was to conduct health literacy outreach to the largely Hispanic population of the Lower Rio Grande Valley community in Southern Texas by engaging high school students as peer tutors (Warner et al. 2005). While the target population was community residents, NLM also expected the student tutors to benefit from the program by developing health information/health literacy and leadership skills. The outreach centered on the NLM MedlinePlus consumer health website. The program was funded by the NLM and implemented by the Regional Academic Health Center (RAHC) of the University of Texas Health Sciences Center at San Antonio (UTHSCSA). RAHC conducted the program at the South Texas High School for Health Professions (Med High), a magnet school offering intensive health related courses with practical components in clinical settings. The program was titled *Med High Peer Tutor MedlinePlus Pilot Project*.

Initially, four high achieving, accomplished Med High 11th-graders with an interest in health and education were selected for training as peer tutors. All four were active leaders in student organizations and effective public speakers. Two students were fluent in Spanish. The RAHC and school librarians jointly trained the students to use MedlinePlus and PubMed websites. The training was extensive, focusing on search techniques for locating health information addressing health concerns common in the local community. Once trained, peer tutors conducted 15 training activities, such as presentations in the school's health occupation classes, student orientation activities, open houses for parents and community members, and training for teachers and administrators, reaching the total of 2000 participants.

The program was evaluated via an extensive mixed methods approach that combined surveys and focus groups, as well as web analytics data for the in-school use of MedlinePlus at Med High. The evaluation found that the program impacted the participants in peer-tutored activities in a number of ways. First, analysis of web analytics suggested increased use of MedlinePlus site on school computers, particularly for topics addressed in training activities. When surveyed, a number of Med High students commented on using MedlinePlus for school projects. Furthermore, about 50% of those surveyed said that they had recommended the site to family members of friends searching for specific health information, and about 30% described using the site for personal health information needs. The program also had an impact on the peer tutors, who talked about greater self-confidence and sense of empowerment that came from being in control of their presentation activities. Peer tutors also talked about greater ease talking to adults and improved presentation and communication skills.

Approaching health literacy as something that best flourishes in a community setting, the program was able to impact a large number of community members via a small number of well-trained, enthusiastic tutors. The program's evaluation team attributed the program's success to three key elements. The first was working with the community and conducting community assessment when developing and evaluating the project. This allowed targeting the program to community health information needs and addressing specific concerns, drawing on adolescents' Internet skills and motivation, and building partnerships (e.g., between the school and the library). The second was using *Diffusion of Innovation Theory* to inform the program's development. The third was empowering the peer tutors by giving them control over the activities and allowing creativity. The program continued into the following year, in an extended form, with 14 students selected for training as peer health information tutors. Its success also made it one of NLM model approaches of community health information outreach to adolescents.

6.6.2 South Carolina Teen Health Leadership Program

The objective of this program was to improve health information literacy, develop leadership skills, and ignite interest in health careers in adolescents living in a primarily low-income minority community (Keselman et al. 2015b). The program, entitled *Teen Health Leadership Program*, or THLP, was funded by NLM and conducted in partnership with the Medical University of South Carolina (MUSC), Communities in Schools national organization, and Charleston County Schools. It was implemented at St. John's High School of Johns Island in South Carolina.

This current program started in 2009. In the first, pilot, year, the program recruited five students. The number of participants grew, reaching 24 students in 2015–2016. The program was conducted during weekly afterschool meetings. A Communities in Schools youth specialist and an MUSC librarian served as coaches. At the outset, students divided into teams, with each team identifying a health concern of significance to their community. Next, students spent some time developing health information literacy skills: learning about quality resources, information seeking, and information evaluation criteria. After that, they used those skills to develop health information resources and conduct outreach activities in their school and the larger community. The resources, developed by students, ranged from flyers, posters and presentations to short films and, most recently, GIS maps of community resources.

In 2014 NLM evaluated the program focusing on two cohorts of participants who graduated in 2012 and 2013. The evaluation objectives included qualitatively describing the program's impact on a number of indicators, including participants' health information literacy, health knowledge, behaviors, leadership skills, sense of community belonging, and career plans. The evaluation was done as series of individual interviews with the program's graduates.

Results suggested that the program had broad impact. Participants talked about their increased ability to find reliable health information and about a sense of empowerment from their ability to share that knowledge with peers and families. They also talked about increased health knowledge and healthier habits, tying changed habits both to knowledge (e.g., realization of the crippling effect of diabetes) and communal practices (e.g., exercising or preparing healthy snacks with other project members).

The program's impact reached beyond information literacy and greater awareness of healthy lifestyle habits. Participants made numerous comments about how THLP increased their confidence and helped them develop leadership skills. Learning about health concerns that plagued their community increased students' sense of belonging and desire to make a change. Participating in community education and outreach thus helped students overcome shyness and provided them opportunities to show initiative, collaborate with others, and practice public speaking. Several students gave examples of how the ability to navigate health information gave them a sense of confidence in interactions with friends and family members, changing their standing in those groups. Participants also learned to see themselves through the prism of positive attention of adults outside their immediate world (e.g., during field trips to the medical school or visit to the National Library of Medicine). Students left these interactions with a sense of empowerment, discovering that they can make their voices and concerns heard, serving as their community's ambassadors. Often quoting the formative nature of their high school THLP experience, all the interviewed THLP participants continued their studies in colleges, often choosing health-related majors. Many also continued seeking out leadership experiences in college and the community.

6.6.3 Student Health Advocates Redefining Empowerment (Project SHARE)

In 2010, the National Library of Medicine funded the Health Sciences and Human Services Library of the University of Maryland at Baltimore to develop a health literacy curriculum for high school students. The aim of the curriculum, which spans six multi-lesson modules, is to "build high school students' skills to reduce health disparities at the personal, family and community level" (http://guides.hshsl.umaryland.edu/projectshare). The coverage includes an overview of health disparities, health information, health communication, and principles of advocacy. The library developed and pilot-tested the curriculum.

In 2015, NLM created a partnership with the National Area Health Education Centers Organization (National AHEC Organization) with the aim to assess the applicability of *Project SHARE* in a range of diverse settings. National AHEC Organization then selected five local AHEC centers to implement a version of the program, adapted to their local context. The centers included those at Boston, Brooklyn-Queens-Long Island, Centennial/Southwestern Colorado, Eastern Connecticut, and Montana AHECs. The locations spanned urban and rural settings with high proportion of populations affected by health disparities, including Native American tribal territories.

Like the other NLM programs, National AHEC *Project SHARE* implementations emphasized adolescents' health literacy, social determinants and community nature of health habits and practices, and active community involvement. Participants learned about health disparities and specific health concerns, common to their community (e.g., diabetes, heart disease). They also learned how to evaluate health information sources and where to search for quality health information. Programs also typically involved field trips and guest speakers introducing participants to health and health information careers. Finally, all programs included projects in which students used their newly acquired knowledge and skills to educate others (e.g., fellow-students, parents, members of the local community). For example, students in Colorado AHECs participated in healthy cooking competitions attended by their parents and visitors to local community centers. The cooking was preceded by learning about nutrition, social determinants of nutritional disparities, and nutrition-related diseases common to the community. Then, students modified popular local recipes to make them healthier. The experience combined "classroom" learning about nutritional ingredients, a practical discussion of costs and conveniences in a local supermarket, hands-on cooking, and hosting a communal meal for adult guests. Students in SW Colorado also produced a PDF cookbook with their recipes.

The project included an NLM-led multi-faceted quantitative and qualitative evaluation aiming to document changes in students' health knowledge, health information literacy, communication and leadership skills, sense of self and community, and career plans. The analysis is under way at the time of writing of this chapter.

6.6.4 *Promoting Health Information Literacy Through Comic Books Design*

The objective of this 2014–16 project was to increase health information literacy skills of high school students by engaging them in developing education comic books for younger (middle school) students (Carson et al. 2016). The project was conducted as partnership between NLM and South Carolina AHEC at three Low-country South Carolina high schools with primarily minority, low-income student population.

The project was delivered as an afterschool club or as a combination of in-class and afterschool activities. At each setting, students received instruction in creative writing and storyboarding, learned about quality health information resources and information evaluation strategies, researched a health issue important to their community, and used low-cost comic book design software to create educational comic books. In the first year, the issues for the comic books were selected by the program staff. In the second year, they were chosen by the students and included smoking and smoking cessation, substance abuse and recovery, and depression (https://www.scahec.net/hcp/comic/currenteditions.html).

Project evaluation by South Carolina AHEC staff suggests that participating in the program increased students' self-reported knowledge of their researched topics and knowledge of quality health information resources and evaluation criteria (Carson et al. 2016) In addition, students also felt that participation helped them enhance their interviewing and public speaking skills and sparked or strengthened an interest in health careers. Most first-year project participants were enthusiastic to return for the second year. All second-year project participants reported having shared information researched during the project with their peers. All said that would recommend the project to others.

6.7 Conclusion

Research studies and educational programs reviewed in this chapter illustrate that health information outreach initiatives can benefit adolescents in a number of areas, including but not limited to health outcomes. They can contribute to understanding health, engender healthier lifestyle habits, improve ability to engage with health information, generate interest in health careers, and support informed citizenship and community advocacy. The present review also illustrates the challenge of assessing the impact of health information on health outcomes. When it comes to the information-health outcomes connection, the glass appears to be half-full, but its exact content depends on the many nuances of the health and informational context.

Health education/information outreach appear to be most effective when they incorporate the following characteristics:

- deliver information in a way that builds conceptual understanding, bridges knowledge gaps, and explains, rather than simply dismisses, misconceptions
- connect conceptual knowledge of foundational aspects of health to "real life" health issues
- aim to engage and impact social and cultural determinants of health and target health information practices at a community level
- involve community outreach /social action
- include opportunities to create authentic products, events, or processes

While a number of quality programs incorporate a subset of the above characteristics, designing a program that incorporates all of them is a difficult challenge. The challenge is largely related to the constraints and conventions of educational settings. For example, a science classroom is a natural fit for deepening conceptual knowledge, which can be extended into a discussion of "real life" health practices. However, as science teachers need to adhere to curricular structure, standards, and testing schedules, they are usually not able to engage students in social action and community outreach in the format of their science classes. Afterschool activities and clubs, on the other hand, have greater flexibility with respect to going out into communities, addressing social determinants of health, and supporting growth of essential "soft skills," such as leadership and communication, but rarely have the structure that is set up for in-depth science instruction.

Growing recognition of the mutual potential benefits of science and health education, as well as the novel emphasis on integrated curricula, hold promise for health education that is both scientifically rigorous and personally and socially relevant. The promise is also upheld by developments in information and communication technology. For example, technology can provide tools for conducting in-depth science instruction in afterschool programs taught by instructors who are not science experts. It can also support developing social action activities and materials, connecting with other relevant projects, creating and publishing information in different formats, and more.

Health informatics has the potential to support health information programs for adolescents by developing e-learning activities, information products and information authoring tools. In addition, it can support research around such health information programs. Presently, program evaluation is a challenge that requires significant cost, expertise, and time investment that are rarely available to community projects. Health informatics can help researchers by providing electronic data collection and analysis tools. A synergy of fields such as cognitive science, education, public health and health informatics have the potential to create health information initiative that would positively impact adolescents' lives on multiple levels, from personal health, to civic engagement, to academic performance.

Discussion Questions

1. What are the challenges in demonstrating the impact of conceptual understanding of health on daily life?
2. How can health informatics support health information programs for adolescents in ways beyond the ones described in this chapter?

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Chapter 7
Using Behavior Measurement to Estimate Cognitive Function Based on Computational Models

Misha Pavel, Holly Jimison, Stuart Hagler, and James McKanna

Abstract The measurement of cognitive performance is important in diagnosing and monitoring interventions for a wide variety of neurological conditions, such as dementias (Alzheimer's, vascular, etc.), multiple sclerosis, Parkinson's disease, and stroke recovery. These risk factors for cognitive decline are further aggravated with advancing age. The encouraging news is that recent research has shown that there is significant neuroplasticity in the adult brain, and that even the elderly are capable of achieving measurable changes in brain organization and function. Maximizing effectiveness of such interventions requires continuous (or at least very frequent), unobtrusive assessment of cognitive functions. This chapter describes how new behavioral informatics with computational models can be used to assess various cognitive functions in the wild and over time using new behavioral metrics, including walking speed, computer interactions and embedded measures in cognitive computer games. This new approach to cognitive monitoring offers substantial improvements over conventional infrequent assessments performed in the clinic. Namely, repeated measures in the home environment offer the ability to measure within-subject trends and potentially detect cognitive problems and intervene at an earlier stage.

Keywords Cognitive monitoring • Assessment of cognitive function • Inference of behaviors • Behaviors • Behavioral informatics • Computational modeling • Computational cognition • Activity monitoring • mHealth

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7.1 Introduction

The Centers for Disease Control and Prevention defines cognitive health functionally by noting that “a healthy brain is one that can perform all the mental processes that are collectively known as cognition, including the ability to learn new things, intuition, judgment, language, and remembering” (Centers for Disease Control and Prevention. Healthy Aging 2016). These functions are of critical importance to individuals’ health, wellbeing, and overall ability to function in society. One might therefore think that the assessment of cognitive functions should be relatively easy. Yet the ability to detect and treat cognitive problems has been extremely challenging for a number of reasons. First, although clinicians can observe an individual’s performance on neuropsychological tests and compare the results to that of a population, there is a great deal of measurement variability both within and between subjects. Second, standard tests are greatly influenced by culture, native language, education and experience with tests (De Santi et al. 2008). Third, physical brain changes and their cognitive correlates can be monitored using imaging techniques such as MRI and PET scans, but the variability among individuals and their functional cognitive performance makes single point-in-time diagnosis very difficult (Dinse 2006; Driscoll et al. 2009). New methods that provide within-subject trends through more frequent monitoring are required to improve care in this area.

The measurement of cognitive performance is important in diagnosing and monitoring treatment for a wide variety of neurological conditions, such as dementias (Alzheimer’s, vascular, etc.), multiple sclerosis, Parkinson’s disease, and stroke recovery. Particularly confounding though is the fact that the brain changes both structurally and functionally with aging, even in the absence of neurodegenerative disease (Driscoll et al. 2009; Salthouse 2009). The shrinking of the parenchyma in the brain can lead to as much as a 10% reduction in brain volume after the age of 80 (Drachman 2006), and the plaques and neurofibrillary tangles associated with Alzheimer’s disease are often found in the normally aging brain (although statistically much greater in number and area in the brains of people with Alzheimer’s (Caserta et al. 2009).

The encouraging news is that recent research has shown that there is significant neuroplasticity in the adult brain, and that even the elderly are capable of creating measurable changes in brain organization and function (Bherer et al. 2005; Colcombe et al. 2004; Beason-Held et al. 2008; Buckner 2004; Kramer and Erickson 2007). With new efforts in the areas of cognitive training for healthy individuals (Vance 2009; Vance et al. 2011; Hagler et al. 2014a; Jimison et al. 2010; McKanna et al. 2009) and optimization of rehabilitation interventions (Kelly et al. 2014), it becomes increasingly important to be able to find more sensitive and reliable measures of cognitive function to guide cognitive assessment and interventions.

This chapter describes an approach to using unobtrusive techniques to obtain behavioral data that can be used to estimate components of cognitive function (such as working memory, divided attention, executive function, verbal fluency and motor speed) over time for individuals in a home environment. The advantage of this approach over conventional neuropsychological exams is that individuals can serve as their own controls and need not be compared to a population. Tracking within-subject trends makes cognitive measures much more sensitive and allows for earlier detection of cognitive problems. Additionally, the approach also provides real-time feedback for dynamic and tailored interventions that can be delivered to the home. Having sensitive measures of cognitive performance would enable us to optimize coaching and eventually even support the development of drug-based therapeutic approaches.

One of the major benefits of the unobtrusive, continuous monitoring approach we describe in this chapter involves the capability to gather large amounts of baseline data for each individual. The availability of the individual baseline data allows for the early detection of subtle changes indicating potential decline, thereby leading to early intervention. To leverage this approach to the fullest requires a quantitative theoretical framework and specific models that can relate the observable aspects of behavior to the underlying cognitive functions.

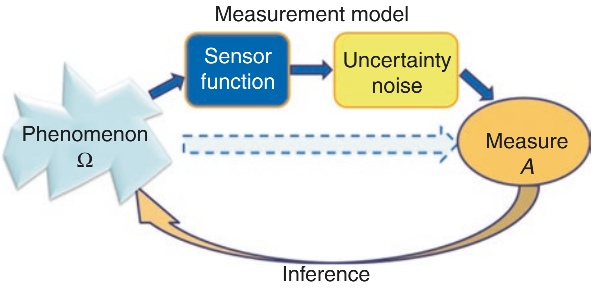
In this chapter we describe model-based approaches used to analyze behaviors in a number of examples, ranging from unobtrusive monitoring of speed of walking to embedded metrics in adaptive cognitive computer games. For each example, we identify the target cognitive function, the underlying computational model and the results obtained thus far. Before we consider these examples of individual function, we will first describe the underlying theoretical framework.

7.2 Measurement: Model-Based Approaches

Measurement involves the ability to capture properties of objects and events by mapping them to a numerical representation. In general, the basic notion of measurement involves mapping a phenomenon of interest to numbers in a way that relationships and functions within the phenomena map into the operations within the numerical sets. For example, when we measure length (one of the most elementary measurements) (Krantz et al. 1971; Roberts 1985), each object is assigned a number that represents its length. Like numbers, two lengths can be compared, and the addition of two length measurements corresponds to a combination—or concatenation—of the two corresponding objects. Based on this "additivity" principle, we can measure objects by taking a very short object as a ruler and concatenate many copies of this small object. This principle has been used in psychophysics to construct psychological scales. For example, we can concatenate just-noticeable-differences (JND) to form perceptual scales for phenomena like stimulus intensity.

A specific model to measure a cognitive function is constructed by combining understanding of the underlying physical, biological and psychological principles with empirical data. In most situations, the parameters of the measurement function cannot be estimated directly. Rather, the phenomenon of interest must be transformed to quantities that *can* be measured as shown in Fig. 7.1. Formally, the

Fig. 7.1. Measurement process



phenomenon of interested Ω, e.g., memory size, is typically sensed indirectly and mapped to a numerical set A $F:\Omega \rightarrow A$ such that the measurement function reflects relationships in the phenomena in the numerical set.

The key concept illustrated in Fig. 7.1 is that the mapping from phenomena to numbers requires a model of the measurement transformation. For example, even an apparently simple measurement of the mass of a human body requires multiple transformations from mass to force, and then from force to displacement. The measurement process in this example requires at least two models involving laws of physics. For example, body mass m is converted to force f with $f=m\times g$ (where g is the gravitational constant), and then secondly force is converted to another quantity, such as distance, that can be measured directly. The models can become more complex for biological and physiological phenomena, but that makes it even more important to formalize the model. For example, when we ask for a subjective judgment about aspects of subjects' states, e.g., self-efficacy using a Likert scale, we need to make explicit our assumptions about the resulting measurements; at a minimum, we must indicate whether we are dealing with interval scales or transformed interval scales.

Another fundamental modeling issue involves the representation of uncertainty that generally arises from two sources: (1) the measured phenomenon may have inherent uncertainty, and (2) the measurement process may introduce uncertainties, i.e., measurement error. A typical goal of a measurement process is to reduce the measurement uncertainty by methodology or by repeated measurements. In contrast, the inherent uncertainty may frequently be an actual property of phenomena. For example, variability of gait (Hausdorff 2007) or heart rate variability (Thayer et al. 2009) are important indicators of an individual's heath state. In either case, it is very important to incorporate uncertainties into measurement models to assure proper inferences (Falmagne 1980).

Measurement-based approaches have been used extensively in perceptual and motor domains to characterize the internal representations of perceptual phenomena such as sound or light intensity, frequency, etc. The corresponding internal scales were developed in part by incorporating information from just noticable differernces (JNDs) as a function of the independent variable. The results leverage various empirical regularities, for example, that JNDs increase smoothly with the intensity levels and, to the extent that these functions are linear, they are frequently characterized in terms of Weber's Law (Fechner 1966). Such regularities are not limited to perceptual processes, but are also representative of cognitive and possibly affective functions (Moyer and Landauer 1967; Longo and Lourenco 2007) and extended to generalization processes (Shepard 1987). We hypothesize that the principles of measurement can be extended to characterize many psychological processes and provide examples of these approaches in the subsequent sections.

The theoretical framework for measurement, captured by the theory of measurement (Krantz et al. 1971; Roberts 1985; Coombs et al. 1970), is beyond the scope of this chapter, but the principles of measurement underlie the efforts of assessment and inference. The remainder of this section will describe the limitations of existing approaches and then illustrate the more informative, model-based approaches using specific examples.

7.2.1 Existing Approaches to Cognitive Assessment and Their Limitation

As noted in the introduction, existing approaches to clinical assessment of cognitive processes have their roots in the first half of the last century and were developed under two important constraints. The first constraint was the limited technology available at the point of testing, even if the tests were administered in a clinic. With a few exceptions, the original mode of the test administration was, therefore, paper and pencil, and the tests were performed in the presence of a trained clinician armed with a manually operated stop watch. The measured aspects of performance were often limited to the number of errors and the total time (measured manually) that a participant took to complete the test, as noted in our later description of the Trail-Making Test. It has been observed empirically that these test results are variable across multiple administrations, even if separated by sufficient time intervals to reduce learning effects. Unless the potential learning effects are modeled explicitly, repeated administration of these fixed paper-and-pencil tests in order to reduce standard errors by combining results is questionable (Nesselroade 1991; Sliwinski 2008). Even this approach has shortcomings, as it does not directly assess the within-subject variability. As it turns out, analysis of variability is not only important for detection of changes, but also because increases in variability in performance over time have been linked to neurological dysfunction (Kliegel and Sliwinski 2004; Charles and Pasupathi 2003).

The second constraint was due to the limited understanding of the underlying neuropsychological processes and lack of techniques for accurate quantitative characterizations of human cognitive and neuropsychological processes. This knowledge gap regarding the use of high resolution data has, in part, been responsible for the clinical community often not taking full advantage of potentially useful measurements from recent computer-based implementation of a subset of the paper and pencil tests, e.g., (Zelazo et al. 2013). For example, performance on the well-known and very useful Trail-Making Test (TMT) is typically summarized by the overall completion time and the number of errors. Consequently, the results and interpretations of the tests are typically limited to estimation of correlations between the test scores and the traditional clinical assessment. As we will illustrate in the subsequent sections, it is possible to make significantly more specific inferences of cognitive and sensory-motor processes by recording fine-grained performance data combined with computational modeling.

7.2.2 Computational Model-Based Approaches

To mitigate some of the shortcomings of the traditional approaches, we developed computational (mathematical) models that can relate the unobservable characteristics of cognitive functions to observable and measurable features of the individual participants. The modeling approaches to interpreting data have many advantages. In essence, these models relate observable data to a small set of parameters whose value is estimated by fitting data to the predictions of the models. The resulting optimal parameter values are then used to represent the properties of the underlying cognitive processes. For example, the efficiency of the search process in the TMT can be represented by the amount of time spent per searched item.

It is important to note that the ability to represent empirical data in terms of a small number of parameters (degrees of freedom, *df*) embodies very important advantages of the model-based approach. In particular, a model with low *df* typically results in a significant increase in statistical efficiency relative to empirical summaries of the same data. An effective computational model can account for (predict) many observations with a small number of parameters. Consequently, a model that has a small number of parameters needs a smaller number of observations to make good predictions. By the same token, it needs fewer empirical observations to estimate its parameters to a given degree of accuracy and characterize the underlying processes. For example, a single parameter—e.g., a "buffer size"—may be able to represent an individual's short-term memory with sufficient accuracy to account for that individual's performance. Before we discuss specific examples of the model-based approaches, however, it is useful to describe two general approaches to modeling: (1) the data-driven and (2) the mechanistic model-based approaches.

Data-Driven Models of cognitive processes are based on purely empirically-motivated modeling. The model structure is determined *a priori* based on mathematical convenience and the ability to capture the empirical data. These models include more traditional linear and nonlinear regression, logistic regression, ANOVA, reduction of dimensionality (principal component analysis, factor analysis, multidimensional scaling), clustering (mixture models, hierarchical clustering schemes), classification and regression (maximum likelihood and Bayesian approaches, artificial neural networks), and time-series analysis (Kalman filters, hidden Markov models) etc., as well as more recent machine learning approaches, such as support vector machines and random forests. Using the machine-learning approach to modeling, the empirical data set used for training is typically divided into three subsets (the training, validation and testing data sets) in order to optimize performance without overtraining the model (Hastie et al. 2011).

The resulting data-driven models are typically capable of accounting for the training data as well as for those unseen data whose distributions are well captured by the training set. Performance outside of the training data sets, however, is unpredictable. Consider for example a simple linear regression between a number of items in memory and the probability of remembering up to four different items. This relationship may well appear to be linear for up to four items, but the linear prediction may fail as the number of items increases beyond four.

Mechanistic (Process Models) of cognitive processes are based on various information processing and neurophysiological constraints. Computer science advances over the last 50 years have provided ideas regarding the structure of information processing models. Among the most influential was the early work of Newell and Simon (Newell and Simon 1972) proposing deterministic approaches. Their computer processor analogy was later extended by many to account for the probabilistic nature of human information processing (Shiffrin 2010). Even models that were originally strictly rule-based, e.g., ACT-R, have more recently been amended to incorporate uncertainties and relate the operations to physiological measurements (Borst and Anderson 2015). A number of alternate approaches have been proposed over the years, e.g., neural network models, whereby attempts were made to relate cognitive processing capabilities to neuronal structures (Rumelhart et al. 1988a; Rumelhart et al. 1988b).

The general approach in the development of mechanistic models involves considerations of known characteristics of the cognitive processes to be modeled and the selection of a plausible architectures that can rendered as a parametric model. The parameters are then estimated in a similar way to that of the data-driven approaches. To the extent that the mechanistic models represent the underlying processes, they may be more likely to generalize beyond the training data sets and be more accurate. It is important to remind ourselves that models are only approximations of the mechanisms–as expressed by George Box: “Remember that all models are wrong; the practical question is how wrong do they have to be to not be useful.” (Box and Draper 1987).

7.2.3 Incorporating Context and Data Science

An astute reader will note that the proposed approach to monitoring in the wild without a controlled environment will be exposed to various interfering factors from the environment and general context of the monitored activity. Therefore, during the interpretation of the data it is important to incorporate context. Although there has been considerable amount of work on context (Dey et al. 2002) the recognition and incorporation of context is still a major open question. Context typically refers to information or variables that affect the interpretation of measurement but are not essential variables. In experimental design, we frequently refer to these as confounding variables and attempt to control or randomize their effect. One of the issues hindering a rigorous definition of context is that it is task dependent (Bettini et al. 2010). A given variable may be an independent variable of interest in one task, and context in another. For example, a participant's activity level may be the key variable in measuring energy expenditure, while it is a contextual (confounding) variable in detecting heart beat anomalies.

The effects of context are particularly important for monitoring and assessment in real-life situations. Since it is impossible and undesirable to completely control contextual effects, it is important to reduce their effect by either averaging observations or by assessing and inferring context.

7.3 Game-Based Assessment

An obvious and direct way of monitoring individuals that has become popular in recent years is through the use of computer games. These games offer the opportunity to vary the difficulty and diversity of tasks while providing a self-motivating environment for the participants. As we have noted previously, some of the fundamental limitations of traditional cognitive tests involve our inability to administer them repeatedly over short periods of time, due to the fact that these tests do not change (i.e., they can be practiced and learned, rendering them ineffective). Additionally, these static tests are quite boring, must be interpreted by highly-trained experts, and give a limited amount of (often subjectively-interpreted) information. Computer games offer an excellent opportunity to overcome each of these obstacles. They can change implementations while keeping the fundamental rules of interaction the same, providing novel challenges each time. They are fun to play, and thus people are willing to engage with them on a daily or weekly basis for long periods. This allows for frequent, regular assessment opportunities, resulting in useful data for modeling the details of cognition, taking into account individual trends rather than simply comparing performance to population averages. The individuals' performance can be parametrized and statistically evaluated, and the difficulty of each individual task can be altered based on previous performance by the player. Finally, a well-defined basis for task rules and their relationship to cognition means that the system itself can provide a detailed cognitive characterization based on player performance, allowing for large savings in time and money relative to trained clinician visits.

To this last point, it is important to note that game score (and indeed, mere performance on the game) is often insufficient to characterize the cognitive ability of the player. Game score is a player-facing motivational (or training) tool, to help make the game more fun, encourage the player to get to the next level, or reward the player for incorporating a more complex tool or strategy within the game. While related to cognitive ability, these rarely share a 1:1 relationship, because game performance often does not take difficulty into account. Most "serious" games, or games for impact, are designed to keep players at a motivating, yet challenging, level of performance (Bogost 2007). This is accomplished by varying the difficulty of the tasks—making them easier when the player fails, and making them more challenging when the player learns to overcome the current set of challenges. Thus, without being able to accurately incorporate the relative difficulty of each of the tasks within the game into the cognitive model, performance alone gives a very poor picture of the underlying abilities.

Although "serious" games have been used in a number of projects to assess and even train cognitive skills, many of these attempts have either produced well-controlled but not motivating games (Anguera et al. 2013; Mahncke et al. 2006) or have used highly-motivating off-the-shelf games that were less well controlled and thus produced less interpretable results (Castel et al. 2005; Green and Bavelier 2003). The approach discussed in the next several sections focuses on the assessment of cognitive functions using interactive cognitive computer games. A key distinguishing feature from other similar efforts is the use of computational models of the underlying cognitive phenomenon to transform raw performance data to clinically meaningful parametrization. In the following sections, we describe some detailed approaches to inferring estimates of individuals' cognitive functions from computer games.

During the last decade, researchers and game developers have begun to appreciate the ability of computer games to affect cognitive and motor behaviors (Green and Bavelier 2003), and the potential of computer games as platforms for assessment and training (Ifenthaler et al. 2012; de Freitas 2006). Games specifically designed to approximate laboratory or clinical measurements or remediation exercises (Smith and Trenholme 2009; Ball et al. 2002), including our "Scavenger Hunt" game (Hagler et al. 2014b), often sacrifice elements that make a game fun to play. Games that are fun to play, on the other hand, introduce a variety of complexities and uncertainties that render the scores difficult to interpret in terms of the underlying cognitive functions.

7.3.1 Memory Game: Working Memory and Updating

With its storage and updating processes, working memory is clearly one of the most important cognitive functions, supporting individuals in almost all aspects and tasks including the activities of daily living. Among the most important functions of working memory is the updating ability (Morris and Jones 1990), that is, the ability to monitor and represent incoming information and delete or replace information that is no longer relevant to the task. As such, updating has been suggested to be an important component of fluid intelligence (Cattell 1963; Engle et al. 1999; Salthouse et al. 2003), although often only weakly correlated (Salthouse et al. 2003). The key role of working memory provides a strong motivation for its characterization and frequent monitoring.

Unfortunately, currently accepted neuropsychological pencil-and-paper tests are typically administered in a clinical setting by trained clinicians, making them quite costly and infrequent. In addition, since they have been normed on a fixed set of stimulus material, frequent and repeated exposure would lead to distorted scores or require explicit models (Nesselroade 1991; Sliwinski 2008), and even this approach lacks the ability to assess variability that may be related to neurological dysfunction (Kliegel and Sliwinski 2004; Hultsch et al. 2000).

As a consequence of these issues, most neuropsychological tests are rarely used in practice; instead primary care providers often use a very simple and limited test called the Mini-Mental State Examination (MMSE) (Folstein et al. 1975). This is a very short and simple test (Jones and Gallow 2000) designed to detect a serious cognitive decline with simple questions such as "what is today's date?," the location of the office visit, etc. The MMSE has a high specificity regarding cognitive decline, but it is very insensitive due to a substantial ceiling effect. In addition, the results depend on a variety of socio-economic and cultural characteristics of the tested individuals (Niewenhuis-Mark 2010). Since the computerized versions of this test generally do not provide any additional information, they suffer from shortcomings similar to those of their clinical counterparts (Wild et al. 2008).

In contrast, a computer game that can enhance motivation, increase and control stimulus complexity and provide variable challenge has the potential to become an important monitoring tool. One example of such a game designed for aging adults is the memory game "On the Flipside," with a sample screen shown in Fig. 7.2. This

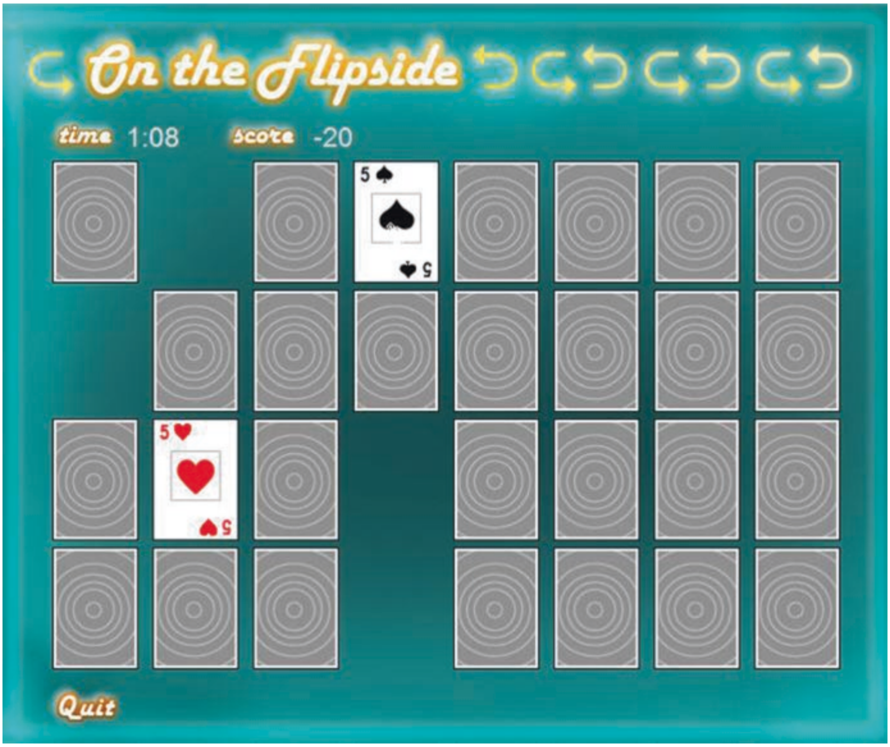


Fig. 7.2. A screenshot of the Memory game

game is designed to mimic the well-known card-matching game known variously as "Concentration" or "Memory." Play starts with a grid of face-down cards; at each turn (on each trial), the player turns over two cards. If they match, the score increases and the two cards are removed. If not, the two cards are turned over to the initial position. In order to make the game more challenging, the card face values as well as the definition of what matches can be manipulated. In addition to the standard playing cards, the set of cards in our implementation of the Memory game includes images of domino pieces, clocks, etc. This allows us to test more abstract matches such as matches between analog and digital clocks time displays.

The participants' performances depend in part on chance, but also on the difficulty of a particular round and on their ability to remember previously seen cards in the current round—ignoring those seen in prior rounds. The difficulty of this game can be manipulated by the size of the card array (number of cards), the number of possible matches and the probability of exposing a previously seen card on a location that has not yet been exposed. These difficulty metrics are manipulated over a sequence of rounds to provide participants with a challenging but not frustrating experience.

While the game score for each round contributes a motivational aspect, a model-driven approach to analyzing fine-grained behavioral details provides a window to the underlying cognitive processes and allows us to assess specific aspects of the skill levels over time. The Memory game can be approached in two ways: modeling the response times and modeling working memory performance. Using behavioral measures directly is necessary because the raw scores are contaminated by a variety of gaming-related effects including chance. As in any experimental or real-life task, there is always the possibility of a speed-accuracy tradeoff. In addition, speed of processing, undoubtedly an important component of cognitive function, is likely to be reflected in the response times. We therefore account for both speed and accuracy to illustrate the type of analysis that is necessary to characterize the underlying mechanisms of cognition.

Modeling response times typically requires a detailed task analysis for correct attribution of time delays to specific processes. We illustrate this approach using a model of the Memory game, shown in Fig. 7.3a, that comprises two statistically inde-

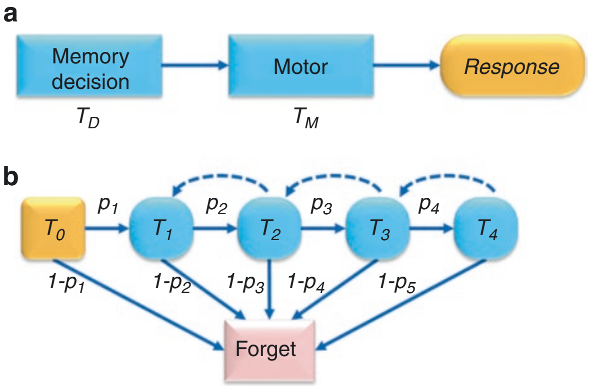


Fig. 7.3. Model of the processes operating while playing the Memory game. The temporal model is shown in (**a**) and the state transition model for an item in (**b**). The *dashed arrows* show a possible extension of the model

pendent stages: (1) decision and updating, in which the subject decides which card to flip, and (2) motor, in which the subject moves the mouse and clicks on the card. The model is based on a long tradition of decomposing complex processes into a small number of additive stages (Hagler et al. 2014b; Donders 1869; Sternberg 1969).

The Decision and Update stage is characterized by the *decision time* T_D—a random variable—required by the player to decide which of the face-down cards to select. The distribution of T_D depends on a number of game characteristics as well as on the instantaneous state of the board and the player's memory.

The motor stage is characterized by the *motor time* T_M, a random variable representing the time the subject takes to move the mouse to the chosen card. We assume that each movement of the mouse, on average, obeys Fitts' law (Fitts 1954; Fitts and Peterson 1964; MacKenzie 1989) in that during a movement toward a card whose center lies a distance D away and has a width Walong the direction of motion, the expected movement time is given by: $E\{T_M\} = a + b\log(D/W + 1)$. The value $\log_2(D/W + 1)$ can be interpreted as the amount of information (in bits) the subject must process to complete the movement; in that case, the parameter b measures how much time the subject spends processing each bit of information. The motor parameters a and b, therefore, characterize the subject's motor performance in terms of how quickly the subject can move a mouse pointer or finger to the card.

The actual working memory performance is characterized by a leaky buffer in which each item's state can be described by a model illustrated in Fig. 7.3b. In this model that generalizes prior versions (Cowan 2000), the probability of forgetting at each stage may depend on the stage, i.e., the number of events since the item was seen. Although the actual values of the transition probabilities must be determined empirically for each individual, the probability that a card seen t moves ago remains in memory can be well approximated by a Weilbull distribution of the form $P_{remember}(t) = \exp(-(t/\nu)^k)$, where ν and k are parameters. An interesting aspect of this formulation is analogous to survival analysis in that the dependence of the forgetting parameters $1 - p_t$ on t can be described by the corresponding hazard function that indicates the probability of forgetting an item at time (or move number) t given that it has been in memory until time t. For example, if all the probabilities p_t were identical, the forgetting curve would be exponential, and the hazard function would be constant.

Prior to an attempt to use this model to characterize individual players, it is necessary to consider responses that are due to guessing rather than remembering. For example, if there are three cards left on the board, the correct card can be chosen by chance with probability 1/3. To correct for this type of chance effect, we need incorporate a model for guessing $P(t) = P_{guess}(n) + [1 - P_{guess}(n)]P_{remember}(t)$ where n represents the state of the board. In practice, the estimation of $P_{guess}(n)$ may require a more sophisticated analysis, as the player may remember some of the cards, and the probability of randomly choosing the correct card may be $P_{guess}(n) > {}^{1}\!/_{n}$.

In order to demonstrate the model-based approach described above, we asked 30 older adults (25 female and 5 male, age 80 ± 6.0 years) to participate in longitudinal study by playing computer games using their home computers (Jimison et al. 2004; Jimison et al. 2007). Following informed consent and a series of neuropsychological tests, the enrolled participants were encouraged to play as many games as they could

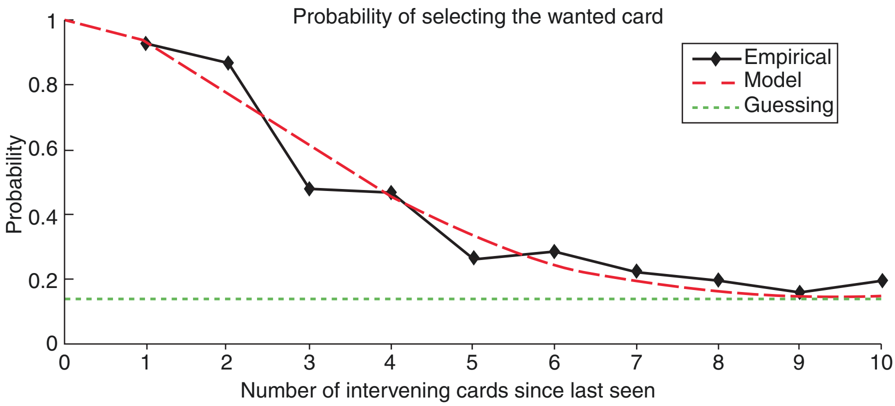


Fig. 7.4. Probability of selecting the wanted card for a single subject. An empirical estimate of the probabilities (*black*), the probabilities according to the model with guessing included (*red*), and the estimated contribution of guessing the correct card (*green*) are indicated

over a period of one year. The neuropsychological tests were repeated at the end of 6 months and then again at the end of the year. We restricted our data analysis to those participants who played at least a minimum number of rounds throughout the monitoring period. This reduced the cohort to 19 individuals. A discussion of the details of the analysis is beyond the scope of this chapter, but we will highlight some of the results.

Figure 7.4 shows an example of the probability of a particular participant recalling a card after the number of intervening events (card flips) shown on the abscissa and the corresponding Weibull fit. The buffer size derived from the parametric representation of the Weibull fit for this participant is 3.0 cards, and the individual's hazard function is approximately constant, suggesting that an exponential model would also account for the data. By monitoring and tracking changes in this estimated working memory buffer length for an individual over time we are able to detect within-subject trends that may be useful in providing earlier detection and intervention.

7.3.2 Divided Attention

Attention (including both focused and divided attention) is critical for almost every cognitive action we take. Focused, or selective, attention can be thought of as the ability to focus on a single relevant stimulus, or a single stream of such stimuli, while excluding other (less relevant) stimuli. Without this skill, cognition would quickly be overwhelmed by the simple amount of stimuli present in the environment, and we would be unable to function. Divided attention describes the ability to attend to multiple tasks, or multiple parts of a task, either simultaneously or by switching back and forth fast enough that the measurable effect is the same. This cognitive skill is highly associated with driving ability (Ross et al. 2009; Mathias and Lucas 2009; Parasuraman and Nestor 1991; Brouwer et al. 1991), and as such is critical to independence in the aging population. In the U.S., with many homes being far from services and public transport being rare or nonexistent in great swaths of the country, the loss of driving privileges with aging is associated with loss of social structure, increased isolation, and hastening of physical (as well as cognitive) decline (Oxley and Whelan 2008).

Divided attention is one of the skills which declines earliest at the onset of cognitive decline (Scalf et al. 2007); this makes it ideal to use as a screening tool for more generalized cognitive decline that might lead to Alzheimer's or other forms of dementia. The loss of divided attention skill is also highly associated with other age-related risks, including falls (Verghese et al. 2002) and the onset of Mild Cognitive Impairment (MCI), often a precursor to Alzheimer's Disease (Parasuraman and Nestor 1991; Sarter and Turchi 2002). Although there are numerous experimental approaches to the assessment of divided attention, few tools exist to measure it in real life. Accurate measurement of variability in this skill over time, relative to a patient-specific baseline, would allow inference of other forms of cognitive decline, most importantly those leading to MCI or Alzheimer's Disease. Further, divided attention is a cognitive skill that is ripe for computerized assessment and modeling. The test frequently used by neuropsychologists to measure divided attention (Trail-Making Test B) additionally measures processing speed, executive function, planning, short-term and working memory, as well as visual and auditory comprehension (Mathias and Lucas 2009), making it far from an ideal and specific test for divided attention alone.

For the purposes of detection and modeling, divided attention is one cognitive skill particularly engaged by (and demanded of) players of modern "first-person shooter" (FPS) games. Green and Bavelier showed that college students who enjoyed playing FPS games had significantly greater divided attention skill, as measured by the Useful Field of View test, than those who played non-FPS games or those not playing games at all (Green and Bavelier 2003). As one might expect, they found that the most important features of a game for assessment of divided attention are the speed of the game and the predictability of the stimuli (Green and Bavelier 2007). These findings were later shown to be true for other age groups as well, including those over 65 (Belchior 2007). As casual games often appeal to a wider audience than FPS games (Gander 2013), our own work has focused upon divided attention monitoring in a casual game environment. We developed a game called 21 Tally (see Fig. 7.5), which is a puzzle game involving blackjack played in two dimensions simultaneously. A player is shown a four-by-four board containing a certain number of cards and empty spaces, and must decide in which of these empty spaces to place the next card in the deck, shown off to the bottom-left of the board (as in Fig. 7.5). When this next card is played, rows and columns totaling 21 will score positively, while those summing to more than 21 will score negatively (bust). Thus, for each new board, the player attempts to obtain as many totals of 21 in rows and columns as possible while receiving as few over-21s (busts) as possible. New boards are shown for a certain period of time (the "stimulus period"), as in the left side of Fig. 7.5, after which they are flipped face-down (as in the right side) to await player response. During the game testing we used algorithm-generated boards that were designed to emphasize divided attention; specifically, each one had equal numbers of cards and empty spaces (eight each), contained no aces (to avoid confusion between scores of 1 and 11), had only one best answer, and required decisions in one or both directions. The stimulus period was varied utilizing a staircase algorithm to determine the point at which participants could answer 50% of the boards correctly.

Fig. 7.5. Two screenshots from "21 Tally." *Left*: stimulus, displayed for a certain duration based on the participant's previous correct or incorrect responses. *Right*: awaiting response, in which the participant could see card placement but nothing else. Note that there were equal numbers of cards and blank spaces, and that there was only one best answer (in this case, the bottom right corner, which will not bust in either direction)

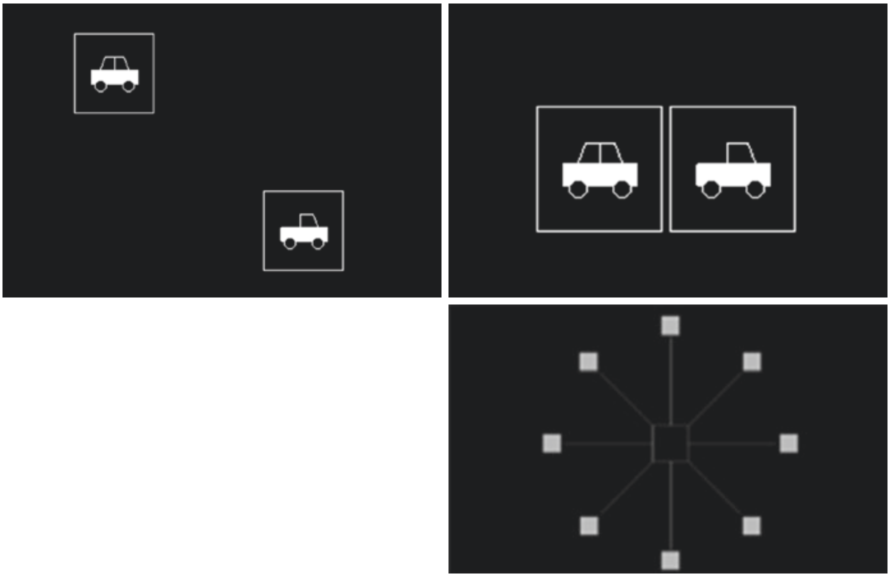


Fig. 7.6. Useful Field of View subtest 2 (divided attention) screenshots. *Left*: stimulus, which appears for a duration determined by the staircase algorithm, eventually approaching the 75% accuracy duration. *Top right*: query page waiting for a response as to which shape was in the center. *Bottom right*: query page waiting for a response as to the location of the car on the periphery

The Useful Field of View test (and particularly subtest 2, or UFOVs2) is one of the standard tests of divided attention that has been shown most highly correlated to driving ability in older participants (Ball 1997; Clay et al. 2005). This test involves the simultaneous presentation of a central and a peripheral image, as shown in Fig. 7.6. The central image is either a truck or car, and the peripheral image (always a car) is in one of eight locations (the cardinal and semicardinal directions). After seeing both images presented, the participant must identify which image was presented in the center and where the peripheral image was located on the screen. The stimulus presentation duration is decreased if the participant gets both answers correct and increased if either is incorrect, in a staircase algorithm designed to converge on the duration needed for the participant to achieve 75% accuracy. This stimulus duration is the score for the UFOVs2 test.

Regardless of correlation to driving ability, this is a poor method for measuring divided attention ability, because it conflates divided attention with simple speed of processing. That is, a person with good divided attention ability but poor speed of processing might get a similar score to a person with good processing speed but poor divided attention ability, since the only score is a stimulus duration involving accuracy on both tasks simultaneously. A better way to determine divided attention ability is to vary the difficulty of each task independently, and use the scores obtained during configurations where only one task is difficult to predict the score when both tasks are difficult. In such a test, participants with high divided attention ability will have duration thresholds that closely approximate their predicted values if performing both tasks independently, while those with lower divided attention ability will have higher thresholds since they require more time to account for the division of attention between the two tasks. Thus, the larger the interaction between the two tasks as difficulty increases, the lower the participant's divided attention ability. This removes the confound of speed of processing across subjects, since we relate the speed at which each task configuration was performed only to the speed at which other configurations were performed by the same subject.

Comparing the performance of participants across age groups on the 21 Tally game and the UFOVs2, varying the difficulty of each individual task independently, we found a large correlation (Pearson's r = 0.89) between the magnitude of the interaction between the two tasks as difficulty increased in each.

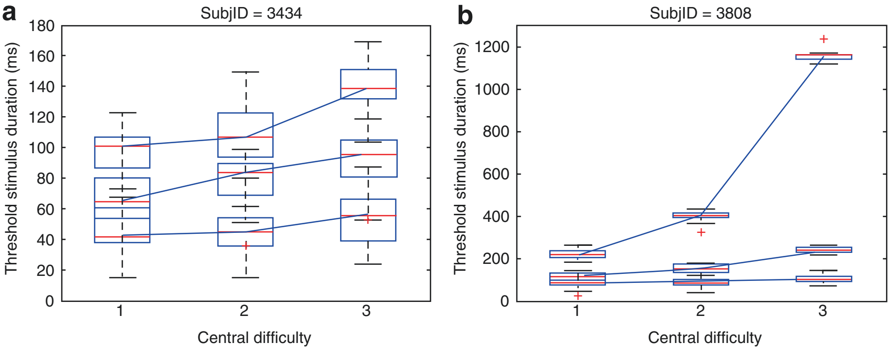


Fig. 7.7. Example UFOV results, showing no interaction (*left*) and a large interaction (*right*). Each point (center of the box) is the 75% threshold value for a trial set with particular conditions: central difficulty is easy on the left and hard on the right, while peripheral difficulty is easy for the bottom and hard for the top. Box plots represent the 25–75 quartiles, with the whiskers showing the full range of stimulus durations used in the ANOVA and + representing outliers. P value for significance of interaction term on the left = 0.41, and on the right = $2.8e^{-234}$

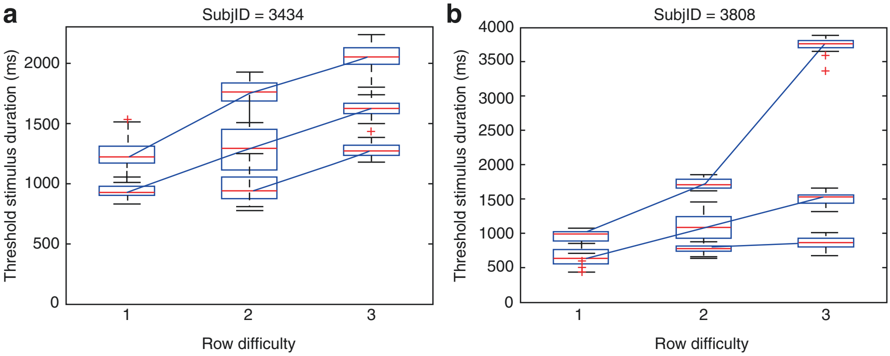


Fig. 7.8. Example 21 Tally results, showing no interaction (*left*) and a large interaction (*right*). These are the same subjects as in the Fig. 7.7. Again, each point (*center* of the box) is the 75% threshold value for a trial set with particular conditions: central difficulty is easy on the left and hard on the right, while peripheral difficulty is easy for the bottom and hard for the top. Note that the [easy, easy] condition for Tally Puzzle (*bottom left*) was not measured, as it violated the single-correct-answer constraint of our experimental board construction. Box plots represent the 25–75 quartiles, with the whiskers showing the full range of stimulus durations used in the ANOVA and + representing outliers. The p-values for significance of the interaction terms calculated by two-way ANOVA are $p = 0.15$ (for part **a**) and $p = 5.9e^{-132}$ (for par **b**)

Figure 7.7a and b show visual examples of two participants at opposite ends of the spectrum of divided attention. The participant on the left has very little effect of interaction as both tasks get more difficult, and the most difficult task seems to have a relatively linear relationship to the difficulty of each (meaning that for this participant, the two tasks are independent). By contrast, the participant on the right has a large interaction as the two tasks become more difficult, and takes far more time to reach the 75% accuracy threshold on the most difficult configuration than would be expected were the two tasks independent. For both participants, the pattern noted in UFOVs2 holds true also for the "21 Tally game," giving strong evidence that both are measuring divided attention ability (Fig. 7.8a and b).

These examples of cognitive computer games with embedded summary metrics of cognitive functions, such as working memory and divided attention, demonstrate how computational models can be used to estimate meaningful clinical measures in a home environment in real time. Our other previous work in this area using our Scavenger Hunt game to measure executive function has shown that the inferred game metrics correlate highly (similar to test-test reliability) with the standard neuropsychological executive function Trail-Making Test (Hagler et al. 2014b). The resulting correlations are comparable to those obtained by assessing the reliability of the TMT. The most important advantage of the model-based analytic approach is the ability to attribute any decline in performance to particular processes, including the attentional, working-memory, and sensory-motor components.

7.4 Behavioral Informatics: Assessment of Behavioral Metrics in the Wild

An important realization about the interplay of different neural systems taking root during the last several decades includes an acknowledgement that overt sensory-motor behaviors are closely coupled with cognitive skills and executive functions. Perhaps it is quite obvious when we consider the fact that almost every neuropsychological test requires a motor response even if it is verbal utterance or eye movements. We argue, however, that this connection is deeper and more profound in that many sensory-motor tasks require several aspects of cognitive function. In particular, we are suggesting a framework whereby a cognitive system is intimately connected with the sensory system by generating predictions and expectations and then monitoring the actual events or outcomes. The cognitive system is then prepared to respond if the perception deviates from the expectations. This type of a framework can account for a number of observed phenomena and enables us to develop computational models of the underlying processes. To take full advantage of this type of approach, it is important to monitor behaviors in real life. In this section, we explore several examples where empirical observations are consistent with this framework.

In addition to the deep connection between overt behaviors and cognition, there is a phenomenon whereby patients (or experimental subjects) behave differently in a clinical or laboratory setting than in their real life. If the goal of the observations is assessment of their abilities and functionality as it applies to real-life situations, it is necessary to complement the tests in clinics with observations in the wild.

7.4.1 Walking Speed

Walking speed has been recognized for years to be an important indicator and possible predictor of cognitive and physical functions (Camicioli et al. 1997; Austin et al. 2010; Dodge et al. 2012; Coppin et al. 2006). In particular, gait velocity has been successful at predicting dementia (Waite et al. 2005; Wang et al. 2006), cognitive decline (Marquis et al. 2002), future disability (Guralnik et al. 2000), and future risk of hospitalization in aging populations (Studenski et al. 2003). Researchers have also evaluated and described links between gait velocity and both executive function (Coppin et al. 2006; Ble et al. 2005) and cognition in general (Holtzer et al. 2006).

Although walking speed is typically measured infrequently and only in clinical settings, it can be measured unobtrusively even with very inexpensive and simple sensors, such as passive infrared (PIR) sensors that are typically used for inexpensive security systems (Hayes et al. 2009; Austin et al. 2011a). Although these inferences are possible, they require computational modeling in order to yield unbiased estimates of the speed of walking (Hagler et al. 2010). The general approach is rather simple: PIR motion detectors are placed in hallways or other restricted areas of the participant's dwelling with the expectation that the participant's predominant activity at those locations is walking in, more or less, a straight line, as described in (Hagler et al. 2010). The detectors then register events corresponding to an individual passing through the sensor's field of view. The resulting raw data are represented by a sequence of event times.

Naively, one would think that the slope of a regression line between the location of the sensors and the event times would provide a good estimate of the speed of walking. Hagler and his colleagues in our laboratory discovered that these estimates are biased (Hagler et al. 2010) and found a model-based approach to mitigate this bias. The solution required a model that incorporated spatial noise terms in addition to the temporal error terms. One may be tempted to level criticism at inferences made from the data obtained by monitoring in the wild, raising arguments of confounding variables and unpredictable events. These objections have been mitigated by comparing estimates of speed of walking from in-home monitoring with those from clinical settings (Hagler et al. 2010).

Using the PIR-based method for longitudinal monitoring of walking speed, we developed a way to analyze these raw data to obtain a picture of the longitudinal evolution of the distribution of walking speed over weeks, months and even years. The computational model embodied a process describing an evolution of the walking speed distribution over days using a kernel density estimator in combination with moving windows for short-term data aggregation.

Using this model, Austin and his colleagues (Austin et al. 2011a) analyzed samples from a longitudinal study monitoring elders over 4 years. An example of the results are shown in Fig. 7.9. Time is depicted on the abscissa, and the distribution is shown along

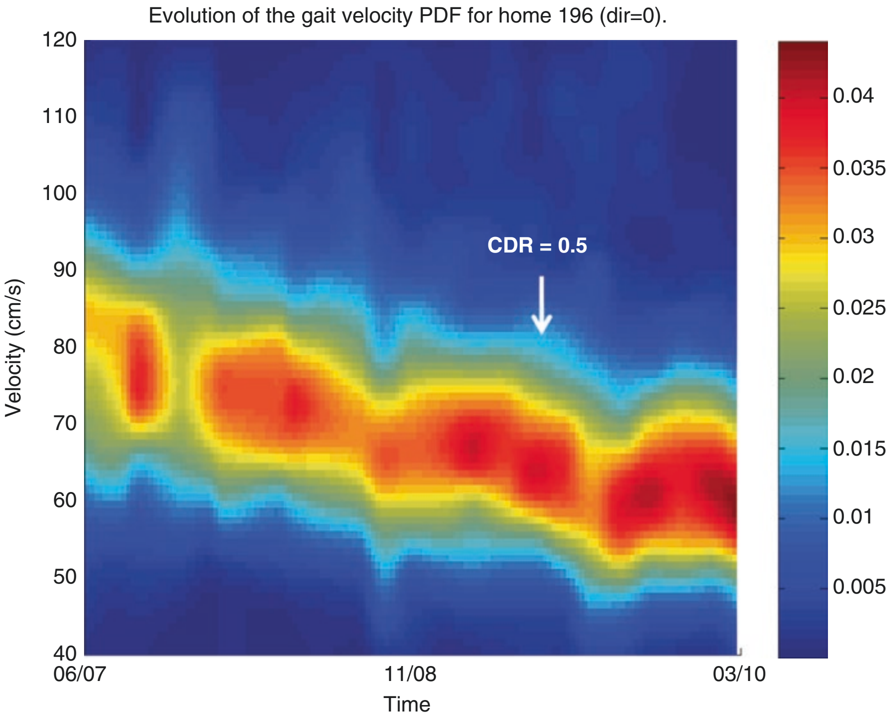


Fig. 7.9. Example of walking speed distribution for an individual over several years. This individual shows a decline in walking speed with a diagnosis of mild cognitive impairment (Clinical Dementia Rating (CDR) = 0.5) shown by the *arrow* in 2009

the ordinate. The data suggest a slow decline over about three years. In fact, this patient was diagnosed with a mild cognitive impairment several years after the monitoring began. Understanding the process in conjunction with the computational model and resulting algorithm would enable an earlier detection, making it possible for an early intervention.

7.4.2 *Keyboard Typing Speed*

As we noted above, sensory-motor speed is an important factor tightly linked to a variety of cognitive functions. Although there are several ways to assess sensory-motor speed, one the most commonly used techniques is finger tapping as a part of a neuropsychological examination to detect both motor and cognitive impairments (Strauss et al. 2006). The Finger Tapping Test uses a particular mechanical counter that is activated by pressing a lever to reach a low limit. A patient is asked to press and release the lever as many times as possible within 10 seconds. This is repeated five times and the average is taken as an indicator of the sensory-motor speed. A decline in the tapping scores appears to be a predictor of cognitive impairment in the elderly (Camicioli et al. 1998) on par with other standard neuropsychological tests.

The fact that such an apparently automatic behavior as finger-tapping is connected to cognitive functions is somewhat surprising, and we were therefore motivated to investigate this relationship (Austin et al. 2012). The resulting computational (state-space) model provides early insights regarding this connection: cognitive interference affects only specific phases of the periodic movements. These results led us to contemplate the possibility of using typing speed as a surrogate for measurement of sensory-motor speed. In this study (Austin et al. 2011b), participants were monitored over a month while typing familiar sequences on a computer—in particular typing user identification during their login procedure.

The resulting linear regression between the finger-tapping test and typing speed is shown in Fig. 7.10. The correlation coefficient is 0.77 for the non-dominant hand and

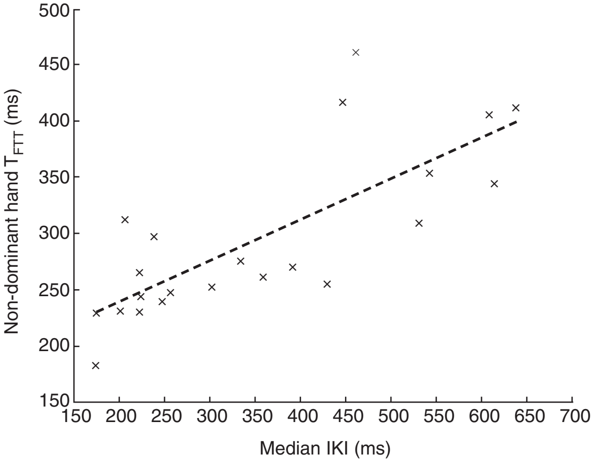


Fig. 7.10. Linear regression between non-dominant hand finger-tapping and typing speed values across participants

0.7 for the dominant hand. It is apparent from these results that although this approach to monitoring appears to be promising, with a strong correlation between the finger tapping test and the typing results, more research is required to capture the variability across participants. In the future, it would be useful to monitor typing speed continuously and explore the interaction between concurrent typing and cognitive processes.

7.4.3 Mouse Movements

Another example of the model-based approach involves inferences based on people's interactions with computers. In modern graphical user interfaces, computers are controlled using variations on the point-and-click interaction which can take the form of a computer mouse, a mouse pad, or a touch screen. As users spend much of their computer time controlling the computer using one of these forms of point-and-click interaction, a potentially very large amount of very rich data is available concerning how the user moves the pointer. Indeed, much work has been done in looking at mouse movement data as a means of verifying the identity of the computer user (see e.g. (Kaminsky et al. 2008; Zheng et al. 2011) among many others). Going beyond identifying the computer user, mouse movements represent a potential tool to assess subject performance and track changes in subject performance, consequently providing data related to cognitive and sensory-motor processes. Using a combination of additive factors method (Hagler et al. 2014b; Donders 1869; Sternberg 1969) with models of pointing (Fitts 1954; Fitts and Peterson 1964), it was possible to develop models that enabled us to separate cognitive and sensory-motor components of the mouse moves and make inferences about the individual's cognitive processes.

To investigate the clinical potential of mouse movements and their dependency on cognitive processes, the mouse movements were recorded for 42 cognitively intact older adults and 20 older adults with MCI who were enrolled in a longitudinal study of in-home monitoring technologies. MCI was associated with making significantly fewer total mouse moves ($P < 0.01$) and making mouse movements that were more variable, less efficient, and with longer pauses between movements ($P < 0.05$). Mouse movement measures were significantly associated with several cognitive domains (P values <0.01–0.05) (Seelye et al. 2015). Computational modeling enabled us to distinguish movements concurrent with cognitive tasks from those representing rapid pointing moves.

7.5 Summary, Limitations and Future Advances

In this review of behavioral informatics applications for monitoring cognitive functions, we focused on a small subset of the benefits and issues associated with the new approaches to cognitive assessment and monitoring that are made possible by rapidly advancing technology. The main points include:

1. Continuous—or at least frequent—monitoring of cognitive and executive functions enables the assessment of within-subject trends and subtle changes in an individual. In addition, continuous monitoring permits the assessment of variability, resulting in a more complete characterization of the state of monitored individuals.
2. Data from multiple sources pertaining to an individual combined with models can enhance accuracy and insights in patient state.
3. A key benefit of behavioral informatics involves the ability to monitor in the wild (in real life) rather than occasional testing in clinics and laboratories contaminated by a variety of state dependencies resulting from the clinic visits.
4. The maximal benefits can only be achieved using computational modeling in assessing detailed characteristics of cognitive processes underlying executive functions and higher level processes, such as problem solving and fluid intelligence (Cattell 1963).

Although the examples from our work show promising opportunities, we have barely scratched the surface, and there remains much to be done in several key areas. First, our ability to develop effective computational models characterizing behaviors in the wild is in its early stages. Advances are required in the development of new computational frameworks to capture the complexities, uncertainties, and most importantly, dynamics inherent in the behavioral informatics approach (Hekler et al. 2016). Closely related is the need to capture and characterize contextual information and its effect on the monitoring results as noted in Sect. 7.2.3. In addition to the rapid advances in monitoring behaviors, similar advances in monitoring physiological metrics are beginning to open the possibility of inferring instantaneous affective states of individuals and assessing their effects on cognitive functions.

The ability to infer instantaneous cognitive and affective states in the wild also opens the possibility for interventions that would amplify an individual's cognitive abilities. Steps along this line of research include our work on augmented cognition. Similar advances are expected in precision education and training with a combination of behavioral and physiological interventions, such as transcranial current stimulation.

Discussion Questions

1. Is there evidence that monitoring and assessment of behaviors could provide a means to assess cognitive functions?
2. How can a computer implementation of various tasks enable more frequent or even continuous assessment of cognitive functions?
3. What are the advantages of game performance assessment using computational models of the underlying cognitive processes as compared to utilizing the raw game scores?

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Chapter 8
The Slippery Slope of Sexual Decision-Making in Young Adults: The Role of Social and Cognitive Factors

Nicole A. Yoskowitz, David R. Kaufman, Courtney A. Denton, and Vimla L. Patel

Abstract Sexual decision-making in young adults continues to present challenges for public health and social science researchers more than three decades after the first HIV epidemic. The objective of this chapter is to identify relevant social and cognitive factors that may influence decision-making about risky sexual behavior in young adults. More specifically, the chapter focuses on our research on sexual decision-making among heterosexual urban college students in a high-risk HIV/AIDS community. Participants completed two weeks of daily sexual encounter diaries, followed by in-depth interviews. Both quantitative and qualitative methods were used to analyze the data. Results showed that participants' decisions about the use of condoms varied by particular social factors, such as partner influence and condom use attitudes; and cognitive factors, such as perceptions of relationship status and HIV/STD risk assessment. Participants' justification of their behavior differentiated higher- from lower- risk individuals. The findings suggest that in

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order to intervene effectively with higher-risk individuals, it is important to understand the nature of the evidence used to make decisions and the conditions under which these decisions change. Risky decision-making in the context of education, the role of technology, and adequate interventions are discussed.

Keywords Decision-making • Risk perception • Sexual behavior change • Young adults • Qualitative methods • Social factors • Cognitive factors • Interventions

8.1 Introduction

8.1.1 Overview of the HIV/AIDS Problem Among Young Adults

Between 2005 and 2014, the overall number of newly diagnosed HIV cases decreased by 19% (CDC (US) 2016). In part, this decline in diagnosis is attributed to improved dissemination of HIV/AIDS-related knowledge, better treatment plans and the use of technology. Decreases in newly diagnosed HIV cases were also noted among high-risk populations including young adults, women, African Americans and Hispanics/Latinos. However, the African American and Hispanic/Latino populations remain disproportionately affected by HIV (CDC (US) 2016). In 2014, African Americans comprised 12% of the US population; however, this group represented nearly 44% (19,540) of individuals diagnosed with HIV (CDC (US) 2016). Similarly, although Hispanics/Latinos only represented 17% of the US population in 2014, this group accounted for approximately 23% (10,201) of HIV diagnoses (CDC (US) 2016). Although challenges to prevent HIV transmission exist in all groups, the CDC has highlighted lack of awareness surrounding partners' risk factors (e.g., multiple partners, drug use, unknown HIV status), cultural stigmas associated with testing for sexually transmitted infections (STIs), limited use of preventative measures (e.g., condoms) and socioeconomic factors (e.g., lower education level, limited access to health care) as major barriers for HIV prevention in African American and Hispanic/Latino communities (CDC (US) 2015; CDC (US) 2016a). Women in these populations are particularly susceptible to HIV infections, with a vast majority of cases attributed to heterosexual transmission (CDC (US) 2016b). Even more disconcerting was the fact that youth aged 13–24, a population where condom use is notably low, accounted for approximately 22% of new HIV diagnoses (CDC (US) 2013; CDC (US) 2016c). Many young women in at-risk communities, including those in monogamous relationships, face a genuine risk from their primary sexual partners (Dolcini and Catania 2000; Hock-Long et al. 2013).

For many years, HIV research has overlooked the dynamics of intimate and committed relationships (Amaro and Raj 2000; DiClemente et al. 2008; Karney et al. 2010). Understanding the risk of HIV transmission between heterosexual partners in relationships that are perceived as committed and monogamous has become increasingly important for HIV prevention programs. The goal of this chapter is to identify social and cognitive influences on sexual decision-making and risky sexual behavior as manifested in male use (or nonuse) of condoms, focusing on the heterosexual, young adult population to explore particular factors that mediate sexual behavior in a high-risk community for HIV/AIDS.

8.1.2 Risky Sexual Behavior in Young Adults

Condom use has been the target of hundreds of studies of risky sexual behavior in heterosexual young adults, as it significantly reduces the risk of transmitting STIs such as HIV (El Bcheraoui et al. 2013; Newman and Zimmerman 2000; Sheeran et al. 1999). Individual studies have examined the association between reported condom use and psychosocial factors, attitudes toward condom use, demographics, and HIV knowledge. In one meta-analysis, condom use was most strongly associated with personal attitudes, intentions, and perceptions of partner's attitudes, affect (i.e., the degree of trust and beliefs about partner), and relationship status (Sheeran et al. 1999). Most interestingly, perceptions and knowledge about HIV, AIDS, and other sexually transmitted infections were not as strongly associated with condom use behavior, as were perceptions of behavior and the context of that behavior within a particular sexual situation (Anaebere et al. 2013; Manlove et al. 2007; Morrison-Beedy et al. 2002). In addition, peer influence and beliefs about partners' attitudes toward condom use were also found to be significantly associated with condom use.

8.2 Social and Cognitive Factors in Sexual Decision-Making

8.2.1 Theoretical Framework

It is widely recognized that normative models of decision-making cannot adequately explain how young adults make sexual decisions involving risk (Sheeran et al. 1999; Moatti et al. 1997). In real world settings, decision-making occurs under cognitive, socio-cultural, and situational constraints, which may not be reflected by a single judgment under conditions observed in a laboratory study (Patel and Arocha 2000; Patel et al. 2002). Decision-making often includes the individual decision-maker as well as other sources of influence; these constraints affect young adults' decisions to use condoms during sexual encounters. Partners, the environment in which a decision is made, as well as societal and familial beliefs can be sources of influence during the decision-making process. Models of sexual decision-making that capture subjective values, perceptions, and views of "rational" decisions to accept health risks are needed to fully understand high-risk behavior (Pinkerton and Abramson 1992).

Social Cognitive Theory

In this chapter, heterosexual college students' condom use behavior is explained in terms of social cognitive theory, focusing on the dynamic and reciprocal interaction between personal, environmental, and behavioral factors (Bandura 1986, 1992). Social cognitive theory also emphasizes the role of cognitive processes in regulating behavior. The mind constructs its own reality by selectively encoding information from the physical and social environment, parsing its meaning, and storing the information in memory (Jones 1989). For example, a woman who desires a monogamous relationship may interpret her male partner's insistence that they not use a condom as his "commitment" to monogamy, which will affect her decision to use or not use condoms. Cognitions can also change over time due to maturation and experience, which can lead to a reevaluation of one's behavior. This theory provides the organizing rubric for understanding the causal influences in young adults' sexual decision-making.

Cognitive Analysis of Decision Making

In this research, we also draw on theoretical frameworks and methods from cognitive science, a multidisciplinary field concerned with analyzing and modeling complex human performance (Bechtel et al. 1998). A cognitive analysis of decision-making is predicated on the belief that mental or internal representations mediate the decision process. For example, an individual's perception of risk of contracting an STI is based on his or her understanding of the mechanisms of transmission and beliefs about his or her partner. Although the cognitive representation is important to our decision processes, it is also important to recognize that risky decisions are significantly shaped by socio-cultural, environmental, and affective factors. In our research, the target behavior is condom use and the specific situation (environment) is a sexual encounter. The social and cognitive factors considered in relation to gender and condom use behavior are sensation seeking, social influences, relationship characteristics, and perceptions of partner, peer and family attitudes.

8.2.2 Role of Cognitive Factors

Sensation Seeking

Sensation seeking, or "the propensity to seek out novel or risky sexual stimulation" (Kalichman and Rompa 1995), is a personality factor that has been explored in relation to gender differences and risky sexual behavior. Research indicates that men display higher risk behavior and report higher levels of sensation seeking than women (Rolison and Scherman 2003). In heterosexual men, impulsivity has been associated with the frequency of unprotected sexual intercourse, and sensation seeking has been associated with the number of lifetime sexual partners (McCoul and Haslam 2001). More recently, a large study of heterosexual, sexually active young adults found that both sensation seeking and impulsivity were related to multiple types of risky sexual behavior, including insufficient condom use, sexual acts with a non-monogamous partner, and alcohol or drug use (Charnigo et al. 2013). In addition, state impulsivity, also known as the degree of impulsivity in a specific situation, was associated with male avoidance of condom use (Davis et al. 2016). A meta-analysis of the relationship between impulsivity and risky sexual behavior among adolescents found a small, but significant association between these constructs (Dir et al. 2014). Results of this meta-analysis also found that gender moderated the relationship between impulsivity and risky sexual behavior, as effect sizes were larger in samples with a higher proportion of females (Dir et al. 2014). Sensation seeking is one aspect of impulsivity that has been frequently studied with relation to risky sexual behavior. However, other aspects of impulsivity, which have been less studied, may also be important to understanding this relationship.

Locus of Control

The construct of locus of control has also been examined in relationship to sexual behavior (Burnett et al. 2013; Lee and Mancini 1981; Werner-Wilson 1998; Werner-Wilson and Vosburg 1998). Locus of control describes the degree to which an individual believes he or she can control the events affecting his or her life (Lee and Mancini 1981). When emphasis is placed on internal forces, the individual believes that his or her decisions impact and navigate his or her life path. On the other hand, external locus of control describes the belief that the environment largely controls the individual's decisions and the individual feels disempowered to effect change. Lee and Mancini investigated the association between locus of control and sexual behavior in college students (Lee and Mancini 1981). They found that men with an external locus of control were more likely to have a higher number of sexual partners, men with an internal locus of control were more likely to have sexual intercourse more frequently, but with fewer partners, and women with an internal locus of control were more likely to use effective methods of contraception (Lee and Mancini 1981).

Religiosity and Spirituality

More recently, the concept of locus of control as it relates to God (i.e., beliefs about God's control over one's behavior) has been explored in relation to college students' sexual behavior (Moore 2014). A person's religious values and/or level of spirituality may also influence one's sexual responsibility and condom use, as well as the type of relationship in which one engages (Iles et al. 2016). Research on religiosity and spirituality as predictors of sexual behavior suggests heightened internal locus of control and higher levels of condom usage among individuals of faith (Iles et al. 2016). In a large study of adolescent girls, it was determined that sexual responsibility (e.g., responsible and planned use of birth control) was positively associated with personal devotion (e.g., praying frequency and religious importance) and frequent attendance of religious events (Miller and Gur 2002). Among college students, when evaluating "God locus of control," no significant association was found between "God locus of control," number of lifetime or recent sexual partners, or condom use during sexual intercourse (Moore 2014). However, stronger beliefs about God's control over one's sexual behavior was associated with a lower likelihood of having engaged in oral or vaginal sexual intercourse, further supporting the role of locus of control in influencing sexual behavior and attitudes (Moore 2014).

8.2.3 Role of Social Factors

Peer, Parental, and Societal Influences

Young adults' risky sexual behavior and safer sex practices can be differentially influenced by their family, peers, and society (Kotchick et al. 2001). For example, autonomous decision-making by youth (i.e., low parental control) and negative peer pressure have been directly related to sexual risk taking (Raffaelli and Crockett 2003). In addition, a recent meta-analysis found that parental monitoring is significantly associated with higher rates of condom use (Dittus et al. 2015). Peer norms have also been shown to be more strongly related to sexual risk behavior for African American and Hispanic adolescents who did not have discussions with their parents about sex and condom use (Whitaker and Miller 2000; Nappi et al. 2009). In addition, adolescents' perceptions of peer or maternal attitudes towards sex have been shown to be a better predictor for adolescent sexual behavior than their peers' or mothers' actual attitudes towards sex (Dittus and Jaccard 2000; Lewis et al. 2007). A young adults' risky sexual behavior is not merely influenced by their peers' and parents' actual attitudes—perceptions of peer and parent attitudes are also predictive of risky sexual behavior (Lewis et al. 2007).

Partner Influences

Individuals rely on a range of cues to guide their sexual decision-making and evaluate the risk that a potential partner may have HIV (Harman et al. 2009; Stoner et al. 2003). The level of trust and commitment between partners is a key factor in risk assessment and determines sexual risk behavior (Ewing and Bryan 2015). Despite being the preferred method of contraception among heterosexual adults (Regnerus and Uecker 2011), condoms are less likely to be used with committed partners than casual partners (Friedman et al. 2001). Couples in long-term, committed relationships often discontinue use of condoms, employing birth control pills or refraining from contraceptives (Ku et al. 1994; Maxwell and Boyle 1995). In other words, feelings of trust and commitment are associated with a shift in behavior and cognition from a focus on infection and pregnancy prevention methods to protection against pregnancy alone, or often no protection at all. In a study of college students' sexual behavior, students who reported being in monogamous relationships relied on perceptions of love and fidelity, and therefore did not employ risk precautions, whereas those with concurrent sexual partnerships were far more likely to use condoms and use them consistently (Lam and Lefkowitz 2013; Netting and Burnett 2004).

This pattern of behavior may be due to a reliance on heuristics of perceived safety such as (a) "known partners are safe partners," (b) "monogamous relationships are safe relationships," and (c) "trusted partners are safe partners" (Misovich et al. 1997). Trusted partners become long-term, committed, and possibly monogamous partners; this status permits partners to abandon condoms (Bauman and Berman 2005).

However, long-term, committed relationships are not without risk. Concurrent sexual partnerships may contribute to burgeoning HIV rates (Adimora et al. 2002; Kershaw et al. 2012; Santelli et al. 1998). Sexual activity outside of the primary, committed relationship dramatically increases the chances of introducing infection into that relationship (Kershaw et al. 2012). In fact, women are far more likely to be infected with HIV by their primary heterosexual partner than by any other source (CDC (US) 2010; Susser and Stein 2000). In a 20-year study analyzing changes in sexual behavior among college students, researchers found that three patterns of sexual behavior persisted in fairly stable proportions over this period: celibacy (30%), monogamy (60%), and concurrent partnerships (10%). The students who reported being in monogamous relationships expressed faith in perceptions of love and fidelity for protection, whereas those with concurrent sexual partnerships were far more likely to use condoms consistently (Netting and Burnett 2004). In addition, among adolescents 15–18 years old, Newman and Zimmerman found that many of the participating females engaged in low-risk strategies (e.g., condom use); however, their efforts were seriously compromised by their male partners, who often engaged in high-risk activities (Newman and Zimmerman 2000).

Expectations of monogamy may translate into assumptions that one's partner is monogamous, which is associated with the level of trust in the relationship (Bauman and Berman 2005). The level of trust is known to influence sexual risk assessment, ultimately dictating condom use (Masaro et al. 2008). Thus, condoms are less likely to be used with committed partners than casual partners (Hock-Long et al. 2013; Friedman et al. 2001). This may be due to a reliance on heuristics (Misovich et al. 1997). In addition, individuals have often relied on perceived personality characteristics, such as appearance and conduct, to evaluate the risk that a potential partner has HIV (Harman et al. 2009; Stoner et al. 2003).

8.2.4 Role of Gender and Sexuality

The influence of the aforementioned cognitive and social factors on condom use and sexual decision making is also moderated by the individual's own attitudes towards condom use, the symbolic nature of condoms, and by gender. This section describes the importance of these factors and how they may influence sexual decision-making and behavior.

Attitudes Toward Condom Use and Symbolism

Condoms are used differently by varying age groups and are often accompanied by divergent social meanings, such as perceived level of power in the relationship and previous sexual experience (Powell 2010; Conley and Rabinowitz 2004; Marston et al. 2006). Historically, contraception of all forms has been associated with promiscuity, creating a large stigma surrounding condom use as protection against STIs and pregnancy. Presently, despite general acceptance of contraceptives, many first sexual encounters still occur without use of a condom due to feelings of embarrassment or lack of access to condoms (Eder 2011). Attitudes toward condom use are closely related to an individual's perceived risk (Marston et al. 2006), which is often subjectively determined while assessing partner "cleanliness" based on characteristics such as appearance and level of familiarity (Sparling and Cramer 2015). Males are more likely than females to report negative attitudes about condom use, which is associated with less condom use (Harlow et al. 1999).

Gender Differences

Gender differences have also been found among adolescent sexual practices (Santelli et al. 2000) in selection of partners (Sprecher et al. 1994) and use of safer sex practices (Impett and Peplau 2003). These differences can be partly explained by the presence of certain gender differences in negotiations about condom use (Amaro 1995; Flood 2003; Soet et al. 1999). Women may feel pressured by their partner to conform to his standards and attitudes. Attempts to force condom use can invoke the belief that one is infected with a disease and can symbolize lack of trust, sexual promiscuity, infidelity, and/or deception (Ali et al. 2004). Reintroduction of condoms after discontinued use can threaten the emotional comfort and security of the relationship (Moore and Rosenthal 1998; Sobo 1993).

8.3 Young Adult Sexual Decision-Making: The Study

In order to understand how social and cognitive factors may influence the sexual decision-making process, and ultimately condom use, we will present some results of a study that focused on this aim. This example will highlight how cognitive and social-environmental factors differentially mediate sexual decision-making in urban college students, and will provide a descriptive model of their interaction.

Cognitive methods of analysis were used to characterize four patterns of condom use behavior and the corresponding reasoning strategies in urban college students, as well as the conditions under which such behavior and reasoning change (Patel et al. 2006, 2007). Although condoms are the most effective method of preventing HIV transmission, young adults were found to have various misconceptions about use, resulting in use of heuristics when deciding to practice (or not practice) safe sexual behavior (Patel et al. 2006, 2007).

Cognitive methods include a wide range of techniques for understanding how individuals perceive, comprehend or make decisions in response to environmental stimuli in laboratory or naturalistic situations. We show low and high-risk sexual behaviors to be associated with distinct sets of beliefs about safer sex practices (Patel et al. 2007). Individuals with low-risk behavior utilized risk-related cues to interpret sexual situations, aiming to avoid risky behavior, and those with high-risk behaviors were shown to be more attuned to their emotions and to the gratification of 'immediate pleasure seeking' (Patel et al. 2007).

Our data collection methods include collection of think-aloud protocols, use of explanation tasks and structured interviews. Data analysis techniques used were protocol analysis (Ericsson and Simon 1993), semantic networks to represent reasoning patterns, as well as thematic analysis. The integrative framework and convergent methodologies introduce a novel approach to a complex issue of sexual decision-making in young adults.

The study design incorporated a "mixed methods" approach, integrating both quantitative and qualitative methods of data collection and analysis and reflects a semi-naturalistic study paradigm.

8.3.1 Study Methods

Participants

The sample included 60 heterosexual young men and women attending Brooklyn College, a New York City undergraduate urban college. The college is situated in the East Flatbush-Flatbush neighborhood in Brooklyn, a high-risk community for HIV/AIDS.

Participants were recruited from Brooklyn College via distribution and posting of flyers across the college campus, through campus newspaper advertisements, and by announcements in classes and clubs. Flyers advertised the study as one on "sex and decision-making." Interested students were screened for eligibility prior to enrollment in the study. Eligibility requirements included (a) age (18–24), (b) heterosexual orientation, (c) fluency in English, (d) a moderate level of HIV knowledge (correct answers to at least nine of twelve items on an HIV knowledge measure; Koopman and Ried 1998), and (e) current sexual activity (engaging in either vaginal or anal sexual intercourse at least once in the previous two weeks). Half of the sample was male ($n = 30$) and half was female ($n = 30$), based on design. None of the participants were in a relationship with any of the other participants. All participants were attending the college on either a part-time or full-time basis. Of these 60 participants, 50% were African–American ($n = 30$), 37% were White ($n = 22$), 5% were Asian ($n = 3$) and 8% reported themselves as other ($n = 5$). Regarding ethnicity, 10% of participants identified themselves as Hispanic ($n = 6$). The average age was 21 years (range of 18–24).

Design and Procedure

Enrollment in the study included completion of two weeks of daily diary data, chronicling participants' sexual encounters, followed by an in-depth interview after diary collection (O'Sullivan et al. 2006). The in-depth interview focused on the investigation of the reasoning strategies and situational factors of participants' sexual encounters, guided by information collected in the diaries. During the second round of data collection 6 months later, participants completed a questionnaire assessing psychosocial factors that may be associated with risky sexual behavior. Approval for the study was obtained from the local institution's Institutional Review Board.

Participants attended an individual training session (lasting approximately 40 minutes) on how to complete the daily diaries. After giving consent, participants provided demographic and sexual history information. Then they were instructed to complete the structured diary forms each day and to mail the forms back daily to the study offices over the two-week period, at which point they were asked to participate in an in-depth interview. Participants were provided pre-addressed, stamped envelopes for returning the diary forms. All participants completed and returned at least 12 of the 14 daily diary forms. They were reimbursed $20 upon completion of the training session, $40 for completing the diary portion of the study, and another $30 for the in-depth interview upon its completion.

Daily Diary Collection

The daily diary used was a modified version of that used by Howard and colleagues (Howard et al. 1999), which required responses to structured items. For each day, participants were asked (1) to record whether they had engaged in some type of sexual activity with a partner, and if so, (2) to indicate from a list the sexual activities that occurred, (3) the condom use during the encounter (if any; only male condoms were of interest), (4) whether the encounter involved their own or their partner's use of alcohol or drugs, and (5) their sexual history with that partner. In addition, participants were asked to indicate the type of relationship they had with each sexual partner, the length of time they had known this partner, and when they had first engaged in sexual activity with this partner. Completion of the daily diary took approximately 5 minutes or less each day.

In-Depth Interview of Encounters and Sexual History

A semi-structured interview questionnaire was developed for in-depth inquiry into the sexual encounters recorded in the diaries. In addition, information was collected regarding participants' prior and current sexual histories. The interview covered the following topics:

1. *Attitudes towards sex*: How do you define, and what are your attitudes toward monogamy, "casual sex" and condoms (and their use)?

2. *Relationship history*: How would you describe your current relationship? Have you had discussions of HIV or other STI testing and sexual history?
3. *Specific sexual encounters recorded in diaries*: Describe events including planned or unexpected sex, condom use, and feelings about the experience.
4. *Avoidance of sexual encounters*: Do you ever avoid a potential sexual encounter with your partner? How do you communicate this?
5. *HIV knowledge*: How are HIV/STDs transmitted? How can they be prevented? Does the risk of contraction of HIV/STDs affect your sexual behaviors?
6. *HIV education*: What are your opinions on HIV/AIDS education, as well as sex education in general?

The face-to-face interviews took place as closely as possible after the completion of the two-week diary period, and were conducted by one of two interviewers (one male, one female) who were not involved in data analysis. During the interview, the participants were asked to elaborate on each encounter logged in the 2-week diary, using mnemonic information from the diary forms to facilitate recall of the specific encounters. The interviewer probed for more information, where necessary. Information was collected concerning participants' lifetime sexual history to make a complete assessment of their sexual decision-making during analysis. All interviews lasted one hour and were audiotaped.

Assessment of Personal and Social Environmental Factors

A psychosocial factors questionnaire was also developed to assess the degree to which sensation seeking, and perceptions of partner, peer, family, and societal norms may correlate with the patterns of condom use. The questions were formulated (after completion of the diary/interview data collection) from a review of the diaries and transcriptions of the in-depth interviews. Participants completed the questionnaires during the second round of data collection six months later, which were further analyzed.

Measures

Background Questionnaire

Participants were asked to provide the following information: age, country of birth, race, ethnicity, current employment circumstances, relationship status, number of children (if any), and income.

Sexual Sensation Seeking

They also completed the eleven questions from the Sexual Sensation Seeking Scale (SSSS; Kalichman and Rompa 1995). This measure has been related to HIV-risk behavior in several different samples of gay men and with behavioral correlates of sexual permissiveness in college students (Gaither and Sellbom 2003). To establish their level of sensation seeking behavior, participants in the present study were asked to answer the questions on a scale of 1–4 with one meaning “not at all like me” to four meaning “very much like me”. Cronbach’s alpha coefficient for internal consistency was found to be 0.74 in our sample.

Social and Environmental Factors

To examine the degree of influence of partner, peer, and family values and societal norms on the sexual decision-making, questions were developed based on the *theory of reasoned action* (Ajzen and Fishbein 1980), where information based on behavior intention, perceived outcomes and beliefs related to the behavior, and salient referents can be elicited. These questions helped identify the participant’s beliefs regarding condom use (during each act of sexual intercourse). For each referent (boyfriend/girlfriend, close friends, and parents), the participant was asked (1) “how much do you believe that your (add referent) thinks you should use a condom every time you have sex?” The questions were on a 5-point Likert scale, with one meaning “not at all” (thinks should not use a condom) to five meaning “very much” (thinks should always use a condom); and (2) To what extent do (add referent)’s views regarding safe sex practices influence your personal choice to use a condom or not? An additional question was also asked about the extent to which society’s views regarding safe sex practices influenced the participant’s personal choice to use or not use a condom during sexual intercourse. The questions were on a 5-point Likert scale, from “not at all” (not influenced) to “very much” (very much influenced).

Data Coding and Analysis

Patterns of Condom Use

From prior analysis of the interview data, four patterns of condom use were defined based on participants’ reports of lifetime and current condom use and sexual relationships (Patel et al. 2006). We have used these patterns to categorize participants’ behavior: (1) Pattern A: condom use is consistent through all relationship phases (i.e., friendship/pre-relationship, transition, initial dating, stable dating, encounter outside of stable relationship), (2) Pattern B: condom use is consistent during dating phase, inconsistent during stable dating phase, and consistent with casual partners and partners outside the primary relationship, (3) Pattern C: condom use is inconsistent initially, then a significant event occurs (e.g., pregnancy, abortion, separation) resulting in consistent condom use, and (4) Pattern D: condom use is inconsistent through all relationship phases.

Coding for "Current" Relationship Status

Current relationship status was coded categorically into three types: monogamous, non-monogamous, and casual. A person was coded "monogamous" if he/she only had one primary committed relationship with a sole sexual partner. He/she was never coded "monogamous" if the person had two or more concurrent sexual partners. "Non-monogamous" applied to those who were in a primary stable and committed relationship, but had more than one concurrent sexual partner, whereas "casual" applied to those with one or more concurrent partners, but no committed relationship with any of these partners.

Qualitative Analysis

All interviews were transcribed verbatim, and checked for transcription accuracy by two research assistants. Based on findings from the psychosocial questionnaire, the NVivo program software was used to extract excerpts from interviews pertaining to the themes/categories of interest (i.e., perceptions of relationship status, social influences, and feelings of safety) by pattern of condom use and gender. Based on multiple searches, a closer examination was conducted of the extracted qualitative material to provide a context for explaining the quantitative findings.

8.3.2 Results

In this section, the findings are first presented with an overview of the two-week diary data and differences on the key factors by pattern of condom use and gender. This is followed by the reporting of qualitative findings with excerpts from participants' interviews to elaborate and provide a richer context and meaning for understanding the quantitative results.

Quantitative Findings

Sample Characteristics

Of the total of 60 participants in the study, 21 (35% of sample; 13 men, 8 women) were categorized as Pattern A, 21 (35% of sample; 6 men, 15 women) as Pattern B, 8 (13% of sample; 6 men, 2 women) as Pattern C, and 10 (17% of sample; 5 men, 5 women) as Pattern D. Chi-square tests were conducted to examine differences in condom use patterns across gender, ethnicity, and race. No significant differences emerged across these categories.

Sexual Activity and Condom Use During the Diary Period

Sexual activity (e.g., kissing, oral sex, and sexual intercourse) was reported by all participants over the course of the two weeks of the diary period, and all reported at least one instance of sexual intercourse (max = 6). Table 8.1 gives the descriptive statistics on percentage of condom use during the diary period, as well as the other factors explored in the psychosocial questionnaire, by pattern of condom use and gender. In general, Pattern A (consistent condom users) and Pattern C (currently consistent condom users) participants reported higher percentages of condom use ($M = 82\%$ and 94%, respectively) than did Pattern B (currently inconsistent condom users; $M = 21\%$) and Pattern D participants (inconsistent condom users; $M = 40\%$). Details on this aspect of the study are reported elsewhere (Patel et al. 2006).

In general, we found that individuals who were classified in a pattern representing consistent condom use showed higher levels of condom use during the two week diary period. This provides some evidence that our identified patterns of condom use behavior accurately reflect daily reported condom use.

Current Relationship Status

Fisher's exact chi-square tests were used to examine differences in the proportions of participants reporting the three relationship types (monogamous, non-monogamous, and casual). Overall, a gender difference was found for current relationship status, $X^2(2) = 16.46$, $p < 0.001$. Most women reported being in a monogamous relationship (90%), whereas a majority of the men reported being in a non-monogamous or casual relationship (60%). Among Pattern B participants (currently inconsistent condom users), all women except one were coded as being in a monogamous relationship (87%), whereas most men were coded as being in a non-monogamous relationship (67%). Among Pattern A participants (consistent condom users), most women were in a monogamous relationship (88%), whereas only 46% of men were in a monogamous relationship. Among Pattern C participants (currently consistent condom users), 100% of the women were in a monogamous relationship, whereas only 33% ($n = 2$) of the men were in a monogamous relationship. Similarly, among Pattern D participants (inconsistent condom users), 100% of the women were in a monogamous relationship, whereas only 40% ($n = 2$) of the men were in a monogamous relationship.

These findings highlight gender differences in relationship status among groups of consistent and inconsistent condom users. In this research, we found that men and women differed in reports of their relationship status. Most women reported being in monogamous relationships, whereas most men reported being in non-monogamous or casual relationships. We defined monogamy in this study as the presence of only one partner. According to this definition, most women reported having only one partner, whereas many men reported having more than one partner, even though they still perceived themselves to be in a monogamous relationship. This difference was most pronounced within Pattern B (shift from consistent to inconsistent

Table 8.1. Means and standard deviations for condom use (%), personal factors and social environmental factors by pattern of condom use and gender

	Pattern of condom use															
	A[a]				B[b]				C[c]				D[d]			
Variable	Women (n = 8)		Men (n = 13)		Women (n = 15)		Men (n = 6)		Women (n = 2)		Men (n = 6)		Women (n = 5)		Men (n = 5)	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Condom use during intercourse (%)[e]	85.00	35.05	80.23	37.01	11.13	23.34	44.58	50.13	75.00	35.36	100.00	0.00	40.00	54.77	40.00	41.83
Personal factors: sensation seeking[f]	22.50	3.07	25.00	6.40	25.20	4.81	28.67	6.92	23.00	7.07	25.50	4.09	25.00	4.95	30.20	4.44
Social-environmental factors																
Society influence[g]	4.13	0.99	3.31	1.49	3.27	1.28	4.17	0.41	3.50	2.12	4.00	1.10	3.80	1.30	3.80	1.10
Partner attitude[h]	4.00	1.07	4.62	0.51	1.93	1.22	2.00	1.10	2.50	2.12	3.83	1.12	2.80	1.64	3.00	1.87
Partner influence	4.25	1.39	4.46	1.13	4.13	0.92	4.50	0.55	1.50	0.71	4.33	1.21	4.40	0.55	4.40	0.55
Peer attitude	4.38	0.74	3.62	1.26	3.93	1.22	4.50	0.84	5.00	0.00	3.33	1.21	4.00	1.00	3.60	1.67
Peer influence	3.50	1.60	2.38	1.45	2.00	1.13	4.11	0.41	3.00	2.83	2.83	1.47	2.40	1.52	2.40	1.52
Family Attitude	5.00	0.00	5.00	0.00	4.47	1.13	5.00	0.00	5.00	0.00	5.00	0.00	5.00	0.00	5.00	0.00
Family influence	3.63	1.41	4.23	1.17	2.53	1.19	3.67	1.37	4.50	0.71	4.00	1.10	3.40	1.34	3.00	1.41
Relationship factors																
Number of lifetime partners	4.88	8.20	8.38	9.03	7.40	8.23	21.00	16.37	5.00	5.66	10.17	4.71	4.80	2.86	17.00	17.51
Number of lifetime relationships	2.00	1.07	3.08	1.75	3.53	3.54	3.83	2.32	2.50	2.12	4.50	3.62	2.80	1.10	1.80	1.92
Length of current relationship (months)	18.38	16.02	11.85	12.38	27.40	26.94	26.17	20.36	26.50	33.23	13.50	17.54	21.80	14.41	9.80	10.16

[a]consistent condom use. [b]consistent to inconsistent (current) condom use. [c]inconsistent to consistent (current) condom use. [d]inconsistent condom use. [e]data from the diary period. [f]Higher scores indicate higher on sensation seeking (min = 11, max = 44). [g]Rated on Likert scale from 1 ("not at all influenced") to 5 ("very much influenced"). [h]Rated on Likert scale from 1 ("should never use a condom") to 5 ("should always use a condom")

condom use), where all women except one were in monogamous relationships, but most men were in non-monogamous relationships. This is consistent with recent reports of Americans stating they are monogamous, when in actuality they may have one or two partners outside of their primary relationship (Alexander 2005).

Psychosocial Factors

Table 8.1 gives detailed descriptive statistics for each pattern of condom use by gender for each of the psychosocial factors measured. For the personal factors, men scored higher than women on the sensation seeking scale ($M = 26.7$ vs. 24.3, respectively). Men in Patterns B and D scored very high on sensation seeking ($M = 28.7$ and 30.2, respectively), whereas women in Patterns A and C scored the lowest on sensation seeking ($M = 22.5$ and 23.0, respectively). For the social-environmental factors, most participants reported a strong influence of societal standards on their sexual behavior ($M = 3.7$). The means for each pattern by gender indicated that males in Pattern B were the most influenced by peers regarding condom use behavior ($M = 4.1$). There was very little variability in reports of perceptions of families' attitude toward condom use. However, it is important to note that all participants, except four, reported that their families think that they should use condoms every time they engage in sexual intercourse. In addition, participants in Patterns A and C (currently consistent condom users) reported stronger family influences on their behavior than did participants in Pattern B (currently inconsistent condom users). Interestingly, partners' attitudes towards the frequency of condom use differentially mediated behavior. Pattern A and Pattern C participants perceived that their partner's attitude was to use condoms often or all of the time for sexual intercourse, whereas Pattern B and Pattern D participants perceived that their partner's attitude was to use condoms sometimes, rarely, or never for sexual intercourse.

For the relationship factors, men reported having more lifetime partners than did women ($M = 12.7$ vs. 6.1, respectively), although participants' average number of lifetime relationships (between 2 and 5) was much lower. In addition, Pattern B participants tended to have longer current relationships than those in Pattern A ($M = 27.1$ vs. 14.3 months, respectively).

The quantitative results largely echo previous research findings. Specifically, consistent with past research, we found that men scored higher on sensation seeking than women (Hoyle et al. 2000; Rolison and Scherman 2003). Participants reported moderately strong to very strong influences of partner's and society's attitudes toward condom use on their behavior, which is consistent with the meta-analysis of Sheeran and colleagues (Sheeran et al. 1999). More specifically, those in Pattern A, the consistent condom users, perceived that their partner's attitude was to use a condom for every act of sexual intercourse, whereas those in Pattern B, the inconsistent condom users, perceived that their partner's attitude was to never or rarely use a condom for sexual intercourse. Both groups reported strong influences of their partners' attitudes on their condom use behavior. For Pattern A, this resulted in consistent condom use, but for Pattern B, it resulted in inconsistent or no condom use. This finding corresponds to past studies in which a partner's negative attitudes toward condom use were associated with less condom use (Harlow et al. 1999). Most participants indicated a strong influence of societal standards on their sexual behavior, yet their behavior varied significantly from each other. It is possible that societal norms and values differentially mediate an individual's behaviors.

Qualitative Findings

The three main themes found from analysis of participants' transcripts include (1) perceptions of relationship status, (2) social influences, and (3) feelings of safety. Table 8.2 gives quotes from participants' transcripts for each theme, by pattern of condom use and gender, to illustrate the nature of participants' perceptions and reasoning supporting their decisions about condom use.

Table 8.2. Examples from participants' transcripts of major themes by pattern of condom use and gender

		Theme	
Group	Perceptions of relationship status	Social influences	Feelings of safety
Pattern A			
Women	All the time [discussed monogamy with partner], we just don't see other people but a man is a man. (#16, monogamous)	That's how I was taught [to use condoms] and… before we even had it [intercourse] I let him know…there are a lot of things going on around, I want to stay safe from them. (#28, monogamous)	…he knew a lot about me, so I felt comfortable. (#4, monogamous)
Men	We had a discussion on it [monogamy]. It's a monogamous relationship and we speak about things as far as like getting married, in the future, or having children. (#51, monogamous)	Tell the truth, ...the people around me influence me. Like my friends. 'Cause we all... decided when one knucklehead got his girl pregnant [to always use condoms]. (#66, casual)	I guess my trust in the condom…and my trust of her [partner] (#18, non-monogamous)
Pattern B			
Women	Our method of birth control was using a condom until we started trusting each other… maybe the trust wasn't all that tight, but I give him the benefit of doubt. (#6, monogamous)	It would make me feel like…it's so weird, like using a condom, strips away emotions. You're just having like hotel sex. Pay-by-the-hour sex. (#1, monogamous)	Just looking at him and speaking to him about his past sexual history…it didn't seem like a big issue, it just wouldn't occur to me like he'd have any disease. (#11, non-monogamous)

(continued)

Table 8.2. (continued)

		Theme	
Group	Perceptions of relationship status	Social influences	Feelings of safety
Men	Q: With your partner have you also discussed sexual activity with other people? A: We're not supposed to have it (laughs). (#34, non-monogamous)	If you're hanging out with a bunch of guys and a bunch of girls are there, that's the first think you think about, is like, I wanna have sex with these girls. (#84, non-monogamous)	I'm not worried to be with her, I'm the only partner she's had since we broke up, I've known her partners …that's why I say I trust her ... that's why I say very safe. (#32, non-monogamous)
Pattern C			
Women	I didn't talk specifically about that [monogamy] with him because as far as I am concerned, it should be understood. And I think he understands that. (#49, monogamous)	[motivation from] TV and commercials and I know that it's not good to have attitude where it can't happen to you because it can happen to everybody. (#49, monogamous)	I said no [to condom use] … I wasn't [worried about getting pregnant], I don't know why. I just felt safe at the time ((#7, monogamous)
Men	I really trust her, I don't think she's cheating on me, I'm not cheating on her and we do get tested …I feel that we have opened our heart for each other (#44, monogamous)	When I was in high school they had people come and talk about it [HIV/STDs], and I heard stories about girls giving it to guys and stuff like that and I just want to be safe from all of that. (#79, casual)	I feel really safe because I know we both don't have any STDs. (#40, monogamous)
Pattern D			
Women	If he's gonna do something, he's going to do it anyway, so I'm not going to be on his back about it … I trust him enough that I know he's not cheating on me. (#70, monogamous)	I learned all about AIDS from basketball and like Magic Johnson, and, what's her name, Pamela Anderson has Hepatitis C or something…you hear from public media that lets you know that there is stuff out there. (#70, monogamous)	I trust him, and I know he's not going to give me anything, but at the same time, if he's cheated before he could be doing it, but...I guess it's more trust that he wouldn't do that to me. (#59, monogamous)
Men	I could see other people and we had an agreement, because she ain't going to have sex with nobody else… (#31, non-monogamous)	We've discussed it [HIV/STDs] a couple times. Not to get tested for it, but because we're taking a human sexuality course. (#94, monogamous)	What safe sex means for me is…sex with knowledge…you have to know your partner, and where they've been… (#35, non-monogamous)

A = consistent condom use. B = consistent to inconsistent (current) condom use. C = inconsistent to consistent (current) condom use. D = inconsistent condom use

Perceptions of Relationship Status

Men and women who were categorized as being in monogamous, non-monogamous, and casual relationships reported differing perceptions of relationship status based on different definitions of monogamy. For example, participants defined exclusivity and monogamy in their relationships largely on the basis of assumptions, rather than facts. This point is illustrated in one women's interview transcript (consistent condom user, Pattern A):

> I know that on both our sides, we're both monogamous, both true to each other. I would not go to anybody else, and I know for a fact that he'd not go to anybody else behind my back.

When asked if the issue of monogamy was explicitly discussed, she replied that in the beginning it was assumed that they were both monogamous, but as they became closer, she had expressed to her partner her expectation of a monogamous relationship. This woman stated that she does not have any partner outside of her primary relationship, and she projected that information on to her partner's activity outside of the relationship. This assumption, however, had not altered her condom use behavior. Her subjective view of her partner's fidelity had not hindered her ability to regulate her behavior. This distinguishes her and others in Pattern A from those in Pattern B.

A woman currently not using condoms (Pattern B) reported her trust in her husband:

> We're not together all the time, so I don't know what he's doing all the time and I don't know, he could slip on me or someone could pursue him to the point that he does something even if he doesn't want to do and he's not safe. I know he doesn't walk around with condoms, because I'm his wife and he's not supposed to be cheating . . . so if he does get put in a situation where he is going to have sexual intercourse, I know he's not going to have the condoms on him, cause I know he doesn't carry them, so I trust him, a lot.

This woman is married, so monogamy is implied based on the bond of trust associated with the marital relationship. She reported a deep-rooted trust for her partner, which she used to protect herself from the possibility of her husband having unprotected extramarital sexual encounters. This rationalization formed the basis of her decision not to use condoms during sexual activity.

Perceptions of partner's attitudes also differed between Pattern A and Pattern B. Those in Pattern A, the consistent condom users, perceived that their partner's attitude was to always use a condom, while those in Pattern B, the inconsistent condom users, perceived that their partner's attitude was to never or rarely use a condom. Both groups reported strong influences of their partner's attitudes on their condom use behavior. For Pattern A, this resulted in consistent condom use, but for Pattern B, it resulted in inconsistent or no condom use. However, most participants, regardless of pattern of condom use, agreed that their family and peers believe that condoms should always be used during sexual intercourse.

A woman in Pattern C used condoms inconsistently with her boyfriend until they separated for one summer. After the separation, they used condoms consistently.

> …I'll find something like a letter or a phone number and I'll be like where did that come from and I feel like, if you're going out with me, you should have total trust in me to be able to tell me everything and if you can't tell me that somebody called you, I feel like maybe there's something else you're hiding.

Monogamy was a key concern for this participant. Her assertion was based on concrete evidence (e.g., a letter or phone number found on the partner) that cast doubt on whether her partner was being honest and faithful. The decrease in trust in her partner was a decisive factor in her choice to consistently use condoms.

A woman who inconsistently used condoms (Pattern D) reported concluding that her partner did not have encounters outside their relationship, based on his actions and feelings towards her having encounters outside the relationship.

> . . . I'm the type of person, that I do what I want, but it's, it's bad, but he gets mad at that, and I mean, I trust him, cause I have the idea that if he's gonna do something, he's going to do it anyway, so I'm not going to be on his back about it, he's always on my back about hanging out with different guys and…I trust him enough that I know he's not cheating on me.

She stated that her partner clearly expressed his disapproval of her getting too close to other men, which she used as evidence of his commitment to fidelity. In other words, because her partner's actions have demonstrated to her that he wanted her to remain monogamous; she assumed that her partner was also monogamous, leading to trust in her partner.

This research shows that participants rely on inaccurate, irrelevant, or unstable beliefs and perceptions of their relationships to support their feelings of trust and safety with their partner. This then influences their assessment of risk involved in sexual activity, often leading to conclusions that the risk is low or negligible. Participants in Pattern B—those who initially used condoms regularly, but abandoned them as their trust and commitment to the relationship grew—illustrate vulnerability in a population that lacks other common risk factors. Calling attention to this vulnerability is highly relevant to prevention efforts. In addition to focusing efforts on specific at-risk populations and behaviors, this study illuminates how risk develops predictably over time, based on precise, but potentially flawed judgments.

Social Influences

From the quantitative results, most participants indicated a strong influence of societal standards on their sexual behavior. This can be interpreted within the qualitative data. An example from the interview transcript of a male participant (Pattern B) illustrates the effect of external influences on his evaluation of potential sexual partners, such as where she went to school:

> … I'm prejudiced to an extent, in terms of backgrounds, everything, like, I talk to a girl and like "What kind of high school you go to? Public? Private?"…Cause I only went to private school, and I judge people...I feel like private school and public school is two different lifestyles, two different upbringings, it really is what it says in terms of promiscuity? Public schools I feel are more promiscuous…

The quote exemplifies the kinds of social judgments and selective use of evidence that participants used in assessing risk. Specifically, the evidence used come from everyday experiences and thus has a natural validity.

In terms of other social influences addressed in this study, participants reported a relatively strong influence of their partner's attitudes toward condom use on their condom use behavior and a moderate influence of peers' attitudes toward condom use on their condom use behavior. It was also found that current consistent condom users (Patterns A and C) were more influenced by their family's attitudes toward condom use than inconsistent condom users (Patterns B and D), who were only somewhat influenced by their family's attitudes toward condom use.

Similar to the quantitative findings, the qualitative results lend more support to the idea that both societal norms and values, as well partner and peer attitudes play important roles in shaping an individual's sexual behaviors. More specifically, it is the individual's perceptions of social norms and peer and partner attitudes that are influencing their decision making and subsequent behavior (Lewis et al. 2007).

Feelings of Safety

Participants reported feeling very safe during their sexual encounters (M = 6.20), on a scale ranging from 1 (low) to 7 (high). They also reported low levels of risk ($M = 0.96$) associated with their sexual activity on a scale ranging from 1 (no risk) to 7 (high risk). The safety rating was intended to capture the participant's comfort level during each sexual encounter, whereas the risk rating was supposed to represent how much actual risk was involved in participation in the encounter. There was a strong negative association between the risk and safety ratings ($r = -0.74$).

The relationship between feelings of safety and risk is supported by participants' interviews. One monogamous woman, practicing consistent condom use (Pattern A), stated:

> I feel very safe with him because I don't think he's been with anyone and he's been checked-up, he gets tested.

She reported that she usually initiates condom use during sexual activity, even though she feels safe with this partner. Her reasons for her feelings of safety were that her partner has not had any other partners (monogamous) and he was tested for sexually transmitted diseases. This illustrates how this woman had not been constrained by her emotions in making a decision to use condoms.

On the other hand, most men relied on feelings of safety, based on subjective information, to support their decisions to use or not use condoms. For example, a non-monogamous man, currently inconsistently using condoms (Pattern B), justified his feelings, and thus his behavior, on the length of time he had known his partner's other sexual partners.

> I'm not worried to be with her, I'm the only partner she's had since we broke up, I was her first and after we broke up, I've known her, the partners, for a year through friends, I actually met them, OK, basically that, that's the truth, that's why I say I trust her so...that's why I say very safe.

Because he met these other sexual partners, he discounted the risk during sexual activity with his primary partner. Another non-monogamous man inconsistently using condoms (Pattern D) articulated a similar argument:

> Well if you know the person that you're sleeping with and you know the people they slept with are, at least you have a really good idea of the type of person that they are, you know they wouldn't lie to you and … you can trust them and it's just much, much safer.

Another male participant (Pattern D) used appearance and observations as a tool to determine the risk involved in participation with a sexual partner:

> I try to be as safe as I can and see if I notice any weird behavior on her part. Like when she's around, and see how she deal[s] with other guys and try to keep my ears open and if she's sleeping with two or three different guys in the same day ... it might be easier for her to be infected.

This participant attributed his inconsistency in condom use to differences in his partner's behavior and viewed her promiscuity as a source of evidence for a greater risk of infection.

The strong negative association between participants' risk and safety ratings of their sexual encounters suggests that participants are equating their comfort level with their partner with their level of risk in the sexual encounter. This indicates that a point of emphasis for education and prevention initiatives should address the potential for discrepancy in perception of risk with actual risk.

Pinkerton and Abramson (1992) challenge the idea that all risky sexual behavior is the result of an irrational decision, and that "many risk-taking individuals have interpreted the available information and concluded that risky sex is a reasonable gamble" (p. 566). They argue that an individual's perceptions of risk, sexual satisfaction, and the fear of possible consequences (HIV/AIDS) can render the choice to engage in such behavior as a calculated and rational one. Thus, it is important to understand one's perception of the benefits and risks of the behavior, and the individual's unique experience that provide the context for engaging in risky sexual behavior.

The qualitative results highlight the role of perceptions, observations, and gut impressions in participants' assessment of risk during their sexual encounters. These perceptions influenced participants' condom use, and were also used to justify their behavior. The major factor that differentiated between those who consistently and inconsistently use condoms was the nature of the explanations used to justify their behavior.

We know that knowledge is not in itself sufficient to produce stable behavior change. Providing adolescents and young adults with the tools to identify and weigh pertinent evidence related to level of risk and safety, as well as ways to counter unsupported beliefs and cognitions, could increase these individuals' ability to make informed decisions about safer sexual practices.

Specific prevention strategies can emphasize the need for young people to evaluate their perceptions of the benefits and risks of their behaviors, and focus on the interpersonal dynamics that foster risk (Karney et al. 2010). Young people, especially women, rely on perceptions of peer norms and partners' attitudes to calibrate their behavior. Strategies such as personalized interactive scenarios allow young people to develop better communication skills, and explicitly gain practice talking about their expectations for condom use, exclusivity, and trust with their partners. This kind of activity may help reduce reliance on risk-augmenting perceptions.

8.4 Conclusions and Future Directions

This chapter highlights the complexities of sexual decision-making, emphasizing the influence and significance of cognitive, social and contextual factors. The study summarized in this chapter suggests that there are discernible patterns of condom use among individuals that are not merely binary (e.g., users/nonusers), but reflect both relatively stable (e.g., personal beliefs) and contextual factors (e.g., changing beliefs about partners). In addition, the study focused only on young urban college students. There are a myriad of other well-studied populations, for example, reflecting a range of demographics (e.g., African Americans, Hispanics, etc.) and sexual proclivities (e.g., men who have sex with other men, bisexual).

Even if the factors (such as beliefs about monogamy) were largely stable rather than periodically shifting, the permutations for tailoring interventions are enormous, possibly even intractable, thereby complicating any intervention strategy. However, there are ways to manage complexity and achieve positive results providing that one understands the nuances and attends to the contextual factors. The CDC has identified effective evidence-based interventions designed to increase safe sex in populations more likely to have unintended sexual health outcomes (e.g., pregnancy, HIV and STDs) (CDC (US) 2012). There have been numerous interventions and many are able to achieve an episodic reduction in high risk sexual behavior and infection transmission, but there is little evidence that they build sustainable skills (e.g., negotiating condom use with a partner) and behaviors (Alexander et al. 2015). Alexander and colleagues (2015) reviewed the literature and determined that many interventions fail to attend to the contextual and affective influences on sexual behavior change. They further argue that there is a need to augment strategies beyond condom use and skill development and that this may enhance sustainability of sexual health promoting behaviors (Alexander et al. 2015).

In recent years, mobile technology has penetrated just about every facet of life, including consumer health. There are more than 165,000 mHealth apps available for the iTunes and Android stores with approximately 2000 apps related to the prevention of HIV and STDs (Terry 2015; Muessig et al. 2013). mHealth apps can be used in a number of ways, including knowledge resources, reminders, and behavior inventories, and may also include more interactive components such as games, diaries, and goal-trackers. Muessig and colleagues evaluated apps that met specific criteria including whether the app provides information: (1) about HIV or other STDs; (2) about ways to reduce the risk of sexually transmitting or acquiring HIV/STDs; or (3) about how to use or obtain male or female condoms (Muessig et al. 2013). Fifty-five out of the nearly 2000 met one of the criteria. Comparatively, this class of apps was not very popular based on reviews and frequency of download. Very few apps “modeled condom negotiation, HIV/STD status disclosure, or sexual decision making in the context of relationships” (p. 17; Muessig et al. 2013). However, a few of the apps employed a tailored and/or interactive approach and showed promise for integrating mobile phone technologies into more comprehensive HIV prevention and care (Muessig et al. 2013). The authors argue for the need for public health practitioners to work with app developers to incorporate elements of evidence-based interventions for risk reduction. However, it is important to know that the nature of evidence used by the general population is not the same as the scientifically-based evidence used by the practitioners. Some understanding of the target users and their beliefs are important to consider.

There have been numerous efforts to employ health information technologies to educate various populations about healthy sexual behavior. The evidence is equivocal at this point and many technology-based interventions targeting adolescent and adult women are limited in terms of number of studies, sample sizes, and use of technologies to provide interventions (Blackstock et al. 2015).

The use of social networking sites and tools among adolescents and young adults has the ability to influence communication about sexual health and risk behaviors and attitudes toward these behaviors. They can also potentially be used as an intervention tool to promote health behaviors. Barman-Adhikari and colleagues demonstrated that homeless youths, who are among the most vulnerable of populations, employ mobile devices to discuss sexual risk and protective behaviors (Barman-Adhikari et al. 2016). Several studies document youth’s acceptability of receiving sexual health information and prevention messages through technology, which is a promising development (LeGrand et al. 2016). In a recent survey of high school students, Widman and colleagues found that almost half (49%) of the adolescents communicated via technology about their sexual health with partners, although rates varied depending on the topic (Widman et al. 2014). The most frequently discussed topics were sexual limits (42%) and condoms (39%). Females were more likely than males to discuss HIV, pregnancy, and sexual limits using technology. Those who discussed condoms and birth control with their partners via technology had consistent condom use rates that were three times higher than youth who did not discuss these topics. This suggests the opportunity to engage couples, an important contextual factor in sexual decision making. However, few technology-based interventions specifically target couples (Mitchell 2015).

Technologies can be used to reduce HIV infection rates through the promotion of healthy sexual behaviors and cognition. However, interventions do not work unless they are based on the understanding of the processes involved in making these risky decisions, such that we can intervene at an appropriate level (see Chap. 5; Sivaramakrishnan and Patel 2017). This is still a relatively young field with relatively few robust studies with few frameworks and no theories to guide us. The advent and tremendous growth of mobile technology and social media offer great promise. They enable both researchers and public health practitioners to tailor tools to particular populations and increase dialogue about issues that are very difficult to discuss face-to-face, for example, with one's partner. There is now an abundance of empirical research documenting the broad range of factors influencing sexual decision-making. Interventions that capitalize on this body of knowledge and strategically employ interactive technologies tailored to specific demographics and concomitant contextual factors are more likely to increase healthy sexual behaviors and reduce harmful risks.

Discussion Questions

1. How can changing beliefs and reasoning strategies affect changes to sexual behavior?
2. Why are behavioral health interventions that exclusively focus on an individual's knowledge about HIV less likely to succeed?
3. Explain how relationship status and perceptions about one's partner has a significant impact on sexual decision making.

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Chapter 9
Numeracy and Older Immigrants' Health: Exploring the Role of Language

Sospeter Gatobu, Laurie Hoffman-Goetz, and Jose F. Arocha

Abstract Conveying numerical information across language and cultural barriers presents unique challenges, which have not been well addressed in the literacy and numeracy literature to date. The primary language spoken prior to learning English may be an important factor in health numeracy for English-as-a-Second Language (ESL) immigrants. This is because languages differ in the number of numeric concepts such as whole numbers, probabilities, proportions or rates embedded in their structure. Some languages have more of these numeric concepts than others. Speakers of a language with fewer numeric concepts may be constrained in their numeracy skills and may have difficulties comprehending numeric information that contains numeric concepts that are absent in their primary language. Some languages, such as Kikuyu—a language spoken by the Agikuyu people of Kenya—lack concepts and words for some numerical forms, such as fractions and ratios. In contrast, Mandarin has many numeric concepts. In this chapter we consider how language may affect numeracy of older non-native speakers of English whose primary languages differ in the representations of numeric concepts.

Keywords Numeracy • Health numeracy • Numeric concepts • Primary language • Older immigrants

9.1 Introduction

Numeracy is a necessary skill in healthcare, and especially in health decision-making processes. Individuals with low numeracy and health numeracy skill have less knowledge about their health (Peters et al. 2007, 2008; Huizinga et al. 2008; Apter et al. 2006) and make less use of preventive health services (Huizinga et al. 2008).

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Higher levels of numeracy are related to healthy social, personal, and community functioning (Apter et al. 2009; Dennis and Barnes 2002). Low health numeracy is more likely in the elderly, in those who belong to a racial or ethnic minority such as immigrants, and in persons with low levels of education (Lipkus et al. 2010).

Definitions of numeracy and health numeracy overlap. Some consider numeracy as one component of general literacy (Rootman and Ronson 2005), while others regard literacy and numeracy as distinct but parallel concepts, with proficiency in one having little to do with proficiency in the other (Ginsburg et al. 2011). Numeracy refers to an individual's ability to understand and use mathematical information for everyday functioning in different contexts (Ginsburg et al. 2011; Statistics Canada 2005). Health numeracy is the extent to which people access, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical and probabilistic health information to make effective health decisions (Golbeck et al. 2005). Other related components of numeracy concept are numerosity, numbers, and counting.

Numerosity refers to perceived or inferred 'manyness'; it exists in all languages including those without explicit number words (Wiese 2003), and it is related to counting; when people count, they assign a numeral to each object in a series or row; the numeral corresponding to the last object counted indicates the sum of objects (Menninger 1969). Although all languages have a system by which the speakers count objects, variations exist in how counting is actualized (Pica et al. 2004). Some languages have a single system to represent both written number words and numerals, that is, the written character for a number represents both the number and the word for it (Menninger 1969). Others have two systems: one for numerals and the second for number words. It has been argued that learning, and use of numbers later in life is easy or difficulty depending on the number word system.

Research shows that multilingual persons either use their primary language to process numeric concepts presented in a second language (Campbell and Epp 2004), or they use the language in which they learned such concepts (Spelke and Tsivkin 2001). Therefore, if a language lacks some of the numeric concepts used in, for example, health information, its speakers can process such information using the language in which they learned the concepts. However, they may not be as efficient as they would be if they had learned the concepts first in their primary language.

Although many factors can account for low numeracy and health numeracy among immigrant populations, the focus of this chapter is primary language. Conveying numerical information across language and cultural barriers presents unique challenges, which have not been well addressed in the literacy and numeracy literature to date. In this chapter we discuss the influence of primary language on immigrants' numeracy and health numeracy skills, including how it could boost an individual's self-efficacy in numeracy (mathematics self-efficacy). We also discuss how speakers of two different primary languages that differ in the quantity of numeric concepts embedded in them process numeric tasks presented in English.

We present a brief background on immigrants, their health status and their numeracy skills. We also discuss primary language and the embedded numeric concepts, mathematics self-efficacy, and processing of numeric information by multilinguals. In addition, we consider how primary language could affect numeracy and health numeracy among older English-as-a-second language (ESL) immigrants. We conclude the chapter with a brief discussion on the implications this may have on health education and promotion among immigrants, and also, implications for the design of health informatics applications and technology-mediated communication and instruction.

9.2 A Brief Review on Immigrants, Their Health Status, and Their Numeracy Skills

9.2.1 Diversity in Immigrant Populations

The number of immigrant population in the western countries is increasing at an unprecedented rate. Even without the latest wave of immigrants to Europe and North America, the western world has been the destination of choice for people from unstable and insecure regions of the world. For example, it is estimated that 250,000 immigrants arrive in Canada annually, and immigrants already constitute about 20% of the Canadian total population. In terms of age, over one-quarter of all seniors in Canada are immigrants. In 2001, 28.6% of persons aged 65–74 and 28% of those aged 75–84 were immigrants (Statistics Canada 2006). Similarly, immigrants constitute a sizeable portion of the US population. In 2014, there were more than 42.4 million immigrants or 13.3% of the total population (about 319 million), and this number is growing. Between 2013 and 2014, the foreign-born population in the US increased by 1 million, or 2.5%. In terms of age, the immigrant population in 2014 was older than the U.S.-born population, with the median age of immigrants being 43.5 years, compared to 35.9 years for the native born (Zong and Batalova 2016).

Immigrants are diverse in terms of regions of origin, culture and language. According to the 2006 Canadian census, over half (58.3%) of the immigrants were from Asia, 16.1% from Europe, 10.8% from Central America, South America, and the Caribbean, 10.6% from Africa and the rest (4.2%) from the United States. Immigrants in Canada speak a variety of different languages, with more speakers of Chinese (18.6% either Cantonese or Mandarin), followed by Italian (6.6%), Punjabi (5.9%), Spanish (5.8%), German (5.4%), Tagalog (4.8%), and Arabic (4.7%) (Canada 2009).

In 2014, Mexicans comprised the highest proportion (28%) of the 42.4 million immigrants in the United States. India (5%), China (including Hong Kong) (5%), and the Philippines (5%) were the next largest countries of origin. Other countries included El Salvador, Vietnam, Cuba, and Korea (3% each), the Dominican Republic and Guatemala (2% each). Immigrants from these ten countries represented about 60% of the U.S. immigrant population in 2014 (Zong and Batalova 2016). Over 21% of immigrants in the USA speak a language other than English at home. Spanish is the most spoken language (62%), followed by Chinese (including Mandarin and Cantonese, 5%), Tagalog (about 3%), Vietnamese (2%), French (including Cajun and Patois, 2%), Korean, Arabic, and German (almost 2% each), and Russian (1%). In 2014, approximately 50% (20.9 million) of the 42.1 million immigrants ages 5 and older had limited English proficiency (Zong and Batalova 2016).

9.2.2 Immigrants' Health Status and Their Numeracy Skills

It has been shown that immigrants are on average healthier than the native-born populations, which has been referred to as the "healthy immigrant effect", an effect largely attributed to health screening during the immigration process (McDonald and Kennedy 2004). However, with time the health status of immigrants not only converges with the native-born population (Vang et al. 2015), but in some cases, immigrants end up presenting poorer health outcomes (Rootman 2008). To illustrate, immigrants in Canada are more likely than non-immigrants to develop type 2 diabetes; prevalence rates are between 1.35 and 12% across immigrant groups, with Asians and Africans being at a higher risk of developing the disease (Adhikari and Sanou 2012; Creatore et al. 2010). Similarly, individuals who migrate to the United States at a younger age are more likely to become overweight or obese the longer they live in the United States of America (Roshania et al. 2008).

Many factors contribute to the health status of populations (Preston and Taubman 1994; Feinstein 1993; Baker et al. 2000; Gazmararian et al. 1999). One of these factors is numeracy (Zanchetta and Poureslami 2006). Numeracy is often included in literacy, a term that is generally used to refer to both the ability to read and understand written information (Montori and Rothman 2005; Nelson and Reyna 2007). Some researchers however differentiate the two constructs, but acknowledge that literacy levels influence numeracy (Charette and Meng 1998).

Some authors argue that numeracy is a distinct concept from literacy (Golbeck et al. 2011; Ancker and Kaufman 2007). In addition, it has been shown that health numeracy and health literacy are only modestly correlated, with low levels of numeracy found to be quite frequent among individuals in the highest literacy level (Ancker et al. 2011). Numeracy is defined as the ability of an individual to understand and use mathematical information for everyday function in the workplace, at school, and in social contexts (Statistics Canada 2005; Statistics Canada and OECD 2005). Numeracy is also referred to as 'quantitative literacy' (Schwartz et al. 1997), 'statistical literacy' (Gal 2000) and 'mathematical literacy' (Breen et al. 2009). Although numeracy is an important component of everyday life, even people with high numeracy skills may fail to apply or effectively transfer those skills to other contexts, such as a health context (Lipkus et al. 2001). As mentioned earlier, the skill set needed to make sense of numeric information in the health context is health numeracy (Reyna et al. 2009).

Health numeracy enables individuals to access, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical and probabilistic health information in the health context; it is the ability to use this information to make informed health decisions (Golbeck et al. 2005). Just like numeracy, health numeracy is often subsumed under health literacy, a term most authors use to represent the two constructs (Gazmararian et al. 1999; Baker et al. 1999). The Canadian Council on Learning uses the collective term to describe health literacy; it includes prose literacy, document literacy and numeracy skills (Canadian Council on Learning 2008). Although health literacy and health numeracy are related, health numeracy requires specific skills (Golbeck et al. 2011). Health numeracy proficiency can be decomposed into different abilities: basic, computational, analytical, and statistical. Individuals with basic health numeracy can make sense of simple information involving numbers; those with computational health numeracy skills can perform simple arithmetic operations such as counting, addition and subtraction, and those with analytical health numeracy skills are not only competent in basic and computational domains but can also estimate and understand percentages and frequencies (Golbeck et al. 2005; Ancker and Kaufman 2007). Individuals with low health numeracy skills have poor health outcomes compared to those with higher health numeracy skills (Zanchetta and Poureslami 2006). They have less knowledge about health, make less use of preventive health services, and may have greater disease consequences due to failure to adhere to prescribed treatments and medication protocols (Peters et al. 2007, 2008; Huizinga et al. 2008; Apter et al. 2006).

Numeracy and health numeracy skills are not uniform in most populations. Compared to the general population, immigrants have lower numeracy and health numeracy skills, and lower health status (Zanchetta and Poureslami 2006; Shomos 2010). Numeracy can be influenced by many factors including numbers, counting, numerosity, experience, expertise, cognitive processing, language, and subjective dimensions. Particularly for speakers of English-as-a-second language, numeracy can also be influenced by the quantity of numeric concepts in their primary language. English may have numeric concepts that are not present in their primary language. In addition, many immigrants received their formal education in different systems, and in different languages. We discuss primary language and acquisition of numeric concepts in the following paragraphs.

9.2.3 Primary Language and Numeric Concepts Embedded in Them

As mentioned earlier, immigrants have diverse backgrounds in terms of regions of origin, culture, language and education. The relationship between culture, language and thought has been extensively discussed (Brysbaert et al. 1998; Hunt and Agnoli 1991; Kay and Kempton 1984; Macchi and Bagassi 2012). Language is associated with how people acquire and process information. An important factor in processing numeric information is facility with numeric concepts, such as whole numbers, fractions, square roots, negative numbers, exact integers, proportions and ratios (Feigenson et al. 2004). Languages differ in the quantity of numeric concepts embedded in their structure. For example, Mandarin has whole numbers and rational numbers embedded in its structure (Miura et al. 1999). Languages also differ in the number words available in them for use by their speakers. Pirahã, a language that is spoken in the Amazon region in Brazil, has an upper limit of 2 of the numerals and number words available in their language (Gordon 2004). Therefore, a language could be designated as either low or high in numeric concepts depending on the quantity of numeric concepts contained in it.

A language with one numeric concept (e.g., whole numbers, fractions, ratios, percentages) can be considered a "low numeric concept" language, whereas a language with two or more numeric concepts can be considered a "high numeric concepts" language. Languages such as Pirahã would be categorized as a low numeric concept language, compared to other languages such as Mandarin, that have embedded in their structure whole numbers, fractions and percentages. Similarly, Kikuyu language (a language spoken by the Agikuyu people of Kenya) can be designated a "low numeric concept" for having only 1 numeric concept (whole numbers) but lacking concepts and words for fractions, proportions, and percentages (Leakey 1977). It is important to highlight how numeric concepts are acquired, because this influences how, later in life, speakers of given languages interact and make sense of numeric information containing those concepts.

There has been considerable debate about how people acquire number concepts. Some researchers suggest that infants are born with innate basic or primary quantitative abilities, such as counting (Geary 2000). Others argue that infants are not born with such abilities; they acquire the concepts as they develop language skills (Condry and Spelke 2008; Bloom and Wynn 1997). Still others suggest that a language involving exact numbers is a creation of specific cultures (Frank et al. 2008).

In spite of the debate, it is generally agreed that most numeric skills are acquired in a deliberate manner, through culture and formal/informal education (Geary 2000; Kelly et al. 1999). Pre-school children may acquire numeric concepts outside the school environment, but they formally acquire such concepts through the educational system. Therefore, aside from language, the education background, including design and the implementation of the mathematics curricula are also important factors to consider when comparing mathematical performances internationally. The following is a brief comparison of mathematics curriculum focusing on two groups—Chinese individuals receiving their education in China, and East African individuals receiving their education in Kenyan. These two groups are highlighted because they represent speakers of high versus low numeric concept languages.

In mainland China, the official language of instruction is Mandarin. In the first term of the first grade, every child goes through 4–6 weeks of learning proper pronunciation in Mandarin; this is considered the prerequisite for formal education (Barnes 1978). Mandarin been has been shown to convey mathematical concepts more clearly, aiding students in China to better learn and understand mathematical concepts; number words in Mandarin give an advantage to children in learning and performing mathematical tasks (Wang and Lin 2005; Ng and Rao 2010).

In China, the mathematics curriculum is designed to develop student's problem solving skills (Cai and Nie 2007). According to the "Nine-year compulsory education in whole-day primary school mathematics curricula" (http://ywb.cqu.edu.cn/CDYW/views/show-one-item.do?id=35), the main mathematical concepts are introduced in Mandarin at the elementary level, a period of six years. For example, basic counting, addition, subtraction, multiplication, measurements, time and elementary geometry, are taught in the first year. These concepts are further developed in subsequent years. Fractions and statistics are introduced in the third year, and decimals and algebra are introduced in the fourth year, prime numbers in the fifth year and percentages, ratios, proportions and various ways of presenting data (various types of charts and tables) are introduced in the sixth year.

Primary school education in Kenya lasts for eight years. The language of instruction in the first three years (grade 1 to 3) is the primary language (or vernacular) in rural schools; English and Kiswahili languages are used in urban schools due to the diversity of languages represented. English is the only language of instruction from grades 4 onwards (Bunyi 1997; Cleghorn et al. 1989). According to the Primary Education Syllabus (Ministry of Education 2002), mathematics concepts introduced in grade 1 and 2 include whole numbers (counting, reading and place value), addition, subtraction, multiplication, division, measurements and geometry. In grade 3, more content is added to the concepts introduced earlier, while additional concepts are introduced. These include fractions, measurement (length, mass, capacity, money, time) and geometry. However, these concepts are taught in English because they have no equivalent rendering in primary languages. Grade 4 builds on concepts introduced earlier, with some additions in measurement (area and volume). Algebra, tables and graphs are also introduced at this level. Content for grade 5 consists of all the concepts introduced earlier, with only one single addition: scale drawing, where the students learn proportions in linear measurements. Percentages are introduced in grade 6, as are time and speed, and more geometrical concepts. Ratios and proportions are introduced in grade 7. Grade 8 covers all the mathematical concepts introduced in the earlier grades. Students are also prepared for the national examination in grade 8, and those who pass proceed to secondary education.

An important difference in delivering mathematics curricula in China and Kenya is language. In China the curriculum is delivered consistently in the primary language throughout the education system. This consistency is absent in Kenya where the language of instruction changes in grade 4. Moreover, unlike the case of Mandarin, all the mathematical concepts, except whole numbers, are foreign to Kenyan languages. This implies that these mathematical concepts cannot be introduced during the early years of education, unless they are first translated and delivered in vernacular, potentially introducing confusion in the learning process (Cleghorn et al. 1989). Most Kenyans, including those living in urban areas, speak English as a second or third language. Thus, Kenyan and Chinese children may be exposed to the same concepts in elementary education, but the Chinese children may learn them more efficiently and more consistently than Kenyan children.

9.2.4 Mathematics Self-Efficacy

Self-efficacy in mathematics refers to an individual's perceived ability to work with or to make sense of numbers. This perception plays an important role in the willingness in individuals to expose themselves to situation that involve solving problems involving numbers (Pajares and Miller 1994). Among ways that mathematics self-efficacy help improve performance is by reducing mathematics anxiety, a condition that affects some people when presented with mathematical problems to solve (Pajares and Miller 1994; Ashcraft and Moore 2009; Hackett and Betz 1989; Hopko et al. 2003). Rounds and Hendel (1980) identified two factors that constituted mathematics anxiety and labeled them "mathematics test anxiety" and "numerical anxiety". Mathematics test anxiety is fear of math tests and math courses, while numerical anxiety is fear stemming from everyday situations involving the use of numbers (Kagan 1987). Numerical anxiety seems to be related to individual's disposition or attitude towards numbers, and may be the most important factor in mathematics anxiety (Kazelskis et al. 2000). Lyons and Beilock (2012) conducted a study that found that for people with high mathematics anxiety, anticipating a mathematical situation activates pain networks in the brain. Mathematics and numerical anxiety may occur if the individual lacks confidence to perform mathematical tasks, if the problems are new, if the problems are perceived to be complex, or if the time to solve the problems is limited (Hoffman 2010). High level of mathematics self-efficacy reduces mathematics and numeric anxiety and improves numeric problem-solving.

9.2.5 Processing of Numeric Information

Individuals who are bilingual or multilingual often use either their primary language, or the language in which they initially learned mathematical concepts and skills, to process numeric information presented in another language (Campbell and Epp 2004; Dornic 1979; Wang et al. 2007). Individuals' primary language may indicate the language they use to think; individuals who speak a certain language usually think most efficiently about those topics for which their lexicon has proved an efficient code (Hunt and Agnoli 1991). The lexicon of a language plays an important role in the development of schemas, that is, the programmes that organize how information is stored and retrieved from long-term memory (Anderson 1984). Number schemas differ between languages (Hunt and Agnoli 1991), and speakers of a given language can only tap into schemas of numbers they have in their number word system (Gordon 2004), and number words that already exist in their long-term memory. People more efficiently retrieve numeric information in the language in which they learned the numeric concepts, regardless of their fluency in languages (Spelke and Tsivkin 2001).

Individuals process information either intuitively or analytically, also referred to as the dual-process theory (Chandler and Sweller 1991; Sloman 1996). Intuitive processing is relatively quick and it exerts little cognitive demand on the individual. Individuals with lifelong personal experience with given information or problem solving approaches are more likely to process information intuitively. In contrast, individuals engage in analytical processing because they might lack expertise in a given domain, or problem area. Analytical processing is usually slower, and exerts heavier cognitive load compared to intuitive processing of information (Evans 2003; Stanovich and West 1997). It can therefore be argued that that the use of analytic and intuitive approaches on numeracy tasks depends, among other things, on factors such as the numeric structure of one's primary language, the language of basic mathematics learning, and self-efficacy in numbers.

9.2.6 Assessing the Role of Primary Language on Numeracy Among Older Immigrants

We conducted a study to assess whether primary language was among factors that determine numeracy, and processing of numeric health information among immigrants in Canada who speak English as a second language. The study involved 120 participants from two groups of immigrant speakers of English-as-a-second language (ESL) from Kenya (60 Kikuyu-speakers) and China (60 Mandarin-speakers). The primary languages of these two groups differ in terms of the number-word structures and the quantity of numeric concepts embedded in their respective language structures. Details on method are discussed in a separate published article (Gatobu et al. 2016). Participants were 40 years and older, implying that they had lived in their mother countries for most of their lives and therefore were assumed to be proficient in their primary language. Learning and attaining proficiency in a second language is related to the age at immigration (Stevens 1999), therefore, participants in this study would not have fluency in English at the level of native speakers. In addition, we involved participants who had lived less than 15 years in Canada. Although the cut-off for recent and established immigrants is 5 years, length of stay does not seem to improve levels of numeracy among immigrants; in fact, recent immigrants seem to have better numeracy skills than established immigrants (Statistics Canada 2005).

We assessed context-free numeracy using two French Kit tasks, (the addition task, and the addition and subtraction correction tasks) (Ekstrom et al. 1976). The French Kit comprises 72 factor referenced cognitive tests used to measure a wide range of cognitive processes including verbal ability, reasoning, spatial ability and memory. Among the French Kits subtests is the number facility which assesses facility and speed in the performance of basic arithmetic operations. We selected two number facility factor tasks, that is, *the addition* test, and the *addition and subtraction correction* test. The addition test assesses speed and accuracy of operations, and the score is assessed as the number of correct items for each item. The addition and subtraction correction test is a recognition task. Participants are given mathematical problems with answers; they are only required to identify, or recognize the correct and the incorrect answers. All the tasks were timed, although we did not inform the participants to avoid creating math anxiety (Ashcraft and Moore 2009).

In addition, we assessed mathematics self-efficacy using the Mathematics Self Efficacy Scale (MSES), developed by (Betz and Hackett 1993). Participants were asked to assess their mathematics self-efficacy using a 10 point scale (0 = no confidence; 9 = complete confidence). Numeracy in the context of healthy (health numeracy) was assessed using the Short Test of Functional Health Literacy for Adults (S-TOFHLA) which includes a literacy/prose component, and a numeracy component (Baker et al. 1999). S-TOFHLA is composed of 36 prose and 4 numeracy items. It utilizes the cloze procedure with contents drawn from medical instruction used to prepare for a medical procedure, information of Medicaid insurance and patient rights. The four questions of the numeracy component assess understanding of instructions on a prescription bottle, ability to determine correct blood sugar and identifying time of appointment on a card. The scores are weighted for the prose component (72) and for the numeracy component (28) with a composite score of 100. A score of 0–53 indicates inadequate, 54–66 indicates marginal, and 67–100 indicates adequate health literacy and numeracy. The prose component has a reliability of 0.97 and the numeracy component 0.68.

The Newest Vital Signs (NVS) (Weiss et al. 2005) involves comprehension of information on an ice cream nutrition label. The NVS is used to screen patients' ability to read a nutrition label and apply the prose and numeric information to answer six questions that tap literacy and numeracy skills. The numeric and prose/literacy components of NVS overlap, and participants are required to answer numeracy questions within a prose context.

We used the Think-aloud technique to assess processing of numeric information among the speakers of Kikuyu and Mandarin languages. The think-aloud technique is based on the information-processing model of problem solving (Newell and Simon 1972). The technic taps the information available in short-term memory which is then verbalized during problem-solving (van Someren et al. 1994; Ericsson and Simon 1984). The Think-aloud exercise was based on diabetes diet information, and involved calculating the number of grams a diabetic mother ate within one day. The problem solving involved five subtasks tapping skills in different mathematical operations such as simple addition or multiplication skill, conversions of fractions (using either multiplication or division), and addition. Participants were required to find solutions for each subtask, and use the individual solutions to calculate the total number of grams the mother ate in a day. The focus was on the process of arriving at the final number of grams rather than on whether the result was numerically correct. The instructions were written for reading level 6 (SMOG readability formula: http://www.harrymclaughlin.com/SMOG.htm). We collected and analyzed the participants' verbal protocols of their reasoning process based on the dual process theory of information processing (Sloman 1996; Evans 2003; Stanovich and West 2000; Klaczynski 2001) and Schoenfeld's framework (Schoenfeld and Herrmann 1982) for analyzing mathematical problem solving.

Data were analyzed using SPSS (Version 20.0). The means of the numeracy measure (French Kit), self-efficacy (MSES), the S-TOFHLA and NVS by language groups were examined for differences using the Mann-Whitney *U* (a nonparametric) test, because the data did not meet the assumption of normality, and homogeneity of variance, and because of the small size of the study sample (Field 2005). Protocol analysis was used to analyze qualitative data on processing of numeric information.

Multiple regression analyses were conducted to test the role of language and self-efficacy in predicting numeracy, health numeracy and health literacy, after adjusting for sociodemographic factors (language, gender, age, and education, duration of residency in Canada, employment, income, and format of presenting numeric information, that is, numbers versus explanations using words). Using forward and stepwise methods all variables that had a *p* value of 0.05 were identified and forced into the final regression models.

Assessment of numeracy using the addition, and the addition and subtraction correction tasks (French Kit) showed that Mandarin-speakers had higher mean scores in both tasks compared to Kikuyu speakers; the differences were statistically significant ($U = 918.0$, $p < 0.001$ and $U = 456.0$, $p < 0.001$, respectively) (Fig. 9.1).

We used the mathematics self-efficacy scale (MSES) to measure self-efficacy and found that Kikuyu-speaking immigrants had a lower score on this scale compared to Mandarin-speaking immigrants, and the differences were statistically

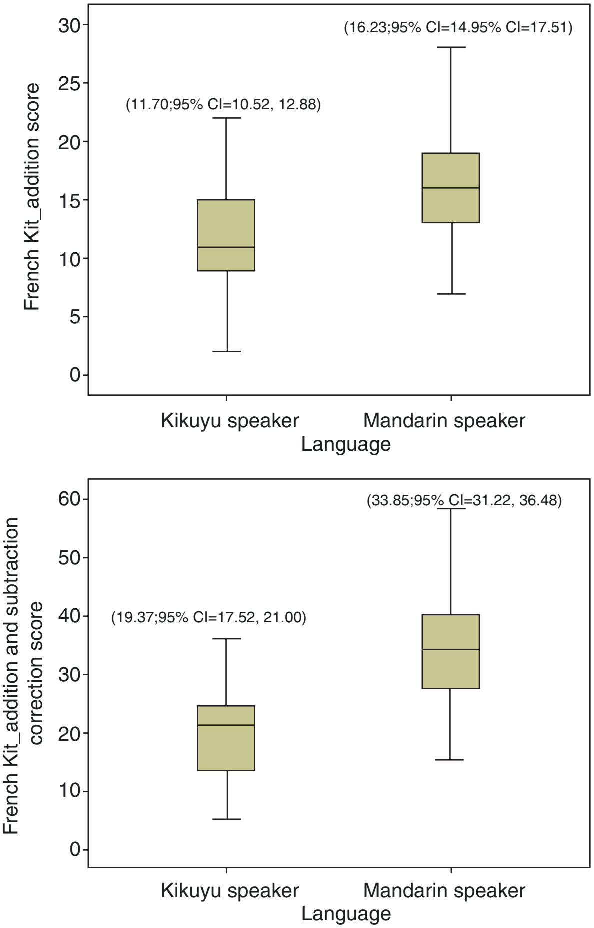

Fig. 9.1. Mean scores: French Kit addition task, and addition and subtraction correction task

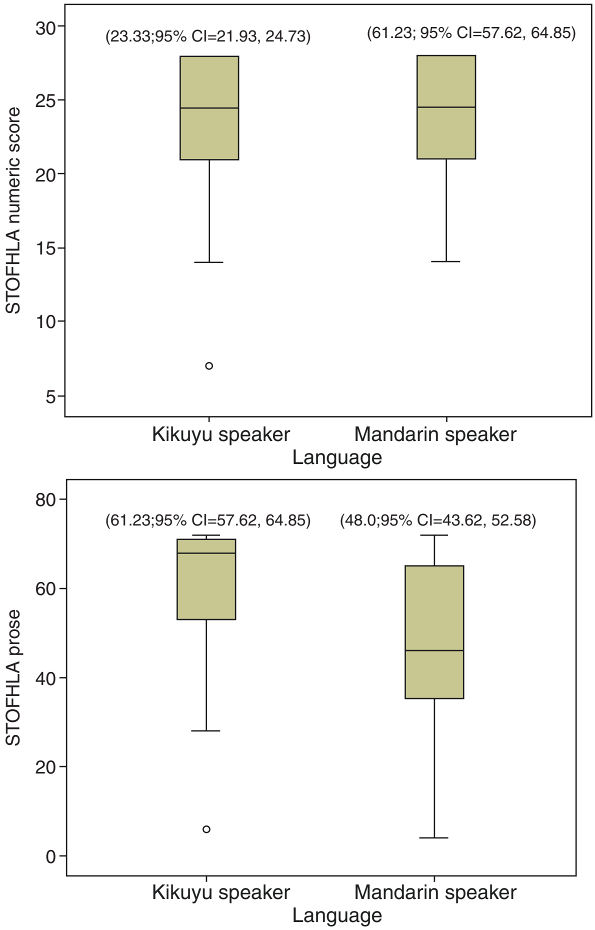

Fig. 9.2. Mean score: STOFHLA Numeracy task, and STOFHLA prose task

($U = 1120.0$, $p < 0.001$). Details on analysis and results of this measure are presented in a separate article (Gatobu et al. 2014).

Golbeck and colleagues (2011), argue that health numeracy and health literacy should be treated as different concepts. We therefore analyzed the S-TOFHLA prose and numeracy components separately, and found that Mandarin-speakers had higher health numeracy scores than Kikuyu-speakers and the difference was statistically significant ($U = 1413.5$, $p = 0.023$). In contrast, Kikuyu-speakers had significantly higher S-TOFHLA prose scores than the Mandarin-speakers ($U = 890.0$, $p < 0.001$) (Fig. 9.2).

No statistically significant differences were found on the composite NVS scores between Kikuyu-and Mandarin speakers. However, because each question in NVS taps prose and mathematical skills to a varying extent (Ozdemir et al. 2010), the individual questions were examined to explore why Kikuyu- and Mandarin-speakers differed on the composite S-TOFHLA scores but not on the NVS scores. This time the performance differed. More Mandarin-speakers (64 and 75%) than Kikuyu-speakers (52 and 52%) answered correctly the two questions that had an easily identifiable numeracy component. In contrast, more Kikuyu-speakers (41, 60, 71 and 69%) than Mandarin-speakers (34, 34, 53 and 53%) answered correctly the four questions that required greater facility in prose/language skills.

Prediction was made for the French Kit tasks, the composite S-TOFHLA, the prose and numeric components of S-TOFHLA, and the NVS. Only the composite score for NVS was used because of the overlap in the prose and numeracy domains for most questions and the difficulty in clearly separating distinct subcomponents. Independent variables were language (Kikuyu, Mandarin), age, gender, education, and residency in Canada. Table 9.1 below presents the results of the multiple regression.

Prediction made for self-efficacy found that mathematics self-efficacy, gender, language and duration of residency in Canada predicted basic numeracy. Mandarin speakers, individuals with longer residency in Canada, and those with higher mathematics self-efficacy (MSES) performed better on the two tests of basic numeracy (addition, and addition subtraction correction); however, mathematics self-efficacy did not predict numeracy in health context. Detailed discussions on this finding are presented in a different article (Gatobu et al. 2014).

9.2.7 Primary Language as an Important Factor in Immigrants' Numeracy Skills

Mandarin outperformed speakers of Kikuyu in numeracy and health numeracy. Mandarin-speakers had higher scores in the addition, and the addition subtraction-correction tasks. They also outperformed Kikuyu-speakers in health numeracy (S-TOFHLA numeracy component). This supports the hypothesis that primary language is an important factor in the comprehension of numeric health information presented in English to people who are more fluent in other languages. These findings are consistent with other studies that show superior mathematical skills among speakers of the Chinese-based languages compared to other groups (Geary et al. 1993; Miller et al. 2005). Among the factors that may contribute to this superior performance are the structures of number words and the quantity of the numeric concepts embedded in the Chinese languages. Compared to languages such as English or French, Mandarin has a more regular structure and a simpler system of naming numbers, which may influence performance in mathematical tasks (Miura et al. 1993). The term 'regular' in spoken and written number system implies a consistent representation of a base system, that is, the counting system used in a given language (Dowker et al. 2008), with many languages using base 10. Mandarin, like other Chinese languages, is considered regular because the spoken and the written number systems correspond. In Mandarin, teens are made of two-digit (11 = ten one; 16 = ten six and so on) and decades as multiples of ten (33 = three ten; 40 = four ten, and so on) (Brysbaert et al. 1998). In contrast, English has an irregular

Table 9.1. Multiple regression table for French Kit, composite S-TOFHLA, S-TOFHLA numeracy and NVS performance among 60 Kikuyu and 60 Mandarin speaking ESL study participants

	French Kit (addition)		French Kit (addition and subtraction-correction)		S-TOFHLA (composite)		S-TOFHLA (numeracy)		S-TOFHLA (prose)		NVS	
Variable	B (SE)	*P*	B (SE)	*p*	B (SE)	*p*	B (SE)	*p*	B (SE)	*p*	B (SE)	*p*
(Constant)	1.50 (2.77)	0.588	0.50 (4.83)	0.918	82.76 (8.45)	<0.001	18.63 (2.88)	<0.001	64.13 (7.40)	<0.001	2.49 (1.10)	0.026
Language	3.14 (0.91)	0.001	11.42 (1.58)	<0.001	−18.21 (2.77)	<0.001	1.47 (0.95)	0.123	−19.68 (2.43)	<0.001	−0.87 (0.36)	0.016
Gender	1.10 (0.96)	0.254	0.05 (1.67)	0.975	5.57 (2.93)	0.059	0.21 (0.99)	0.832	5.36 (2.56)	0.039	−0.01 (0.39)	0.987
Age	0.71 (0.95)	0.455	−0.85 (1.66)	−0.611	−7.91 (2.90)	0.007	1.42 (0.99)	0.155	−9.32 (2.54)	<0.001	−0.56 (0.38)	0.138
≤High school[a]	–	–	–	–	–	–	–	–	–	–	–	–
>High school < University	1.66 (1.58)	0.294	3.78 (2.75)	0.173	12.20 (4.81)	0.013	−0.17 (1.64)	0.920	12.37 (4.22)	0.004	1.85 (0.63)	0.004
University	3.62 (0.56)	0.039	10.99 (3.03)	0.000	26.80 (5.30)	<0.001	1.98 (1.81)	0.277	24.82 (4.64)	<0.001	3.04 (0.68)	<0.001
Graduate	3.72 (1.76)	0.037	7.66 (3.07)	0.014	28.44 (5.38)	<0.001	1.05 (1.83)	0.567	27.39 (4.71)	<0.001	2.89 (0.69)	<0.001
Residency[b]	3.16 (1.11)	0.005	4.25 (1.93)	0.029	6.13 (3.37)	0.072	0.76 (1.15)	0.511	5.37 (2.96)	0.072	0.52 (0.44)	0.245
Unadjusted R^2	0.31		0.56		0.44		0.11		0.52		0.26	
Adjusted R^2	0.27		0.53		0.41		0.05		0.49		0.21	

Language: Kikuyu, Mandarin; Gender: Male, Female; Age: 40–50, >50 years; Education: ≤ High School, as reference for >High School <University, University and Graduate; Residency: < 5 years, > 5 years)

[a] High school and less education

[b] Duration of residency in Canada

number system where the spoken and written systems do on not correspond. In English, teens are presented as one word (e.g., ten, eleven, twelve, thirteen) and decades are presented with a different one word representations (e.g., twenty, thirty, and forty). The regular system makes it easy for Mandarin-speaking children to efficiently learn and apply mathematical operations later in life (Miura et al. 1993; Lefevre and Liu 1997).

A simpler system implies that number words in Chinese are short and easily pronounced compared to numbers words in other languages, such as English. In an experiment on short-term memory for digits between Chinese and English speakers, Stigler and colleagues (Stigler et al. 1986) found that Chinese speakers had better digit memory than English speakers, which was attributed to the short Chinese numbers words. It appears that the regularity of short number words in the Mandarin language places a lighter load on the working memory (Baddeley 1992), and this could potentially improve performance in numeric tasks.

Similar to Mandarin, the Kikuyu language, has a regular structure including the use of base 10 (Leakey 1977). However, it has only one embedded numeric concept (whole numbers). Other numeric concepts which appear in Kikuyu, such as rational numbers or words for exact quantities are borrowed or acquired from other languages including English (Bunyi 1997; Cleghorn et al. 1989; Zavlasky 1973). These differences could potentially affect acquisition, memory and utilization of such concepts, affecting the performance of numeric tasks (Dornic 1979).

This is further supported by the findings (on a separate question of this study) on processing of numeric health information. Participants were required to solve a problem using numeric diabetes diet information. The problem included three items with fractions. More Mandarin-speakers answered correctly two of the items, while Kikuyu-speakers answered correctly only one item. In contrast, in the two items that involved whole numbers, the two groups tied in the number of correct answers they gave, a finding that could be attributed to lack of concept of fractions in Kikuyu. It was even more interesting to observe Mandarin speakers using their primary language to solve the problem. When asked why they were doing that, their response was that it was "*Easier to think in Mandarin than in English*".

Mathematics self-efficacy predicted numeracy performance and, to a lesser extent, health numeracy performance among the immigrants who took part in the study. This is consistent with literature on the relationship between self-efficacy and an individual's ability to solve mathematical problems (Hackett and Betz 1989). Self-efficacy in mathematics is often a result of familiarity with, and experience using numeric concepts and processes (Lent et al. 1991).

Language of instruction and the system of formal education play an important role in the acquisition of numeric concepts. Although the method of instruction for mathematic in Kenya and China were not measured, it could potentially contribute to the findings in this study. Leung (Leung 2001) differentiated between Western and East Asian systems of learning and argued that features and values unique to East Asian mathematics education contribute to the superior performance of East Asian language speakers compared to other groups. One feature of mathematics instruction in China is the emphasis of content over procedure process. Although both process and content are important in mathematics instruction, Chinese learners have the advantage in that they acquire mathematical content, as opposed to Western learners who mainly concentrate on the procedures of doing mathematics. Chinese children also receive instruction in their primary language.

In their review of the effect of Chinese number words, culture and mathematics learning, (Ng and Rao 2010) suggested that number word system and the structure of the language, and contextual factors such as parental support, and the degree of appreciation of mathematics in Asian culture could potentially contribute to superior performance in mathematics among Chinese individuals.

High level of education also contributed to numeracy tasks (addition, and addition and subtraction correction) but not to health numeracy (S-TOFHLA numeric task). However, in a separate analysis using the Observation Oriented Modeling (OOM) (Grice 2011), education beyond high school did not appear to strongly conform to numeracy (Gatobu et al. 2016). It has been observed that attained education remains an imperfect proxy for health literacy and numeracy (Chew et al. 2004). In addition, and with regard to health numeracy (S-TOFHLA numeracy), education may be necessary, but it may not be a sufficient factor in distinguishing performance in the S-TOFHLA numeracy task. Familiarity with the health context in which numeric information is presented may contribute more to health numeracy performance regardless of education attainment.

Age contributed to the general health literacy (S-TOFHLA prose and numeracy score). Relatively younger participants (less than 50 years old) had better health numeracy skills compared to older participants (over 50 years old). Age affects not only physical but also cognitive functioning, and it has been associated with a slowing of working memory and reduced speed of processing of information (Caplan et al. 2011). In a study comparing measures of health literacy and numeracy using the rapid estimate of literacy in medicine (REALM) and NVS it was found that participants who were 60 years and older were more likely to have inadequate health literacy and numeracy skills compared to participants whose age was less than 60 years (Shigaki et al. 2013). An interesting finding was that age did not predict basic numeracy (addition, and addition and subtraction correction), which is in contrast to literature showing an association between older age and low numeracy skills (LaVallie et al. 2012). This may be due to the study sample; more participants ($n = 88$) were less than 50 years old compared to fewer ($n = 32$) who were older than 50 years. Therefore, caution is needed in interpreting this finding.

The length of time in the host country improves numeracy skills among immigrants. Longer duration of residency in Canada was associated with greater basic numeracy skills in the sample of Mandarin- and Kikuyu-speaking immigrants. However, duration of residency did not improve health numeracy. Improvement in basic numeracy can be attributed to the individuals' integration in the host country, and their interactions with more numerate people (Ciampa et al. 2013). Immigrants also have increased opportunities to utilise numeracy skills by for example, filing tax returns, paying bills and adding receipts (Charette and Meng 1998). Language plays an important part in integrating into a new community. Driessen and Merry (2011) found that regular use of the Dutch language was associated with the development of numeracy skills among immigrants in the Netherlands.

Individuals process information either intuitively or analytically. The two methods occupy the opposite sides of a continuum, and individuals' reasoning fall between these two extremes (Keren and Schul 2009). Mandarin and Kikuyu speakers took different approaches to solve the problem. Mandarin speakers mostly used the intuitive approach; they took relatively shorter time to solve the problem, and performed better on the French Kit recognition task, which was used to measure the speed of context-free mathematical performance. In contrast, Kikuyu speakers mostly used the analytical approach. They took more time to solve the problem, and performed poorly in the French Kit recognition task.

It has been argued that highly intuitive individuals have an edge on the analytical individuals when solving problems involving numbers (Thorsland and Novak 1974). Individuals use the intuitive approach when they are familiar with the problem. They have the knowledge in the form of schemas that they can tap into during problem solving episodes (Fischbein 1999). It has been suggested that experienced individuals retrieve information from memory when solving arithmetic tasks (Imbo et al. 2007).

Although we have discussed factors such as education, age, duration of residence, primary language remains the main factor that contributes to numeracy among older immigrants. Primary language seems to provide the foundation on which numeracy skills are built. As discussed earlier, the presence or absence of numeric concepts in a primary language determine the ease in learning and use of the concepts later in life. Speakers of languages that have more numeric concepts in their structures have an advantage over speakers of languages that have fewer numeric concepts when solving problems that involve such concepts. Primary language is the foundation in the acquisition, representation and expression of thought (Frankish 2010). Retrieval of basic numbers in mathematics problem-solving episodes depends on auditory and verbal representations of the first or primary language (Dehaene 1992). Therefore, it can be argued that other factors such as education, self-efficacy, age, duration of residency in the host country build on what the primary language has provided.

9.3 Implications and Conclusion

Immigrants already constitute a sizeable proportion of the population in western countries, with their numbers increasing due to the current movement of people from troubled regions in the world seeking safety. These immigrants encounter many challenges navigating the new cultural, economic, health and social environment. Older immigrants are often fluent in primary languages other than the dominant or the official languages in host countries. Primary language is an important factor in the acquisition, representation and expression of thought (Frankish 2010), and there is an association between the structure of a language including the embedded numerical concepts and the language speakers' ability to use such concepts (Miura and Okamoto 2003). This has implications on programmes that are designed to integrate immigrants in their new environments. Specifically, health education and promotion interventions involving information in number formats may be designed with older immigrants in mind.

Given the documented link between low numeracy and poor health outcomes for immigrants, addressing underlying causes of low numeracy and health numeracy could lead to cost-saving interventions, strategies and policies for national health care systems. Low numeracy among immigrants may translate directly into lower economic performance for individuals and for the country as a whole. Therefore, there is need to address this issue in research and practice.

Investigating and understanding the cognitive component processes involved in numeracy skills may provide a way to more specifically attend to the skill limitations of low literacy individuals, and to develop highly specific training systems focusing on those component processes where people present problems in understanding. Numeracy is a necessary skill for workers in a highly competitive, knowledge-driven economy. Increasing citizens' numeracy and health numeracy knowledge and skills can have an impact on enhancing the competitiveness of the host countries' labour force.

Discussion Questions

1. Language is closely linked to thought. People who learn a second or a third language later in life say that they sometimes find it easier to think in their primary or first language. How can this information be used to present information to people who speak different languages as second or third languages?
2. Electronic and mobile technology has become an important part of life. How can knowledge about language and numeric concepts in different languages be incorporated in the development of electronic and mobile technologies for ease of access and use of information to improve people's lives?

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Chapter 10
Culturally Appropriate Behavioral Change in Maternal Health: Role of Mobile and Online Technologies Over Time

Yuri Quintana and Jennifer McWhirter

Abstract A major challenge in global health is improving newborn and maternal health. A variety of economic, geopolitical, socio-cultural, and technical factors are involved. Online and mobile technologies hold the potential to improve maternal and newborn health by supporting access to education, improving coordinated care, and facilitating patient support. These online and mobile systems have been designed to address a variety of maternal and newborn health outcomes, including: increasing antenatal care attendance; cessation of unhealthy behaviors, such as smoking and drinking alcohol; and increasing vaccination rates of newborns. The success of these systems, however, is very much dependent on how—and whether—they can effect behavioral changes in culturally appropriate ways. This chapter reviews the design of these systems in both developed and developing countries, the technologies and behavioral frameworks used, and the evaluation outcomes. The acceptance of these new patient support networks requires the trust of patients and healthcare providers. Hence, this chapter also reviews the evolution of these systems, and the potential benefits of, and challenges for, their sustained operation.

Keywords mHealth • Mobile health • Maternal health • Behavior change • Health behavior

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10.1 Introduction

Improving maternal and child health is an urgent issue and global priority. In 2013, 4.6 million children died (74% of all under-5 deaths) within the first year of life (World Health Organization 2014). An estimated 270,000 newborns die during the first 28 days of life every year (Liu et al. 2012). Many of these deaths could be prevented if there was improved prenatal care and early detection of high-risk conditions (Proctor 1998; American Academy of Pediatrics Subcommittee on Hyperbilirubinemia 2004).

Preterm deliveries are one such high-risk condition. Let us consider it more closely and how mobile technologies might help to address the issue. Evidence suggests that improving prenatal care may lead to decreased preterm deliveries (Hollowell et al. 2011). Programs that provide face-to-face social support, such as CenteringParenting® (Tilden et al. 2014), have shown better outcomes when compared to traditional prenatal care. Scaling such a program to a larger number of women is a challenge because of the human resource limitations of facilitators and the need to travel to a central location to receive these prenatal services.

Mobile technologies may provide a way to expand the delivery of prenatal care and, thus, improve maternal and newborn health outcomes. For example, mobile apps can be used for the collection of patient-generated data, such as weight and blood pressure, with devices connected to Smartphones, sending reminders by age (e.g., immunization), and care guidance for previously identified neonatal conditions. There are over 40,000 apps labeled as health apps, but few are used on a sustained basis (IMS Institute for Healthcare Informatics 2013). Evaluating the effectiveness of these apps is important, and their success can hinge on the extent to which an understanding of health behavior change has been built in and whether their approach is culturally appropriate. To achieve and maintain behavior change in their target audiences, these apps ought to be designed with an understanding of behavioral models—frameworks we use to understand how and why we make the behavioral decisions we do. Further, understanding cultural and socio-economic issues is vital to understanding the local adoption of mobile applications and the sustainability of programs.

Understanding the use of mobile technologies for health services can also be an effective way to reach lower income populations that may have economic restrictions to reach large specialty centers but may have mobile phone access. A recent study from the Pew Research Center (Pew Internet and American Life Project 2015) showed that 64% of Americans have a smartphone, 85% of Americans aged 19–29 years are smartphone owners, and 62% of smartphone users have used a smartphone to search for health information. It also showed that 15% of Americans have limited options for online access other than a cell phone. Of Americans with a household income under $30 K, 24% have few data access options other than a smartphone, 19% have no broadband at home, and 13% are totally smartphone dependent. The smartphone is increasingly becoming a primary communication medium for younger Americans. For some lower-income Americans, it is their only connection to online services.

Globally, 3.2 billion people are using the Internet, of which 2 billion live in developing countries (International Telecommunications Union 2015). Between 2000 and 2015, people with Internet access has increased almost sevenfold from 6.5 to 43% of the global population. As of May 2015, there are more than seven billion mobile subscriptions worldwide, up from 738 million in 2000. Mobile broadband penetration worldwide has reached 47% in 2015, a 12-fold increase since 2007. In 2015, 69% of the global population had 3G mobile broadband, up from 45% in 2011. The International Telecommunication Union (ITU) figures also indicate that four billion people in the developing world remain offline. Of the nearly one billion people living in the Least Developed Countries (LDCs), 851 million do not use the Internet.

Mobile health applications are also widely developed and deployed on a global scale. The World Health Organization has a Global Observatory for e-health and has noted a rapid growth of mobile applications in all continents across a wide range of application areas (World Health Organization 2011, 2016). Formal evaluations of these programs are needed to understand which programs are effective and how the local context affects their implementation and sustainability.

10.2 Design of Systems

Designers of mobile applications can use several frameworks to guide and inform the design of the system. We outline a few such frameworks below and discuss their application to mobile health.

10.2.1 Design Thinking Techniques

Design thinking is a design process that encourages cognitive activities and multidisciplinary collaborations in the process of design. The notion of design as a "way of thinking" is based on several early cognitive theories proposed in Herbert A. Simon's (1969) book *The Sciences of the Artificial,* design engineering methods in Robert McKim's (1973) book *Experiences in Visual Thinking*, and Peter Rowe's (1987) book *Design Thinking*. The approach was further developed by Stanford professors Rolf Faste and David M. Kelley in the 1980s. Kelley later founded a design company called IDEO in 1991. IDEO (2012) has developed a freely-accessible design thinking toolkit that introduces educators to the process and methods of design.

The design thinking process follows the five steps (adapted from the IDEO Design Thinking ToolKit):

- Phase 1—Discovery: I have a challenge. How do I approach it?
  - Steps: (1) Understand challenge (2) Prepare research (3) Gather inspiration

- Phase 2—Interpretation: I learned something. How do I interpret it?
  - Steps: (1) Tell stories (2) Search for meaning (3) Frame opportunities
- Phase 3—Ideation: I see an opportunity. What do I create?
  - Steps: (1) Generate ideas (2) Refine ideas
- Phase 4—Experimentation: I have an idea. How do I build it?
  - Steps: (1) Make prototypes (2) Get feedback
- Phase 5—Evolution: I tried something new. How do I evolve it?
  - Steps: (1) Track Learning (2) Move Forward?

Each of these phases involves engaging with key stakeholders, users, designers, and expert facilitators to generate ideas and discuss observations that provide a comprehensive understanding of the problems being tackled. This is particularly useful in global health, where designers from higher-income countries may not be aware of the environment or needs of users in low- and middle-income countries. Maternal health delivery preferences also vary by country, and local customs and traditions. Relatedly, mobile technologies are changing rapidly, and the selected technologies need to be appropriate for the target country. Given the complexity of implementing global mobile maternal health programs, a design thinking approach is the particularly useful way to create regionally and context-specific solutions.

10.2.2 Cultural Issues

Maternal health care and delivery preferences vary by region and culture (Kirkwood 2005; Galanti 2008). Among the key issues are: dietary preferences and restrictions, preferences for labor and delivery and midwives, bonding approaches with the baby, approaches to baby naming and postpartum care, and perspectives on death and miscarriage.

In a study of expectant and new mothers in India (Jat et al. 2015), it was found that many women tried to access medical assistance, but various factors delayed their access to appropriate care. Delayed decisions to seek care were the result of the underestimation of the severity of complications by family members, gender inequity, and perceptions of low-quality delivery services. Another study of women in Ethiopia (Yousuf et al. 2013) showed that maternal health is affected by factors that include transportation and women’s education in addition to availability of health infrastructure and skilled health workers. Cultural beliefs, attitudes, and practices were also found to be critical in determining mothers’ health. Interventions and educational materials also need to be adapted to local customs and traditions. For example, in a project in Peru (Gabrysch et al. 2009) the intervention was adapted to make delivery services culturally appropriate by including features to enable a vertical delivery position, including family and traditional birth attendants in the delivery process, and the use of the local Quechua language.

10.3 Behavior Models

Effective health behavior change requires the use of best practices and the informed guidance of the most appropriate health behavior theory for the intervention or program at hand. Some of the most common theories or models used to investigate health behaviors are Social Cognitive Theory, the Health Belief Model, Theory of Reasoned Action/Theory of Planned Behavior, and the Transtheoretical Model/Stages of Change Theory (Glanz et al. 2008). These health behavior models can and have been used to inform the design of mobile health applications. We consider each theory/model briefly below, tying them to mobile health in general, and then, further on, discuss each in the context of maternal health more specifically. The models/theories can be classified into two types: (1) individual health behavior models; and (2) interpersonal or group health behavior models.

10.3.1 Individual Health Behavior Models/Theories

Health Belief Model

The Health Belief Model is a social psychological model that sets out to explain and predict health behaviors by focusing on a person's attitudes and beliefs (Rosenstock 1974). The key assumption of the theory is that a person will perform a given health behavior if they perceive they are susceptible to the disease or condition, if they expect that taking action will help them to avoid the negative health outcome or condition, and if they believe they can successfully perform the action or behavior.

There are six constructs to the Health Belief Model which influence whether a person will engage in a health behavior or not: perceived susceptibility (beliefs about chances of getting the condition); perceived severity (beliefs about the seriousness of the condition or its consequences); perceived benefits (beliefs about the effectiveness of taking action to reduce risk or severity); perceived barriers (beliefs about the costs of taking action); cues to action (factors that motivate readiness to change); and, finally, self-efficacy (confidence in one's ability to take action).

This theory has been used fairly extensively to develop successful health interventions (Sohl and Moyer 2007). When constructs from the theory are used to guide messaging within health interventions, the health behaviors of interest are changed more successfully (Allen and Bazargan-Hejazi 2005; Lipkus et al. 2000). In the context of mobile health applications, the Health Belief Model constructs are most useful to inform the messages, information, or educational content components of a behavioral intervention. There is one exception to this: cues to action. Cues to action can refer to information that would facilitate a person's action towards a behavior, but cues to action have also been operationalized as "prompts" to engage a person to act on health information. In the context of this latter definition, a mobile app itself (and not just the content it delivers) could be considered a cue to action. We will consider how this theory is applied in research on maternal health and mobile health applications later in the chapter.

Theory of Reasoned Action and Theory of Planned Behavior

The Theory of Reasoned Action (Fishbein 1967) and the Theory of Planned Behavior (Ajzen 1991) are two very closely related theories with constructs that focus on individual motivational factors that determine how likely it is that a person will perform a particular behavior.

The Theory of Reasoned Action posits that the best predictor of a person's behavior is their intention to act. An individual's behavior is determined directly by attitude (their beliefs about the behavior and outcome associated with the behavior, including their evaluations of those outcomes); and subjective norms (their perceptions of how people will view the behavior and, in turn, their motivation to comply).

The Theory of Planned Behavior adds to this, indicating that in addition to attitude and subjective norms, their intention to perform the behavior is also influenced by perceived control (beliefs about their ability to perform the behavior or self-efficacy). Perceived control was added to the model because engaging in a behavior is determined by both motivation (intention) and ability (behavioral control).

Transtheoretical Model/Stages of Change Theory

The Transtheoretical Model was developed to explain different stages of change towards a behavior based on the assumption that behavior change is a process that unfolds over time rather than a one-time event (Prochaska and DiClemente 2005). Within this model, the six stages of change are considered to be: precontemplation (no intention of changing behavior); contemplation (thinking of changing behavior in the future); preparation (planning to change behavior, intends to take action in the near future, and has already taken steps towards this); action (behavior change is initiated); maintenance (behavior change is sustained over time); and termination (no temptation to engage in unhealthy behavior or relapse). The Stages of Change are one of four key sets of constructs from the Transtheoretical Model. The other three constructs are: Processes of Change (e.g., finding and learning new information to support the healthy behavior change, making a firm commitment to change, seeking social support for the change), Decisional Balance (the pros and cons of changing), and Self-Efficacy (confidence to engage in healthy behavior, temptation to engage in unhealthy behavior). Importantly, most often when this theory is discussed, the six stages of change are the focus.

Self-Efficacy

Self-efficacy has thus far been mentioned in the context of other health behavior theories; however, it is on its own also considered a theory or model. Self-efficacy is the strength of one's belief in one's own abilities and the ability to persist to succeed with a task or goal (Bandura 1997). The level of belief that a person holds regarding his or her power to affect situations strongly influences the power of that person to face challenges competently. Self-efficacy can have a significant influence on people's behaviors affecting health. Self-efficacy influences the choices that people make that affect health, such as smoking, physical exercise, and dieting. For example, if someone is going to quit smoking, that person has to believe they have the ability to follow through and cease to smoke. A person's self-efficacy beliefs are cognitive states that determine whether a health behavior change will be initiated, how much effort will be expended, and how long it will be sustained.

10.3.2 Interpersonal and Group/Community Health Behavior Change Models

Social Cognitive Theory

Social Cognitive Theory states that when people observe someone performing a behavior, and the consequences of that behavior, they remember it and use it to guide their own subsequent behaviors (Bandura 1977). People do not learn new behaviors simply by trying the behavior and observing the result but, rather, by the replication of the actions of others. Social Cognitive Theory focuses on how personal factors, behavior, and the environment interact. These three factors constantly interact by both influencing, and being influenced by, one another. This theory is relevant to health because it explains how people start and maintain behaviors, and can be used as a framework to design health behavior change interventions or programs.

Patient-Provider Interaction

Patient-provider interaction is an interpersonal health behavior model to explain different types of interactions between provider and patients. Emanuel (Emanuel and Emanuel 1992) presents four versions of this model: the paternalistic model, the informative model, the interpretive model, and the deliberate model. In the paternalistic model, the physician provides the patient with select information that will encourage the patient to consent to the intervention that the physician considers best and, in extreme versions of this model, the physician authoritatively informs the patient when the intervention will be initiated. In the informative model, the physician provides the patient with all relevant information for the patient to select the medical interventions he or she wants. The physician would inform the patient of his or her disease state, the nature of possible diagnostic and therapeutic interventions, the nature and probability of risks and benefits associated with the interventions, and any uncertainties of knowledge. In the interpretive model, the physician helps elucidate the patient's values and helps the patient select from the available medical interventions that realize these values. In the deliberate model, the physician helps the patient determine the best health-related values that can be realized in the clinical situation. The physician suggests why certain health-related values are more worthy and should be aspired to.

The models used for teaching medical students about the patient–physician interaction have remained relatively static (Emanuel and Emanuel 1992; Egnew and Wilson 2010). More recent models (Agarwal and Murinson 2012) propose a revised paradigm that models autonomy, health care-related values formation, and medical knowledge as varying from patient to patient. More recently, patient-physician advocacy groups, such as the Society for Participatory Medicine (2016), have arisen with the mission to promote a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.

Diffusion of Innovations

Diffusion of Innovations is a theory proposed by Everett Rogers (2003) that seeks to explain how and why new ideas and technology spread in society. There are four elements that influence the spread of a new idea: the innovation, communication channels, time, and the social system. There is also a point at which an innovation reaches critical mass and can become sustained. This theory has been used to study the adoption of innovation in many sectors, including healthcare. Berwick (2003) discussed the rate of diffusion of innovations within healthcare organizations and noted three major factors: (1) the perceptions of the innovation, (2) the characteristics of the individuals who may adopt the change, (3) and contextual and managerial factors within the organization. This theory has also been used to understand the promotion of healthy behaviors. Rogers (2003) defines homophily as "the degree to which pairs of individuals who interact are similar in certain attributes, such as beliefs, education, social status, and the like". Individuals usually interact with others similar to themselves and as a result engage in more effective communication because their similarities lead to greater knowledge gain as well as attitude or behavior change. Thus, homophilous people tend to promote diffusion among each other (McPherson et al. 2001).

10.4 Case Studies

10.4.1 Early Maternal and Newborn e-Health Systems

In the Baby CareLink project (Gray et al. 2000), an Internet-based system was developed to connect parents to neonates in the intensive care unit. The goal of the project was to increase family engagement, knowledge, communication, and collaboration with the healthcare team that was managing critically ill children in a neonatal intensive care unit (NICU). In this system, parents could view their baby in the intensive care system via remote video, access medical status of the baby via a secure portal, and view parent-focused education on the care of the neonate. Baby CareLink included communication tools that:

- Enabled the clinical care team to share healthcare information about the neonate;
- Enabled parents to receive daily updates from care providers and correspond with the providers;
- Provided parents and a defined network of family members access to a shared care plan.

The evaluation demonstrated that use of Baby CareLink helped parents to gain a better understanding of the complexities of the NICU and enhanced communication between parents and their child's care team (Safran 2003). The long-term sustainability of the network was a major challenge since at the time the cost to implement the system was high. The system could only be used with an Internet browser, not mobile phones. However, the program demonstrated the feasibility of delivering maternal care education to parents and provided key insights for future remote maternal health applications.

MAMA, the Mobile Alliance for Maternal Action (2016), was launched in 2011 as a 3-year, public-private partnership between USAID, Johnson & Johnson, the United Nations Foundation, BabyCenter. The goal was to catalyze a global community to deliver vital health information to new and expectant mothers and their families through mobile phones. With health content provided by BabyCenter and verified by an external medical advisory board, MAMA and its partners created a core set of messages that can be timed and targeted to where the woman is in her pregnancy, or her baby is in his or her development. The program helped to facilitate maternal mobile maternal health projects in several counties.

Currently, there are hundreds of mobile apps for maternal health care, but few have formal evaluations, and even fewer have been designed with behavioral models. We review some recent evaluations and the behavioral models used in these applications.

10.4.2 Mobile Health Applications and Text Message Services Explicitly Using Health

Behavior Theories

Text4baby (Evans et al. 2012) is an antenatal care mobile health program that is well-grounded in behavioral theory. This program, launched in 2010, delivers text messages to otherwise underserved pregnant women and new mothers with the goals of improving their health, health care beliefs, practices, and behaviors towards more favorable clinical outcomes. The pilot evaluation of the text4baby mobile health program was a randomized controlled trial involving 90 low-income pregnant women. The intervention group received messages from text4baby on antenatal care and health behaviors/beliefs in addition to regular healthcare.

The program was based on Social Cognitive Theory, the Transtheoretical Model, and the Health Belief Model. Combining core principles from each of these theories, this program's theory was that belief-targeted messages would positively impact specific beliefs, which then will lead to associated improvements in health related behaviors. Examining the results of the evaluation, we see that this theory was upheld in one belief area. Text4baby was successful in changing expectant mothers' beliefs and attitudes regarding birth and pregnancy behaviors. For example, mothers who used text4baby were three times more likely to believe that they were prepared to be new mothers compared to those in the control group. Importantly, the results also indicated that education influenced reaction to, and perhaps comprehension of, the content of the text messages. Participants with higher levels of education were, in some cases, more likely to have their beliefs influenced by the text messages than those with lower levels of education. It could be that women with greater education, and thus greater literacy skills, can better understand the content being shared in the text messages, which better facilitates belief and behavior change. For example, those with higher education were more likely to hold the belief that alcohol during pregnancy will harm the unborn baby. This highlights the importance of health literacy and readability in mHealth interventions for maternal health. While it is important for a theory to guide and inform mobile health interventions, the content of those interventions should be written in such a way that it is clear, comprehensible, and actionable to ensure their effectiveness.

Quit4Baby (Abroms et al. 2015) is a smoking cessation text messaging program designed specifically for pregnant smokers in the United States. Quit4baby was designed as an add-on to Text4baby (discussed previously), which is an existing national text message program providing perinatal health information to pregnant women since 2010. In the pilot study for the Quit4baby mobile app, participants—in this case, 20 pregnant women who were current smokers or had quit smoking very recently—received one to five text messages per day over the course of the 4-week trial. The messages provided, as appropriate, content to motivate participants before quitting, after quitting, and for those who did not quit. The messages also provided tips and games, and contained stories of smokers who had successfully quit. The app also had a "quitpal", a peer female former smoker who had quit during her pregnancy, who offered app users evidence-informed advice on quitting smoking.

The development of Quit4baby was informed by Social Cognitive Theory. The researchers used this behavioral theory to inform their intervention by aiming to improve self-efficacy to quit smoking (the app provided encouragement and motivational messages), describing outcome expectations in connection to quitting smoking (to improve beliefs about the likelihood and value of quitting smoking), facilitating observational learning (through the peer-modelling of the "quitpal"), increasing capacity to quit (achieved through a quit plan and date, as well as interactive support, all designed to make quitting easier), and regular calls to the quitline. The results indicated that participants found the program helpful in quitting smoking. They rated the program content, skills it taught them, and the encouragement and social support it provided as favorable. Future research is still needed to determine if this tool is effective for actual smoking cessation during pregnancy; however, the mobile app upon which Quit4baby was based, Text2quit, has confirmed that it increased quit rates among adult smokers.

Odeny et al. (2014a) tested whether interactive text messages improved attendance at clinics and infant HIV testing in Kenya. In this study, 391 HIV-positive pregnant women who were enrolled in a program to prevent mother-to-child transmission (PMTCT) of HIV, were randomized to receive either text messages or usual care. The text messages were sent to mothers during pregnancy and weekly for the first 6 weeks after the baby was born. The message content of the text messages was informed by the constructs of the Health Belief Model, combined with results of previous empirical research on factors that influence the study's outcomes of interest. In fact, the authors published a very helpful and detailed separate paper on how the messages were developed (Odeny et al. 2014b). The researchers used focus groups to help them determine what the message content ought to be, with the focus group discussion structured by the Health Belief Model. The participants in the focus groups consisted of mothers and health workers from health clinics. Each of the six constructs from the Health Belief Model formed a topic discussed by the focus group participants:

- Perceived Susceptibility explored perceptions of the risk that their child could be HIV positive, and the risks related to not attending a health clinic for early infant testing;
- Perceived Severity was addressed through questions about mothers' perceived consequences of not attending a health clinic after delivery and of HIV testing for infants;
- Perceived Benefits focused on beliefs about why mothers should return to the health clinic and bring their infant for HIV testing, including the potential benefits of this;
- Perceived Barriers explored mothers' material costs of returning to the health clinic and bringing their infant for HIV testing, as well as what might prevent them from doing this and the help that would be needed to overcome this;

- Cues to Action were determined by querying mothers about the types of text messages that would help them understand the importance of postnatal health clinic visits and infant HIV testing;
- Self-Efficacy was investigated by asking the women what types of messages would be encouraging and increase self-confidence in connection to attending postnatal clinic visits and ensuring HIV testing for their infants.

The results of the research conducted by Odeny and colleagues indicate that text messaging significantly improved maternal postpartum visit attendance. Further, those receiving text messages had significantly higher HIV testing rates compared to those in the control group. The implications of this work are that SMS can increase clinic visits and HIV testing of infants. The success of their mobile health behavioral intervention was due, at least in part, to the careful attention to the message content, ensuring it was developed based on previous research and guided by theory.

Mauriello et al. (2015) tested an iPad behavioral intervention for pregnant women, called Healthy Pregnancy: Step by Step, to address smoking cessation, stress management, and fruit and vegetable consumption. In their research, conducted in the US, 335 pregnant women were randomized to either receive three interaction sessions with the iPad intervention or to receive brochures in order to test the efficacy of the program. The researchers were interested in whether using the iPad intervention during pregnancy influenced the number of behavior risks.

Citing the utility of Transtheoretical Model-based interventions in terms of effectiveness on behavior change, Mauriello et al. (2015) selected this theory to guide their work. Thus, their program, Healthy Pregnancy: Step by Step, was grounded in the Transtheoretical Model's stages of change (precontemplation, contemplation, preparation, action, maintenance) and other constructs from the theory (decisional balance, self-efficacy, processes of change). By taking the steps of change into account, they were able to develop a population-based, but individually tailored, program. The women participating in the study received stage-matched and tailored guidance through the iPad program during their regularly scheduled prenatal care appointments about the areas of focus (smoking, stress, fruit and vegetable consumption) based on their responses to risk assessment questions. The women were able to interact with and use the program while they waited for their prenatal appointment. The results of the research indicate that women receiving the iPad-delivered intervention reported significantly fewer health risks at 1 month and 4 months postpartum than those receiving standard care (brochures), suggesting the mHealth program successfully reduced health risks and led to sustained healthy lifestyle behaviors.

10.5 Discussion

10.5.1 Design Challenges

There are several design challenges that arise in the development of mobile and online health technologies that are especially challenging in the context of developing countries.

Understanding local environments—Low resource healthcare providers have unique challenges such as limited computer facilities, unreliable Internet, lack of infrastructure to store electronic data, limited personnel with technical skills in mobile technology management, and limited budgets. Consequently, the design of the system and the cost to implement and manage needs to consider these limitations. The local environment may also change during the project due to changes in government, possible civil unrest, staff turnover, and environmental conditions such floods or natural disasters.

Time—Countries with limited resources are among the most overloaded with patient loads. The ratio of patients to providers is very high. Any solution needs to keep in mind that the time to train and install a new system must be kept very low to succeed. Patients may also have limited time to engage in behavioral changes if they are economically stressed and have multiple jobs and families to take care of.

Diversity of culture—Some regions have a large and diverse populations that may vary in customs and traditions, including indigenous groups with different languages. So the design may need to focus on a narrower set of the population if there are going to be cultural adaptations and to optimize the incentives for behavior change.

Literacy—Low literacy levels may pose a challenge for the patient to understand written, text-based educational materials. Designing mobile health interventions to take this into account needs to be addressed, perhaps through the use of more visual educational content. Patient consent for enrolling in scientific studies may be a challenge when patient have low literacy levels or are illiterate. Patient advocates may be needed to help transmit educational messages and do informed consent.

10.5.2 Limitations of Applications of Behavioral Models

The challenges of applying some of these behavioral models to mobile health applications in the context of maternal health, particularly in developing countries, is that poor maternal health outcomes do not only occur because of some behavioral choice to either do or not do a healthy or unhealthy behavior. For example, a pregnant woman may be aware that she is at increased risk of dying from a complication during labor if she gives birth at home alone compared to at a health clinic staffed with a midwife, nurse, or doctor, but there may be no material way for her to reach a health clinic. Perhaps there is no money to take transportation, perhaps there is no transportation even available, or perhaps she did arrive at the clinic only to be turned away because there were too many women in labor there or because she did not have money to pay for the health service. These are examples of the real and deeply concerning barriers that women can face in developing countries with respect to childbirth, and it is important to remember that factors in the larger system and world are vital to address, at the same time that individual behaviors are addressed, perhaps as guided by the individual behavior models outlined in this chapter.

Interpersonal and group behavior change models may help to address some of the limitations of the individual behavior models noted above. While many maternal mobile health apps are targeted to individual behavior, it remains very true that technology, systems, and even apps, too, can also be used to address the bigger picture, system issues related to maternal health. Consider, for example, an online platform that might connect healthcare providers with limited training in labor complications to health care providers with extensive training in labor complications in real time to help share information and expertise to manage potentially dangerous situations. Or, an app that could be used by patients themselves to notify a nearby clinic that they are on their way, enabling the clinic to plan ahead for their arrival. Apps focused on individual's health behaviors, in combination with system-level approaches, are needed if mobile health interventions of maternal and newborn health are to be effective and sustainable in the long term.

10.5.3 Implementation Challenges in Developing and Developed Countries

Implementating mobile health care systems in developing countries pose some particular challenges focused around socio-economic and cultural issues. In some countries more than half the population will not be able to afford mobile phones and the phone may be shared among multiple family members. Sharing phones will reduce the availability of messages and the privacy of those messages. In some cases, male partners may not be supportive of the spouse and the services being offered by phone. Further, mobile service may be limited in some regions, and may be particularly limited for data service and Internet access via phone. Payment for services or reimbursement for services via mobile banking may also be limited.

10.5.4 Evaluation Challenges

Some new, formal evaluation frameworks are emerging for mobile health applications. However, many of these lack specific evaluations on design methodologies or use of behavioral models. A group of researchers met at the mHealth Evidence Workshop at NIH in 2011 and arrived a consensus framework for evaluating mobile health applications. Some of the key challenges for evaluation that were discussed at this workshop are listed below (Kumar et al. 2013).

Comprehensive data sets—Mobile health allows for the collection of data from multiple sensors, divergent physiologic, behavioral, environmental, biological, and self-reported factors that can be simultaneously linked to other indicators of social and environmental context. These rich data sets may enhance the validity and reliability of the inferences and improve the statistical power of the assessment process. The vast amounts of data may be a challenge to collect in a uniform format that can be analyzed while ensuring patient confidentiality and privacy.

Reliability—Reliability refers to the consistency of a measure. A measure is said to have a high reliability if it produces consistent results under consistent conditions. Example methods in this regard include test–retest and inter-method reliability.

A particular challenge for mobile health is to capture and account for variability in user behaviors during a usage session or between sessions.

Validity—Validity is considered to be the degree to which an assessment measures what it claims to measure. Sample measures include concurrent validity, convergent validity, divergent validity, predictive validity. The challenge for mobile health is that many mHealth assessments have no gold standard (or "ground truth") as a point of comparison.

Future mobile health applications will need to have more comprehensive data sets and reproducible evaluations that yield both valid and reliable evaluation results.

10.6 Conclusions

While it is an exciting and expanding field, there are also challenges and areas for improvement on mHealth and MNCH research and practice. For example, the impact of mHealth on MNCH-related behaviors could be more effectively measured with: more research guided by health behavior theories and frameworks; more research focusing not only on the technical aspects of the app and its use, but at least as much on the development and testing of the content of the app with relevant experts and stakeholders (e.g., patients, health education and communication experts); and, as in many types of health and medical research, the use of larger sample sizes and stronger experimental designs. While there are many challenges in the design and evaluation of global maternal mobile health systems, the early success of the case studies presented show promising opportunities for the future development of successful and sustainable systems that achieve long-term behavioral outcomes.

Discussion Questions

1. Discuss some behavioral frameworks that can be used to guide and inform the design of the mobile health systems.
2. Identify design challenges that arise in the development of mobile health systems. Which ones are especially challenging in developing countries?
3. Give some examples of cultural adaptations of mobile maternal health systems.
4. Discuss some implementation challenges of mobile health apps for maternal health.

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Part IV

Information Technology and Cognitive Support

Chapter 11
Addressing Health Literacy and Numeracy Through Systems Approaches

Jessica S. Ancker

Abstract Health literacy and health numeracy refer to the skills and competencies that patients use to obtain health information, understand it, and apply it. However, the informatics literature and the patient education literature show that patients' ability to obtain, understand, and apply health information is strongly influenced by factors other than their individual skills. For example, with poorly designed medication instructions, only high-literacy patients can choose the correct dose, but with well-designed instructions, both high- and low-literacy patients can do so. Clearly, understanding is influenced by not only by patient skills but also by healthcare provider communication skills, the design and accessibility of information resources, and the policies and resources of the healthcare system itself. In this chapter, we describe a distributed cognition model of health literacy and numeracy and demonstrate how it suggests systems approaches for addressing the problem. From this perspective, a patient's failure to understand health information is always attributable to at least two weaknesses in the system: e.g., limited literacy skills combined with poorly designed information resources. Interventions can then be targeted to strengthen weaknesses at multiple places in the system. Case examples illustrate ways in which this perspective has stimulated effective health informatics interventions to address health literacy and numeracy.

Keywords Health literacy • Health numeracy • Cognition • Health communication

11.1 Introduction

Anecdote 1: *At a doctor's appointment, a man with diabetes notices a poster in English offering access to an electronic patient portal that would allow him to look up his test results and make doctors' appointments. The man is comfortable using*

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English, but prefers reading in his native Spanish when he can. He uses computers, but is not entirely sure if he could set up a portal account by himself. He leaves after his appointment without asking about the portal.

Anecdote 2: *A woman calls the doctor when her baby seems fretful and uncomfortable. She suspects a recurrence of teething pains. The doctor agrees and recommends an over-the-counter liquid pain reliever. When the mother brings home the product, she sees that the dosing instructions are based on the baby's weight, but she doesn't have a scale. The instructions also say something about mL, which is a term she's never seen before. She's embarrassed to call the doctor back to admit that she can't figure out the instructions. She is fairly sure that a small baby should not get very much medicine, so she pours a very small amount into a spoon and tips it in her baby's mouth.*

Anecdote 3: *After a mammogram, a woman learns that she has a condition called ductal carcinoma in situ (DCIS). She is extremely upset by the term carcinoma, which she recognizes as related to the term cancer. But after talking with her doctor, she becomes unsure about whether DCIS is really cancer. The doctor provides the URL to a website about taking tamoxifen to prevent future breast cancer, but the website says that tamoxifen will increase her risk of stroke and endometrial cancer. She is not sure how to make a decision about something that lowers one risk but increases another one.*

11.2 Classic Definitions of Health Literacy and Health Numeracy

These real-life case examples illustrate very common problems that patients encounter when grappling with medical information. The people in these stories are encountering challenges accessing information resources, understanding unfamiliar medical vocabulary, exploring the implications of complex medical concepts, applying abstract population-level information to concrete and personal decisions, and operationalizing instructions. Any healthcare provider will be able to provide dozens of examples of situations such as these.

The challenges described in case examples such as these are generally attributed to problems with *health literacy* and *health numeracy*. Health literacy has been defined as, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker 2000; Davis et al. 1993; Williams et al. 1995; Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs AMA 1999; Kirsch et al. 2002; Institute of Medicine 2004). People with low health literacy encounter difficulty with both oral and written communication about health, medicine, and the healthcare system. Numbers are an important part of contemporary medicine, because they are used describe laboratory values, risk information, dosages, frequencies, and many other medical concepts. Accordingly, health numeracy has been described as, "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (Golbeck et al. 2005). A number of validated assessment instruments are available to measure patients' health literacy and health numeracy (Box 11.1).

Box 11.1 Examples of Assessments for Literacy and Numeracy Skills

Health Literacy

1. The **Rapid Assessment of Adult Literacy in Medicine (REALM)** (Murphy et al. 1993) assesses ability to pronounce medical words.
2. The **Test of Functional Health Literacy in Adults (TOFHLA)** (Nurss et al. 2001) and its short form **(S-TOFHLA)** (Baker et al. 1999) assess ability to answer questions in "cloze" form, i.e., select the appropriate word choice from a list to complete a sentence.
3. The **Newest Vital Sign (NVS)** (Weiss et al. 2005) is four to six comprehension questions about the text and numbers in a nutrition label.
4. The **Chew scale** (Chew et al. 2004) is three self-report questions about ability to complete medical forms and apply instructions.
5. The **Single Item Literacy Screener (SILS)** (Morris et al. 2006) is a single question, self-reported ability to complete medical forms.

Health Numeracy

1. The **Schwartz and Woloshin test** (Schwartz et al. 1997) is 3 multiple-choice items about probabilities.
2. The **Lipkus numeracy scale** (Lipkus et al. 2001) is expanded to 11 multiple-choice items on probabilities.
3. The **Subjective Numeracy Scale** (Fagerlin et al. 2007; Zikmund-Fisher et al. 2007a) assesses self-efficacy and preferences for numerical information, without requiring calculations.
4. The **Berlin Numeracy Test** (Cokely et al. 2012) is a computer-adaptive test that can be as short as 2 items or as long as 4; this test discriminates between high levels of numeracy (it includes a question about statistical significance).
5. The **Abbreviated Numeracy Scale** (Weller et al. 2013) is 8 multiple-choice items focusing largely on probabilities.
6. The **Numeracy Understanding in Medicine Instrument** (Schapira et al. 2012) (20 items) and **Short NUMI** (8 items) (Schapira et al. 2014) are multiple-choice instruments spanning probabilities, medication instructions, and nutrition information.

Population-level surveys suggest that at least 14% of American adults (some 30 million individuals) have low health literacy; this is similar to the number who have low general literacy (Kutner et al. 2006). In small-scale studies, low health numeracy is found to be more prevalent than low health literacy and is often found among individuals with adequate or high literacy (Ancker et al. 2011a). Population-level estimates for health numeracy are not available, but nationwide data do suggest that the prevalence of low general numeracy is higher than the prevalence of low literacy. Different sources have estimated that 27–30% of American adults test low in numeracy (Kutner et al. 2006; Rampey et al. 2016).

Low health literacy and low health numeracy both are associated with negative health-related outcomes. For example, people with lower health literacy are more likely than others to delay seeking healthcare (Bennett et al. 1998), to have limited knowledge about their medical conditions (Williams et al. 1998; Kalichman et al. 1999), to have poor self-reported health status, to underuse preventive services and to overuse emergency services, and to have higher mortality rates (Williams et al. 1995; Baker et al. 2002; Baker 2006; Berkman et al. 2011; DeWalt et al. 2004). People with low numeracy also have difficulty drawing meaning from medical numbers (Reyna et al. 2009; Reyna 2008), tend to make suboptimal decisions on the basis of numerical information (Peters et al. 2006), have less confidence and trust in numerical information (Fagerlin et al. 2007; Zikmund-Fisher et al. 2007b; Gurmankin et al. 2004), and often avoid shared decision making (Galesic and Garcia-Retamero 2011). As a result, low health literacy and numeracy are recognized as important challenges facing public health in America and worldwide.

11.3 Weaknesses in the Classic Definitions

The accepted definitions conceptualize health literacy and health numeracy as a combination of cognitive skills and conceptual knowledge within each patient's head. Yet a closer inspection of the rich literature on this topic reveals that the patient's ability to understand and use information in support of their own health and medical decisions is actually influenced by many factors in addition to their own skills.

For example, patients understand and apply both conceptual knowledge and instructions much better when they engage with their healthcare provider in collaborative discussions. In a procedure called "teachback," the healthcare provider invites the patient to express their understanding in their own words, and then engages in a conversation to clarify misunderstandings and fill in missing information (Dinh et al. 2016; Kornburger et al. 2013). Teachback improves disease-specific knowledge, medication adherence, self-efficacy, and self-management behaviors (Dinh et al. 2016). Other effective discussion techniques include structured medication counseling (Yin et al. 2014) and shared decision-making discussions (Kaplan 2004). The impact of these procedures clearly demonstrates that patients' ability to use medical information is not solely a function of their personal skill levels. Instead, it is also strongly influenced by the communication skills and strategies of the healthcare provider.

A second example is found in the rich literature on risk communication through graphic illustrations. Data graphics (visual illustrations of quantities) make abstract risk information more concrete and comprehensible (Ancker et al. 2006; Zikmund-Fisher et al. 2007c; Hawley et al. 2008). What is particularly promising is that these graphics can narrow the gap between individuals with high and low levels of literacy or numeracy. This is a particularly useful feature given that people with low levels of numeracy tend to overestimate risks that are described in numerical terms; graphics can help prevent low-numeracy individuals from overestimating risks and makes their decision-making more similar to that of high-numeracy individuals (Reyna et al. 2009; Peters et al. 2006; Ancker et al. 2011b). Pictographs, sometimes called icon arrays or icon graphics, depict a field of small icons (human figures, faces, or even dots) with a certain proportion colored differently to show the size of a risk (Fig. 11.1) (Ancker et al. 2006; Hawley et al. 2008; Tait et al. 2010). Even without training, people are generally quite good at estimating the proportion of colored-in icons, as this estimation task relies upon universal perceptual processes rather than skills learned in school (Ancker et al. 2006, 2011c). These pictographs, like other types of visual illustrations, are disproportionately helpful for patients with low numeracy, and they are also liked, trusted, and perceived as useful by these

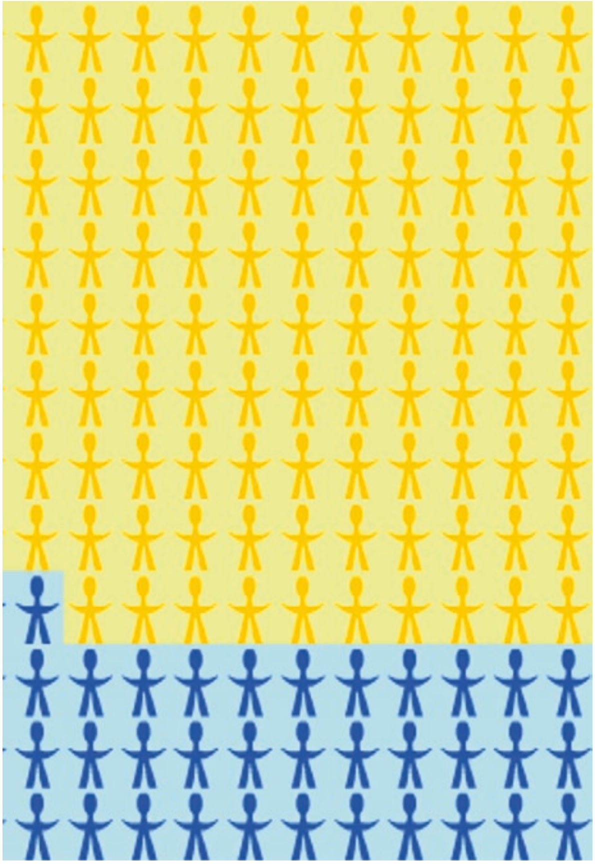

Fig. 11.1 Icon arrays or pictographs show risks as number of people affected out of a larger number

patients (Ancker et al. 2011b; Tait et al. 2010; Trevena et al. 2013). If patients' ability to use medical information were dependent only upon their personal skills, these differences in information design would not make much of a difference.

11.4 Distributed Model of Health Literacy and Numeracy

This analysis does not mean that traditional definitions of health literacy and numeracy are wrong, but instead implies that they are too narrow. Patients' ability to use health information is clearly influenced by multiple factors (Fig. 11.2).

Of course, the *patient* has highly relevant cognitive skills, such as the ability to read, navigate documents, search for health information online, and converse orally about medical topics. Patients also have conceptual knowledge—also known as mental models (Leventhal et al. 2011; Meyer et al. 1985)—which they use to contextualize and understand written and oral information. Patient mental models of health, illness, and therapy may be similar to those of health professionals, or they may be quite different (Leventhal et al. 2011; Meyer et al. 1985; Patel et al. 2002).

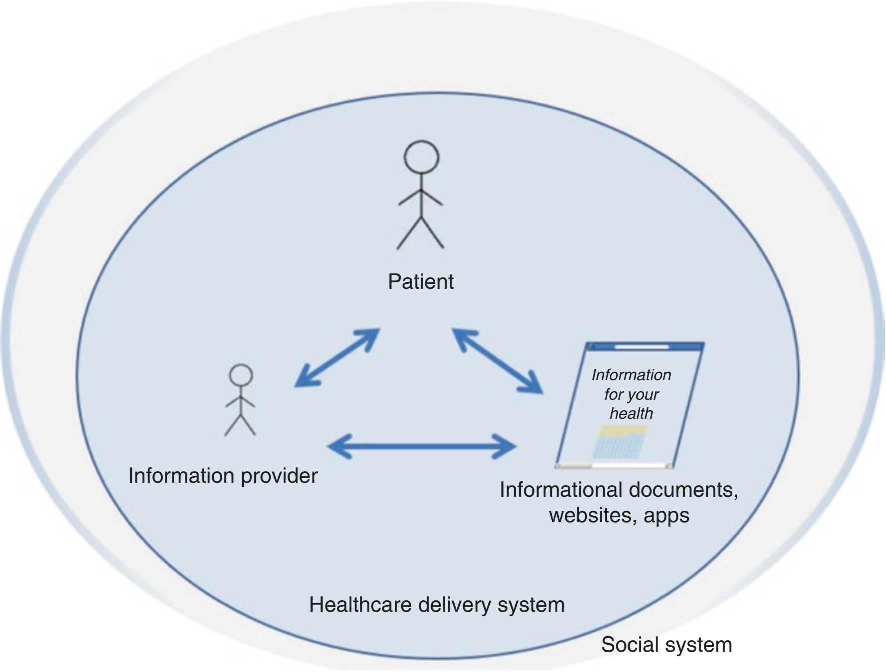

Fig. 11.2 The system influencing patients' ability to understand and use health information. The system includes the patient's skills, the provider's skills, the design and accessibility of information resources, the policies and priorities of the healthcare system, and the policies and priorities of the social system

In addition, understanding and use of information also depend on the communication skills of the *information provider*. Information providers might be healthcare providers (doctors, nurses, allied health professionals) or other people such as friends and family, public health practitioners, community health workers, and even advertisers (Dinh et al. 2016; Yin et al. 2014).

Patients are also strongly influenced by the design and accessibility of *information resources and artifacts*. By information resources, we mean written and electronic patient education materials, patient portals, health information websites, decision aids, apps, and other materials developed specifically for informational purposes. By artifacts, we mean objects constructed to be used for health and medical purposes, including home medical devices such as syringes and glucometers, and measuring devices such as eyedroppers and medicine cups (Schneider et al. 2009; Yin et al. 2010a).

It is also important to recognize that all of these elements—patient, information provider, and information resources—are embedded in the *healthcare system* itself. This system influences patient ability to access and apply health information in important ways. For example, the healthcare system determines how much training healthcare providers receive in communication skills, whether providers are financially incentivized to engage in shared decision-making conversations with patients, and whether resources are allocated to develop comprehensible educational materials.

Finally, the healthcare system is itself a part of a larger *social system*, which determines important factors such as the quality of the general education system as well as the complexity of the healthcare system. For example, healthcare is noticeably more complex in the United States than many other developed countries. In the US, patient care is highly fragmented, the insurer has a strong influence on what services and providers a patient can access, and healthcare is prohibitively costly to the 10% of adults who do not have health insurance. As one scholar put it, "Navigating [the American] health care system carries with it a high literacy burden" (McCray 2005).

For these reasons, it can be somewhat limiting to think of cognition as taking place solely within one patient's head. Instead, it can be extremely revealing to view cognition as a process that is distributed across individuals, groups, and information resources and artifacts, all of which are embedded in larger social systems (Patel et al. 2001; Edwards et al. 2015; Perry 2003; Ancker and Kaufman 2007). Our cognition is embedded in our social situation, including our conversations and interactions with others. Our cognition is also in part formed by the wide variety of artifacts we interact with, including medication instructions, computers, and telephones. In turn, we actively employ artifacts to help us think. For example, we have documented patients using calendars, notebooks, spreadsheets, and business cards to help them think about and remember their personal medical information (Ancker et al. 2015). When this distributed cognition perspective is applied to the problems with health literacy and numeracy, it reveals that health literacy is not only a patient-level phenomenon (Baker 2006; Ancker and Kaufman 2007; DeWalt et al. 2011; Rudd 2010). "Health literacy should be viewed as both a patient and a system phenomenon" (Paasche-Orlow and

Wolf 2007). This perspective is one implication of a movement in the social and health sciences toward "systems thinking" (Leischow and Milstein 2008; Leischow et al. 2008; Mabry et al. 2008). Systems thinking, or systems science, examines causes of health and illness not only at the level of the individual patient but also those working at the level of the society, the economy, the ecosystem, or the world; studies not only each component cause of health and illness, but the interactions between them; recognizes that actions at one level of complexity may affect properties of another; and therefore sees that systems are dynamically changing over time, and nonlinear or synergistic, meaning the result is more than the sum of its parts.

Systems approaches to addressing health literacy and numeracy exploit the systems thinking perspective. The systems approach recognizes that every failure to understand and use health information results from the combination of multiple weaknesses in the system. If a patient does not access online information resources that are not available in his preferred language, the problem is caused by lack of fit between available information resources and the needs of the patient. If a patient unfamiliar with milliliters has trouble operationalizing medication instructions written in milliliters, the failure is the result of lack of fit between the measuring artifact and the needs of the reader. If a patient encountering a complex medical concept has trouble synthesizing risk information and applying it to her own decision, the failure is the result of lack of fit between the available information, the needs of the patient, and the communication skills of the provider.

Systems approaches are exciting because of what they suggest about the role of health informatics. If patients' ability to use health information were solely determined by individual skills, then the only successful intervention would be to educate patients. By contrast, the systems approach reveals that we have many opportunities to intervene, because strengths in some factors compensate for weaknesses in others. Healthcare providers trained in communication skills can work with patients of all different literacy levels to help them apply medical information (Kornburger et al. 2013). Decision aids can present information in comprehensible and standardized ways to help patients synthesize complex information and make difficult decisions (O'Connor et al. 2007). And well-designed information systems and medical artifacts can make it easier for patients with basic levels of literacy to access and apply information. In other words, we can intervene not only with patients but also with doctors, nurses, website designers, patient education specialists, medical schools, and even policymakers who determine allocation of spending within the healthcare system.

11.5 Case Examples of Effective Systems-Level Interventions for Health Literacy and Numeracy

In this chapter, we provide three case examples of informatics interventions that improved patients' ability to access, use, and apply health information. None of these case examples involve intervening directly with patients to improve the reading and computational skills that contribute to health literacy and numeracy. Instead, two of the case examples involve intervening at the level of the healthcare organization (and specifically its health information technology), and one involves intervening at the level of the information itself.

11.5.1 *Improving Access to Electronic Health Information Through an Organizational-Level Intervention*

Low health literacy is a serious concern for the Institute for Family Health (IFH), a federally qualified health center that provides free and low-cost healthcare in New York City and neighboring regions. The health center recognizes that health literacy is a potential barrier to providing high-quality health care to low-income, uninsured, Medicaid, and Spanish-speaking patients.

To improve patients' access to information, IFH was an early adopter of an electronic patient portal, implementing Epic's MyChart in 2008. In a collaborative project, we helped IFH analyze usage over the first 4 years of MyChart use. We found that patients covered by Medicaid (suggesting that they had lower income) and those of minority race were much less likely to use the portal (Ancker et al. 2011d). In addition, we found that the disparities first arose because minorities and low-income patients were much less likely to receive an access code to establish an account on the electronic patient portal (Ancker et al. 2011d).

This immediately suggested organizational-level responses by IFH. The health center transitioned to an opt-out policy, registering all patients for the portal unless they explicitly declined. In addition, IFH implemented a Spanish-language portal as well as a mobile app to increase access options for its patients. The number of patients who received access codes for portal accounts rose immediately (Fig. 11.3). A 2015 analysis demonstrated that these organization-level changes were accompanied by marked improvements, with black patients becoming just as likely as other groups to use the portal (Ancker et al. 2017). English-speaking Hispanics also became just as likely as non-Hispanics to use the portal (Ancker et al. 2017).

A narrow concept of health literacy would have attributed the disparities to skill differences on the part of the patients. The systems approach, by contrast, demonstrated the disparities could be narrowed by organization-level technology access policy.

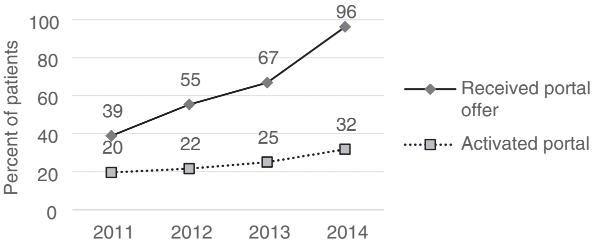

Fig. 11.3 Increased access to an electronic patient portal after an op-out access model was rolled out in 2011

11.5.2 *Improving Access to a Medical Encyclopedia Through an Organizational-Level Intervention*

Low health literacy is also associated with less familiarity with medical terms, which means that even if patients do use the portal, they may not be able to apply the information to their own health decisions. The Institute for Family Health worked closely with Epic Systems, Inc., and the National Library of Medicine to create a seamless system for patients to be able to look up medical terms in the electronic patient portal. In the system, called MedlinePlus Connect, medical terms in the portal are automatically translated to active hyperlinks to NLM's plain language patient resource, MedlinePlus. This means no search engine is needed; a patient facing an unfamiliar medical term can simply click to get an explanation.

By the third year of use, these context-specific hyperlinks were used *more often* by black patients than by whites, *more often* by English-speaking Hispanic patients than non-Hispanics, and *more often* Medicaid patients than by privately insured patients (Ancker et al. 2016b). It is clear that many of the sociodemographic factors associated with low health literacy and the digital divide do not present barriers to accessing patient education information if access is made extremely convenient. In fact, it appears that this convenient plain-language patient education is particularly sought-after by patients in traditionally disadvantaged groups.

11.5.3 *Reducing Dosing Errors Through Information-Level Interventions*

Children are especially vulnerable to even minor medication dosing mistakes because they are small and their bodies are developmentally immature. As a result, medication instructions for their parents need to be extremely clear. Yet parents often misinterpret medication instructions (Patel et al. 2002). Some reasons for misinterpretations include the complexity of the description of the procedures, the complexity of the calculations needed, and the parent's prior beliefs about illness and therapy (Patel et al. 2002).

In an ongoing project, we reviewed medication instructions produced by electronic medical record systems, demonstrated that commonly used instructions are frequently misinterpreted, and showed that relatively simple wording changes can improve parents' ability to select the correct dose for their child. One instruction that was commonly used in the electronic medical record system was, "Give 2 pills every 12 hours." We found that some parents interpreted this to mean giving their child a total of 2 pills over 24 hours, others interpreted it to mean giving a total of 4 pills, and some even more. Inspired by work with adult patients (Davis et al. 2009), we revised this to read, "Give 2 pills in the morning and 2 pills in the evening" and almost eliminated misinterpretations.

In this case, the misinterpretations arose from textual complexity that made it challenging for parents to understand quantities and procedures. First, a mere six words were used to describe two distinct concepts: the dose (1 dose = 2 pills); and the procedure (2 doses to be given per day). Second, the parent was required to perform a calculation (if the first dose was given at 6 AM, the reader had to add 12 h to determine when the second dose should be given). The revision unpacked the instruction so that each concept was expressed in its own clause, and it eliminated the need to perform calculations by specifying the time of day for each dose.

Another example of a problematic instruction was a guidance to mix in one scoop of formula "for every 2 fl oz" of water. Parents had a difficult time understanding the abbreviations and computing the right amount of formula to make a 6-ounce bottle. We obtained much better results with a revision that used the word "ounce" and listed the number of scoops needed for 2 ounces, 4 ounces, and 6 ounces of water.

A final example was an instruction to "Give on an empty stomach." We found that parents who read this instruction were guessing about when to give the medicine; some said they would give it before a meal while others said after. It is likely that the parents had developed different intuitive models of their children's digestion (Patel et al. 2002).

These medication instruction misinterpretations might be attributed to patients' limited health literacy and numeracy. However, it is at least as compelling to attribute them to poor prescription-writing skills that did not match the cognitive needs of the parents. The fact that very minor wording changes almost eliminated misinterpretations demonstrates that weaknesses in one factor (patient skills) can easily be addressed by improving the effectiveness of another complementary factor (the written instructions). Others have found similarly large effects with relatively minor changes that alter instructions so that procedures and doses are described with less complexity, and that interpretation does not rely on medical knowledge that only healthcare providers are likely to have (Yin et al. 2010a, b, 2011; Davis et al. 2009; Bailey et al. 2014).

11.6 Conclusion

Individual-level models of health literacy and numeracy specify the skills, conceptual knowledge, and competencies that patients use to access important health information, interpret it, and apply it to their own health and healthcare. These models have been very helpful in stimulating research into the very serious problems that patients often encounter with health information.

The distributed model of health literacy and numeracy offers an important step forward by demonstrating that access to and understanding of health information is a function of multiple factors working in concert. Failures to access, use, and apply health information arise, not when patients have limited abilities, but when limited abilities are combined with some other weakness in the system. For example, a patient with low numeracy may fail to recognize the magnitude of a health risk if it is explained poorly by a rushed healthcare provider or written up in highly technical jargon. The same patient is likely to understand and use the information if she can work with a provider who has excellent communication skills or if she can read a well-designed decision aid that explains risks with graphics supplemented by well-written text.

We do not have to target patient skills directly in order to improve patient access to health information. Instead, health informatics interventions can focus on the information provider, the information design, or the healthcare organization itself to improve the ability of our patients and families to access health information, process and interpret it, and apply it to their lives.

Discussion Questions

1. What is the evidence suggesting that "health literacy" is not determined purely at the level of the individual patient?
2. Imagine opening up a health center in a poor urban neighborhood where average levels of health literacy and health numeracy are known to be low. What are some interventions to improve communication effectiveness that could be applied at the level of the:
   (a) organization,
   (b) information technology,
   (c) physicians, nurses, and staff,
   (d) patients?
3. If you implemented these interventions, are there ways that they might interact with each other?

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Chapter 12
Aging, Cognition, and Technology Systems

Jessica Taha and Sara J. Czaja

Abstract In today's healthcare environment, patients are increasingly expected to assume more responsibility in managing their health. As technology is becoming ubiquitous in healthcare, self-management of one's health typically requires the patient to interact with a variety of technologies. These changes in the healthcare system are coupled with a rapid aging of the US population, resulting in a greater need for technologies to assist older adults in managing their health. However, age-related declines in cognitive abilities can impact the success with which older adults are able to use healthcare technologies. To be useful to and useable by older adults, technology must be compatible with the needs, preferences, and abilities of diverse older adult populations. This chapter provides an overview of aging, cognition, and technology systems, with a focus on the implications for use of healthcare technology and the capability of technology to support cognitive aging. We also discuss factors that influence the adoption of technology among older adults and provide a case study on the interdisciplinary collaboration necessary for successful technology development.

Keywords Aging • Cognition • Technology • Health self-management • Older adults' healthcare • Quality of life technologies • Aging and chronic conditions • Age-related cognitive declines • Technology adoption • Human/technology interaction

12.1 Technology Systems in the Context of Aging

12.1.1 Introduction

The traditional medical model, in which patients are fairly passive and rely on physicians to manage their health, is evolving into a collaborative care model in which patients are expected to assume more responsibility in their *healthcare* (Czaja 2015;

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Mitzner et al. 2013). Health self-management activities can be quite complex depending on the patient's conditions and "may involve adherence to a diet, exercise regime, and/or medication schedule as well as coordination of a care network and use of medical technologies (e.g., scale, blood glucose monitor, blood pressure monitor)" (Mitzner et al. 2013, p. 279). Self-management of one's health now also typically requires a patient to interact with a variety of technologies. Patients frequently use the Internet to locate information pertaining to their medical conditions or to access their electronic personal health records (PHRs) to perform a wide range of health management tasks, such as making appointments and requesting prescription refills, reviewing lab results, and messaging with their doctors. Increasingly, patients also monitor their health conditions at home and communicate the results with their clinicians using various telehealth technologies. Furthermore, assistive *technology* is also increasingly being used in *health self-management*. Wearable technologies, such as smart watches and smart clothing, and smart home applications are relatively recent technological developments aimed at discreet monitoring of health indicators (Czaja 2015).

Changes in the healthcare model are coupled with a rapid *aging* of the population in the United States, resulting in a greater need for technologies to assist older adults in managing their health. Moreover, greater efforts are needed to ensure that older adults have access to and are capable of using existing and emerging healthcare technologies. The population age 65 and over increased from 36.2 million in 2004 to 46.2 million in 2014 and is projected to double to more than 98 million in 2060 (A Profile of Older Americans 2015). The rapid growth occurring in the number and proportion of older Americans is due in part to the baby boom generation reaching age 65. The oldest baby boomers began reaching age 65 on January 1, 2011; from that date until 2030, approximately 10,000 Americans turn 65 each day (Cohn and Taylor 2010). By 2030, when the last baby boomer turns 65, about 1 in 5 Americans will be an older adult. Life expectancy is also increasing in the United States and many adults are now living into their 80s and beyond (The State of Aging and Health in America 2013). In 2014, adults reaching age 65 had an average life expectancy of an additional 19.3 years (18 years for males and 20.5 years for females) (A Profile of Older Americans 2015). The prevalence of chronic disease increases with age, and changes also occur in *cognition* and sensory perception. These factors not only affect the need for healthcare among older adults, but as technology is becoming ubiquitous in healthcare, also the ways in which older adults interact with healthcare technologies.

Many healthcare tasks are now accomplished using eHealth applications accessed via computers or tablets, and mHealth, or healthcare supported by mobile devices, is growing rapidly. Although *technology adoption* is increasing among older adults, there is still a digital divide between younger and older adults and also within older adult subgroups. For example, while the national broadband adoption rate is around 70%, only 47% on seniors have high-speed Internet at home. Home broadband access among older adults drops off considerably with increasing age: 65% of those aged 65–69 have home access, 55% of those aged 70–74 have home access, 34% of those aged 75–79 have home access, and only 20% of those aged 80+ have broadband access at home. Furthermore, while more than half of all Americans have a smartphone, only 18% of adults age 65 and over use one; similarly, only 18% of adults age 65+ have a tablet (Smith 2014). Taken together, these statistics on technology adoption among older adults indicate that many are not utilizing the advances in eHealth and mHealth technologies.

The goal of this chapter is to provide an overview of aging, cognition, and technology systems with a focus on the implications for the use of healthcare technology and the capability of technology to support cognitive aging. We begin the chapter by discussing aging and the increased incidence of chronic health conditions, as managing *chronic conditions* often results in a greater need for healthcare technology. We also discuss the age-related changes that occur in cognition and sensory abilities, and the impact that these changes may have on older adults' use of healthcare technology. We then review a scheme for classifying the types of technologies that aim to improve the *quality of life* of older adults and offer a brief discussion on ambient assisted living technology. The latter part of the chapter focuses on factors that influence technology uptake among older adults, including a model of *human/technology interaction*. Finally, we look at the cooperative effort needed to develop technology to support quality of life for older adults and provide a case study detailing the collaboration used in one of our research projects investigating the use of electronic personal health records among older adults.

12.1.2 The Aging Population and Chronic Conditions

Older age is associated with an increased incidence of chronic disease. The type, number, and severity of chronic conditions vary from person to person and these differences can impact the success with which patients are able to manage their care (Mitzner et al. 2013). Chronic diseases can affect a person's ability to perform activities essential to their health. Initially, they may have difficulties in performing instrumental activities of daily living (IADLs) such as taking medications as prescribed. As functional abilities further decline, they may lose the capacity for performing more basic activities of daily living (ADLs) such as ambulation, taking care of personal hygiene and feeding themselves (The State of Aging and Health in America 2013).

On average, 80% of adults aged 65 years and older have at least one chronic health condition and 50% have at least two (Healthy Aging 2009). Recent data on chronic conditions among Medicare beneficiaries age 65 years and older indicated that 61% had hypertension, 48% had high cholesterol, 34% had ischemic heart disease, 31% had arthritis, and 28% had diabetes (Fig. 12.1) (Chronic Conditions Among Medicare Beneficiaries 2012). As age increases, the prevalence of multiple chronic conditions rises. As shown in Fig. 12.2, slightly more than half of beneficiaries less than 65 years had two or more chronic conditions compared with 63% of those age 65–74 years, 78% of those 75–84 years, and 83% of those 85 years and older.

Aging is also accompanied by changes in hearing and vision. Hearing loss is a chronic condition that affects nearly two-thirds of American adults aged 70 years

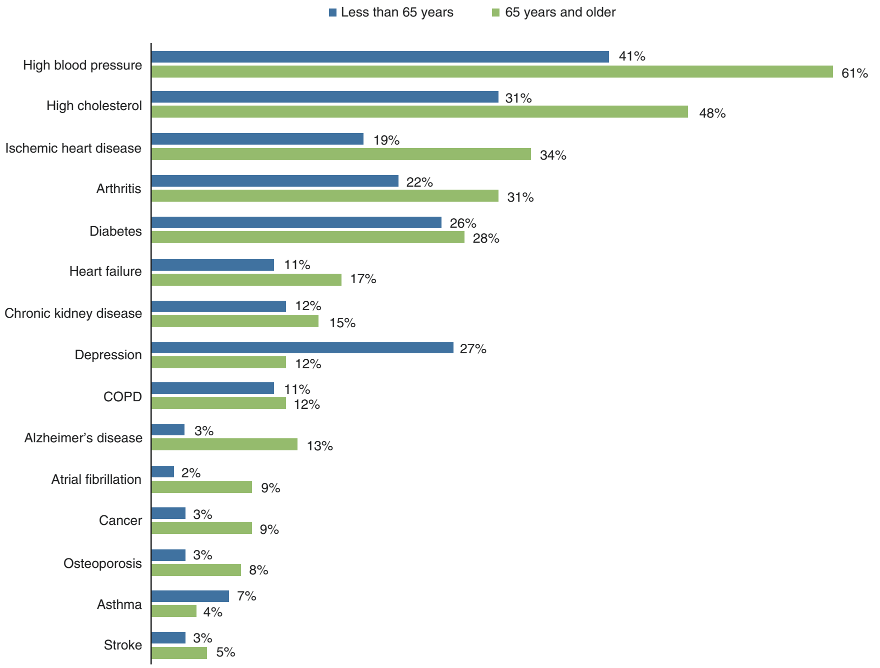

Fig. 12.1 Percentage of medicare FFS beneficiaries with 15 selected chronic conditions (Chronic Conditions Among Medicare Beneficiaries 2012)

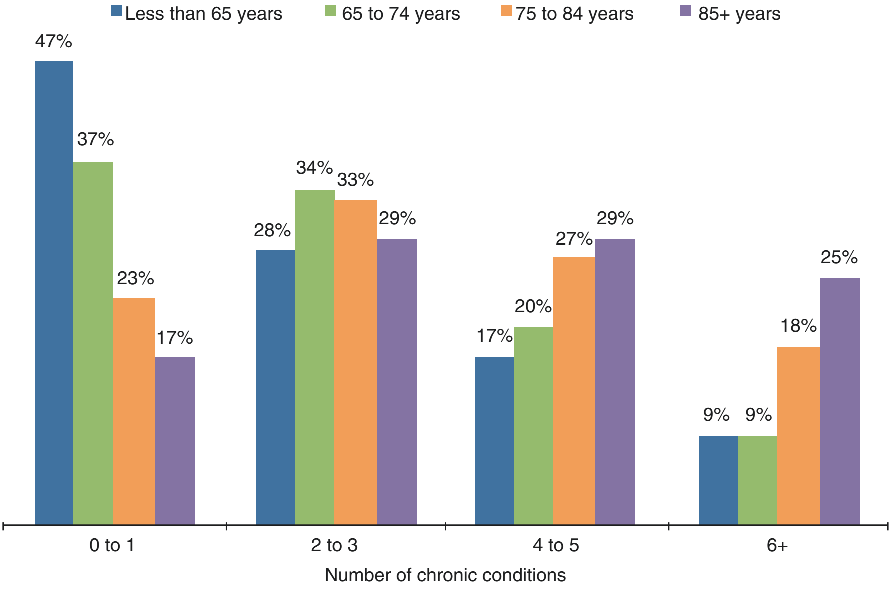

Fig. 12.2 Percentage of Medicare FFS Beneficiaries by number of chronic conditions (Chronic Conditions Among Medicare Beneficiaries 2012)

and older (Lin et al. 2011a) and can have a large impact on the quality of life and health of older adults. Studies have shown that hearing impairment is independently associated with falls (Lin and Ferrucci 2012) and poorer cognitive functioning (Lin et al. 2011b). Similarly, vision impairment, which includes age-related macular degeneration, cataracts, glaucoma, and diabetic retinopathy, is correlated with depression, poor quality of life, cognitive decline, and mortality (Wang et al. 2001; Rovner and Ganguli 1998; Harrabi et al. 2015). Sensory impairments, such as problems with vision and hearing, are known to increase with age; the prevalence of vision and hearing impairments more than doubles among individuals aged 80 years and over compared with those aged 70–79 (Dillon et al. 2010).

In addition to managing their own health, older adults may also be acting as caregivers to their partners or other older relatives. A national survey of informal caregiving in the United States indicated that spouses make up about 20% of caregivers of persons aged 65 or older (Spillman et al. 2014), while another study reported that nearly 1 in 10 caregivers (7%) in the United States is age 75 years or older (Caregiving in the US 2015). Older caregivers reported that their responsibilities include communicating with health care professionals and advocating for the care recipient. These duties become more challenging as the care recipient's number of conditions increases. When the care recipient has three or more conditions, 35% of caregivers report difficulty in coordinating care. The burden of care may also be greater for older caregivers as they are more likely than their younger counterparts to be caregiving without other unpaid help (Caregiving in the US 2015).

As discussed by Czaja (2016), various technologies can provide support for those in a caregiving role (Czaja et al. 2012). Many caregivers use the Internet to find information regarding the condition of the care recipient, treatment/interventions, and caregiving activities and supportive services (Fox et al. 2013). In addition to using technologies to assist in coordinating healthcare for the care recipient, older caregivers may also participate in technology-based interventions directed at improving their well-being. A recent study evaluating a videophone-based psychosocial intervention aimed at reducing stress and burden and enhancing quality of life of family caregivers of patients with dementia was found to be helpful in alleviating stress, increasing their knowledge and skills, and providing emotional support (Czaja et al. 2013).

12.2 Aging and the Use of Technology

12.2.1 Age-Related Changes: Implications for Technology Use

To be useful for older adults, technology must be compatible with the needs, preferences, and abilities of diverse older adult populations. People in their 60s and 70s are generally very different from those in their 80s, who are in turn very different from people in their 90s (Blazer et al. 2015). While aging is an extremely heterogeneous process, there are *age-related cognitive declines* that are typical and well documented in the literature. To characterize cognitive aging, cognitive abilities are frequently

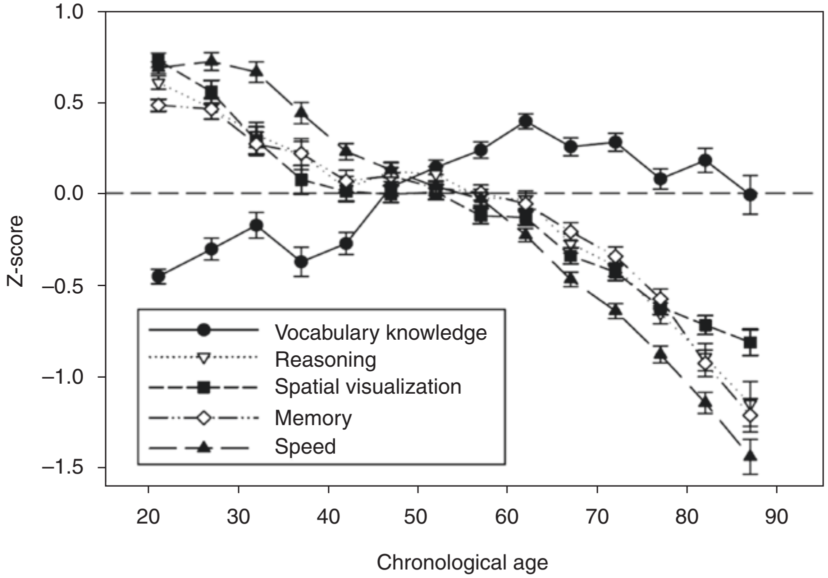

Fig. 12.3 Cognitive abilities as a function of age based on data from studies by Salthouse and colleagues (e.g., Salthouse 2009) figure from Salthouse (2010)

separated into two broad categories: crystallized intelligence and fluid intelligence (Horn and Cattell 1967). Crystallized intelligence, which is based upon experience and knowledge, includes abilities such as verbal skill and knowledge of a particular topic (Verhaeghen 2003) Fluid intelligence, on the other hand, requires simultaneous processing and mental manipulation of information, and includes abilities such as working memory, reasoning, processing speed, and visuospatial skills (Verhaeghen 2003). Distinguishing between crystallized abilities and fluid abilities is important in understanding the age-related changes that occur in cognition, as studies indicate that crystallized abilities tend to remain relatively stable with increasing age while fluid abilities tend to decline (Schaie 1996). Figure 12.3 illustrates the changes in cognitive abilities generally seen in normal aging.

Fluid cognitive abilities are involved in processing new information (Blazer et al. 2015) and are associated with aptitude for learning new technologies (Hanson 2010), thus age-related changes in fluid abilities may impact an older adult's ability to use technology. As one gets older, there is a general slowing of processing speed, which has an influence on other cognitive processes such as working memory and attention (Blazer et al. 2015). Working memory involves the active use of information or holding on to information while also handling incoming information and is important to many health-related tasks such as adhering to a medication schedule (Insel et al. 2006), while attention, the process of allocating cognitive resources, can impact one's ability to notice anomalies or trends in health-related data (Mitzner et al. 2013).

Many of the studies investigating the impact of cognitive abilities on technology use have focused on computer and Internet use (van der Wardt et al. 2012). It has been demonstrated that measures of fluid abilities are strong predictors of Internet use among older adults (Czaja et al. 2006, 2010). Different cognitive abilities have been found to impact the success of Internet searches, depending on the complexity of the search (Sharit et al. 2008). Online health information seeking can be quite complex, requiring the searcher to locate, filter, and integrate information from multiple sites. In a recent study examining the ability of adults to solve complex health-related problems online, greater search accuracy was largely attributable to higher processing speed, reasoning ability, and executive function (Sharit et al. 2015). As these abilities tend to decline with age, using the Internet to find health information may be especially difficult for older adults.

In addition to declines in cognitive abilities, hearing loss and/or vision impairment can also have an impact on older adults' abilities to use technology to manage their health. Medical devices may be complex, with multiple steps and many opportunities for errors and feedback or error information may be difficult to interpret for those with sensory declines (Fisk et al. 2009). Often the visual displays on medical devices provide critical information but are small and difficult to read. Changes in hearing capabilities impact older adults' abilities to detect sounds and particular tones and comprehend speech (Fisk et al. 2009). This can make it difficult for older adults to detect an alarm such as a low battery indicator on a medical device or comprehend an automated speech message.

As discussed in the following section, many technologies are now emerging to support older adults as they experience age-related declines in cognition and sensory perception. Some technologies are designed to enhance the quality of life of individuals with functional limitations due to illness and aging, while others are designed for healthy older adults to prevent or delay disability. Technologies are also being developed to improve the quality of life for older adults by enhancing social connectivity, stimulating new interests, and elevating their mood.

12.2.2 Technology to Support Physical and Cognitive Aging

The term "Quality of Life (QoL) Technologies" has been created to describe innovative and intelligent technologies specifically designed to affect the quality of life of those who use them (Schulz et al. 2015; Kanade 2012). QoL technologies describe a wide range of devices such as home safety systems; glucose meters and blood pressure monitors; technologies that enable individuals to communicate, organize, and share information with each other; and assistive technologies that compensate for sensory, physical, and cognitive impairments (Schulz et al. 2012). While QoL technologies are created for users in every age group, "technologies for older adults are the subset of QoL technologies that (a) take into account life-span developmental changes in sensory-motor functioning, cognition, and motivation, and (b) address issues of major concern to both older individuals and society such as health, functioning, autonomy, and psychological well-being" (Schulz et al. 2015, p. 725).

Recently, Schulz et al. (2015) suggested an organization scheme for QoL technologies that categorizes technologies based on three functional processes or methods used to achieve improvement across five life domains (Table 12.1). As indicated in the table,

Table 12.1 Organization scheme for QoL technologies

	Life domains				
Technology functions	Physical and mental health	Mobility	Social connectedness	Safety	Everyday activities and leisure
Monitoring/measurement (person, environment)	Physiological functioning (e.g., heart rate, blood pressure, and oxymetry), affect, health behaviors	Speed and variability of gait, distance covered, vestibular functioning, driving behavior, daily exercise	Frequency and duration of mobile and fixed communication device uses; frequency and duration of time in direct communication with other humans; frequency and time spent in social situations	Frequency of falls, location, driving ability	Frequency, accuracy, and speed of daily task performance; frequency and duration of leisure activities
Diagnosis, screening	Clinical conditions, risk status for clinical conditions	Risk for falling; ambulatory ability, adequacy of daily physical exercise	Social isolation, social integration	Emergency situation, being lost, at risk for driving accidents	Critical cognitive functioning, critical ADL/IADL status
Treatment, intervention	Remote behavioral treatment, chronic disease management, prevention and wellness interventions, clinical decision support	Guidance assistance, risk mitigation (e.g., risk of falling), encouragement and support for exercise	Enhanced social integration, connectivity through computers/communication technologies	Emergency response systems, computerized driving assistance; alert systems	Task assistance or training, entertainment, education

QoL technologies focus on: (1) monitoring or measuring the environment or the individual; (2) diagnosing or screening to identify problems, needs, or desires; and (3) treating or intervening to address identified problems, needs, or desires. These methods are used to improve the quality of life of the user across five domains: (a) physical and mental health; (b) mobility; (c) social connectedness; (d) safety; and (e) daily activities and leisure. This organization scheme is helpful in categorizing the vast amount of QoL technologies available, although it is noted by the authors that these technology function/life domains are not mutually exclusive. For example, a technology that may be aimed at improving the physical health of the user may improve the user's safety as well.

Much of the research regarding QoL technology has been directed at improving the physical and mental health of older adults through monitoring conditions, providing feedback to the user or clinician, or delivering treatment or interventions (the first column of Table 12.1). While many traditional healthcare technologies require the direct participation of the user, there has been a trend toward ambient systems that assist the user through sensors that are wearable or placed in the home. These types of technologies can provide innovative approaches to adapting to the challenges of aging.

12.2.3 Ambient Assisted Living (AAL) Technologies

Ambient assisted living (AAL) technologies are the result of a progression from individual devices assisting with one ADL to ambient systems (Blackman et al. 2016). Ambient intelligence is a relatively new model of information technology "aimed at empowering people's capabilities by the means of digital environments that are sensitive, adaptive, and responsive to human needs" (Rashidi and Mihailidis 2013, p. 579). In a scoping review of AAL technologies, Blackman et al. (2016) identified AAL devices that are currently available or soon to be on the market and could be used by people with some degree of cognitive impairment, ranging from normal cognitive aging to early stages of dementia. The AAL devices reviewed included: technologies that use a TV platform to connect individuals with chronic diseases to a health channel that monitors vitals and care activities; sensors incorporated into a system to track performance of ADLs and behavior change; technologies that track location, offer telemonitoring, and connect to emergency services; and sensors that monitor beds for moisture and connect to caregiver alert systems. While many QoL or AAL technologies may seem like helpful devices for older adults, there is often a disconnect between designers and the end user, which results in a much slower uptake of technologies among older adults than generally expected.

12.3 Factors That Influence Technology Adoption Among Older Adults

Generally, older adults in the US are late adopters of technology as compared to younger adults. Although Internet adoption rates among adults aged 65 years and older are steadily increasing, from 35% in 2008 to almost 60% in 2014, they are still well below the national average, as approximately 86% of all US adults go online (Smith 2014). Similarly, cell phone adoption is increasing among older adults. In 2012 about 69% of older adults owned a cell phone, whereas 77% of older adults owned cell phones in 2014 (Smith 2014). Cell phones are now used by the majority of older adults in every age subgroup: 84% of those aged 65–69 years and aged 70–74 years have a cell phone, 72% of those aged 75–79 years have one, and 61% of those aged 80+ use a cell phone (Smith 2014). Aside from age, there are quite a few other factors that influence technology adoption among adults. Models of human/technology interaction can be useful in understanding the impact that different factors have on one's decision to use or not use various technologies.

12.3.1 Model of Human/Technology Interaction

The Technology Acceptance Model (TAM) (Davis 1989) is an early framework explaining uptake of technology among adults. TAM identified two major factors that determine users' decision to use a new technology: perceived usefulness and perceived ease of use. Peek et al. (2014) indicated that systematic reviews have shown that these two variables explain about 40% of an individual's intention to use a technology in a variety of contexts including healthcare (Holden and Karsh 2010; King and He 2006; Legris et al. 2003). However, perceived usefulness and ease of use are impacted by other variables pertaining to the individual user, the technology system, and the task at hand.

Investigation into the relationships between the user, task, and technology system within the social and physical environment has provided additional information necessary in understanding the issues surrounding technology adoption. Successful use of technology depends on the match between the capabilities of the user and the demands of the technology and the task (Fisk et al. 2009). Figure 12.4 shows a comprehensive view of the interactions between user, technology, and task.

As indicated in this figure, an individual's cognitive, motor, and perceptual capabilities affect his or her use of a technology to complete a task. These capabilities vary between users and are influenced by factors such as age, education, health status, health literacy, and technical experience. Both the technology system and the task at hand place demands on the user's individual capabilities. The features of the technology system, including the hardware or software interface and instructional support must not overly burden the user's capabilities in order for adoption to occur. At the same time, task features such as complexity and familiarity must also be within the bounds of the user's capabilities. Further impacting these relationships are the social and physical context in which the technology is being used. These social and environmental factors can either positively or negatively influence one's successful use of technology, leading to either its adoption or abandonment.

While this model of human/technology interaction is applicable to users of all ages, older adults have their own set of characteristics that can affect use of technologies. Thus, research has been aimed at identifying the facilitators and barriers

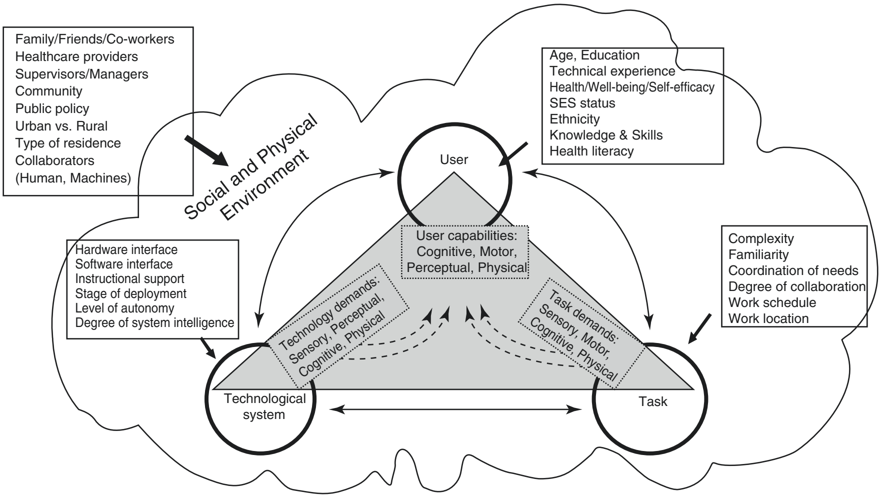

Fig. 12.4 Model of human/technology interaction (Fisk et al. 2009)

of use among this group. Next, we will examine some of the factors that impact technology use among older adults, followed by a focused look on the acceptance of a subset of AAL technologies directed at helping older adults "age in place."

12.3.2 Factors That Influence Technology Adoption in Older Adults

Technology adoption among older adults is a complex issue affected by multiple factors. Thus, research investigating older adults' technology adoption has been conducted in a variety of disciplines such gerontology, information technology, behavioral sciences, human factors, consumer studies, and design. A review of studies across these fields (Lee and Coughlin 2015) identified ten factors that influence technology adoption among older adults: *value*, or perception of usefulness and potential benefit; *usability*, or perception of user friendliness and ease of learning; *affordability*, or perception of potential cost savings; *accessibility*, or knowledge of existence and availability in the market; *technical support*, or availability and quality of professional assistance throughout use; *social support*, or support from family peers, and community; *emotion*, or perception of emotional and psychological benefits; *independence*, perception of social visibility or how a technology makes them look to others; *experience*, or relevance with their prior experiences and interactions; and *confidence,* or empowerment without anxiety or intimidation.

Older adults encounter other barriers to the use of health technologies including: lack of familiarity and access, uneasiness with asking for assistance, lack of trust, and privacy concerns (Fischer et al. 2014). A recent report from the Pew Research

Center detailing older adults and technology use (Smith 2014) indicates that despite gains in the number of older adults now online, 41% of those aged 65 years or older do not use the Internet at all, 53% do not have broadband access at home, and 23% do not use cell phones. The older cohorts within the group have even less familiarity with the Internet. Only 47% of those 75–79 and 37% of those 80+ use the Internet. This means that those older adults with the greatest health technology needs also have the lowest familiarity with technology (Flynn et al. 2006). Many of those who do not use the Internet do not believe they are missing out on important information; only about half of the non-users surveyed in the Pew report agreed with the statement "people lacking Internet access are at a real disadvantage because of all the information they might be missing" (Smith 2014). Similarly, in a qualitative study of older Internet users and nonusers, we found little difference between groups in satisfaction with health information (Taha et al. 2009). Related to lack of familiarity is lack of trust, another common barrier to technology use seen among older adults. This can be a lack of trust in that the technology is necessary for their health or a lack of trust in the accuracy and reliability of the technology (Fischer et al. 2014).

Many older adults indicate that they need assistance when learning to use a new technology device. Over ¾ of older adults (77%) surveyed by Pew indicated that they would need someone to walk them through the process of learning to use a new device such as a smartphone or tablet, while just 18% would feel comfortable learning on their own. However, it may be difficult for those who need assistance to get the help they need. Changes in cognition have been associated with a decrease in the ability of older adults to seek out the help needed to develop technology skills (Freese et al. 2006).

For many older adults, privacy concerns are another barrier to using technology for healthcare. As discussed in the next section, this is especially a concern when it comes to monitoring their home life. However, if the technology can be used to prolong their independence, enhance their quality of life, or improve their health, some older adults are willing to forgo a little privacy (Fischer et al. 2014). Wilde et al. (2008) found that older adults would accept surveillance in the home and sharing of health information if it was to be used by their physicians to preserve their autonomy and health.

12.3.3 Factors Influencing Acceptance of Technology for Aging in Place

Technology for aging in place is defined as "electronic technology that is developed to support the independence of community-dwelling older adults by alleviating or preventing functional or cognitive impairment, by limiting the impact of chronic diseases, or by enabling social or physical activity" (Peek et al. 2014, p. 237). These types of technologies include sensor-based networks for activity monitoring, fall and wandering detection, and various ehealth applications. Although these technologies could be very helpful for older adults, questions have been raised on the

Table 12.2 Factors impacting acceptance of technologies for aging in place

Theme	Factor	
Concerns regarding technology	High cost	Privacy implications
	Forgetting or losing technology	False alarms
	Obtrusiveness	Burdening children
	Ineffectiveness	Impracticality
	Low ease of use	Negative effect on health
	No control over technology	Stigmatization
Benefits expected of technology	Increased safety	Perceived usefulness
	Increased independence	Reduced burden on family caregivers
Need for technology	Perceived need	Subjective health status
Alternatives to technology	Help by family or spouse	Current technology
Social influence	Influence of family and friends	Influence of professional caregivers
	Use by peers	
Characteristics of older adults	Desire to age in place	Cultural background
	Familiarity with electronic technology	Housing type

readiness of community-dwelling older adults to accept and use such systems. In a recent review of studies examining acceptance, Peek et al. (2014) determined that most work is qualitative and examines pre-implementation acceptance factors. The authors distinguished 27 acceptance factors, divided into six themes: concerns regarding technology; benefits expected of technology; need for technology; alternatives to technology; social influence; and characteristics of older adults (Table 12.2). This review found very few studies in which quantitative analyses were performed to determine the impact of variables on pre-implementation acceptance of technologies for aging in place, and no studies in which post-implementation variable were quantitatively analyzed. However, qualitative results on post-implementation acceptance illustrated that some pre-implementation concerns turn into problems in the post-implementation stage. For example, studies have found that once older adults have experience with these technologies they are still concerned with privacy (van Hoof et al. 2011; Horton 2008) and stigmatization (Porter 2005; Ezumi et al. 2003).

12.4 Future Directions in Technology to Support Quality of Life for Older Populations

Successful technology development will depend on interdisciplinary collaboration between clinicians, human factors experts, engineers, computer scientists, informaticists, designers and policy experts (Schulz et al. 2015). Understanding the preferences, needs, and abilities of the technology end-user is the first step in development

(Kujala 2003). Some healthcare technologies may have multiple end-users, for example, a technology that shares patient-collected health information with clinicians and caregivers (Schulz et al. 2012). As such, these technologies require investigation into the needs and opinions of all potential users. Schulz et al. note that "understanding end-users and their tasks, ascertaining the acceptability and usefulness of a novel technology during its design and development, and testing the technology with various stakeholders in a variety of environments are central principles of user-centered design" (Schulz et al. 2012, p. 2403). Healthcare technologies may be rejected or abandoned by the intended user if the technologies are deemed too complex, intrusive, or stigmatizing (Kujala 2003; Nielsen 1993). To illustrate the collaboration necessary for development of user-friendly healthcare technologies, we present the following case study from our research center.

12.4.1 Case Study in Collaboration: An Example from CREATE

The Center for Research and Education on Aging and Technology Enhancement (CREATE) is a multidisciplinary center representing a partnership between University of Miami, Florida State University, and Georgia Institute of Technology. CREATE is concerned with ensuring that the benefits of technology can be realized by older adults to support and enhance their independence, productivity, health, safety, social connectedness, and quality of life (CREATE 2016). The following case study, detailing the creation and testing of a simulated patient portal of an electronic PHR at the University of Miami site of CREATE, illustrates the need for interdisciplinary collaboration in development of healthcare technology.

First, the simulated portal was developed with the help of computer programmers and engineers. Design of the portal was based on Epic's MyChart, a typical PHR that allows patients to link to relevant websites pertaining to their medical conditions, schedule appointments and medication refills, review lab results and view graphical representations of results over time, and communicate with their provider. Next, a fictitious patient was created with input from a physician who helped ensure the validity of the medical information created to populate the PHR. This fictitious patient "Pat" was dealing with chronic conditions typically seen in older patients and often occurring simultaneously, such as high cholesterol, heart disease, and diabetes. The physician also assisted in creating a set of tasks that patients typically perform through use of the portal. Human factors experts evaluated the tasks and rated their difficulty to establish two groups of tasks; "simple tasks" such as locating the date and time of an upcoming appointment, and "complex tasks" such as interpreting graphical information about high blood pressure (Taha et al. 2014a).

Next, the human factors experts performed a detailed task analysis for each task to: (1) establish the elemental steps necessary to complete the task and, (2) determine the cognitive skills needed to perform each elemental step in the task. For example, one of the tasks required participants to find a graph and then answer the following question: "What does the first graph show about Pat's risk of heart failure compared with the normal risk?" The graph had a bar for normal risk (labeled '1.0×') and bars representing Pat's elevated risk for heart attack (labeled '2.9×'), stroke (labeled '3.9×'), heart failure (labeled '2.1×'), and kidney disease (labeled '3.1×') (Taha et al. 2014a). In this task, the elemental steps were to: locate the link to "High Blood Pressure Health Risk Calculator," view the graph, locate the bar that represents risk of heart failure, comprehend that "2.1×" means "2.1 times greater than normal risk" and write down the correct response. The cognitive skills necessary to complete the elemental steps included: verbal ability to comprehend the question, executive function to plan a solution, selective attention to find the correct link, working memory to hold onto information while searching for the risk of heart failure, processing speed to support working memory, focused attention to select the correct information from the graph, and statistical (domain-specific) knowledge to understand the information presented in the graph. Upon establishing the cognitive abilities presumed to be necessary for task completion, psychologists were consulted in the development of a battery of cognitive tests that would be administered to participants prior to their use of the simulation. Human factors experts also developed a usability questionnaire and post-study interview questions for participants to provide their opinions regarding use of the system.

Usability testing of the portal was conducted with 107 middle-aged and older adults aged 40–85 years. Results indicated that while both groups experienced problems using the system to perform complex health tasks, older adults (those aged 60–85) had greater difficulties. For example, in the task requiring participants to view the graph and determine the patient's risk of heart failure compared with normal risk, none of the older adults were able to provide a completely correct response. Results of the study identified a number of factors affecting the ability of participants to use the portal to complete health tasks, including Internet experience, cognitive abilities, numeracy, and age, and determined that these factors vary depending on task complexity (Taha et al. 2013). With respect to the differing cognitive abilities necessary for task performance, results pointed to the need for implementing aids within the PHR that are specifically designed to support the cognitive functions associated with a particular task. Despite the problems encountered, results from the usability questionnaires and post-study interviews indicated predominantly positive feelings toward PHR use among both middle-aged and older participants (Taha et al. 2014b).

12.4.2 Conclusions

The aging of the US population has many implications for the use of technology, especially in the utilization of technologies to manage their health. This growth in the older population in the United States will be accompanied by an increasing prevalence of chronic diseases associated with aging, which has profound implications for healthcare (Dall et al. 2013). In today's healthcare environment, more demands are being placed on patients in self-management of their health, and in order to be useful, technologies must be compatible with the needs and capabilities of diverse older users. Perceived benefit has a strong influence on older adults' choice whether to use a new technology (Melenhorst et al. 2006), and technologies that are too complex or stigmatizing are not going to be adopted by older users. Given that older adults experience age-related changes in cognition, it is of great importance that designers consider the cognitive demands associated with technology use and develop healthcare technologies in line with older adults' capabilities. Development of useful healthcare technologies necessitates user-centered design and will require collaboration between experts from multiple disciplines including medicine, engineering, and health informatics.

Discussion Questions

1. What are quality of life (QoL) technologies? What function do they serve across various life domains?
2. How do social and environmental factors affect the interaction between user, technology, and task?
3. Describe the barriers older adults encounter in their use of health technologies.

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Chapter 13
eHealth Literacy as a Mediator of Health Behaviors

David R. Kaufman, Jelena Mirkovic, and Connie Chan

Abstract eHealth literacy names a set of core literacies involved in the meaningful and productive use of health technologies. In this chapter, we present an integrative theoretical and methodological cognitive framework for elucidating the nature of these barriers and for fashioning design solutions. The Chan–Kaufman analytic framework differs from other frameworks in that the goals are to develop a diagnostic approach rather than a screening tool. The framework can be used to classify task demands and characterize the barriers encountered in users' task performance. The methods are illustrated in the context of a health information seeking problem. We then review the research pertaining to the challenges in each of the consumer health domains including information seeking, patient portals, mHealth, social media, and telemedicine. The chapter discusses implications that need to be addressed when developing new health related programs and tools. eHealth tools afford an almost infinite number of new means to achieve health behavior change in the promotion of wellness and in the monitoring and management of chronic illness. The essential question is how do we tune these technologies such that they better address the needs of patients and health consumers at varying levels of eHealth literacy.

Keywords eHealth literacy • Health behavior change • Digital divide • Task-analytic framework • Cognitive complexity • Health information seeking • Patient portals • Social media • mHealth • Telemedicine

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13.1 Introduction

The Internet and related computing technologies are increasingly ubiquitous in people's lives. In the last decade, there has been a tremendous growth in the availability of healthcare related programs and tools. Many of the consumer-facing tools have the objective of mediating health behaviors to both facilitate the management of chronic illness and to promote well-being. These tools run the gamut from telemedicine systems to the growing body of mobile Health (mHealth) tools including fitness trackers. Although these developments offer significant promise for enhancing health, there remain significant barriers. A subset of these barriers can be attributed to properties of the system such as usability and others can be explained by the competencies of the user. eHealth literacy refers to a prerequisite set of literacies involved in the productive use of health technologies. In this chapter, we present an integrative theoretical and methodological cognitive framework for elucidating the nature of these barriers and for fashioning design solutions. We then review the research and theories pertaining to the challenges in each of the consumer health domains [information seeking, eHealth, mHealth, social media, telemedicine] and outline relevant implications that should be addressed when developing new health related programs and tools.

13.1.1 Health Literacy

Literacy and health literacy are fundamental components of pursuing health and well-being in modern society (World Health Organisation 2013). Health literacy is increasingly a prerequisite for patients to be able to engage the healthcare system productively and meaningfully. It is a measure of their ability to read, comprehend and act on medical instructions. Health literacy also includes knowledge and a broad range of communicative competencies including cultural knowledge, listening, speaking, quantitative, writing and reading skills (McCray 2005). The scope spans communication with providers, reading and understanding health information, medication compliance, informed consent, managing insurance issues, using medical devices and decisions about treatment. In addition, health literacy is a moving target given the incredibly fast-paced changes in healthcare including the dramatic influx of new treatment strategies and range of digital technologies. Although these offer new opportunities for improved health, they potentially exacerbate the mismatch between people's skill and the demands of the healthcare system. An influential report from the Institute of Medicine indicated that 50% of the American adult population may experience difficulties in acting on health information (Nielsen-Bohlman et al. 2004). A more recent European health survey (collected in 2011) similarly found that almost half the population surveyed exhibited limited health literacy (Sørensen et al. 2013). There is evidence to suggest that low literacy is associated with poor healthcare outcomes (Schillinger et al. 2002;

Ferguson et al. 2015). In addition, the financial costs for limited health literacy are prohibitive (World Health Organisation 2013).

Although there is a substantial body of research on health literacy (discussed in several other chapters in this volume), there is little consensus on the core construct. Sørensen and colleagues developed a comprehensive integrated model of health literacy based on an evaluation of the most prominent conceptual models of health literacy published in the literature (Sørensen et al. 2012). They identified four dimensions of health literacy including: (1) access information relevant to health, (2) understand information relevant to health, (3) process/appraise information and (4) apply/use information. The four dimensions can be applied to three core health domains including healthcare, disease prevention and health promotion (Sørensen et al. 2012). These dimensions place a premium on cognition and action, which represents a starting point for eHealth literacy.

13.1.2 eHealth Literacy

The concept or construct of eHealth literacy refers to a set of skills and knowledge that are essential for productive interactions with technology-based health tools (Norman and Skinner 2006a). Norman and Skinner introduced the Lily Model of eHealth literacy, comprised of six literacy types (Norman and Skinner 2006a, b). These literacies highlighted the fundamental skills consumers require to derive benefits from eHealth. They used the model to develop the eHealth Literacy Scale (eHEALS), an eight-item self-report tool to measure "consumers' combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems" (Norman 2006b). This is in keeping with the research and practice in health literacy which has led to the development of a range of assessment tools including the Test of Functional Health Literacy (TOFHLA) (Baker et al. 1999) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Murphy et al. 1993). Both the TOFHLA and REALM serve as immensely useful screening tools. eHEALS has similarly proved to be valuable as an instrument for identifying consumers and patients who may or may not benefit from an eHealth intervention or knowledge resource (Norman 2011).

13.1.3 eHealth Technologies and Health Behavior Change

eHealth is an emerging subfield within medical informatics that develops information and communication technology tools and applications for use in healthcare (Eysenbach 2001; Norgaard et al. 2015). eHealth refers to "health services and information delivered or enhanced through the Internet and related technologies" (Eysenbach 2001). eHealth tools are rapidly being developed to engage people in activities that have potential to improve their health and wellbeing. These include management of their own health care, communication with providers and peers on social networks, meeting their informational needs, making knowledgeable health decisions, using patient education resources, and promoting healthy lifestyles (Kreps and Neuhauser 2010; Pagliari 2007). Some examples of eHealth technologies include: patient health records, health information portals, telemedicine, online support or chat groups, interactive behavior change tools, decision support tools, fitness trackers and chronic disease management systems (Atkinson and Gold 2002; Eysenbach 2000). In general, the proliferation of consumer-facing technology and personal health information technology has exploded over the past several years (Alper 2015). In addition, investments in these health information technologies continue to rise increasing from $1 billion in 2011 to $4.6 billion in 2014 (Alper 2015).

A number of health conditions can potentially be improved and even prevented by modifying behaviors and lifestyle, including chronic conditions such as cardiovascular disease and diabetes. Behavior changes may include changes to diet and nutrition, exercise, and smoking cessation which can reduce risk factors for chronic conditions. Behavioral interventions often leverage the interactive features and functionalities of eHealth technologies including mobile phones (text messages, video messages, phone calls, mobile apps), Internet (health information portals, patient health records), computers (e-games, disease management programs), telemedicine, and social media (blogs, wikis, online communities, social networking sites) (Korda and Itani 2013).

A number of reviews have found that eHealth technologies, can result in positive impact on behavior change, which in turn can yield improved health outcomes (Webb et al. 2010; Cugelman et al. 2011; Murray 2012). For example, van Vugt and colleagues reviewed the online behavioral change interventions developed for Type 2 diabetes patients and concluded that techniques most often applied were feedback on performance, providing information on consequences of behavior, barrier identification/problem solving, and self-monitoring of behavior (van Vugt et al. 2013). These techniques were also linked to positive outcomes for health behavior change, psychological well-being or clinical parameters. The authors discuss the lack of other potentially effective behavioral change techniques (e.g. coaching, social element, role models, coping planning, demonstration of behavior, use of imagery) due to potentially high implementation costs for selected delivery method (Internet in this case). Wildevuur and Simonse reviewed the technology-based interventions supporting chronic patients [diabetes mellitus, cardiovascular disease, chronic respiratory disease, cancer, and stroke] and health care professionals in patient centered care and self-management (Wildevuur and Simonse 2015). The most commonly used delivery channels were telemonitoring/telemedicine systems, Internet-based interventions and mobile/smartphone interventions. The impact of reviewed interventions on quality of life and health-related quality of life were positive, even though the impact on cost and efficiency seems to be positive but less conclusive. Clearly those individuals with lower health and computer literacy are differentially impacted and benefit less from the intervention. Some of the potential techniques that can be used to improve health behavior are: tailoring (Krebs et al. 2010), video-coaching (Alley et al. 2016) and social media based interventions (Korda and Itani 2013).

However, some reviews found that study periods were too short in duration to measure the lasting impact of eHealth interventions on behavior change and health outcomes, that the sample size of qualifying studies were limited, or that variations in sample size limited comparability, and that additional empirical research is needed to generalize results (Murray 2012) and highlight additional opportunities for eHealth interventions. Gee et al. propose the eHealth Enhanced Chronic Care Model which incorporates the role of eHealth technologies in improving outcomes for people with chronic conditions (Gee et al. 2015). This model offers a framework for studying the effectiveness and impact of the range of eHealth interventions.

13.1.4 Reconceptualizing the Digital Divide and Barriers to Change

Whereas previous research has described the potential benefits from the effective use of eHealth tools for behavioral change, studies have also documented a range of barriers that preclude health consumers from fully engaging in and benefiting from eHealth interventions (Sørensen et al. 2012; Oregon Evidence-based Practice Center 2008). Barriers such as low literacy, limited health literacy, access to technology, and technological familiarity significantly impede consumers' use and ability to navigate and negotiate eHealth applications (Jensen et al. 2010; Neter and Brainin 2012). Related research shows that eHealth literacy-related knowledge and skills are particularly lacking among vulnerable populations such as seniors (Sharit et al. 2008), underprivileged youth (Subramaniam et al. 2015), immigrants (Kreps and Sparks 2008) and individuals with lower levels of education (Connolly and Crosby 2014; Knapp et al. 2011). Previous studies showed that individuals with lower health literacy levels are less likely to use computers and Internet technology to search health information (Jensen et al. 2010) and are less likely to use personal health record technologies (Kim et al. 2009; Yamin et al. 2011). Additionally, this group relies more heavily on non-established criteria when evaluating online health information (Diviani et al. 2016).

Health literacy and eHealth literacy levels are dynamic, and can be influenced by an individual's health status, motivation, education, and changes in technology (Tennant et al. 2015). For example, most consumers do not critically question the quality of online health information and rely heavily on their subjective evaluation criteria rather than established web quality guidelines (Diviani et al. 2016). To address this issue, eHealth tools can be designed to educate consumers on how to minimize risks by critically evaluating sources of information and by protecting private or sensitive information. However, despite having such knowledge, consumers do not always practice these skills or exercise good judgment (Subramaniam et al. 2015; Czaja et al. 2006).

The combination of access, resources, knowledge and skill barriers interact with one another to create obstacles to effective use of eHealth. This is of concern because, according to Eysenbach's "inverse information law", access to information is often most difficult for those who need it most (Eysenbach 2007).

13.2 eHealth Literacy Framework

13.2.1 The Evolving Construct of eHealth Literacy

Since the introduction of the Lily Model of eHealth literacy in 2006 (Norman and Skinner 2006a), eHealth technologies have advanced and accordingly, the construct of eHealth literacy has evolved in response to these dynamic tools (Norman 2011). New frameworks and models have been introduced that expand the scope, component constructs, application, and measurement of eHealth literacy. Gilstad proposes that eHealth literacy should also consider knowledge and skills necessary to effectively interact with community resources and healthcare professionals (Gilstad 2014). The author proposes additional component constructs of eHealth literacy to include: the bodily experience, procedural literacy, contextual and cultural literacy, and communicative expertise (Gilstad 2014).

Kayser et al. (2015) present a novel eHealth literacy framework for understanding users' needs. The approach leverages the user-task-context matrix developed by Kushniruk and Turner (2012) that differentiate between types of users, their context of use and how these factors interact with usability and safe use of these systems. The proposed framework extended this model to include knowledge about users' competences within the various domains of eHealth literacy (Kayser et al. 2015). They present a multifaceted approach leading to the development of a new eHealth literacy instrument in the form of a comprehensive eHealth questionnaire. A primary goal is to inform the design processes in order to enhance the understanding of users' needs amongst designers of eHealth systems and applications (Kayser et al. 2015).

Norgaard, and colleagues employed a stakeholder-based approach to expand the eHealth literacy model to include the interaction and relation between individuals and eHealth systems (Norgaard et al. 2015). Through workshops and concept mapping, they developed the eHealth Literacy Framework with these seven domains: (1) Ability to process information, (2) Engagement in own health, (3) Ability to engage actively with digital services, (4) Feeling safe and in control, (5) Motivation to engage with digital services, (6) Having access to systems that work, and (7) Digital services that suit individual needs (Norgaard et al. 2015).

Koopman et al. developed the Patient Readiness to Engage in Health Internet Technology (PRE-HIT) instrument to assess patient readiness and willingness to engage with health technologies (Koopman et al. 2014). The instrument was developed through patient focus groups and identified additional eHealth literacy factors including: privacy and security concerns, computer anxiety, desire for self-management, need for information, convenience and perceived superiority of information from health professionals (Koopman et al. 2014).

13.2.2 Towards a Cognitively-Based Framework

Understanding the knowledge and skills required to interact with eHealth tools can inform the need for mediating interventions such as educational initiatives, design and development guidelines, and evaluation heuristics. Few research efforts have used a systematic approach to analyzing barriers across eHealth interventions. In this section, we present a detailed approach to characterize dimensions of complexity and to reveal skill and knowledge barriers to engaging in and benefitting from eHealth, across a variety of health domains and technologies.

Chan and Kaufman (2011) introduced a micro-analytic framework and set of methods for characterizing the different cognitive dimensions of eHealth literacy. The Chan–Kaufman analytic framework can be used to classify task demands and characterize the barriers encountered in users' task performance. In their work, the authors applied the framework analysis to three information seeking tasks for participants using two different health-related websites (MedlinePlus.gov and Medicare.gov) across different health topics (Chan et al. 2009a). The analysis provided task descriptions that summarized the skills and knowledge that participants needed to perform each task. The Chan–Kaufman framework differs from eHEALS in that the goals are to develop a cognitively-based analytic and diagnostic approach rather than a self-report screening tool. The objective is to identify and diagnose barriers, and like Kayser et al. (2015), contribute solutions that could inform designers, developers and consumer health practitioners. As described in the framework section below, a cognitive task analytic approach which focuses on the domain, task and application coupled with a method for characterizing the performance of users on a range of eHealth tasks was used to understand the core skills and knowledge needed to productively use eHealth tools.

The Chan–Kaufman analytic approach has been applied to reveal challenges experienced by health consumers in performing information-seeking tasks (Chan and Kaufman 2011; Chan et al. 2009a). The framework has been found to effectively characterize the knowledge and skill-related barriers in online consumer health information seeking activity, and reveal eHealth literacy and cognitive dimensions underlying the barriers (Chan et al. 2015).

13.3 Chan–Kaufman Framework

The Chan–Kaufman framework draws on the Lily Model of eHealth literacy and Bloom's Taxonomy of the Cognitive Domain (Chan and Kaufman 2011). The framework is intended to serve both (1) an analytic purpose which focuses on domain tasks and applications and (2) as a tool to analyze patients or consumers behavior as they interact with an application. In this latter respect, it can be used gauge the competencies of a consumer to productively employ eHealth tools or participate in a HIT-mediated behavioral health intervention.

13.3.1 eHealth Literacy Model

As a starting point, the framework uses the Lily Model proposed by Norman and Skinner (2006a). The model describes six components of eHealth literacy:

- *Computer Literacy* describes the skills to use computers to solve problems, ranging from basic knowledge such as how to open a browser window to developing computer applications.
- *Information Literacy* encompasses the skills to articulate information needs, to locate, evaluate, and use information, and to apply information to create and communicate knowledge (Catts and Lau 2008).
- *Media Literacy* is the ability to select, interpret, evaluate, contextualize, and create meaning from resources presented in a variety of visual or audio forms (Thoman 1999). This also includes the ability to assess privacy and security of different resources.
- *Traditional Literacy and Numeracy* encompasses three sub-components: (1) Reading and understanding written passages, (2) Writing, which includes effective written and verbal communication of ideas, and (3) Numeracy, which describes quantitative skills and the ability to interpret information artifacts such as graphs, scales, and forms (Ancker and Kaufman 2007; Rudd et al. 2000).
- *Science Literacy* includes familiarity with basic biological concepts and the scientific method as well as the ability to understand, evaluate, and interpret health research findings using appropriate scientific reasoning (Laugksch 2000).
- *Health Literacy* is the acquisition, evaluation, and appropriate application of relevant health information that allows consumers to communicate about health, make health decisions, and utilize health services (McCray 2005; Rudd et al. 2004).

These six facets of eHealth literacy operate in combination when working on eHealth tasks. They constitute the set of core skills and knowledge. A premise is that these literacies will be variably involved in the performance of a particular task. For example, science literacy may be engaged for some tasks and not others.

13.3.2 Levels of Cognitive Complexity

The six eHealth literacies describe the skills and knowledge related to eHealth tasks, but cannot explain variation in task performance. Bloom's Taxonomy of the Cognitive Domain is a well-known taxonomy developed to classify levels of intellectual behavior in learning (Krathwohl 2002). It was developed in 1956 and updated in 2001; it has been widely applied to develop educational objectives and curriculum, to assess learning, and to create test items. The taxonomy describes a hierarchy of six cognitive processes that increase in complexity and cut across factual, conceptual, procedural, and meta-cognitive knowledge. These six dimensions, listed in order of increasing complexity, are defined as (Amer 2006):

- *Remembering* is retrieving, recognizing, and recalling relevant knowledge from long-term memory.
- *Understanding* includes constructing meaning from oral, written, and graphic messages through interpreting, exemplifying, classifying, summarizing, inferring, comparing, and explaining.
- *Applying* involves using knowledge to execute a procedure.
- *Analyzing* comprises breaking material into constituent parts, and determining how the parts relate to one another and to the overall structure or purpose through differentiating, organizing, and attributing.
- *Evaluating* involves making judgments based on criteria and standards.
- *Creating* consists of putting elements together to form a coherent or functional whole; reorganizing elements into a new pattern or structure through generating, planning, or producing.

The framework can be expressed as a matrix with the six facets of eHealth literacy along one axis and the six levels of complexity along the other axis, resulting in 36 combined categories. In the framework, the category of traditional literacy and numeracy were further categorized into reading, writing, and numeracy and analyzed each separately, as shown in Table 13.1, such that there are a total of eight different literacy types. In the preliminary application of the framework, it was evident that this revision was necessary to achieve sufficient level of detail for analysis (Chan et al. 2009b). The criteria for each of the cells was developed through an iterative process of review and adaptation, drawing on evidence from peer-reviewed articles discussing eHealth and each type of literacy. This matrix of eHealth literacy and complexity definitions constituted the framework and codebook, providing the foundation for analysis.

Table 13.1 Framework shown as a matrix of literacy types and cognitive complexity levels

	Increasing levels of cognitive complexity (Bloom's taxonomy)					
Literacy type	Remembering	Understanding	Applying	Analyzing	Evaluating	Creating
Computer	*The contents of this table are intentionally left blank. This table illustrates the structure of the framework coding tool, which can be used by researchers to map skill demands to the corresponding framework each cell of the table*					
Information						
Media						
Reading						
Writing						
Numeracy						
Science						
Health						

The framework coding can be used in at least two complementary ways (shown in Fig. 13.1). The first way is to use the framework coding in cognitive task analysis to characterize the demands of eHealth tasks with reference to specific tools. This analysis can be performed by a trained analyst and involves a set of judgments. The second approach is to use the same categorical scheme to describe human performance on these tasks. The basis of the methodological framework involve coordinating the task analysis and analysis of human performance.

The following example illustrates how the framework can be used with cognitive task analysis to characterize the demands of an eHealth task in a specific domain. The task questions, shown in Fig. 13.2, ask a user to use the Consumer Reports website, a resource that provides evidence-based information related to health issues, to research and respond to three questions. The cognitive task analysis for this task revealed the eHealth literacies and cognitive complexity levels required to answer each question (Table 13.2). The literacy requirements for the task show that information and reading literacy were both required most frequently (95%) and were required across all three questions. No media or science literacy was required

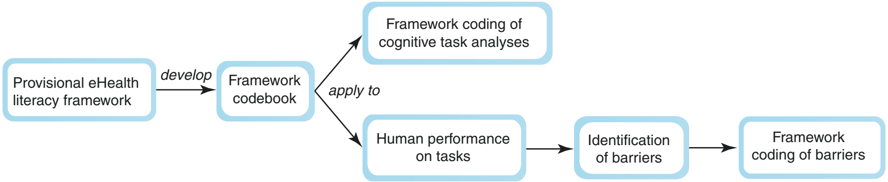


Fig. 13.1 Process of employing a framework to characterize eHealth demands and barriers

You are a 56-year-old female, and you would like to start doing regular physical activity. Use the “Healthy Living” resources to read more about exercise and fitness options. There are a few fitness tests available to test fitness levels.

A. When you test your aerobic fitness, you find that you are able to walk one mile in 15 minutes and 26 seconds. How does your result compare to the results of the aerobic fitness test?

B. To improve your aerobic fitness, you decide to walk regularly as part of your workout. In the article on “Walking Workout”, what are 2 workout accessories that you would need to purchase to improve your workout?

C. You consider purchasing a treadmill at home to do your walking workout, and explore the articles on treadmills on the website. Which treadmills are recommended as Consumer Report’s “Best Buys”?

Fig. 13.2 Task questions

Table 13.2 Summary of CTA results for task question

Literacy	Question A	Question B	Question C	Whole task
Media Literacy	0%	0%	0%	0%
	N/A	N/A	N/A	N/A
Computer Literacy	50%	75%	67%	63%
	Applying (3)	Applying (3)	Applying (3)	Applying (3)
Health Literacy	17%	50%	0%	21%
	Remembering (1)	Applying (3)	0	Applying (3)
Information Literacy	100%	75%	100%	95%
	Analyzing (4)	Evaluating (5)	Analyzing (4)	Evaluating (5)
Reading	100%	100%	83%	95%
	Understanding (2)	Applying (3)	Analyzing (4)	Analyzing (4)
Writing	17%	25%	17%	16%
	Understanding (2)	Applying (3)	Understanding (2)	Applying (3)
Numeracy	67%	0%	17%	26%
	Analyzing (4)	N/A	Analyzing (4)	Analyzing (4)
Science Literacy	0%	0%	0%	0%
	N/A	N/A	N/A	N/A
Total # steps	6	4	6	19

For the task, the following is displayed: the proportion of steps that utilize that eHealth literacy (percentage in top half of cell) and the highest level of cognitive complexity used in that literacy (number and complexity level in bottom half of cell)

to complete this task. Computer literacy was also often required (63%) to navigate the website and find appropriate resources. Reading literacy was required at a higher complexity for Question C than in Questions A and B. While Questions A and B ask users to extract and use some information from text, Question C asks users to integrate pieces of information about treadmills and about ratings. Question B generally required the highest cognitive complexity levels. Numeracy was required at level 4 (*Analyzing*) for both Questions A and C, to interpret exercise results and treadmill ratings that were presented in a table. Most literacy types were required at level 3 (*Applying*). The highest cognitive complexity required was *Evaluating* (level 5), for information literacy, and was only required at level 5 for one question. This task can be considered a task of low/intermediate complexity because it did not require the widest range of literacies, and most literacies were only required at cognitive complexity levels between 2 and 4.

The framework was also used to analyze user performance on the same task and characterize the types of barriers users encountered in answering the task question (Chan et al. 2015). For example, during Question C, some participants that did not closely scrutinize the table had difficulty finding the "CR Best Buy" label. This type of barrier reflects difficulty with both numeracy and information literacy because participants had to extract relevant information that was presented in a tabular format. Users also encountered barriers in trying to answer Question A. Participants struggled with the component steps that required them to *understand* (level 2) the question (e.g., did not know they had to look for information about fitness tests in order to begin to answer Question A), *segment* (level 3) the webpage to find the appropriate menu selection (e.g., they had difficulty identifying and recognizing the "fitness tests" link as the entry point to finding the answer to Question A), and *interpret* (level 4) the resources effectively (e.g., compare their results with the aerobic fitness rating levels).

eHealth interventions for behavior change often require ongoing and significant interaction with eHealth technologies. The Chan–Kaufman framework provides an analytic method that applies to both eHealth users and to eHealth tasks. The framework is applicable to the study of a wide range of technologies. Application of the framework can reveal strengths and weaknesses of existing eHealth interventions as well as opportunities to improve or adapt eHealth interventions to take advantage of evolving technology features. The framework is consistent with the approach offered by Arocha and Hoffman-Goetz in this volume (Arocha and Hoffman-Goetz 2017). They argue that an "embodied" micro-level approach is needed as an alternative to the standard abstract, variable-based approach reflected in the general tests to assess health literacy and numeracy. The embodied approach serves to clarify the actual dynamics underlying the tasks of making sense of health information and this is what we are endeavoring to do with the Chan–Kaufman framework.

13.4 eHealth Literacy and Consumer Health Domains

13.4.1 Health Information Seeking Resources

Interaction with different eHealth tools and tasks makes different kinds of demands on person's skills and knowledge. Health information seeking provides an ideal test domain for eHealth literacy because of the unique challenges it presents and the ubiquity of the task. Presently, over 3.6 billion people use the Internet worldwide (Internet World Stats 2016). As access to affordable, high-speed Internet access increases, the percentage of people using the Internet to search for health-related information continues to increase significantly. According to a recent Pew Internet Survey, 87% of U.S. adults use the Internet and 72% of adults have sought health information online in the past year (Pew Research Center 2014). Greater access to the Internet has dramatically increased the availability of health information (Cline and Haynes 2001). Consumers who seek health information are more likely to be active participants in their health, which improve the likelihood of improved health outcomes (Hibbard and Greene 2013). However, there are many individuals who continue to experience difficulty accessing relevant health information and clearly do not reap the benefits of online information. Online health information resources are highly variable in quality, accuracy and trustworthiness (Cline and Haynes 2001). Seeking health information online poses several risks as many users are not prepared or sufficiently knowledgeable to evaluate the enormous amounts of unverified health information available on the Internet.

Increased use of internet health resources by consumers and patients has raised concerns about how consumers look for high quality health information (McCray 2005). Aside from the issue of evaluating the trustworthiness of websites, there is the problem of comprehensibility. Much of the material available online is written at grade levels well above the reading level of lower literacy consumers (Zeng and Tse 2006). Consumers experience difficulty in processing this material and may in fact misunderstand what they read resulting in deleterious consequences. Google and other search engines remain the primary source for searching for health information (Fox and Duggan 2013). Health information seekers typically enter short phrases and rarely search beyond the first page of results (Eysenbach 2001; Morahan-Martin 2004). There are a host of information retrieval strategies used by more skilled users. As described in the above example, health information-seeking covers the gamut of eHealth literacy skills including computer literacy, basic literacy, numeracy and information literacy. It has provided a fertile test bed for developing eHealth literacy theories. In addition, information-seeking skills are employed in almost all other consumer health domains.

13.4.2 Personal Health Records

Personal health records (PHRs) have emerged as perhaps the most promising consumer health tool. They offer a great opportunity to reduce the cost of healthcare, increase access, and improve care quality (Ford et al. 2016). Facilitating patients' access to health information and enhancing their communication with providers are important steps toward health promotion, self-management of disease, and shared medical decision-making (Ancker et al. 2011). PHRs provide patients with a window into their electronic health record (EHR) and enable patients to exchange secure messages with physicians, request appointments, and order medication refills. PHRs have the potential to integrate data from multiple sources since many consumers and patients receive care from several health care providers, and consequently their health data are distributed across multiple record systems (Tang et al. 2006).

The use of PHRs has grown dramatically in the last decade. In an earlier study [circa 2010], it was noted that there were 91 different PHR commercial products in use by firms, institutions, or governments, but only 7% of American adults used PHRs (Jones 2010). The growth in the use of PHRs has been spurred on in part by the widespread adoption of EHRs and the Meaningful Use mandate which requires EHR systems to allow patients to see their medical records, transmit their records to others, and communicate with their provider through a secure portal (Ford et al. 2016). It was reported that over 30 million users were employing at least the basic functions of a PHR of accessing health information and exchanging messages with providers (Ford et al. 2016). Ford and colleagues developed models of PHR adoption that suggest that growth in use of basic and more advanced functions will continue at a rapid pace (Ford et al. 2016).

Patients express great interest in the adoption of PHRs, whereas providers have been somewhat more equivocal fearing new workflow demands and concern about whether patients can use the knowledge to good effect (Weitzman et al. 2009). People with disabilities and chronic conditions, frequent users of healthcare services, and those who are caring for elderly parents express the most interest in PHRs (Archer et al. 2011). However, there is evidence that a digital divide still remains. In a large scale retrospective study, Ancker and colleagues found substantial difference in the use of portals on the basis of race, ethnicity, sex, language, insurance type, age, and health status (Ancker et al. 2011). Noblin et al. found that the primary factor explaining patient willingness to adopt a PHR was the patient's health literacy as measured by the eHEALS (Noblin et al. 2012). The eHEALS mean percentage showed that of those consumers who intended to adopt the PHR, 65% indicated a high perceived health literacy level. Therefore, 35% of patients who do want to view and use a PHR do not feel comfortable with their ability to use the information they are provided for health decisions. For those patients not intending to adopt a PHR, 38% self-reported a high level of health literacy. Patients who report or score highly on the health literacy measure are more likely to adopt a PHR than those patients who have a lower level of health literacy (Noblin et al. 2012).

To the best of our knowledge, there have been no studies evaluating eHealth literacy in the context of PHRs. There have been some usability studies dating back to early patient-centered record systems (predating the modern PHR) (Cimino et al. 2002), but comparatively few in recent times. A noteworthy study was conducted with the Veterans Affair's MyHealtheVet program (Haggstrom et al. 2011). Users' progress was recorded as they performed four PHR scenarios: (1) registration and log-in, (2) prescription refill, (3) tracking health, and (4) searching for health information. Users experienced considerable difficulty on all tasks except for the prescription refill. Navigating the system was found to be rather difficult and learning to employ the range of functions was problematic.

Sarkar et al. conducted a large-scale survey of patients with diabetes who employ a patient portal (Sarkar et al. 2010). The survey reached an ethnically diverse population who varied considerably on a range of demographic variables including educational attainment. After accounting for the other factors, patients with limited health literacy had higher odds of never signing on to the patient portal compared with those who did not report any health literacy limitation. In addition, self-reported health literacy was more strongly and consistently associated with lack of patient portal use than was lower educational attainment (Sarkar et al. 2010). The authors investigated independent associations of health literacy on each portal function (for those with computer access) and found that those reporting limited health literacy were consistently less likely to complete each patient portal function. The portal function most likely to be used, across all literacy levels, was the "Labs View" function (Sarkar et al. 2010). This is a comparatively passive use function and serves as a vehicle for delivering information. On the other hand, the low health literacy group reported having difficulty or not using the more interactive tasks like making an appointment or emailing one's provider. The authors conclude that this group likely experienced problems with the navigation of more complex Internet-based tasks.

Although usability studies can be very informative in explaining the potential problems that users are likely to encounter, they do not address the core literacies and competencies involved in executing a task. The medical information stored in PHRs frequently mirror what is available to providers in EHRs (Archer et al. 2011). Little effort is made to provide the information in a format easily comprehensible to patients. This places a great burden on health literacy. Additionally, PHRs can be as unwieldy as EHRs and this increases the computer literacy demands on the users. Certain PHRs enable patients to access educational material or provide the means to search for information outside the confines of the system and this invokes the range of literacies related to information seeking. There is evidence to suggest that there is broad interest in PHRs, particularly among individuals with chronic illness and those with special information needs such as cancer patients (Baudendistel et al. 2015). Yet, there is little evidence as to whether patients use these systems and whether they do so productively. eHealth literacy research and analysis could serve to elucidate the barriers and help fashion solutions that could make PHRs more broadly useful both in function and in terms of expanding the base population.

13.4.3 Telemedicine

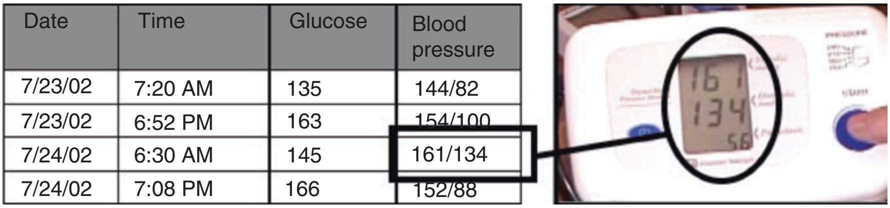
Telemedicine involves the use of modern information technology and employs some form of two-way communication (e.g., telephones, email, Skype) to deliver health services to patients at a distance and to facilitate information exchange between specialists and primary-care providers (Starren et al. 2014). In this chapter, we are focally concerned with patient-centered telemedicine. It is the earliest approach to the remote delivery of care dating back several decades to an era long before the use of home computers (Starren et al. 2014). The telemedicine interactions have been of two types, either occurring in real time (e.g. videoconferencing with a nurse case manager) or asynchronously (e.g. store-and-forward transmission of data from a home glucose meter) (Wootton 2012).

The services to patients cover the spectrum of clinical care from teledermatology to telepsychiatry, but the treatment of chronic illness has been at the forefront of telemedicine efforts in clinical practice and in research. Wootton reported that there have been more than 1300 Medline papers published concerning the use of telemedicine in the most common chronic diseases (e.g., hypertension, diabetes, asthma) (Wootton 2012). The time span of telemedicine projects have ranged from 6 months to many years (Darkins et al. 2008). Telemedicine has incorporated a wide range of technologies for communication, remote monitoring and patient education (Starren et al. 2014). This greatly extends the opportunities for patients to be involved in the management of their condition. It also affords the possibility of studying different dimensions of eHealth literacy.

Kaufman et al. (2003a, 2006) conducted a cognitive evaluation of the IDEATel home telemedicine system (Shea et al. 2002, 2009; Starren et al. 2002) with a particular focus on (a) system usability and learnability, and (b) the core competencies, skills and knowledge necessary to productively use the system. The study employed both cognitive task analytics and in-depth usability testing with a representative sample of users who were older adults, many of whom had minimal computer experience. The focal point of the intervention was the home telemedicine unit which provided the following functions: (1) synchronous video-conferencing with a nurse case manager, (2) electronic transmission of fingerstick glucose and blood pressure readings, (3) email to a physician and nurse case manager, (4) review of one's clinical data on a special purpose patient portal and (5) access to Web-based educational materials. The usability study revealed dimensions of the interface that impeded optimal access to system resources including problematic or non-intuitive widgets, small fonts poor spacing leading to screen clutter and numerous screen transitions. Significant obstacles corresponding to perceptual-motoric skills, mental models of the system, and health literacy were also noted. In addition, anxiety, self-efficacy, and motivation were observed to impact likelihood and comfort with using the technology. Although the study demonstrated a positive impact in patient outcomes such as improved glycemic control, blood pressure levels, and cholesterol levels, there were challenges in getting patients to consistently and productively use the technology.

Numeracy emerged as a significant problem in that some patients lacked the skills to discern trends or patterns of recorded glucose or blood pressure values. Representational fluency reflects the ability to translate between and recognize the identity of different representations of the same quantity (Ancker and Kaufman 2007; Kaufman et al. 2003b). Representational fluency is particularly relevant to the ability to use personal health care technologies and measurement tools such as meters, which represent information in unfamiliar formats. In a diabetes telehealth program for elderly patients, lack of representational fluency made it difficult for some participants to review their glucose and blood pressure values when they switched technologies. These patients, who could unproblematically read their blood pressure from a monitor, but were not able to recognize the tabular representations of the same values (see Fig. 13.3). Some seemed unfamiliar with the conventions of columns and rows and they may have been unable to the systolic over diastolic values of 161/134 as the same ones shown on their BP monitor.

The eHealth literacy problems documented in this study contributed to a large-scale system redesign (Hilliman et al. 2009). The objective was to enhance the patient's experience in using the system and thereby increasing the quality and frequency of



Date	Time	Glucose	Blood pressure
7/23/02	7:20 AM	135	144/82
7/23/02	6:52 PM	163	154/100
7/24/02	6:30 AM	145	161/134
7/24/02	7:08 PM	166	152/88

Fig. 13.3 Mapping values between blood pressure monitor and table presented in patient portal

their interaction with the system. The impact of the redesign resulted in improved patient interaction with the system including more frequent efforts to upload their glucose in closer proximity to measurement time (Hilliman et al. 2009). But challenges in the productive use of other facets of the system persisted which serves to highlight the gulf between the demands of the system and the skills and competencies of this user population.

13.4.4 mHealth and Devices

The growing popularity and use of mobile technology has opened possibilities for new ways to address and circumvent existing barriers to the access and use of eHealth tools and information. Pew Internet Project reported that, in 2015, 62% of smartphone owners have used their phone to search for information related to a health condition (Center PR 2015). eHealth interventions that leverage mobile phones, or mHealth, seek to promote behavior change through methods such as targeted text messaging, interactive mobile apps, email, phone calls, and video messaging (Lai and Siek 2015). The most commonly used mHealth feature is text messaging, and there is evidence that text message-based interventions can yield positive results (Cole-Lewis and Kershaw 2010). Research on mobile devices for health behavior change is still emergent, and available literature is limited to draw firm conclusions about its effectiveness (Coughlin et al. 2016).

Besides the known limitations of mobile devices (e.g. small screen, limited input capabilities) different studies have explored the advantages that mHealth can provide to patients with lower health literacy. For example, touchscreen and picture based interfaces are shown to be very well accepted by this user group and enable use of apps despite limited literacy (Teolis 2010; Kim and Xie 2015). The use of narration and graphics can be useful for patients with low literacy since they decrease reliance on reading skills (Teolis 2010). For example, studies (Meppelink et al. 2015) have shown that spoken animations can even bridge the information processing gap between audiences with low and high health literacy levels.

Recent studies have explored the potential of mHealth to help reduce communication and education barriers for patients with low health literacy levels. For example, Vargas et al. designed an interactive tablet app for individuals with limited health literacy and/or limited English proficiency to support assessing and reporting asthma symptoms for their children (Vargas et al. 2010). The questions in the app are presented as video clips and information is collected through the touchscreen. In the pilot, the app yielded better concordance with the follow-up interview than the paper form, and participants rated it as highly usable and useful (Vargas et al. 2010). Another example is the project described by Bickmore et al. (2009) that uses an animated, empathic virtual nurse to simulate face-to-face consultations between patients and healthcare providers. The system is used for educating and behavior change counselling of patients with low literacy levels. The patients at different levels of health literacy participating in the studies reported high levels of satisfaction and trust of information received from the system and especially expressed appreciation for the time and attention they received from the virtual nurse (Bickmore et al. 2009, 2010).

Additionally, mHealth devices are showing potential to help patients more easily measure their health literacy levels before consultation with their healthcare provider. One example is Talking Touchscreen, a self-administered multimedia (sound, images, text) health literacy assessment tool accessed on tablet devices (Yost et al. 2010; Hahn et al. 2011). The goal of these systems is to both reduce staff burden and costs and potential for interview bias, but also reduce patients' feelings of embarrassment during these interviews. The results of the pilot studies show that patients find this type of tablet app easy to use and that this new method of measuring health literacy is acceptable to patients on different health literacy levels (Yost et al. 2010).

Smart watches are the latest class of devices to emerge as an eHealth tool. They have the potential to support health behaviors by enabling self-monitoring of personal activity, providing feedback on activity levels, and supporting bi-directional communication with health care providers (Reeder and David 2016). After conducting a systematic review of the literature, Reeder et al. concluded that although smart watches are an exciting emerging tool for promoting healthy behaviors, research with these devices is at a nascent stage (Reeder and David 2016). We simply don't know much about their potential impact at this point in time.

Mobile technology continues to advance, and mHealth efforts are also evolving to take advantage of new mobile features and the ways that individuals interact with their phones. A qualitative study among patients revealed opportunities to improve mHealth design and strengthen health care partnerships with the goal to sustain behavior changes and the impacts of behavior change (e.g. incorporating context information to give more valuable meaning of the data on the app, using health care partnerships to receive expert advice and guidance and integration and control of health data on different systems and devices) (Miyamoto et al. 2016). One hypothesis is that some of the eHealth literacy problems are offset by the fact that devices are ubiquitous and used at a high frequency. Many users may be more motivated to find ways to use the tools more productively. Further research should explore how these requirements can be addressed by designing new interventions available and suitable for users with different levels of eHealth literacy.

13.4.5 Social Media

The possibility to reach a large number of people quickly and with minimum costs makes social media a highly relevant channel when promoting and delivering health education, promotion and behavior change interventions and programs. Social media has the potential to provide access to a wider variety of more available, shared and tailored health information and expand peer, social, and emotional support and increase the number of interactions (Korda and Itani 2013; Moorhead et al. 2013). Social network components of behavioral interventions are most commonly used as a way to provide education and social support, but in some cases also as a way to promote accountability and social competition (Laranjo et al. 2014). Recent literature reviews showed that interventions for health behavior change including general and health specific social network sites are feasible and show promise, although more studies are needed in order to determine their full effectiveness (Laranjo et al. 2014; Maher et al. 2014). PatientsLikeMe, a social networking web site for patients with different medical conditions and diagnosis, is one example of a peer-to-peer support site that has shown benefit by supporting patients managing their health conditions (Frost and Massagli 2008; Wicks et al. 2010, 2012).

Social media can also be a valuable channel for reaching more vulnerable populations and providing services that fit their specific needs. For example, a research study by Kobayashi et al. (2015) showed that for older adults, use of Internet and social engagement has potential to protect against health literacy decline during aging, independent of cognitive declines. Additionally, technology can have the potential to support older adults to better combat social isolation and keep healthier behavior habits [e.g. smart healthy cities (Boulos et al. 2015)]. Due to high proliferation of devices and their popularities among the entire population including racial and ethnic minorities, social networks can also be used to help bridge health disparities between different groups.

However, due to greater outreach and uncontrollable and often non-moderated nature of its content, social media poses higher risks than other conventional media (Moorhead et al. 2013). For example, information shared on social media is often from anonymous sources, and messages may be unclear or even distorted (Lau et al. 2012). Also, due to the large volume of available data, there is risk of information overload and individuals may have difficulty filtering information that is relevant and applicable to their personal situation (Adams 2010a). An additional concern is privacy and confidentiality related to data shared on social networks, as users are often unaware of the risks of sharing and disclosing personal and sensitive information online (Adams 2010b). As a result, understanding, processing and evaluating the quality, reliability and security of information from social media can pose challenges for all people regardless of health literacy levels. This only underlines the importance of educating and training users on how to navigate and critically evaluate health information on social media and finding credible information (Kamel Boulos et al. 2013). Some of the strategies that could be applied to ensure quality, security and trustworthiness of the content are: using moderators that regularly monitor and check the quality of the content published, tailoring content to users' preferences and health literacy levels, connecting social media web sites to evidence-based online information, defining and integrating specific rules for behavior on social networks and best practices and following guidance for creating content that is appropriate for people with different levels of literacy and testing it with users (Boulos 2015; Jiménez et al. 2016; Gibbons et al. 2011; Metzger and Flanagin 2011).

Social media presents a new set of challenges for researchers interested in eHealth literacy. Many of these challenges are not yet well understood or well explained by any of the frameworks which place a strong emphasis on cognitive factors. For example, what are the social mores regarding behavior in a breast cancer forum. Clearly, one's mastery of the social mores will be important in negotiating one's legitimate space in a forum. This is but one of the many issues (cognitive and noncognitive) that warrant further scrutiny.

13.5 Conclusion

Health behavior change has always been a hard problem and much effort has been given to understanding the problem as well as to fashioning solutions. In her chapter in this volume, Keselman makes a compelling case for the need to address health literacy at a much earlier stage beginning no later than adolescence (Keselman 2017). The need is to develop a more robust health education system that combines learning about health behaviors (e.g., what to do and what no to do) and science education that imparts conceptual knowledge and a deep connected understanding of scientific concepts and mechanisms. A health education system that demands a high level of proficiency and literacy among its students must be part of the longer term solution to develop an eHealth literate population.

Although it remains a hard problem, eHealth tools afford an almost infinite number of new means to achieve desirable ends such as reducing deleterious health behaviors and promoting adherence to treatment and monitoring regimens for patients with chronic illness. However, we are still learning how to use these tools productively to promote health behavior change interventions. In addition, the new eHealth tools introduce a class of new problems in that they may not be readily usable by a sizable slice of the population who are low in eHealth literacy. Given that many of these people may already be among the medically underserved, eHealth tools have the potential to increase the digital divide and exacerbate health disparities. eHealth literacy names both a construct and a field of research devoted to understanding and reducing such disparities by contributing to the solution space.

Due to the growing popularity and proliferation of new technologies for development and delivery of new personalized, user-tailored and context-adjusted behavioral change interventions, it is of great importance to consider both usability and the demands they place on users' knowledge and skills. As evidenced from previous sections, there is a considerable amount of related work that explore various techniques and strategies for presenting content and promoting interactions and navigation with a system that is easy to use and suitable for people with various eHealth literacy levels. The techniques are often highly context sensitive and depend on e.g. type of the system/service, type of device and interaction methods used, and type of users. Some of the general examples of design guidelines are: use of simple design (e.g. limited use of colors, one font type and size), displaying understandable textual information, avoiding lengthy text and medical jargon, use of tutorials and "how-to lessons" that explains to users how to navigate and use the system, use of icons and visual images in addition to simplified text, and limiting use of advanced and distracting technical features (e.g. pop-ups, hypertext links) (Kim and Xie 2015; Meppelink et al. 2015; Choi and Bakken 2010; Janiak et al. 2013; Choi et al. 2016). There also visualization and graphical representations that can serve to reduce the gamut of numeracy problems that even more advanced users sometimes experience (Ancker and Kaufman 2007). The good news is that the solution space is large and growing. There remains a need for a coherent theoretical and methodological framework to diagnose eHealth literacy problems and select from the available solution designs. The Chan–Kaufman analytic approach is a candidate for such a framework. It has been tested largely in the area of information-seeking tasks and there is clearly a need to expand beyond those narrow confines.

Another problem is that the methodology for this framework is complex, time consuming and requires substantial training. At present, it does not offer a practical solution for developers interested in improving their eHealth system. To further support development of eHealth systems that are suitable for use for people with lower health literacy levels, Monkman, Griffith (Monkman et al. 2015) outlined evidence-based heuristics for evaluating demands on eHealth literacy and usability in mobile consumer health applications. They refined previously developed heuristics developed for web sites (Monkman and Kushniruk 2013) and added new heuristics and recommendations from eHealth/health literacy and usability. These heuristics include the need to: (World Health Organisation 2013) immediately inform users of purpose and engage users (World Health Organisation 2013) use complementary interaction methods, (McCray 2005) provide accurate, comprehensible, and succinct content (Nielsen-Bohlman et al. 2004) provide tailored, flexible, layered content, (Sørensen et al. 2013) use visuals to complement text, but avoid tables, and (Sørensen et al. 2013) simplistic, consistent navigation. The authors of this chapter propose that the heuristics could be developed from our framework to facilitate a more rapid diagnostics process and to facilitate the design process that better addresses the needs of individuals at all levels of eHealth literacy.

Discussion Questions

1. eHealth literacy names a set of six core literacies and five levels of cognitive complexity involved in the productive use of health technologies. Can you think of any other literacies or cognitive processes that are not covered by this model and that may be important in an eHealth literacy analysis?
2. Social media is a burgeoning area of eHealth that is not yet well understood. How would you approach the study of this area from an eHealth literacy frame of reference? How would you expand the Chan–Kaufman framework? Would this framework even be appropriate for this relatively new area.
3. You are working as an eHealth analyst on a team developing a patient portal for adolescents with type 1 diabetes. You have done a thorough analysis of the problem. How could you convey your findings to the development team so that it may inform the design process?

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Part V
Behavioral Measures and Interventions

Chapter 14
From Personal Informatics to Personal Analytics: Investigating How Clinicians and Patients Reason About Personal Data Generated with Self-Monitoring in Diabetes

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Abstract Diabetes self-management continues to present a significant challenge to millions of individuals around the world, as it often requires significant modifications to one's lifestyle. The highly individual nature of the disease presents a need for each affected person to discover which daily activities have the most positive impact on one's health and which are detrimental to it. Data collected with self-monitoring can help to reveal these relationships, however interpreting such data may be non-trivial. In this research we investigate how individuals with type 2 diabetes and their healthcare providers reason about data collected with self-monitoring and what computational methods can facilitate this process.

Keywords Chronic disease (C23.550.291.500) • Self-care (N02.421.784.680) Diabetes • Self-management • Self-monitoring • Personal informatics • Personal data • Reasoning

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14.1 Introduction

Diabetes continues to be one of the most devastating chronic diseases, with a significant impact on the affected individuals, their families, and communities. The Center for Disease Control reports that as of 2014, 29.1 million people or 9.3% of the population have diabetes (National Diabetes Statistics Report 2014), with ethnic minorities disproportionally affected (Alex ADA). Diabetes is associated with a number of complications, including heart disease and stroke, high blood pressure, kidney disease, and nervous system disease, and can lead to blindness and amputations (Amos et al. 1997). Finally, diabetes has a devastating economic impact; in 2012 alone its costs were estimated at $246 billion (The Cost of Diabetes - American Diabetes Association® 2013).

Self-monitoring has long been accepted as a critical component of self-management for a variety of diseases and health conditions, and particularly for diabetes (Glasziou et al. 2005; Drummond et al. 1994; Karter et al. 2001). Previous studies conducted with individuals with diabetes suggested that self-monitoring of blood glucose (BG) levels is associated with better glycemic control and improved clinical outcomes (Martin et al. 2006; O'Kane et al. 2008; Welschen et al. 2005). Researchers in personal informatics proposed that self-monitoring in diabetes can lead to increased self-knowledge, for example to heightened awareness of an individual's current health status (e.g. current levels of blood glucose readings), and changes in this status over time (MacLeod et al. 2013). Others argued that when blood glucose data is combined with records of daily activities, it can help individuals to make new discoveries about the implications of their actions for their health, and to examine comparative efficacy of different approaches to self-management (Li et al. 2010; Mamykina et al. 2006; Polonsky and Skinner 2010). For example, capturing daily meals and blood glucose levels before and after these meals can help individuals recognize nutritional triggers that lead to undesirable rise or drop in their BG levels. Others proposed utilizing the data collected by individuals to assist their healthcare providers in devising personally tailored treatments, including nutritional therapy (Sevick et al. 2008).

The ongoing research in self-monitoring technologies enabled significant advances in mechanisms for collection of data and made self-monitoring devices available to large segments of the population (Ledger 2014). Yet previous studies suggested that few of the personal informatics solutions in chronic disease self-management provide explicit support for discovery of patterns and associations in the captured data (MacLeod et al. 2013; Li et al. 2010). Moreover, there is scarce existing knowledge regarding the questions individuals with diabetes and their clinicians ask about the data, their reasoning about patterns and associations, and the properties of captured activities that are influential for the analysis (Paterson and Thorne 2000). In addition, it is not clear to what degree individuals and healthcare providers could incorporate lessons learned from the data to anticipate the impact of different activities in the future.

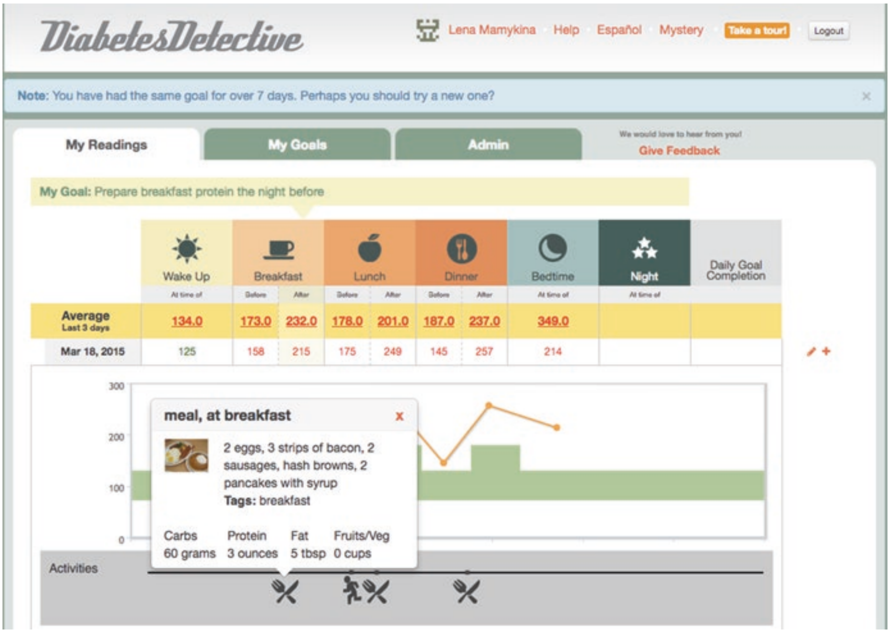
In this chapter we describe the results of a pilot study that investigated how individuals with diabetes and their healthcare providers examine and reason about data collected with self-monitoring. In the first phase of this study, two individuals with type 2 diabetes mellitus (T2DM) collected dense self-monitoring datasets that included digital photographs and detailed descriptions of their meals and snacks, and blood glucose readings before and after these meals for 4 weeks. Because such high intensity of self-monitoring far exceeds what is typical for individuals with T2DM, we limited enrollment to only two participants. The pictures of meals were augmented with nutritional composition (the inclusion of carbohydrate, protein, fiber, and fat) generated by a trained dietitian. In the second phase of the study, conducted 6 months later, we invited the same two participants, and two Certified Diabetes Educators (CDEs) to examine a subset of the data (5 days of meals and BG readings captured before and after these meals) for systematic trends and patterns as to the associations between different nutritional choices and changes in BG levels (retrospective analysis). In addition, we asked them to use these discoveries to predict glycemic reactions to future meals (prospective impact forecasting). Finally, we examined several data science methods that could enhance and facilitate both retrospective association analysis and prospective impact forecasting.

14.2 Generating Self-Monitoring Datasets

In order to generate the datasets for this research, two individuals with type 2 diabetes were recruited among members of TuDiabetes community, an online health forum for individuals with diabetes, using advertisement on the forum's website. Both participants were in their late 40s, one was male and one female (to protect their identity we refer to either of them in a gender-neutral way as "them" throughout this chapter), each had over 10 years of experience living with diabetes, both were managing their disease with oral medications (as opposed to insulin therapy) and both described themselves as actively engaged in diabetes self-management. Both had their diabetes in a relatively well-managed state (with HbA1c of 6.2 % and 6.5 % respectively).

After the initial screening interview, the participants were asked to use a web-based application for diabetes self-management, Mobile Diabetes Detective (MoDD), designed by the research team (Mamykina et al. 2016a); for the purpose of this study, the application was augmented with activity capture capabilities (see Fig. 14.1). This included the ability to upload digital images of meals and include a detailed free-text description. The participants were encouraged to check their BG levels immediately before each meal and 2 hours post-meal; however they were free to check more often post-meal if they preferred. To offset the expense of the more frequent testing the participants were reimbursed for the cost of the BG testing strips (60 cents per strip).

During the data collection phase, the two participants recorded between 75 and 124 meals (including snacks) and between 211 and 271 BG readings; the difference in the total number of the recorded BG readings was due to the fact that P1 captured between 1 and 3 post-meal readings, whereas P2 captured only one post-meal



Note: You have had the same goal for over 7 days. Perhaps you should try a new one?

My Goal: Prepare breakfast protein the night before

	Wake Up	Breakfast		Lunch		Dinner		Bedtime	Night	Daily Goal Completion
	At time of	Before	After	Before	After	Before	After	At time of	At time of	
Average Last 3 days	134.0	173.0	232.0	178.0	201.0	187.0	237.0	349.0		
Mar 18, 2015	125	158	215	175	249	145	257	214		

meal, at breakfast

2 eggs, 3 strips of bacon, 2 sausages, hash browns, 2 pancakes with syrup
Tags: breakfast

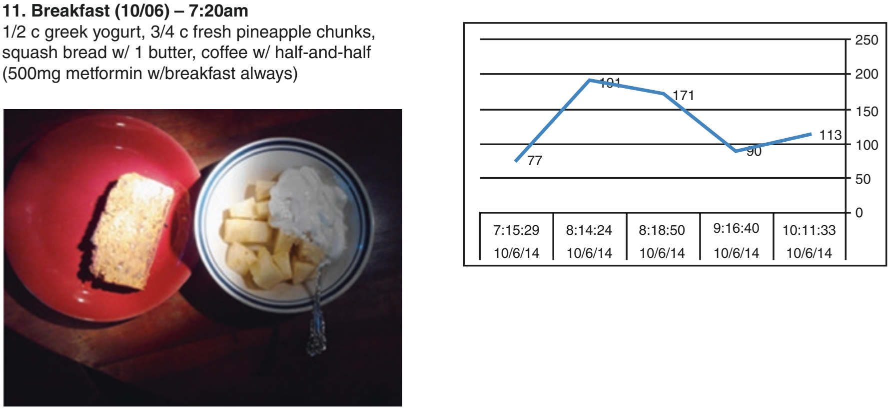
Carbs	Protein	Fat	Fruits/Veg
60 grams	3 ounces	5 tbsp	0 cups

Fig. 14.1 A screenshot of the Mobile Diabetes Detective interface activity capture features

reading for all meals. Both participants collected relatively diverse datasets; their meals included a variety of different ingredients, and the glycemic responses to these meals varied from stable (less than 20 mg/dl change in BG levels) to high (over 60 mg/dl increase in BG, these ranges were devised with the help of experienced diabetes educators members of our research team). Yet, there was also a considerable degree of redundancy in each of the participants' diets. Many of the captured meals were repeated multiple times throughout the study with small alterations.

14.3 Investigation of Reasoning and Predicting

In the next phase of this research we conducted an empirical study to investigate how both clinicians and patients reason about and learn from the data generated with self-monitoring. For this study, we recruited the same two individuals who participated in the self-monitoring study, as well as two Certified Diabetes Educators (CDEs) both with substantial experience advising individuals with diabetes and with extensive knowledge of diabetes self-management. In the rest of this paper we will refer to individuals with T2DM as "participants", and to CDEs as "experts". This study was conducted 6 months after the initial data collection study to minimize the chance that the participants remembered their actual BG readings captured after the recorded meals.



11. Breakfast (10/06) – 7:20am
1/2 c greek yogurt, 3/4 c fresh pineapple chunks, squash bread w/ 1 butter, coffee w/ half-and-half (500mg metformin w/breakfast always)

Fig. 14.2 Screenshot of the data presented to the participants and experts during the retrospective association analysis part of the interviews

Each participant took part in an interview that included two essential components. First, the participants were presented with a subset of their data, which included images of meals collected during 5 consecutive days of the study, and BG readings before and after these meals (see Fig. 14.2). The participants were asked to review each image and its description, examine BG readings before and after the meal, and explain what properties or components of the meal may be associated with the recorded changes in post-meal BG level. At the end of this phase, each participant was asked to discuss any recurring patterns associated both desirable and undesirable changes in BG levels.

Next, the participants were presented with another set of images for 5 different days (not included in the first part) and their descriptions. However, for these meals, they were only provided with the pre-meal BG levels, and were asked to predict corresponding post-meal BG readings and explain their prediction.

Experts' interviews also included the same two components; however, each expert had two separate interviews, each focusing on the data by one of the participants. In total, the study included six interviews that lasted from 1 to 1.5 hours and were conducted either in person or over the phone or Skype. The interviews were audio recorded and transcribed verbatim for analysis.

These studies were approved by the Institutional Review Board of the Columbia University Medical Center (CUMC). All participants reviewed and signed informed consent form before participating. The results of a larger-scale version of this study are described elsewhere (Mamykina et al. 2016b).

14.3.1 Reasoning

The results of the retrospective association analysis generated by patients and experts are presented in Table 14.1. First, inductive coding identified several distinct categories of terms used to generate explanations for differences in pre-meal/post-meal

Table 14.1 Categories of terms used to explain the impact of different meals on the difference between pre-meal and post-meal BG levels and their proportional inclusion in explanations generated by experts and patients

Experts	Experts (% of total number of terms in all explanations)	Patients (% of total number of terms in all explanations)
Product	28.7	42.8
Macronutrient	25.6	25.3
Attribute	11.7	8.4
Dish	9.3	9.6
Physiology	7.4	0.6
Serving size	7.1	3.6
Non-food	5.9	3.6
Food group	3.7	6.0
Medication	0.6	0.0

BG levels between different meals. These included: (1) product—specific products and ingredients used to prepare meals, for example cheese, and coffee, among many others; (2) attribute—a modifier of a product highlighting its nutritional properties, for example low-fat (milk), or multigrain (pancake); (3) dish—holistic description of dishes that may include several products, for example chicken curry soup, (4) food group—aggregation of specific products into groups, for example using the terms "fruits" to indicate various types of fruits; (5) macronutrient—generalizing from specific products to such macronutrients as carbohydrates, protein, fat, and fiber; (6) physiology—explanations referring to general physiology of diabetes; (7) serving size, referring to proportions of different ingredients and products, (8) non-food—explanations referring to other activities, for example physical activity or sleep, and (9) medication.

As one can see from the table, the degree of reliance on these categories differed between the participants and the experts. For both participants and experts, explanations referring to specific products were the most frequent; however, for patients they were predominant (over 40%), whereas educators relied on specific products as much as on macronutrients, and mostly to explain how they arrive at macronutrient content. Moreover, the experts were more likely to pay attention to more subtle nuances, such as whether the products included in meals were non-fat, multigrain, or low-carbohydrate, and the serving sizes. Finally, they were more likely to refer to diabetes physiology, and to explanations beyond meals, for example levels of physical activity or quality of sleep.

The most frequent terms used to explain meals with high glycemic impact and stable glycemic impact are included in Table 14.2. For this analysis we aggregated all the terms in the explanations constructed by participants and both experts.

Here, the terms used to explain high impact meals and low impact meals differed considerably between P1 and P2. Whereas for P1 high impact meals were frequently explained using terms "carbohydrate" (n = 9), "protein" (n = 6), and "yogurt" (n = 6); for P2 these terms included "apple" (n = 5), "low carbohydrate" (n = 4), and "vegetables" (n = 3), among several others. Similarly, for meals in the

Table 14.2 Common terms used in explanations of meals with high impact on BG (over 60 mg/dl difference in BG between pre-meal and post-meal) and meals with stable impact on BG (under 20 mg/dl difference in BG between pre-meal and post-meal)

High		Stable	
P1	P2	P1	P2
Carbohydrate (9)	Apple (5)	Fat (10)	Carbohydrate (4)
Protein (6)	Low carbohydrate (4)	Protein (9)	Bread (4)
Yogurt (6)	Vegetables (3)	Carbohydrate (4)	Fat (4)
Fat (5)	Fat (2)	Avocado (3)	Half a pear (4)
Squash bread (5)	Protein (2)	Butter (3)	Jam (3)
Fiber (4)	Salad (2)	Carb (3)	Protein (3)
Half and half (4)	Active (2)	Chicken (3)	Salad (3)
Sugar (4)	Avocado (2)	Raisins (3)	Wine (3)
Pancake (3)	Chicken (2)	Blue cheese dressing (2)	Avocado (2)
Peanut butter (3)	Bread (2)	Fiber (2)	Cheese (2)
Vegetables (3)		Gelato (2)	Healthy fat (2)

For P1, this is captured for explanations for 1 hour post-meal

"Stable" category, the most frequent terms for P1 were "fat" (n = 10), and "protein" (n = 9), whereas for P2 the most common terms included "carbohydrate" (n = 4) and "bread" (n = 4). The explanations for these differences became apparent when the participants summarized their perceptions of common patterns in the impact of their meals on BG levels. For P1, all three interviews highlighted the high impact of meals rich in carbohydrates (specifically for breakfast), and insufficient inclusion of fiber. In contrast, for P2, all three interviews highlighted over-restriction of carbohydrates, particularly at lunch, as the main reason for spikes in post-meal BG levels.

14.3.2 Predictions

All study participants, including both patients with diabetes and diabetes educators reported having considerable difficulty generating predictions in regards to individuals' glycemic response to specific meals. Correlation examining the relationship between patient and expert blood glucose predictions and the actual captured post-meal BG levels (for 1 and 2 h post-meal for P1 and for 2 h post-meal for P2) are presented in Table 14.3.

As one can see from the table, predictions by both participants were strongly correlated with the actual captured post-meal BG levels. This is perhaps not surprising, given their dedication to self-management and years of experience monitoring their disease. However, there were considerable differences in how well predictions by experts were correlated with the captured readings. For P1, the predictions of expert 1 were poorly correlated with the captured readings at both 1 and 2 h post-meal.

Table 14.3 Correlation between predicted and actual post meal blood glucose readings

	P1 1 h	P1 2 h	P2 2 h
Participant 1	$r = 0.61; p = 0.007$*	$r = 0.22; p = 0.42$	N/A
Participant 2	N/A	N/A	$r = 0.79; p < 0.001$*
Expert 1	$r = 0.24; p = 0.33$	$r = 0.008; p = 0.98$	$r = 0.86; p < 0.001$*
Expert 2	$r = 0.63; p = 0.006$*	$r = -0.06; p = 0.82$	$r = 0.89; p < 0.001$*

Both participants were only asked to predict their own readings, as this required considerable degree of self-knowledge. (*) marks results with statistical significance

Predictions of expert 2 were strongly correlated with the captured readings at 1 h, but then also dropped at 2 h. For P2, all three individuals generated predictions highly correlated with the captured readings.

14.4 Explorations of Data-Science Methods for Facilitating Reasoning and Prediction

In the final phase of the project, we explored two novel approaches to facilitating individuals' reasoning about changes in their BG levels with computational methods. They included (1) Natural Language Processing (NLP) and data mining algorithms to identify associations between terms used in the descriptions of the captured meals, and the captured difference in pre-meal/post-meal BG levels, and (2) computational endocrine models for forecasting an individual's response to meals with specified nutritional content based on this individual's historical records.

14.4.1 Retrospective Association Analysis

To conduct retrospective association analysis we first grouped all meals according to the pre-meal/post-meal BG differences (which we will refer to as a meal's glycemic impact) into four distinct categories: (1) Stable—meals with the difference between pre-meal BG and post-meal BG (both 1 and 2 h when available) of no more than 20 mg/dl; (2) Low Impact—meals with this difference between 21 and 40 mg/dl; (3) Medium impact—meals with post-meal/pre-meal BG difference between 41 and 60 mg/dl, and (4) High impact—meals with this difference above 60 mg/dl. These categories were created with the help of experienced diabetes educators, members of our research team. We then conducted an analysis to identify words and phrases in the meal descriptions for each individual, which are discriminative of either a low/stable/medium or a high meal impact. We trained an Adaboost decision list (Schapire and Singer 1999), where each instance is a meal, features are words, bigrams, and trigrams (phrases two- and three-word long), and labels are "Low" (i.e., stable, low, and medium) and "High" impact. Because each participant had a limited number of instances (120 for P1 and 80 for P2), we trained only 30 iterations

Table 14.4 Individual features (unigrams, bigrams, and trigrams) picked up by the Adaboost analysis as discriminative of high or stable/low/medium impact

High		Low	
P1	P2	P1	P2
Half	With franks sauce	Kale	Ham cheese
Veg	Meatloaf veggies ale	Berries	Sauerkraut
Chunks	Burger salad apple	Beet	Dinner
Wedge of pita	Meatloaf celery almond	Homemade	Apple celery
Flour	Meatloaf ½ apple	Salad w blue	Tuna
Seckel	Vegetables meatloaf apple	Soup w	Beef
Before dinner	With franks sauce	Sauce w	Sausage
W greek yogurt			Vegetables ham
1/3 c fresh strawberries			Ham cheese
Acorn			Ham ½ pear

of Adaboost learning; i.e., up to 30 words and phrases per participant were picked up as discriminative for one of the two labels. The limited size of the dataset from a computational standpoint also motivates our choice of two labels, merging Stable, Low, and Medium impacts into a single label and contrasting it to High impact meals. We examined the results of the learned weak classifiers. Each participant was treated individually, to identify discriminative features specific to each individual.

Table 14.4 shows the unigrams, bigrams, and trigrams picked up by the Adaboost analysis as individual weak hypotheses for classifying into Low (in this analysis stable, low, and medium) and High impact meals. Overall, terms indicative of Low impact were fiber-related food (i.e., kale and berries for P1) and protein-bearing foods (i.e., tuna, beef, sausage, ham for P2). Terms indicative of high impact were "half"—which in fact related to the term "half and half", and seckel, a sweet type of pear. Interestingly, the term "pancake" which was a particularly frequent term for P1's meal descriptions did not rank as highly discriminative in the analysis. We note however that "w greek yogurt" which was always included in the descriptions of meals where P1 had pancakes was identified as a discriminative feature towards High impact meal.

14.4.2 Prospective Forecasting

We selected two mechanistic endocrine models, a relatively simple ultradian model (Sturis et al. 1991) developed to model fast glucose-insulin dynamics in healthy individuals and a complex meal model (Dalla Man et al. 2007) developed as a detailed model of meal-time metabolism as related to glucose-insulin dynamics for both individuals who were either healthy or had T2DM. Both models can take glucose, insulin, and nutrition as input variables and can forecast glucose, insulin, and between 30 and 70 other physiologic parameters. To integrate an individual's data, personalize the models through parameter training, and generate a forecast, we embedded the models in a dual unscented Kalman filter (UKF) (Gove and Hollinger 2006;

Table 14.5 Results of a comparison of predictions generated with the models and predictions generated by experts

	P1 at 1h post-meal	P1 at 2h post-meal	P2 at 2h post-meal
Expert 1	$r = 0.24$; $p = 0.33$	$r = 0.008$; $p = 0.98$	$r = 0.86$; $p < 0.001$*
Expert 2	$r = 0.63$; $p = 0.006$*	$r = -0.06$; $p = 0.82$	$r = 0.89$; $p < 0.001$*
Model 1	$r = 0.28$; $p = 0.2$	$r = 0.3$; $p = 0.23$	$r = 0.76$; $p = 0.001$*
Model 2	$r = 0.47$; $p = 0.03$*	$r = 0.48$; $p = 0.04$*	$r = 0.61$; $p = 0.02$*

*indicate statistically significant correlations

Sedigh-Sarvestani et al. 2012), a data assimilation (DA) methodology (Law and Stuart 2015) used to optimize and forecast nonlinear processes. Using the patient data we then created glucose and nutrition based post-meal glucose and insulin forecasts for both models.

Examination of the predictions generated by the models show that for P1, the predictions generated using meal model (M1) had lower correlation than the patient and one of the experts at 1 h, but did better than the second expert. At 2 h mark for this patient, predictions by both models had higher correlation with captured BG levels, with ultradian model (M2) producing the most accurate predictions. For P2, both models produced predictions that were highly correlated with the actual post-meal readings (Table 14.5).

14.5 Implications for the Informatics for Personal Discovery

The increasing volume of person-generated data opens new horizons in promoting self-knowledge and self-awareness (Li et al. 2010). This has a particular significance for individuals with chronic diseases who must rely on such data to identify beneficial and personally-meaningful self-management strategies. However, to take advantage of these data, individuals need to be able to examine and analyze it, identify recurring patterns and associations between their activities and changes in their health, and incorporate their discoveries into their future choices. In this research, we took initial steps towards understanding these processes with the goal of informing the design of future self-monitoring and self-management technologies.

In regards to the retrospective association analysis, the study suggested that both patients and their healthcare providers use a diverse set of terms to explain differences in BG levels before and after different meals. Not surprisingly, names of different products included in the meals were often included in such explanations. However, whereas for patients product names often dominated, experts were more likely to construct their explanations on a more generalizable level, for example discussing the comparative impact of different macronutrients and estimating the inclusion of these macronutrients in participants' meals. This distinction is important as reasoning on macronutrients level can help individuals to generalize between different products similar in their macronutrient composition. The computational analysis of the meal descriptions and their discriminative power towards low as opposed to high impact meals elucidated key terms for each participant in agreement with the explanations provided by both participants and experts. While these terms may not be as definitive in providing explanations as the terms used by the participants themselves, they can be insightful in drawing participants' attention to meals in their past that used the identified terms in their descriptions. These findings suggest the importance of both rich textual descriptions and macronutrient composition on individuals' ability to analyze captured records for trends and associations. This contrasts with recent suggestions that relying on photo-diaries without inclusion of nutritional information may have advantages over recording more details about nutrition (Cordeiro et al. 2015). This additional information, however, need not contribute to the burden of diet monitoring and could be added using crowdsourcing mechanisms (Noronha et al. 2011).

In regards to prospective forecasting, the study showed that both study participants had a high degree of self-knowledge, exceeding that of the experienced healthcare professionals. However, this may not hold true for the majority of individuals with diabetes who are not as immersed in self-management. Individuals with diabetes often have to rely on healthcare providers to identify both beneficial and detrimental impacts of different nutritional choices on their BG levels; most commonly, experts' predictions are based on limited exposure to individuals' historical records, not unlike the conditions we created in the study. Computational endocrine models can help individuals anticipate the impact of different meals and make educated nutritional choices. Even given the small dataset available for training the models, their performance was often comparable with that of participants and experts. And in at least one case, both models exceeded the ability of human experts to predict longer-term impact of meals. This finding, however, presents the need to design new interaction mechanisms and data presentation techniques to help individuals understand predictions generated with computational models and incorporate these predictions into their decision-making.

Finally, an overarching theme across our findings was that of considerable differences between the two participants in their reactions to different meals and macronutrients in these meals. These differences were evident in explanations for high-impact meals generated by the participants and the experts (high carbohydrate in breakfasts for one, and low carbohydrate in lunches for another). It was also reiterated by the analysis of correlations between the amount of different macronutrients and the change in pre-meal/post-meal BG levels. All these findings suggest a need for deeply personalized approaches to identifying behavioral and, particularly, nutritional strategies for diabetes self-management. In recent years, precision medicine—an approach to the delivery of medical treatment that is tailored to an individual's genetic and molecular make up—has been suggested as the way that medicine will be practiced in the future (Hamburg and Collins 2010). In a similar manner, we propose that data collected with self-monitoring can enable *behavioral precision medicine*, in which behavioral strategies for self-management of chronic diseases are tailored based on both individual's personal data and, potentially, on their genetic predispositions. Early research in Nutrigenetics and Nutrigenomics has already suggested a number of associations between human gene expression and nutrition (Fenech et al. 2011). However, further research is needed to make this approach a reality.

This study has a number of limitations. First of all, it is based on experiences of two individuals with type 2 diabetes and two certified diabetes educators. Moreover, the two patients in the study were immersed in diabetes self-management and knowledgeable about diabetes and nutrition. As a result, this study has limited generalizability. Other individuals' with diabetes may have different experiences with self-monitoring, which may lead to different conclusions. More research is necessary to confirm study conclusions and examine its applicability to broader populations.

Discussion Questions

1. What are the advantages and disadvantages of computational discovery methods as comparing to humans' cognitive abilities?
2. In what ways applications for personal analytics can integrate human intelligence with advanced computational methods to facilitate discovery?
3. What are the implications of these new approaches for the modern self-monitoring technologies?

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Chapter 15
Leveraging Social Media for Health Promotion and Behavior Change: Methods of Analysis and Opportunities for Intervention

Sahiti Myneni, Kayo Fujimoto, and Trevor Cohen

Abstract This chapter describes methodologies used to describe, model, and predict user communication patterns in social media interactions, with the shared goal of facilitating understanding of health-related behavior change. To set the stage, the chapter presents an overview of the documented effects of social relationships on health behavior change. Investigators from a variety of disciplines have attempted to understand and harness these social ties for health promotion. Online communities, which digitize peer-to-peer communication, provide a unique opportunity to researchers to understand the mechanisms underlying human behavior change. Through transdisciplinary methods that draw upon socio-behavioral theories, and information and network sciences, analysis of communication patterns underlying social media user interactions is possible at scale. Such methods can provide insight into development of "healthier life" technologies that harness the power of social connections. Examples of such translational projects and implications for public health practice are discussed to conclude the chapter.

Keywords Behavior change • Social media • Online social networks • Semantics • Network analysis • Health promotion • Smoking cessation • Social influence • Behavior change theories

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15.1 The Role of Social Media in Health Behavior Change

Social media can be defined as the collective forms of electronic communication (e.g. web sites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (e.g. videos) (Kaplan and Haenlein 2010; Kietzmann et al. 2011). Healthcare consumers employ these online venues to interact with peers and care providers, to gain knowledge and reciprocate social support on a variety of health-related issues (Chou et al. 2009; Hawn 2009; Sarasohn-Kahn 2008; Fisher and Clayton 2012). From a research and intervention perspective, the advantages of such platforms over traditional pamphlet-based and web-based static health education material include user-generated online content; wide reach and just-in-time accessibility via web and mobile connectivity; the ability to involve multiple stakeholders (e.g. public health agencies) in the content dissemination process, and research potential to better understand participants' health-related needs (e.g. behavioral, tactical, knowledge-based) (Korda and Itani 2013). On account of these advantages, social media platforms have the potential to facilitate interventions and studies involving large numbers of participants, without undue expense. Interventions disseminated on such platforms have the potential for great impact, on account of the capability to leverage *social influence*.

The influence of social relationships and social support on health behaviors has been well documented (Heaney and Israel 2008; Umberson and Montez 2010). While associations between social relationships and health are complex and not necessarily causal in nature (Lyons 2011), evidence suggests that the positive health enhancing effects of social relationships can be used for the promotion of healthy behaviors such as smoking cessation, physical activity, and nutrition management (McGloin and Eslami 2015; Cavallo et al. 2012, 2014; Cobb et al. 2005). Christakis and Fowler's influential analysis of the Framingham dataset shows an association between the smoking behavior within an individual's social network and the likelihood that this individual will quit smoking (Christakis and Fowler 2008). Similar observations have been made with other psychosocial behaviors (Christakis and Fowler 2007, 2008; Fowler and Christakis 2008; Rosenquist et al. 2010). For example, smoking cessation by a spouse, sibling or friend decreased a subject's chance of smoking by 67%, 25% and 36% respectively, as compared with having no social contacts attempting to quit. In contrast to these positive effects, peer group studies on smoking behavior revealed that smokers are more likely to have friends who are also smokers (Alexander et al. 2001). Several observational studies have shown the effects of social constructs such as social influence, selection, norms, and consequences on an individual's involvement in risky behaviors (Valente 2010). Studies conducted on social relationships have revealed different types of social influence, referred to as peer influence, affiliation influence, and positional influence. Peer influence is a form of direct influence that is explicitly based on direct friendship relations (Alexander et al. 2001). Positional influence defines a form of influence that is exerted by an individual as a result of their occupying a central position in a social network (Freeman 1978). Affiliation-based influence takes into account indirect sources of influence including participation in organized group activities and events (Fujimoto et al. 2012). In summary, social networks can be viewed as complex ecosystems that can have positive and negative influences on health behaviors.

A number of "offline" community-based interventions have been developed and evaluated for *health promotion* and *behavior change*. Such programs generally attempt to segment a target population in order to tailor messages according to gender, age, culture, and so forth. Examples include the Minnesota (Perry et al. 1992), Pawtucket (Elder et al. 1986), Stanford Heart Health (Killen et al. 1989), and COMMIT programs (Royce et al. 1993). With tremendous uptake of social media platforms, users of these online venues turn to their peers to share experiences, ask questions, provide emotional support, and exchange self-help advice with one another. And, since the communication events on these platforms are electronically captured, it may be possible for researchers to (a) understand and predict the sources of social influence, and resulting effects on health behaviors, and (b) model interventions that apply data-driven analytics of social media interactions to inform the design of targeted user-information interactions.

The next sections of this chapter are organized as follows. Firstly, we provide the current landscape of social media uptake in health care research, and summarize the research and intervention opportunities that are made possible in recent times by virtue of health consumer driven social media platforms. Secondly, we present an overview of methodologies that are theory-driven, quantitative, and semi-automated in nature and describe the ways in which these methods can be used to describe, visualize, and model user interactions in social media platforms. We then discuss the ways in which these methods can lead us to social influence patterns underlying peer-to-peer communication events in social media platforms to explain individual and group level *behavior change*. Thirdly, we summarize a series of studies that describe the application of these methods to understand social media interactions in a health-related online community for *smoking cessation*. Finally, the implications for intervention design and public health practice are discussed.

15.2 Overview of Social Platforms in Digital Era

In recent years, the penetration of online social media into everyday lives has been astonishing. More than a billion people (1/7th of the world's population) now use a single social networking service, Facebook (Facebook 2016). Around 72% of American adults have an active account in a social networking service website such as Facebook, Twitter, Linkedin, and Google+ (Duggan et al. 2015). To curb the growing health care costs and improve the efficiency of health and wellness programs, it may be possible to exploit the advantage of these scalable platforms to positively influence health behaviors of individuals, as these networks have the capability to deliver interventions to large populations. Today's social media platforms can be broadly classified as (1) General-purpose social networks, or (2) Activity-specific social network. General-purpose networks such as Twitter and Facebook support social interactions on any topic, while activity-specific networks such as PatientsLikeMe (2016) and QuitNet (2016) provide platforms for participants seeking targeted interactions pertinent to health-related goals. A variety of socio-behavioral interventions have been developed to support healthy lifestyle changes by facilitating attitudinal change, behavioral adherence, and the availability of a support network (Centola 2013; Tang et al. 2015; Prochaska and Prochaska 2011). On account of the availability and accessibility of the World Wide Web via mobile phones, social network interventions can occur in real-time (e.g. community support via mood sensing using a smartphone (Ahmed et al. 2015; Bachmann 2015)), and their capacity for perpetual data collection can provide a rich documentation of habitual behaviors (such as visiting a neighborhood bar) that may influence behavior change (Cohn et al. 2011; Heron and Smyth 2010; Shiffman et al. 2008). Therefore, online social media platforms form the basis for ecological momentary assessments and interventions. These networks form a core component of Health 2.0, which is defined as "user-generated health care promoting patient empowerment and participation" (Van De Belt et al. 2010). As the networks mature with scale, their social value increases, and their data can provide valuable insights into fundamental questions of human behavior. Studies of such network data provide a desirable alternative to traditional retrospective cohort-based investigations, because of their scale, structural control, measurement, replicability, and behavioral fidelity (Centola 2013).

15.3 Opportunities for Research and Implications for Public Health Practice

These virtual platforms open new and important avenues for research, including extending existing socio-behavioral theories to technology-driven interventions; understanding fundamental mechanisms of behavior change; and formulating and evaluating novel interventional approaches. Are theoretical models of socio-behavioral change developed prior to ubiquitous digital communication applicable to both offline and online contexts? (Riley et al. 2011). Social network data contain traces of the cognition and immediate behavior of a person as they attempt to introduce a new change or sustain an existing behavior modification. This provides researchers with an unprecedented opportunity to refine existing theories and models of social networks, social support, and behavior-change that were formulated based on face-to-face communication. Consequently, there is a pressing need for the formulation of new methods and metrics to capture and analyze data patterns derived from *online social networks* to inform our understanding of behavior change at the individual and network level. These new methodological approaches must scale to large online social network datasets. Many network analysis studies do not consider communication content and focus on network structure (Cobb et al. 2005; Centola 2010; Aral et al. 2009; Shalizi and Thomas 2011; Poirier and Cobb 2012).

In contrast, those studies that have considered content have adopted qualitative methods thus limiting their scalability to larger datasets (Myneni et al. 2016a; Hwang et al. 2010; Zhang et al. 2013). So the development of methods to facilitate the inclusion of content into network models is another important research direction. Most current *behavior change theories* suggest strategies that tailor the content that is delivered as part of an intervention. Understanding and leveraging network content may allow us to develop theoretically-grounded approaches to intervention that operate at a network level, thus enhancing their impact and efficacy. Other interesting potential research strategies include: (a) formulating new methods to identify important nodes within online social networks to tailor or deliver a behavior change intervention, (b) disentangling the sociobehavioral factors underlying communication patterns and user engagement in health behaviors, (c) comparative effectiveness research on interventions to see if findings based on retrospective self-reports with sparse observations in the real world are consistent with those based on behavioral data collected online, and (d) interfacing online social networks with other elements of health care such as physicians, insurance providers, and workplace wellness influencers.

15.4 Understanding Communication in Social Media

15.4.1 Theory-Driven Techniques

Prior to the advent of online social networks, several health behavior theories and models have been formulated to attempt to explain behavior change. These theories and models have served as guides for the development and evaluation of both face-to-face and online interventions. The Health Belief Model (Hochbaum et al. 1952), Theory of Planned Behavior (Ajzen 1985), and the Transtheoretical Model (Prochaska and Velicer 1997) belong to the category of intrapersonal models, while Social Cognitive Theory (Bandura 1986) and Social network, support models (Heaney and Israel 2008) are classified as interpersonal models. Intrapersonal models consider individual characteristics that influence behavior, such as knowledge, attitudes, and beliefs. On the other hand, interpersonal models consider group-level dynamics involving family, friends, peers, that provide social identity and support. In the sections that follow, we will describe the main features of those models and theories that have been used most widely as a basis for the design of behavior change interventions.

Health Belief Model (HBM)

This is one of the most widely used conceptual frameworks for explaining and changing individual health behavior. The HBM evolved from a cognitive theory perspective and is a value-expectancy theory, which attempts to explain and predict individual's attitudes toward objects and actions (Hochbaum et al. 1952).

Major components in the HBM include perceived susceptibility; perceived severity; perceived benefits; perceived barriers; cues to action; and self-efficacy. An individual's perceptions of a behavior can be used as predictors of behavior change outcomes under certain conditions that are dependent on demographic (e.g. age, gender) psychosocial (e.g. personality, social class), and structural variables (e.g. prior knowledge, experience). The HBM has been applied to many important healthcare problems focusing on behavioral adherence such as seat belt use (Fernandes et al. 2010).

The Theory of Reasoned Action (TRA)

The TRA suggests behavior is determined by behavioral intention (Fishbein 1979). The intent of a behavior is a function of the person's attitude toward the behavior, their subjective norm associated with the behavior, and their perceived behavioral control. Application areas for this theory include health-related behavior concerning disease prevention and birth control (Albarracin et al. 2001; Fisher et al. 1995).

Social Cognitive Theory (SCT)

The SCT is a theory based on reciprocal determinism between a behavior, the environment, and a person (Bandura 1986). This theory emphasizes self-efficacy, an important concept related to self-confidence. Self-efficacy is defined as "people's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances" (p. 391). Current literature agrees on a common definition that self-efficacy "refers to what a person believes he or she can do on a particular task" (p. 506). Small-scale goal attainment, and confidence building through self-monitoring and continuous feedback is often used to improve a person's self-efficacy. Other important constructs in SCT include behavioral capability; observational learning; reinforcement; outcome expectations and expectancies; emotional coping and self-control. The construct of 'observational learning' has been used by network scientists to provide an explanation for social influence and network clustering of people engaging in the same health behavior (Bandura 2001, 2011). According to SCT, observational learning in behavior change occurs when an individual observes another person engage in a given behavior and receive reinforcements. Another component of SCT called reciprocal determinism takes into account the interactions among individuals, their environments, and behavior goals. The environment in SCT refers to a conglomeration of factors that are external to the individual including his/her social network—family, friends, and peers, and physical objects that might affect behaviors. In case of smoking the physical objects can include availability of patches, access to smoking-designated areas in the work place, and so forth.

The Transtheoretical Model of Change (TTM)

The TTM tries to explain behavior change mechanisms by synthesizing several constructs drawn from other theories (Prochaska and Velicer 1997). *Stages* and *processes* of change are the two main components of TTM. The former component explores the temporality of behavior change, while the later encompasses cognitive and behavioral concepts such as decisional balance (comparative analysis of pros and cons of a proposed behavior change), self-efficacy, and rewards. According to this model, precontemplation, contemplation, preparation, action, maintenance, and termination are the six stages of change, where each stage involves one or more processes of progress. This theory has been successfully applied in several behavior change settings (Prochaska and Prochaska 2011).

Behavior Change Taxonomy

Abraham *et al.* defined a set of "theory-linked" behavior change techniques that can be used to characterize and differentiate between different types of intervention content (Abraham and Michie 2008; Michie et al. 2013). Their taxonomy of 93 theory-linked techniques is the first step towards creating a model of intervention content in the context of theory-driven behavior change constructs. A single behavior change technique can be related to similar behavior change processes from multiple theories. The taxonomy provides a common vocabulary to understand the ways that sociobehavioral and cognitive constructs of the existing behavior change theories have been operationalized in a specific intervention.

15.4.2 Review of Qualitative Studies

Prior qualitative studies on online community interactions have focused on (1) studies of user perceptions of the utility of online communities for a specific health-related illness (e.g., mental health (Donovan 2014), alcoholism (Chuang and Yang 2012), cancer (Klemm et al. 2003), Huntington's disease (Coulson et al. 2007)); (2) characterization of the general conversational interests of specific population (e.g., the elderly (Nimrod 2010)); (3) identification of social support categories (House et al. 1981, 1985) (e.g., informational support, emotional support). Another type of qualitatively-driven social media study involves researchers identifying themselves as such and gathering information in the form of online semi-structured interviews, online focus groups, or internet based surveys to attempt to understand consumers' use of social media. Hwang et al. conducted a network-based survey on the Sparkpeople forum, where members focus on weight loss regimen. The qualitative survey data were analyzed for social support themes using grounded theory techniques. Results indicated that the major social support themes were encouragement and motivation, information and shared experiences (Hwang et al. 2010). In our own work, we conducted qualitative analysis of messages exchanged in QuitNet, which provided insights into the nature of communication events in this community using a combination of the aforementioned theories and behavior change taxonomy. These ranged from discussions on nicotine replacement therapies to stress management strategies (Myneni et al. 2016a). Detailed discussion of these results is provided in the subsequent sections of this chapter.

15.4.3 Automated Methods of Text Analysis

Recent advances in automated text analysis allow for large-scale analysis of the content of communication between members. In this section we review research that has leveraged automated methods of text analysis in an effort to interpret content produced by members of online social networks, with a focus on research in the area of health-related behavior change. However, before we proceed to domain-specific research, we will review general domain research that covers this methodological territory. A recurring theme has to do with the issue of semantic relatedness, on account of the need to identify connections between messages that are similar in meaning, but may not express this meaning using the same words as one another.

Content Analysis in the General Domain

Semantic analysis of social network content using automated methods has been previously applied to the study of research communities in the field of enterprise interoperability. Velardi et al. performed content-based social *network analysis* with the aid of linguistic analysis, text mining, and clustering techniques, in which the semantic relatedness between terms was measured using a taxonomy-based approach (Velardi et al. 2008). Meta-data based approaches have also been used to derive person-word relations (e.g. author-specialization) by extracting social network information using semantic approaches (Matsuo et al. 2007). Classification of conversational and informational questions on social Q&A websites such as Yahoo! Answers has also been attempted using a combination of human coding, statistical analysis, and machine learning (Harper et al. 2009). Another application area of automated natural language processing method is the development of a consumer health vocabulary based on threaded discussions in online social network websites (Doing-Harris and Zeng-Treitler 2011). Doing-Harris et al. have developed a computer-assisted update (CAU) system that consisted of three main parts: a Web crawler and an HTML parser, a candidate term filter that utilizes natural language processing tools including term recognition methods, and a human review interface. The CAU system was applied to the health-related social network website PatientsLikeMe.com to develop and dynamically update the health vocabulary

(Smith and Wicks 2008). Another avenue for automated methods in analysis of online social media content is assessing similarity between two separate texts to derive and understand content structure. Content similarity has been used as a filtering metric along with link analysis to rank influential users in a web forum (Tang and Yang 2010). A precedent for research employing both network models and estimates of semantic relatedness can be found in the psychological literature. For example, Pathfinder networks (PFNETS) employ a scaling technique that builds on relatedness between nodes. If each node represents a concept, the weights of links (or edges) present in the network are defined using human estimates of the relatedness between all pairs of concepts (Schvaneveldt 1990). Consequently the structure of a PFNET is determined by estimates of the strength of the semantic relationships between the concepts within it. Originally, these estimates were obtained from human subjects, but more recent research has utilized estimates of the relatedness between terms that are derived automatically from large text corpora, using methods of distributional *semantics* (Schvaneveldt and Cohen 2010).

Distributional Semantics

A number of methods have been developed to automate the derivation of similarity metrics between terms based on distributional statistics of unannotated electronic text (for reviews, see (Cohen and Widdows 2009; Turney and Pantel 2010)). Spatial semantic models define terms as vectors in high dimensional space according to the distribution of their occurrence across a large text corpus. Semantic space models use different approaches to derive this multi-dimensional space, with an important fundamental difference having to do with the unit of text that is considered an independent context. For example, in Latent Semantic Analysis (LSA), each document in a text collection is considered as a unique context (Landauer and Dumais 1997), so a word is initially represented as a vector with a coordinate for each document in the collection, and values that are derived from counts of the number of times this word occurs in each document (the matrix is subsequently decomposed for the purpose of dimension reduction, which permits identification of second-order relationships between words that don't occur directly). In contrast, the Hyperspace Analogue to Language (HAL) (Lund and Burgess 1996), uses a sliding window around a term of interest as a context (as do some more recent approaches, such as neural word embeddings (Mikolov et al. 2013)), and counts the number of times terms co-occur with one another within this window as it moves through the corpus. So the initial representation of a word is a vector with a coordinate for each term in the vocabulary. In either case, the coordinates of a term vector in semantic space are determined by the distributional statistics for this term, such that similar vector representations are created for terms that occur in similar contexts. Evidence suggests that the semantic relatedness measured using LSA and other distributional models agrees with human estimates, and can be used to obtain human-like performance in a number of cognitive tasks (see for example (Lund and Burgess 1996; Landauer et al. 2006)). In the context of health-related online content, HAL has been combined with supervised machine learning algorithms, which learn to assign labels to vector representations of text from a training set that includes human annotation, to automatically classify consumer health webpages based on language use patterns (Chen et al. 2008). Estimates of distributional similarity derived from context vector representations of words have also been used to identify words within online discussions that fall into particular semantic categories (such as "medications" (Elhadad et al. 2014)), based on their similarity to an example seed term. More recently, other distributional models, specifically probabilistic topic models (which are part of a family of widely-used generative probabilistic models, that includes probabilistic Latent Semantic Analysis (Hofmann 2001) and Latent Dirichlet Allocation (Blei et al. 2003; Griffiths and Steyvers 2002)) and neural word embeddings (a neural-network based approach learns to predict term-to-context relationships, and has gained popularity in recent years) were evaluated for their utility as features for machine learning classifiers on the task of reproducing qualitative coding assigned to content mined from the cancer-related online forum, breastcancer.org (Zhang et al. 2016). The best performance on this task was obtained by using neural embeddings as features for a convolutional neural network (micro-averaged F-measure of 65.4). On the basis of these results, the qualitative analysis was extended to a larger number of messages using the trained classifier, permitting an innovative analysis of the evolution of topic trends over time. While methods for automated analysis of free text are still evolving, these methods have the capability to deal with large amounts of data generated by social media. Our own efforts in this area have also used distributional semantics and machine learning to extend the range of qualitative analysis. However, this work has focused on the integration of estimates of relatedness with quantitative network models, and will be discussed subsequently in the chapter once we have covered this methodological territory.

15.4.4 Quantitative Models of Network Science

Social network analysis has been widely used to examine network influence on individual behavior (Valente et al. 2004). For instance, friends' influence was operationalized as the extent to which adolescents are exposed to friends who use substances, and association with self-use was tested (Ali and Dwyer 2010; Crosnoe 2006; Crosnoe et al. 2004; Ennett et al. 2006; Fujimoto and Valente 2012a, b; Urberg et al. 1997).

Methodologically, the network exposure model (Burt 1987; Marsden and Friedkin 1993; TWTW 1995; Valente 2005) has been a workforce for modeling theories of social contagion (*i.e.*, behaviors change as a result of patterns of friendship relations) based on one-mode network. It specifies the appropriate weight matrix (W) for various network influence processes (Leenders 2002), and statistically testing network effects on individual behaviors. The general formula of network exposure E_i is defined as (TWTW 1995):

$$E_i = \frac{\sum_j W_{ij} Y_j}{\sum_j W_{ij}} \tag{15.1}$$

where W_{ij} is a social influence weight matrix, and Y_j is a vector of alter j's behavioral attribute ($i = 1, \ldots, N$; $j = 1, \ldots, N-1$, $i \neq j$). Exposure is calculated by matrix-multiplying the weight matrix, W (representing social influence matrix), by a vector indicating whether or not each alter j engages in behavior of interest (dichotomous variable coded as 0 or 1). The level of ego's exposure to behavior of interest is measured as the proportion of alters who engage in that behavior in an ego's network.

Affiliation Exposure Model

Network exposure model has been extended to the two-mode version, and the "affiliation exposure model (AEM)" was developed (Fujimoto et al. 2011, 2012), to model affiliation-based social contagion. AEM is designed to measure the degree to which individuals are exposed to behaviors of others through affiliating with the same settings/places. It uses pairwise relationships among individuals formed by sharing at least one settings/places. Mathematically, this requires the conversion of the original two-mode network data, **A**, into a one-mode projection of the *actor-by-actor* c-affiliation data, **C** (=**AA′**). In such converted one-mode co-membership network, each pair of actors is connected if they share at least one common place, thus representing the affiliation-based social influence.

By multiplying C_{ij} by each co-participant's attribute y_j and normalizing it by row-sum C_{i+} (ignoring the diagonal), the resulting affiliation exposure vector of $\underline{F}$ is defined as follow:

$$\underline{F} = \frac{\sum_{j=1} C_{ij} Y_j}{\sum_{j=1} C_{ij}} \qquad for \;\; i, j = 1, \cdots, N \quad i \neq j \tag{15.2}$$

AEM is a promising development since it does not require the collection of traditional network data (sociometrics), but instead just the collection of information relevant to attendance at specific places (*i.e.*, venues, and online meetings), something which is easily implemented in the survey format items common to public health research. Thus, AEM has the potential to contribute to enhancing the utility of network science in public health research areas that have not traditionally collected social network data. AEM has been used by other studies in different domains, including an online community for smoking cessation intervention (Myneni et al. 2015), the diffusion of the ratification of the WHO Framework Convention on Tobacco Control among countries (Wipfli et al. 2010), and a network among gangsters through criminal activities (Papachristos et al. 2015).

Decomposed Network Exposure Model

Different types of relationships may have different levels of influence with others in various health-related behaviors. Standard network exposure models handle a single type of relationship in studying the network influence on individuals' behaviors. To address this issue, some variants of network exposure models, called decomposed network exposure model (Fujimoto et al. 2013), have been introduced that are capable of handling multiple relationships by methodologically segregating the overlapped effect of one type and another types of networks, from non-overlapped effect, on individuals' behavior. For instance, one type of affiliation exposure may be overlapped with another type of network influence based on one-mode network or with another type of network influence based on two-mode network of different type. The decomposed network exposure model allows us to partition the model into two separate models.

$$\underline{D}_{(1)} = \frac{\sum_{j=1} X_{ij} C_{ij} Y_j}{\sum_{j=1} X_{ij} C_{ij}} \qquad for\, i, j = 1, \cdots, N, \quad i \neq j \tag{15.3}$$

Mathematically, Eq. (15.3) was computed by element-wise product of the co-affiliation matrix C by an adjacency matrix X (representing one-mode network), and then row-normalized it and matrix-multiplied it by the behavioral vector of alters y_j. To compute Eq. (15.4), we subtracted an adjacency matrix X from a unit matrix with all elements being one, and everything else being identical to the computation of Eq. (15.3), which is defined in the following formula:

$$\underline{D}_{(2)} = \frac{\sum_{j=1} \left(1 - X_{ij}\right) C_{ij} Y_j}{\sum_{j=1} \left(1 - X_{ij}\right) C_{ij}} \qquad for \quad i, j = 1, \cdots, N, \; i \neq j \tag{15.4}$$

Several empirical studies have applied this model to research on health behavior and public health by decomposing the effect of activity members who are also friends and activity members who are not friends, on adolescent substance use behavior (Fujimoto and Valente 2013).

To summarize, network exposure models enable us to measure a given form of network influence and test its effect on individual behavior to explain how new ideas and practices spread through social networks. One of the limitations in this model would be that network exposure model makes an independence assumption for the error term, which may not hold true for network data.

Network Autocorrelation Model

Network autocorrelation model (Doreian 1980, 1989; Doreian et al. 1984; Dow 1984; Ord 1975), also called the Network effects model (Doreian et al. 1984), assumes that endogenous network variables are correlated with the error term ε, and therefore the standard OLS regression yields biased and inconsistent estimates for both autocorrelation parameter and regression coefficient (Dow 2007; Johnston 1984).

However, these models are limited in the application to health behavioral and public health research, perhaps since all of these have been limited to modeling continuous-scale dependent variable. For instance, the outcome scale of substance use is usually measured by categorical scale (dichotomous or ordered categorical) since the frequency of a given substance use (such as alcohol use, cigarette smoking, marijuana use) is rarely normally distributed, and existing methods of network autocorrelation model does not handle categorical data analysis, except for a few network studies that uses two-stage, least-square regression with school level fixed effects using longitudinal data (Ali and Dwyer 2009, 2010).

Longitudinal Statistical Model

A series of Framingham network studies estimated social contagion effects by modeling the spread of obesity (Christakis and Fowler 2007), smoking (Christakis and Fowler 2008), alcohol use (Rosenquist et al. 2010), happiness (Fowler and Christakis 2008), depression (Rosenquist et al. 2011) and others, across network ties. These studies specified longitudinal regression models where the ego's (i.e. focal node) outcome status at any given time point $t + 1$ was a function of the ego's outcome status at the previous time point t, the alter's outcome status at times t and $t + 1$, controlling for various ego's attributes. Here, a significant coefficient for the alter's (i.e. nodes directly connected to focal node) outcome status at time $t + 1$ represents either an alter's outcome affected an ego's outcome (social contagion) or alter and ego experienced contemporaneous events affecting both outcome statues (environmental confounding) (Christakis and Fowler 2008). The model by Framingham longitudinal statistical model differs from network exposure models in that this model specifies dyadic tie as a unit of analysis, which may worsen the problem of model inconsistency especially for mutual ties. On the other hand, network exposure model specified individuals a unit of analysis (by measuring summary statistics of outcomes of alters who are connect to an individual, and which is computed for each individual).

However, the statistical problems inherent in using network data (or dyadic tie information) in regression models have been catalogued in response to these criticisms of social contagion, and a number of articles were published that discussed these critiques on the statistical procedures (Lyons 2011; Fowler and Christakis 2008; Christakis and Fowler 2013; Cohen-Cole and Fletcher 2008; Halliday et al. 2007; Shalizi 2012; VanderWeele et al. 2012), or proposed some remedies for potential problems of model inconsistency and estimation method used in modeling social contagion such as using instrumental variable (Halliday et al. 2007) or lagging of the alter's stage by an additional period (VanderWeele et al. 2012).

Exponential Random Graph Models (ERGMs)

Exponential Random Graph Models (ERGMs) (Frank and Strauss 1986; Robins et al. 2007; Wasserman and Pattison 1996; Hunter 2007; Wang et al. 2013) are capable of addressing this issue by treating the network itself as endogenous, and viewing the overall network structure as collections of local network processes represented by various structural configurations. ERGMs are designed to stochastically model the formation of network ties and test hypotheses about both local configurations (such as reciprocity, transitivity, etc.) and the distribution of nodal attributes (such as gender, drinking, smoking) within the network. Empirical network studies on health behavioral and public health research that applied ERGMs include assessing community-based participatory action designed to reduce cancer disparities (Valente et al. 2010), modeling peer selection mechanism based on adolescent's obesity or substance use behavior (Valente et al. 2009), and HIV risk transmission networks through venue affiliation among drug-using male sex workers (Fujimoto et al. 2015).

To conclude, the methods discussed so far provide valuable insights into the ways in which multidisciplinary techniques from behavior science, psychology, computer science, and network science can be used to conduct "social listening", thus enabling us to understand and model behavior change, social influence, information spread. Tools such as UCINET (Borgatti and Everett 2002), NetDraw (Borgatti 2002), Gephi (Bastian et al. 2009), and Cytoscape (Shannon et al. 2003) offer GUI based network modeling capabilities. These methodologies are promising in offering insights into designing and implementing network interventions that affect people's health behavior and public health problems, and translating them into practical public health interventions. In the next section of the chapter, we discuss our own efforts of applying the methods discussed so far to analysis of peer-to-peer communication in a health-related online social media platform.

15.5 Leveraging Social Media to Model and Change Behavior: A Case Study of Smoking Cessation

15.5.1 Introduction to QuitNet

QuitNet is one of the first online social networks for health behavior change, and has been in continuous existence for the past 17 years. It is widely used with over 100,000 new registrants per year (www.QuitNet.com). QuitNet has members who are current and former smokers seeking to quit or stay abstinent. The members are globally distributed and come from over 160 countries including Canada, the United Kingdom, Australia and South Africa. QuitNet's website incorporates the United States Public Health Service guidelines for best practice and includes diagnostic tools, social support from peers and experts, and pharmacotherapy (Cobb et al. 2005). It is available to smokers through two main channels: free public internet access and paid contracts. Both versions operate in the same environment and have a single support community, therefore, regardless of the means by which users access QuitNet, they all participate in the same online community. Research materials used for this study were extracted from the publicly available version.

Previous studies on QuitNet indicated that participation in the online community was strongly correlated with abstinence (Graham et al. 2007). Our studies outlined in this chapter include datasets drawn from a previously studied quality improvement database, and is comprised of de-identified messages in the public threaded forums, in which participants post messages and reply directly to each other. We have based our initial exploratory work on a de-identified 10 year data set of the original version of QuitNet, spanning 1996–2015 including and containing more than 400,000 individuals, 10 million inter-member communications and 194 million discrete behavioral observation points, including more than 500,000 that are specific to smoking behavior or medication use. All messages were stripped of identifiers but re-coded for ego id (the individual posting) and alter id (the individual whose message is being replied to), self-reported smoking status of sender and receiver ('0' for aspiring quitter, '1' for current smoker/non-quitter), date and position within the thread. QuitNet members were classified into four groups based on their self-reported smoking status. The classification criteria were as follows:

- 0: Members who were smokers throughout the study period (current smokers)
- 1: Members who stayed abstinent during the entire study period (ex-smokers)
- 0–1: Members who switched their status from smokers to ex-smokers (successful quitters)
- 1–0: Members who altered status from ex-smokers to smokers (relapsers)
- Other: Members who changed their smoking status multiple times (frequent relapsers)

In the next sections of the chapter, we describe a series of our prior studies conducted on QuitNet user communication using a variety of methods described in Sect. 15.4.

15.5.2 *Qualitative Analysis of QuitNet Communication Content*

In this section, we describe the results derived from a grounded theory-based (Strauss and Corbin 1998) content analysis of QuitNet messages. The findings derived from this analysis using our method are then interpreted in the light of existing behavior change theories, in an attempt to understand the interplay between the behavior changes facilitated by Web 2.0 based interventions and existing health behavior models. This analysis enhances our understanding of the applicability of behavior change theories (discussed in Sect. 15.4) which were formulated in the context of face-to-face communication using laboratory-based social science approaches, in the context of online social relationships.

Description of Methods

A grounded theory approach (Strauss and Corbin 1998) was used to analyze QuitNet data to understand the core concepts, the interrelations among concepts and the roles played by these concepts in an individual's smoking cessation activity. The first step in the coding process involved open coding, where a line-by-line analysis was performed on the messages to derive abstract concepts from the data. Each message was reviewed, noting pertinent smoking cessation related concepts in terms of general open codes which were generated dynamically as the data were reviewed. Examples of open codes included "statistics", "crave", "pregnancy", "boredom", "temper", "patch", and "pledge". This process was repeated until no new concepts were produced from the dataset. Appropriateness of code assignment was ascertained using constant comparison, where instances of codes were compared in an iterative manner to make sure they reflected the same concept. The second step was performed by re-organizing and re-grouping the open codes using axial coding. Axial coding allowed for the identification of unifying, repeated patterns underlying the concepts and their relationships, thereby revealing core themes relevant to smoking cessation. Examples of core themes include "Family and friends", "Obstacles", and "Traditions". Initial coding was performed manually, and later the NVivo software suite for qualitative analysis was used to analyze themes and their patterns of occurrence in the data. A total of 585 messages were analyzed, revealing 43 distinct concepts. Furthermore, the analysis was carried out for an additional 210 messages to ensure no new concepts emerged. This qualitative coding allowed for an in-depth evaluation of the interactions among people in the QuitNet social platform and thereby a deeper understanding of the behavior change processes that QuitNet users undergo when attempting to cease smoking. Further, these themes were mapped to theoretical constructs and taxonomy techniques outlined in behavior change theories discussed in Sect. 15.4.1.

Summary of Results and Conclusions

Communication themes ranged from discussions on nicotine replacement therapies to stress management strategies. QuitNet users posted messages seeking help to fight a craving or confessing to a relapse. Importantly, the analysis revealed aspects of community-specific culture such as "Saturday night bonfires"—where unsmoked cigarettes are thrown into a digital fireplace during a virtual gathering and "early morning weather updates" when the users reaffirm their willingness to not smoke.

Fig. 15.1 QuitNet communication themes

Messages also indicated issues with building trust between members. In the case of QuitNet, activities such as pledges and bonfires emerged from within the community and each of those events marks a specific aspect of the smoking-cessation process. In addition to emphasizing progress and positive aspects of smoking cessation, focus on community-building and social togetherness (e.g., bonfires) have helped members adhere to their quit attempts. Like any other virtual community, most content embeds aspects of social support. In addition to support, several other sociobehavioral elements related to behavior change theories were found in QuitNet messages. Our analysis revealed that most QuitNet themes (1) relate to important behavior change constructs belonging to multiple theories and (2) operationalize several techniques outlined in the behavior change taxonomy, thus highlighting the need for empirically-grounded behavior change interventions. Figure 15.1 presents the prevalence of various content types in QuitNet user communication. Detailed description of the thematic definitions, their mapping to the theories and taxonomy techniques can be found in (Myneni et al., 2012, 2013, 2016a).

Qualitative methods form a very important toolkit to conduct nuanced analysis of health-related communications in online platforms. Use of grounded theory analysis has allowed us to develop thematic representations of QuitNet messages that are empirically driven and not theoretically biased. Subsequently, comparison analysis consisting of (1) sociobehavioral constructs from existing behavior change theories and (2) theoretically linked taxonomy of behavior change techniques allowed us to understand the theoretical roots and operational features of consumer-driven QuitNet communication. The methodological process itself is informative, comprehensive, and generalizable, while being both empirically grounded and theoretically aligned.

Future Directions

As part of our ongoing studies, we have extended our empirical and theory-driven qualitative analysis to model user communication in social media platforms specifically designed for chronic diseases and healthy living. Such cross-community and cross-behavior analysis will allow us to generalize the observed phenomena and understand relationship between communication themes, socio-behavioral theories, and user engagement attributes underlying behavior change and chronic disease management.

In the next section of the paper, we describe how we applied automated text analysis methods from distributional semantics in conjunction with machine learning algorithms to enable high-throughput analysis of online social media communications. Such methods facilitate resource-optimized extension of qualitative analysis to large-scale digital health data. This in turn can extend the research and application frontiers of social media, thereby further enhancing their positive impact on health-related behaviors.

15.5.3 Automated Text Analysis of QuitNet

As web forums are the predominant modes of communication in social media communities, recent advances in automated text analysis allow for large-scale analysis of the content of peer-to-peer interactions. Semantic space models, methods of distributional semantics in which both terms and larger units of text are represented in a high-dimensional vector space, have been applied to peer-to-peer interactions in online communities (McArthur et al. 2006; Mc Arthur and Bruza 2002, 2003). The methods of automated text analysis we have employed infer measures of the relatedness between passages of text from the distributional statistics of terms in a large text corpus.

Description of Methods

In our prior work we drew on external distributional information, from the Touchstone Applied Science Associated (TASA) corpus (Landauer et al. 1997), a collection of 37,657 articles designed to approximate the average reading of an American college freshman, to account for terse semantic context available in social media postings. We then used LSA (Landauer et al. 1998) to derive vector representations of terms in the TASA corpus, such that terms with similar distributions would have similar vector representations, and measured similarity between vectors using the cosine metric. In addition, Reflective Random indexing (RRI) a variant of Random Indexing (Kanerva et al. 2000) which was developed to recognize meaningful relationships between terms without requiring they co-occur directly (Cohen et al. 2010). LSA and RRI were performed using the Semantic Vectors package (Widdows and Ferraro 2008; Widdows and Cohen 2010), an open source package for distributional semantics. The log-entropy weighting metric was used, and terms occurring on the stopword list distributed with the General Text Parser software package (Giles et al. 2003) were ignored. This stopword list consists of frequently occurring terms that carry little semantic content. Subsequently, representations of the messages in the QuitNet corpus were generated using an iterative approach (Vasuki and Cohen 2009). In order to use these generated vectors to support automated coding of QuitNet messages, we conducted a series of studies using (a) key word based modeling, (b) nearest neighbors approach, (c) machine learning algorithms using Weka, a popular open source machine learning toolkit (Hall et al. 2009). Detailed explanation of the methods can be found in (Myneni et al. 2012, 2015, 2016b). Accuracy and reliability metrics were employed to assess the performance of the automated methods (Myneni et al. 2012, 2015).

Summary of Results and Conclusions

(a) Incorporation of external corpus: LSA in conjunction with a range of classifiers for categorization of the QuitNet set has shown significant improvements with TASA incorporation. Accuracy measures using Key word models (theme-specific manual inspection, see (Myneni et al. 2012)) and nearest neighbors approach (leave one out cross validation, see (Myneni et al. 2016b)) without TASA pre-training are 0.48 and 0.53 respectively. With TASA pre-training the accuracy improved to 0.64 and 0.74 for key words model and nearest neighbors approach respectively (Myneni et al. 2016b).

(b) Accuracy and Reliability: The optimal F-measures, precision and recall metrics for the cross validation were achieved with the application of reflective random indexing in conjunction with J48 decision tree built within Weka: Recall = 0.76, Precision = 0.78, and F-measure = 0.77. In addition, reliability measurements between two human coders and machine coding were as follows. The reliability between coder 1 and the system is 0.71, coder 2 and the system is 0.74, and these values indicate average coder-system reliability approached coder-coder agreement of 0.74 (Sridharan et al. 2016).

Future Directions

Communication exchanges in online communities are time-stamped which facilitates tracking of semantic changes in the messages exchanged by a user pair or a group of users over a time period. Utilization of time series analysis (O'Connor et al. 2010) and novel methods of encoding sequence within distributional semantic models such as (Widdows and Cohen 2016) may enable longitudinal semantic modeling of QuitNet communication events, thus offering deeper insights into the evolution of behavior change processes as QuitNet users attempt to stay abstinent from smoking.

15.5.4 Network Models of QuitNet

To date, most network analysis studies on health-related online social networks have focused primarily on exploring the structural and functional composition of networks without considering communication content. Efforts have been made to evaluate the quality (in terms of semantic features such as syntactic and semantic complexity, punctuation, and grammaticality) of content in social media (Agichtein et al. 2008), facilitate social tagging, where users to annotate, categorize and share their web content using short textual labels (Fu and Kannampallil 2009). Few efforts have been made to bridge content-rich and content-free analyses to characterize communication in social networks. In the following section, we describe ways in which content-inclusive network analysis has been conducted in our own work on QuitNet.

Description of Methods

Network models were created to characterize content-specific topology of QuitNet user communication. QuitNet users were represented as nodes and communication attributes (frequency, semantic similarity) were used to represent edges within the network. A variety of metrics (e.g. degree, modularity, clustering, pathlength) (Valente 2010) to identify communication-specific factors underlying QuitNet users. We used available open-source network simulation software, Gephi (Bastian et al. 2009) to model these content-specific networks. Further, we have framed communication themes as events and network members as actors, forming two-mode affiliation network data. Subsequently, the two-mode data derived were as illustrated in Table 15.1. The information in the table was based upon the categorization of messages obtained in Sects. 15.5.1 and 15.5.2. Thus, network members and their themes formed the two modes for network analysis using affiliate exposure models. Given that co-participation in our study is dependent on content of communication, this allows for the characterization of the role of content-specific social influence patterns underlying peer-to-peer communication. Consequently, we evaluated the extent to which "membership" in specific content type is predictive of smoking cessation and effective diabetes management.

Summary of Results and Conclusions

This work yielded insights that are interpretable and actionable, enabling the identification of content-specific opinion leaders (high degree nodes indicated by their large size) and their distribution (same color nodes implies clustering into a sub community) as shown in Figs. 15.2 and 15.3. Using coaffiliation networks (shown

Table 15.1 Illustration of two-mode data (Row mode represents QuitNet users and Column mode refers to the QuitNet communication themes)

QuitNet member	QuitNet theme	Social support	Obstacles	Rewards
ID00000XX		1	1	0
ID1111XX1		1	1	0
ID112233X		0	1	1
IDXXX2221		1	0	1

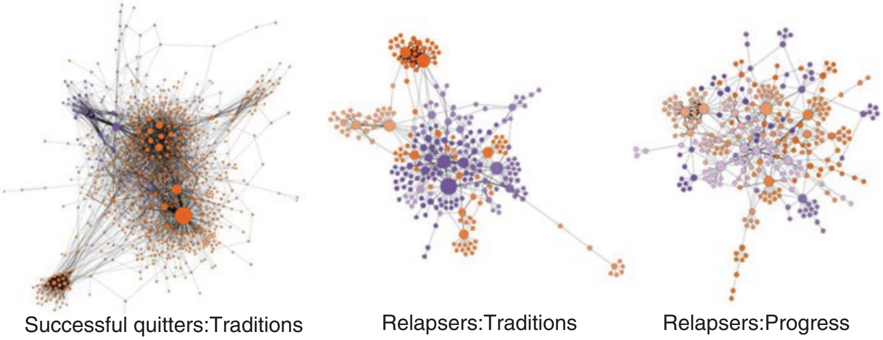

Fig. 15.2 Content-specific QuitNet networks

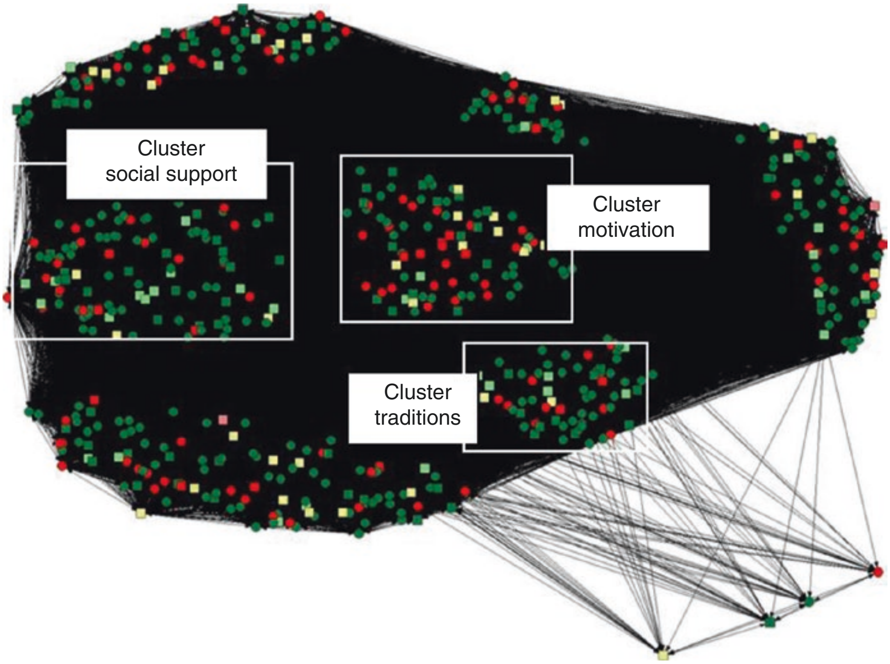

Fig. 15.3 QuitNet coaffiliation network

in Fig. 15.3) we examined the clusters among users based on joint affiliation with at least one common theme. Results revealed similar communication content exchange by users belonging to a common cluster. A two-mode version of network autocorrelation model developed was used to estimate the effect of content-specific affiliation exposure on individuals' abstinence status. The autocorrelation parameter estimate showed that as QuitNet users were more exposed to other users who stay abstinent and share community-centric themes (Social support, Traditions, Motivation), they were more likely to stay abstinent themselves ($b = 0.041$, $P < 0.01$) (Myneni et al. 2015), to the extent that self-reports are accurate.

Future Directions

Current network models attempt to understand behavioral diffusion by analyzing frequency of communication without considering its content. Our prior work on content-inclusive network analysis focused on cross-sectional integration of content with network structure and did not account for network dependencies beyond dyad-level (Myneni et al. 2015) (i.e. who communicates with whom). This is a significant limitation and our ongoing work attempts to negotiate this by modeling networks using ERGMs discussed in Sect. 15.4. Such methods will allow us to incorporate user-theme and user-user relationships to model content-specific social influence patterns. In addition, longitudinal network models can be used to examine content-specific topologies and temporal trends.

15.5.5 Implication for Public Health Interventions

Content-inclusive network analysis of social media communication as facilitated by methods discussed in the chapter so far provides rich empirical evidence that form the basis for data-driven health promotion ventures that provide new directions for research on interventions that health researchers and technology developers can undertake to change human health behavior. Application areas of targeted network interventions include (a) identification of opinion leaders, clusters, and group-specific opinion leaders, (b) “rewiring” networks to improve or reduce network cohesion, and (c) network-attribute interventions (Valente 2012). Content attributes can be used to derive network-attribute interventions, where members exchanging messages related to a particular theme will be segmented as a group to harness the positive effects of their social influence. Examples of these approaches include identifying content-specific key players and creating mentor-mentee relationships based on the needs of the mentee and interests of the mentor. The one-mode network structures obtained from formal network analysis using Gephi reveal differences across themes, the most striking of which is the difference in the high-degree nodes across the themes, which indicate those users with the most connections with whom they discuss content related to a particular theme. Consequently, these high-degree nodes represent the opinion leaders of the network with respect to those particular themes. Identifying key players within groups was shown to be one important step for effective in tobacco control (Puska et al. 1986). Opinion leaders play a pertinent role in social mobilizations and social networks, they act as gatekeepers for interventions, help change social norms, and accelerate behavior change (Obregón et al. 2009; Valente and Pumpuang 2007). The opinion leaders identified through our work discussed in Sect. 15.5.3 were within a group of members exchanging information related to a specific topic of interest such as "Social Support", "Traditions", and "Progress". For example, the identification of those network members who are key players in providing "Relapse assistance" and "Motivation" can help us make the right connections with users discussing about "Craves", thus improving the network's assistance to its members. This new knowledge about content-specific opinion leaders can be transformed into a content-sensitive targeted intervention by incorporating new support features into a social network for providing guidance information to network users with respect to content variety and content-specific opinion leaders. For example, if a network member exchanged messages related to "Progress", then that member can be directed toward similar content types and the opinion leaders for that particular content. In addition, the "Progress"-related opinion leaders can be alerted about the new member to facilitate a connection between this member and an opinion leader. Similarly, if a member posts messages that indicate "Conflict", trust-related issues with another member, then directing them toward messages indicating "Social support" and "Motivation" may be of assistance.

In terms of factors affecting content-based network influence, results indicate that exposure to abstinent members exchanging content related to group-centric inter-personal themes (e.g. "Social support", "Traditions") tend to stay abstinent from smoking behavior. Therefore, online interventions can incorporate an explicit display of member profiles contributing to such content to enhance affiliations to these people. In the context of offline interventions at population level, public support messages incorporating content features highlighting the need to seek social support and be part of a group-based smoking cessation endeavor can help the general public (confronting similar issues) become involved in a support community to sustain abstinence from smoking. Preliminary efforts involving the design of an empirically-informed social support platform inspired by social media analytics can be found here (Myneni and Iyengar 2016).

In summary, online social networks have been gaining in popularity and present health researchers with a unique opportunity to understand human behavior change and deliver scalable and sustainable interventions. However, as demonstrated by QuitNet, these venues can also provide a forum for a community of dedicated users to assist one another in the pursuit of better health, an activity that ultimately has societal benefit beyond the users of QuitNet itself. The development of better tools to analyze social network content of this nature allows us a greater understanding of the ways in which such social networks mediate behavior change, thereby providing us with the opportunity for empirically-grounded interventions to further assist these communities with the attainment of their laudable goals. Content-based network analysis of QuitNet, made feasible by large-scale qualitative analysis using automated methods, has been shown to yield content-specific tailoring strategies that can be used for health promotion and behavior change.

Discussion Questions

1. Text mining and network analysis are important tools for social media analysis. How and why do these methods inform our understanding of human behavior and intervention design for behavior change?
2. Consider a public health behavior change challenge. Identify social media data sources for the behavior under question. Discuss user security and privacy intricacies associated with applying the social media analytics discussed in the chapter.

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Chapter 16
Game Based Behavior Change Methods in Healthcare: *The Case of Obesity*

Ashish Amresh, Ann Lyles, and Kevin Gary

Abstract Obesity, especially in children and adolescents, continues to be a major public health problem. Race, ethnicity, socio-cultural and economical barriers play a significant role towards this problem. Parental awareness is dependent on the above factors and has been shown to help reduce the risks and barriers associated with obesity. Targeted interventions become necessary to improve awareness in the affected population. In this chapter we look specifically at game-based interventions that are targeted and promote behavior change by increasing awareness. Awareness can be broken down into three parameters: attitudes, knowledge and acceptance. Those developing interventions have to be cognizant of these three parameters, include ways to measure and track these during the intervention, and adapt according to these measures. Games naturally align to the above metrics and have been successfully designed in several other areas such as education, training, simulation and national security. Healthcare promises to present a timely opportunity to apply game-based learning methods and build serious games that improve outcomes. While there are several areas in healthcare that can significantly benefit from game-based interventions, the focus here is obesity among the infant and adolescent population. This chapter provides the theoretical constructs, design strategies, and several case studies that have made a significant impact in this area.

Keywords Behavior change • Game based learning • Obesity • Health interventions • Software engineering • Agile methods • Body perception • Avatars • Clicktracing • Clinical trial • Prototyping

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16.1 Introduction

Recent years have seen a sharp increase in obesity rates among children and adolescents in the United States. The National Health and Nutrition Examination Survey (NHANES 2009–10) indicates that almost a quarter of preschoolers (2–5 years) and one third of school age children and adolescents are obese or overweight (Ogden et al. 2016). There are also significant socio-economic and racial disparities evident and Latino children seem to be disproportionately affected by the current obesity epidemic; 38.6% of Latino girls are overweight or obese compared to 25.6% white girls, the rates are even more alarming at 42.9% among 12–19 year old Latino boys (Ogden et al. 2016). *Childhood obesity* has been associated with an increased risk of cardiovascular diseases and Type II Diabetes leading to significant long-term morbidity (Overweight and Obesity 2013). Latino children in the United States are currently at the highest risk for developing Type II Diabetes when compared to their white counterparts (Narayan et al. 2003). Poverty leading to lack of affordability and access to healthy food are some of the major factors that account for high overweight and obesity rates among Latino inner city children and adolescents (Powell et al. 2007). In addition, Latino children and adolescents who are highly acculturated to an American lifestyle have poor eating habits with greater dependence on fast food and spend less time on exercise and physical activity (Unger et al. 2004).

The chapter proposes that game based *health interventions* will enhance knowledge, change attitudes and promote acceptance and is based on recent studies that have explored how *avatars* may influence individual behaviors (Fox and Bailenson 2009) and the information motivation and behavior skills (IMB) model (Fisher et al. 2003). Researchers at Stanford have started to explore a concept they have labeled the Proteus Effect (Yee and Bailenson 2007). The Proteus Effect is a hypothesis postulating that the behavior of an individual conforms to implicit cues provided via a digital self-representation i.e., avatar (Yee and Bailenson 2007). For example, research suggests that if an individual's avatar is created to be taller, this individual acts more confident during negotiation tasks (Yee and Bailenson 2007). In other research, individuals who viewed avatars of themselves running on a treadmill were more likely to exercise than those randomized to a non-exercise condition (Fox and Bailenson 2009). Based on the Proteus Effect, actions of an avatar, (particularly avatars constructed to look like the individual), can act as a model for an individual's behavior. Previous research from social learning theory has highlighted the power of modeling for skill-building, *behavior change*, and shifts in self-identity (Bandura 1975). In theory, an avatar may be a particularly powerful mechanism to explore for promoting new skills, behaviors, and possibly even self-perceptions—all key tasks for promoting positive behavior change.

In order to measure the success of obesity intervention programs that have demonstrated efficacy and were designed to have an impact on knowledge gain, we look at skill development and competency (Trost et al. 2002). The information, motivation, and behavior skills (IMB) model helps provide the theoretical foundation for measuring success (Fig. 16.1) in this manner. It is an empirically supported, partially

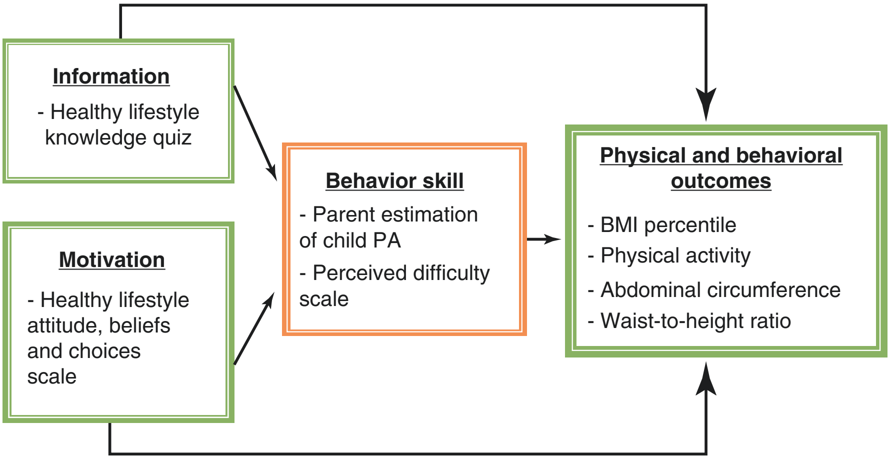


Fig. 16.1 The IMB model

Table 16.1 A taxonomy of games for health

Health area	Personal	Professional	Academic research	Public health
Preventive	Exergaming	Patient communication	Data collection	Public health messages
Therapeutic	Disease management	Pain distraction	Virtual humans	First responders
Assessment	Self-ranking	Measurement	Inducement	Interface and visualization
Educational	First aid, quality of life	Skills and training	Recruitment	Management simulations
Informatics	Personal health records	Electronic medical records	Visualization	Epidemiology

mediating model in which information (e.g., for skills building) and motivation (e.g., supported intentions to make healthy choices) result in behavioral skills (e.g., parental monitoring of a child's physical activity (PA)) for initiating and maintaining preventive health-related behaviors (e.g., increased child PA) (Small et al. 2007; Amico et al. 2005; Fisher et al. 2002; Salmon et al. 2009). By combining the power of game based avatar-driven interventions with the IMB model for measuring success, a robust system for behavior change in healthcare settings can be developed.

The Games for Health (McCallum 2012) project that began in 2004 has created a taxonomy on the different types of games that exist in health care settings. Table 16.1 provides the guidelines for this taxonomy.

In this taxonomy an attempt has been made to distinguish games based on the health area it is targeting and the audience that it is intended for. For example the game MindHabits (2016), based closely on psychological research by Mark Baldwin aims to improve emotional outlook and coping skills. Based on this taxonomy, this would be categorized as therapeutic/personal. When we are targeting behavior change based health games or interventions they fall under the educational/personal category. Ace's Adventures is an example of such a game where the objective is to teach young children traffic safety in a fun and interactive setting. It should be noted that it is not always the case that an educational health game must cause behavior change, though majority of the games aim to bring about some change in the participant's lifestyle or activities of healthy living. Ace's Adventures is purely about information dissemination and is not looking at any specific change in behavior. This brings about an important consideration for behavior change based health games, i.e., in order to be successful, knowledge gain cannot be the only yardstick of measurement. We refer back to the IMB model for guidance and see that knowledge or information coupled with attitudes, beliefs or motivational agents have to work in conjunction to improve participant skill and participant's willingness or acceptance to apply the skill.

16.2 Designing Games for Health Applications

Designing games for behavior change has its roots in the design of educational games. Considerable research has been done in the area of educational game design and the field has converged as prime area under serious games research under the umbrella of *Game-Based Learning* (GBL) (Perrotta et al. 2013). Deci (1971), proposed a model for intrinsic and extrinsic motivation which fits well with the problems surrounding game-based learning. Games are often seen as being intrinsically motivating because there are usually no real world rewards for playing them, yet video gaming has become a massive industry (Kong et al. 2012). The intrinsic and extrinsic motivation model serves as the foundation of self-determination theory (Deci and Ryan 1985). Self-determination theory is a macro theory of human motivation, health and development (Deci and Ryan 2008). This theory posits that humans are intrinsically motivated to improve themselves. In general, humans will actively attempt to master the forces in their environment around them, as well as the forces of emotions and drives within themselves (Deci and Ryan 1985). By mastering these forces, humans can integrate them into their internal structure of self. Self-determination theory states that there are three basic needs that every person desires to fulfill. These are autonomy, competency and relatedness. Autonomy is a feeling of control over one's self and the environment around him or her. Competency is feeling that one can perform a task adequately, and relatedness is a feeling of belonging or affiliation with a group. Mastering those internal and environmental forces helps satisfy the autonomy and competency needs. It follows that a person becomes determined to better him or herself by mastering and learning more of these forces and incorporating those into their self. This determination forms the basis of self-determination theory. GBL and its connection to the theory of self-determination is explained in detail by Ryan et al. (2006). Baranowski et al.

(2013) provide an introduction to the application of GBL to healthcare settings and guide those starting to build games or applications in this area. The important differentiating factor between games and other interventions is that games are "fun" to play and this does not change in the context of GBL. Fun is the driving element for behavior change, a catalyst that when applied correctly will drive the other principles of GBL that include competency, autonomy and relatedness. This leads to important considerations for creating game based health interventions (GBHI) when identifying the goals, the outcomes, the interactions, the scoring, the rules, the winning/losing conditions for the game. To understand the element of fun in games we need to look at Koster's (2013) theory of fun, where he explains that gamers are in fact learners and are constantly discovering patterns that they can apply successfully to advance in the game. The ability to apply a pattern is synonymous to player skill and greater the skill, higher the chance of success in the game. With GBL the patterns that players discover have to be connected with the domain knowledge that the game is trying to advance. With GBHI we take a step forward and incorporate not only knowledge gain but also change in attitude and acceptance of the knowledge in activities of daily living. In the case of obesity these activities are physical activity (PA) and diet. As shown in Fig. 16.2, every action in a game can be represented as an atom, or the smallest denominator of the game. This atom follows a very specific path in the player's mind. It begins with a well-defined problem, a good explanation of what it requires (preparation), a place or playground or game frame to practice or prepare by applying a series of game mechanics (rules/controls), and a system that provides accurate feedback when the mechanics have been applied. The system then updates the conditions that result from the application of these mechanics and the player has incrementally established a pattern. Repeated

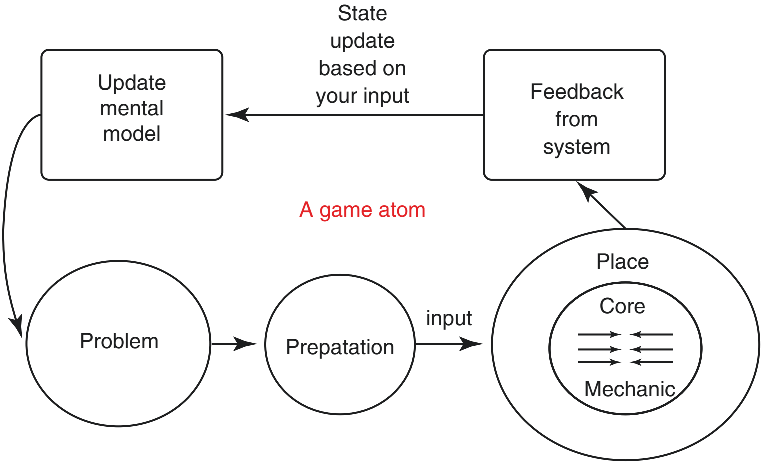


Fig. 16.2 Game patterns based on Koster's theory of fun

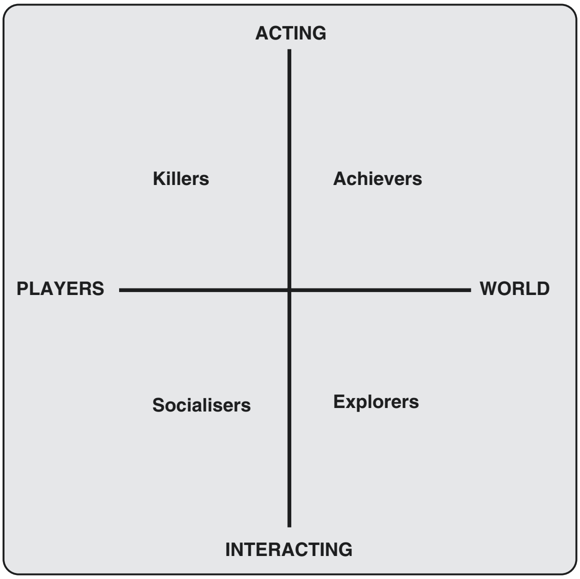


Fig. 16.3 Bartle's player types. Permission granted by original author to use the figure

application of such patterns, or slight variations of it, help the player advance in the game and ultimately reach the goal of solving the problem.

The next important design consideration is the player and according to Bartle (1999) (Fig. 16.3), players can be classified into four distinct categories: Achievers (those that try to go for a high score), Explorers (those that try to understand the rules and find new ways of applying them), Socializers (those that are in the game to interact with peers or AI) and Killers (those that like to impose their will on other players). A design that provides meaning and value to majority of player types will have wider acceptability. In health care settings we are often faced with a situation where a well-defined audience is already known for the intervention. For example, if we were to make a game for cancer survivors to help with their recovery, we already know the characteristics of our audience; we also know in such situations that they are intrinsically motivated to play the game as there is a well-stated benefit of participating in the intervention. Motivation, therefore plays a major role in the design of GBHI and knowing whether or not the audience will be intrinsically motivated or not helps determine if majority of Bartle's player types have to be accommodated for. The lack of intrinsic motivation among the participants does not automatically mean that GBHI is an appropriate choice for inducing extrinsic motivation and conducting the intervention. There may be several reasons that need to be accounted for before deciding to conduct a GBHI. First and foremost, it needs to be determined if there already exists a game that could be used instead of creating one (game development is not simple and costs money). A place to check is the health games research database (2016). It is also important to consider what barriers exist while creating a GBHI for improving a medical outcome; the database consists of research studies conducted in several areas and settings. The next consideration is whether the cost justifies the numbers impacted as game development is expensive.

Numbers could vary from participant size to medical savings. It is important to get a strong perspective on the benefits before starting to design a GBHI. Finally, is the team knowledgeable and multi-disciplinary to undertake such an effort. Game designers talk a language that could be far from what researchers or clinicians understand, and eventually the game mechanics that would need to be developed for a GBHI has to be a combined effort. If there are barriers in communication, the final product could suffer and not deliver the intended outcomes.

16.3 User Center Design Principles for Prototyping to Application Development

In traditional approaches to game development, the end-user typically has very little role until the game has been developed substantially and testing phase of the game has begun. However recent approaches to user-centered design (UCD) (LeRouge et al. 2013) has become essential for developing mHealth applications (Patwardhan et al. 2015). GBL requires the understanding of the users to be successful in helping the users achieve their goals, this necessitates the application of user-centered design principles during the early stages of developing a GBHI. According to Vrendenburg et al. (2002), UCD requires the users are well-defined and participate from design to completion, their tasks are understood, their environment has been built, and an iterative evaluation plan exists for refining the tasks within the environment (Fig. 16.4). GBHI has some natural synergy with UCD, and it is easy to incorporate the principles of UCD into GBHI. In GBHI, the end users are identified and

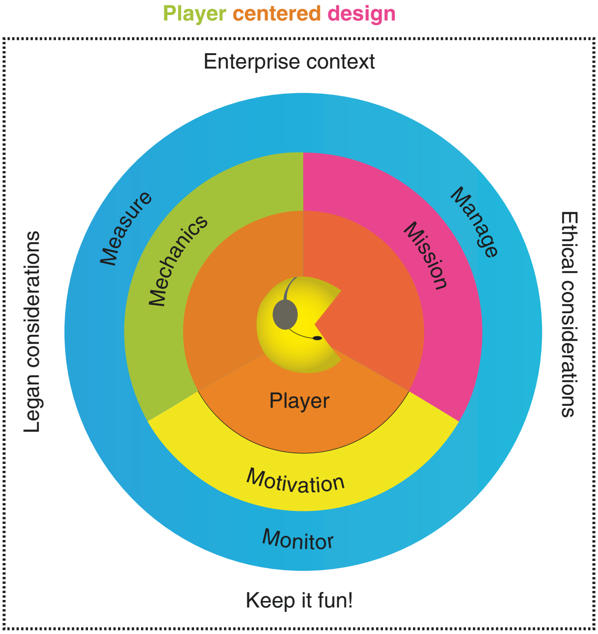


Fig. 16.4 Player centered design. Permission granted by original author to use the figure

known, the game design mechanics can be prototyped and tested with the users, and tasks and interactions can be refined iteratively before going into extensive development.

To satisfy the principles of UCD, also termed Player Centered Design when used to design games (Kumar 2013, these four well validated techniques for the design of the intervention could be incorporated: (1) Goal-setting, the specific measurable outcomes for users to strive for over a particular period of time (Locke and Latham 2002), (2) Self-monitoring, the ability of the user to derive meaning from the feedback the system provides and take appropriate actions without external intervention (Butryn et al. 2007), (3) Modeling, where the system is able to communicate and demonstrate ideal behaviors without expert intervention (Bandura 1977) and (4) Positive-reinforcement, where the system is able consistently reward the user for positive behaviors (Hekler et al. 2010). *Design, prototype and iterative playtesting methodology* is used to satisfy the above principles while going from prototype to application. The following methods could be employed: (1) Paper-prototyping is a process that maps information flow and begins to map out interaction, usually through sticky note cards that can be rearranged and exchanged; (2) Physical-prototyping is a process that usually integrates toys, hardware and roleplay, ranging from board-game style interaction to systems design to simulate experience; (3) Software-prototyping is done through rapid iterations and team evaluation to enable real-time interaction with hardware; (4) Personal interviews with end users is conducted to test software usability; (5) Informal focus groups are conducted to crowdsource ideas and understand group dynamics, generating group-based discussion where end users will provide think aloud feedback (Li et al. 2012) on the usability of the system and discuss their perceptions of the cultural appropriateness of the system for people like them; (6) Observational studies are conducted to gather systematic evidence of real-time affective responses to interaction and interface design, including calibrating depth and length of play; and (7) Extended playtesting is conducted to gather holistic and contextually-based design data, including calibrating length of play, sounds, or other features that might need to be changed depending on the environment (clinic, home, school, etc.).

16.4 Software Engineering Methods

Software development of game-based health applications presents several engineering challenges. First amongst these is the rapid pace of technological change in such platforms. Highly correlated with this is the rapid pace of advancing user expertise with the platforms, even (or especially) in youth populations. The user-centric design approach to comprehensive user experience presents another challenge, as this can sometimes be at odds with *agile software engineering* methods. Finally, the desire to extend game-based solution to the mobile platform raises significant concerns related to security, privacy, fault tolerance, platform dependence, and adequate connectivity.

As if these engineering challenges weren't enough, the relative immaturity of the fields of game-based health applications and mobile health applications (mHealth apps) creates several confounding factors for integrating clinical practice, clinical research, and engineering methods. The rapid pace of technology evolution creates time-to-market pressures, seen in the dominance of mHealth apps of popular app stores without clear clinical validation (Lalloo et al. 2015; Mosa et al. 2012). Further, the relatively slow pace of clinical research and the (appropriately) careful attention paid to each incremental evolution of clinical practice often results in a lag between the understanding of the impact of a specific technology and its currency in the marketplace (Dennison et al. 2013). In other words, much of the literature on mHealth technology innovations is outdated by the time it is published. The pace of clinical research is also under pressure, with new mixed methods of evaluation being studied to address the time pressures. Finally, the software engineering community recognizes that working with clinicians and in clinical settings creates unique challenges in the classic areas of requirements elicitation, software verification and validation, and evolution. Software engineers new to the domain must grapple with the specificities of IRB approval, possible FDA approval of software as a medical device, Information Technology (IT) infrastructures and policies that can at times seem archaic, and the intimidating, naturally siloed domain of highly specialized doctors. It is beyond the scope of this chapter to address these issues in their entirety; rather we discuss several issues that have been most prominent in our collaborations with clinicians in clinical settings, namely the ability to be *agile* in the engineering of such apps in a clinical context; the need for new ways to validate different app-based contexts and user populations through continuous data collection and analysis of the user experience; and the challenges in creating portable, extensible apps the support the speed of the domain.

Software engineering has long suffered from an inability to form fixed process controls around software development. Such process controls are typically part of a *forward-engineered* process; they are constraints defined on a process that goes from requirements identification, through design and design validation, implementation, and transitioning to a target environment. The historical derivation of software lifecycle models from systems engineering models has led to the development of a discipline where alternatives are evaluated and considered in the front-end of the lifecycle (requirements and design) but little substantive change can be handled once construction of the system or application has begun. This approach works well for many healthcare domains, where software is treated as a medical device (though that constraint has recently softened) and many innovations are in the systems domain (image and robotic-guided surgery, for example). As more IT innovations ripple through the healthcare domain (medical records, remote monitoring applications, etc.), the ability to successfully leverage traditional front-loaded, forward-engineered processes diminishes. IT applications, with the majority of features relying on pure software, tend to be highly specialized, deployed on ever-evolving environments (cloud, containerization), and subject to frequent change requests downstream after implementation is underway. Such applications, of which we consider game-based and mHealth apps a subset, are far more suitable to *empirical process controls*, which are embodied in the current trend of *agile software development*.

Agility in software engineering is more a philosophy than a process model. It embraces the ability to handle change throughout the lifecycle process, working rapidly and iteratively with continuous feedback, and promotes constant collaboration between customers and engineers (Beck et al. 2001). This philosophy provides several benefits to IT developers, including those in healthcare applications. The ability to move fast with continuous feedback means engineers can adapt to changing clinical and environment requirements. As game-based and mHealth apps emerge and mature, the need arises to adapt constantly as clinicians understand the impacts on their clinical problems. Agile can help address this issue. At the same time, the need for constant collaboration with clinicians is difficult to realize in practical settings. Consider Scrum, perhaps the most popular agile methodology today (Schwaber and Beedle 2001). In Scrum, a *product owner* is the person who dictates what the product is and what features it requires. This person ideally is the person responsible for conducting the clinical protocol (the clinician). But how many clinicians can realistically be constantly available to provide feedback and answer questions from engineers?

Agile, and Scrum in particular, believe in frequent release cycles and develop software applications in short iterations known as sprints (Fig. 16.5). These are 1–4 week periods where new features are addressed in the application. This approach is somewhat the antithesis of both the UCD approach to design discussed in the previous section, and IT requirements in clinical settings where the transitioning processes (the processes to deploy and situate new technologies in the clinical environment) are far more formal and complex than other IT domains. Researchers and practitioners alike are seeking to address the issues with UCD and agility (Blake et al. 2005; LeRouge et al. 2013) but the latter issue remains difficult to absorb. By extension, clinical research processes also present obstacles to agility. Clinical research science painstakingly (and appropriately) considers each new feature of a technology as a modification of an existing procedure (a monitoring procedure, an adherence measure, an intervention protocol). This is not an area where reacting to changing process variables can be naturally embraced as it is in agility.

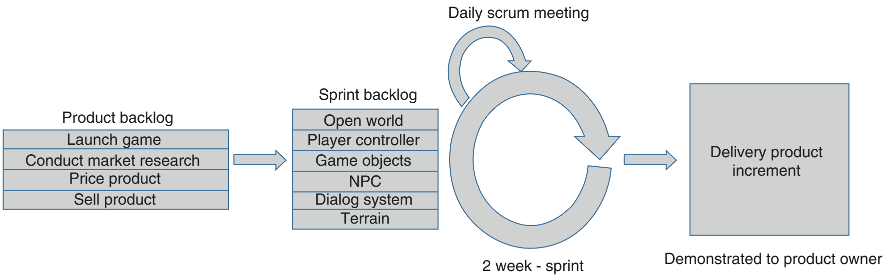


Fig. 16.5 Example Scrum model utilized during the implementation of a game-based application

The rapid pace of technology is embodied in more than just the software process. Technology platforms continuously evolve; consider that iOS (Apple's operating system for mobile devices) has released 8 major versions in just over 6 years and Android (Google's corresponding OS) has released 11 major versions over roughly the same time period. Further new Application Programming Interfaces (APIs) are released on an even more frequent basis (Android is currently at API level 23). This creates a moving target for developers to continuously hit to keep their apps relevant. Device capabilities and form factor (primarily screen size) are also important, particularly on the Android world, where dozens of vendors produce compatible devices. Finally major vendors (Apple, Google, and Microsoft) control the distribution channels for apps through online "stores".

There are several strategies for dealing with these cross-platform issues. One is to adopt an intermediate technology platform that either cross-compiles to a native environment (e.g., Xamarin), or provides an intermediate target for compilation (e.g., Cordova). For the healthcare domain we advocate the use of the HTML5 standard. This new standard is cross-platform (web, mobile, and many gaming platforms), provides new rich media capabilities, supports responsive design across form factors (specifically the ability of CSS to customize user experience to the device), and takes advantage of the increasing power of Javascript to provide dynamic features and programmatic connectivity to remote servers. We have developed both native and HTML-centric apps and have found our apps to be more maintainable, flexible, and deployable to multiple environments leveraging the HTML5+Javascript+CSS stack and these are presented later in the chapter as case studies.

The power of game and mobile platforms to be constantly connected to the Internet presents a pathway for remote monitoring applications. The ability for clinicians to gather data presents a variety of challenges ranging from security and privacy to equal access to the technologies' capabilities. However this ability to collect data creates tremendous opportunities for broad categories of applications. Remote monitoring applications leverage on-the-person biosensors or self-reported measures to collect data regarding patient well-being. Remote intervention apps move into features where the remote clinician may direct care (telehealth). This is evolving into app-directed interventions, where the app, based on predefined criteria, fosters behavior-changing actions in the patients.

Our work has focused on the use of self-reporting instruments for chronic diseases in youth such as obesity, and also asthma, anxiety and depression, and sickle cell disease. The pervasive nature of chronic disease makes them suitable for continuous remote monitoring and protocol adherence reminders (medication, symptom reporting, e.g., Wang et al. 2014). The challenge then becomes how to encourage chronic disease patients, especially youth, to participate in remote monitoring and protocol adherence. This brings us full circle to game-based healthcare and a focus on user experience. As discussed earlier in this chapter, games can provide both the intrinsic and extrinsic motivation for remoting monitoring and adherence. The user experience may be designed through a process such as UCD or through elicitation with clinicians and subject-matter experts (SMEs), but a challenge exists in knowing whether the design leads to better clinical outcomes.

Typical approaches to user experience evaluation involve a post-survey asking the subjects' perspectives on app use. Though worthwhile, we seek more direct evidence in order to understand what aspects of the rapidly evolving game and mobile experience reinforce clinical outcomes. Therefore we instrument our apps with *clicktracing* features that enable us to understand which features of an app are properly used, and whether the app is used as designed. Our initial pilot of this technology in an anxiety and depression prevention app (Patwardhan et al. 2015) has led to insights regard what features are most impactful in getting middle school children to follow an anxiety prevention training protocol. One example insight is that we found that gamification features may actually distract some youths from completing a desired protocol step, and must be moderated to reinforce but not distract the youths. Other researchers are also identifying the need to examine detailed interactions with evolving technologies (Lindley et al. 2014; Owen et al. 2015) in order to understand how this situated pervasive experience affects clinical outcomes.

16.5 Perceptions and Avatars

A significant proportion of adolescents, whether obese or healthy weight, misperceive themselves as overweight, resulting in incongruent body image (Maximova et al. 2008). Misperceptions of their body size includes both underestimation and overestimation (Brener et al. 2004; Standley et al. 2009; Yan et al. 2009; Wang et al. 2009). Adolescents with inaccurate *body-size perceptions* are less likely to participate in lifestyle behaviors (e.g., healthy eating, physical activity) and thus less likely to change their body sizes.

It is also common in the United States for adolescents to attempt to lose weight. Almost half (46%) of high school students in grades 9–12 reported that they were trying to lose weight (Centers for Disease Control and Prevention 2012). It is important not only for adolescents to attain and maintain healthy bodies, but also engage in healthy weight control behaviors to reach these goals. When adolescents engage in unhealthy weight control behaviors such as dieting and restrictive eating patterns, diet pills, and laxative use, they are at high risk of negatively influencing their psychological well-being (low self-esteem, depression, development of eating disorders). Body misperceptions paired with unhealthy weight control behaviors have the potential to affect the adolescent's quality of life emotionally, physically, and academically (Ricciardelli and Yager 2016).

Adolescents are aware of the need to eat healthfully and participate in daily physical activity; however, tools to monitor progress as a result of these positive behavior changes are rudimentary and not visually stimulating. There is a need for sophisticated, visually stimulating, and interactive tools to help adolescents positively and more accurately perceive their body sizes while also monitoring progress toward targeted goals. Simplistic feedback models relying solely on measured body weight or body mass index can fail, as changes in these indices may be quite small following substantially healthful lifestyle changes. In addition, these methods also do not allow the adolescents to express their body perceptions to other influential people in their lives such as providers, parents, coaches, and instructors. These omissions can be detrimental to successful behavior change. If we can demonstrate that positive behavior changes can affect adolescent's body composition, which in turn can affect their body perceptions, body shapes, body satisfaction, and self-esteem, the adolescents may sustain the positive behavior changes and attain and maintain healthy bodies. It is necessary to develop and nurture accurate and accessible ways to represent body perceptions among adolescents while visually monitoring progress.

Using internet-based programs that promote health can be advantageous for adolescents. These programs can reduce training time, increase capacity for dissemination, increase engagement, and include current health recommendations (Cousineau et al. 2010). We have developed a prototype, mobile, avatar-based, interactive application to identify adolescents' body size perceptions and visually monitor progress toward targeted goals. The application is entitled, the Having a Positive Perception of You Application (HAPPY App). We designed and developed the various 3-dimensional (3D) avatars generated within the app to provide (a) actual representations of their bodies based on measurements, (b) representations of how adolescents perceive their body shapes, and (c) representations of target body shapes (within reasonable parameters). As the actual body measurements change, the actual avatar also changes. This will allow the adolescents to relate to and feel a similarity to the 3D avatar, also known as identification, and increase the likelihood of performing a learned behavior (Bandura 2002; Bandura and Huston 1961) which also supports the Proteus Effect.

The HAPPY App prototype included 3D avatars both male and female adolescents comprised of a Perceived Avatar (what the adolescents thought their bodies looked like), Target Avatar (how the adolescents wanted their bodies to look), and Actual Avatar (what the adolescents' bodies actually looked like within reasonable parameters based on body measurements). Prior to the development of the Actual Avatar, we classified computer models based on previous body scans taken of male and female high school students. The models were classified based on the ratio of height and weight. The measurements included height, weight, chest (breast/bust), waist, hips, biceps, thigh and calf to create baseline models. The classified models were then used to build a pipeline to display and manipulate them via a web app. The three avatars, Perceived, Target, and Actual, were then finalized for the application. Being 3D the application allowed the adolescents to design and view each avatar from different viewpoints.

16.6 Case Study on Games/Avatars and Adolescents

How did the adolescents react when instructed to design and compare their avatars? We conducted a pilot test to find out how male and female adolescents would react to their Perceived, Target, and Actual Avatars in the HAPPY App (manuscript in preparation). This case study presents what procedure they followed to design their avatars and their reactions to their avatars. We first measured the adolescents to obtain their height, weight, and circumferences of their body parts (arm, chest/bust, waist, hips, thigh, and calf). The female adolescents also had their bust girth in addition to their chest/bust measured. A total of 42 high school male and female students created and viewed their avatars. The majority of the students were female (67%), white (74%), non-Hispanic (86%), ranged in age from 15 to 18 years, and were enrolled in Grades 9–12.

Perceived and Target Avatars: We developed a Perceived Avatar that was based on the 50th percentile avatar as determined by the adolescent's gender, weight, and height. The adolescents then entered a non-identifying case number, gender, height, and weight into the app to populate a baseline avatar. The adolescents made the body parts bigger and smaller using a slider on the mobile device to represent what the adolescents thought they looked like (Perceived Avatar). The completed Perceived Avatar then populated on the next screen so the adolescents could manipulate the same avatar body parts to represent what they wanted to look like (Target Avatar). This feature allowed the adolescents to work from their current perception instead of starting over with a baseline avatar.

Actual Avatar: Once the Perceived and Target Avatars were generated, we had the adolescents enter their body part measurements into the app. From the measurements entered, an Actual Avatar populated onto the screen. Throughout the app the students could use the controls to move the avatars a full 360 degrees. Upon completion, the adolescents were asked to answer questions about how they felt creating and viewing the avatars. They were asked about viewing the avatars, the comfort level of creating and viewing the avatars, representation level of the avatars, intent to use the avatars in the future, and satisfaction and dissatisfaction with the avatar app.

Reactions to the Avatars: When asked what the students thought about being able to view the avatars of themselves, almost half of the students thought it was good to be able to see their avatar characterizations of their bodies, and one-quarter thought the avatars were helpful. When asked if the avatars were a good representation of themselves, over three-quarters responded *yes*. Those who said *no* explained there should be *more details and measurements*. When asked if they were comfortable viewing the avatars, 95.2% responded *yes.* When asked if they would use the avatars in the future to see how their bodies change 95.2% responded they *would use [them] in the future*. When asked what they liked about the avatars almost a quarter responded they liked the visual representation of their bodies with almost one-fifth liked the realistic nature of the avatars. Almost one-third of the adolescents indicated they disliked *nothing* about the avatars and almost one-fifth wanted more detailed avatars. Further suggestions provided by the adolescents indicated they wanted to be able to change the clothing and hair styles on their avatars.

Taken together, the adolescents had generally positive reactions to the avatar application, specifically to being able to see their actual selves, in being comfortable creating and viewing the avatars, and by being willing to use the application in the future. The adolescents also indicated the application was generally easy to use. This case study was with a small, non-diverse sample with further development and input required from economically and racially/ethnically diverse samples. The avatars in this app provide (a) visual representations of the adolescents' perceptions of their bodies and actual body shapes, (b) a way to interact with these individualized representations, (c) access to immediate feedback, and (d) a method to monitor changes being made to their body composition which can help them to engage and sustain positive health behaviors.

16.7 Case Studies on Use of Game Based Learning in Children

We present the design of two studies that apply GBL to improve obesity outcomes in children (Amresh et al. 2015; Amresh and Small 2014). The objective of the first study was to improve the nutritional intake in Latino children by helping them understand the difference between healthy and unhealthy foods. In this game, the child has to feed a superhero/avatar proper meals during the day (breakfast, lunch and dinner) in order for the superhero to be able to accomplish the missions in the game. The basic game mechanic is driven by a causality engine where the food choices selected by the child have a direct consequence on the storyline and success in the game. As shown in Fig. 16.6, the food preparation screen results in the performance of the superhero's actions. The setting and narrative style is chosen to mimic a comic-book as it was found to be appealing to the target audience. If bad choices are selected (chocolate ice-cream, pop tart) then the superhero doesn't have enough stamina or energy to break open the door in the game. Choosing healthy options (oatmeal, wheat toast) results in success. The child can repeat the scenario any number of times till he or she succeeds and completes the mission. The cause and effect based style of GBL that improves knowledge by repetition is defined as a "*burst game*" mechanic (Amresh et al. 2014). This mechanic applies the principles of self-determination theory and in this study they manifest by providing autonomy (children are in control of their choices), competence (repetition improves skill) and relatedness (the setting/characters are relevant to the child's social fabric).

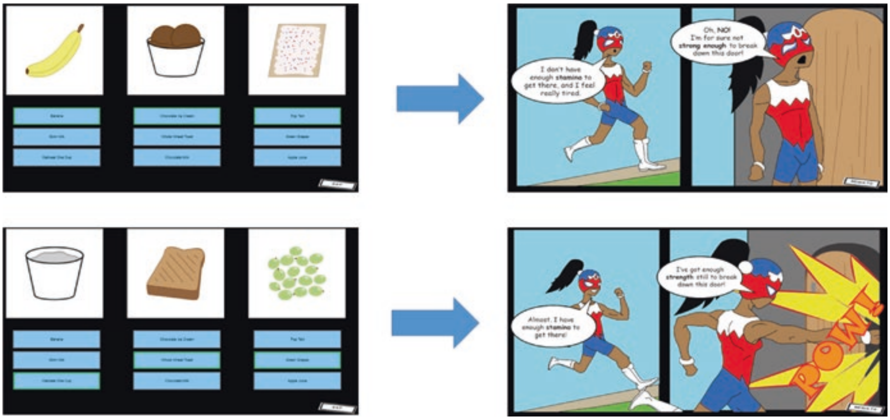
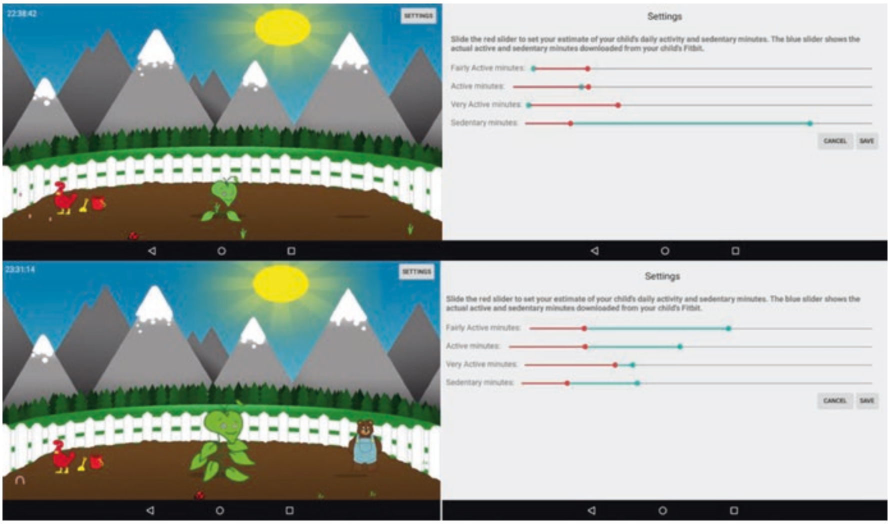


Fig. 16.6 Causality engine design for GBL in nutrition education application



Slide the red slider to set your estimate of your child's daily activity and sedentary minutes. The blue slider shows the actual active and sedentary minutes downloaded from your child's Fitbit.

Slide the red slider to set your estimate of your child's daily activity and sedentary minutes. The blue slider shows the actual active and sedentary minutes downloaded from your child's Fitbit.

Fig. 16.7 Results of increased PA on plant growth and the garden environment

The objective of the second study was to increase the physical activity (PA) levels in infants by improving the estimation skills of their parents. The design of the application builds on the IMB model (Fig. 16.1), in which information (e.g., for skills building) and motivation (e.g., supported intentions to make healthy choices and child's intentions to succeed in the game) result in behavioral skills (e.g., parental skills to estimate and monitor child's PA) for initiating and maintaining preventive health related behaviors (e.g., increased child PA). The game was designed to represent a virtual garden where the virtual plant (avatar) is being controlled by the parent-child dyads on a mobile/tablet application. The growth of the plant avatar and the neighboring garden environment was dependent on two factors: (1) The PA levels received from a Fitbit (pedometer) device that was worn by the child at all times and (2) The PA estimation skills of the parent.

Figure 16.7 shows the results of increased PA on the garden environment, the red bars indicate the estimated values while the blue bars indicate the actual values. The check-ins by the parent happen every day during dinner time and the application updates the environment after the check-in is completed. The targeted time for the intervention is 2 weeks and the expected outcomes are to improve parent's PA estimation and goal setting skills as well as child's motivation to increase PA by performing the appropriate tasks.

16.8 Conclusions

In this chapter we covered the principles of GBL and how that translates to health care settings by providing case studies the improve obesity outcomes. For those that plan to apply GBL for developing healthcare interventions, it is important to understand the target user, create personas, apply UCD practices, follow agile software development methodologies and most importantly remember that games are attractive interventions because they are fun to play. Staying true to developing game mechanics that promote fun while driving skill/competency is critical for the success of the intervention. While the choice of GBL is to promote behavior change, it should be noted that if not implemented in the appropriate manner it could result in negative health outcomes. In the case with promoting PA, if the game is overly addictive or has long periods of narrative or story-based involvement then indirectly the game is promoting sedentary behavior. Games in such situations should look at connecting toe exergaming devices and applications for promoting positive behavior change. Translation of the acquired skills/knowledge into real world setting after the intervention finishes should also be considered in the design of the intervention. To summarize, games that can be tailored to the target population, provide short and incremental game design mechanics, with proper and timely feedback and loaded with incentives have the potential to succeed as health care interventions.

Discussion Questions

1. How does the Multiple User Dungeon (MUD) model proposed by Bartle where players are classified into four categories can be used advantageously to develop healthcare intervention games? Will this classification effect the game design patterns (read Koster's theory of fun) that would need to be designed for the intervention?
2. Agile software engineering methods are now a standard practice in most software development companies, however healthcare application developers have been slow to adopt this methodology. What are the significant challenges that health and mobile health applications pose to incorporating agile methods into intervention based application development?

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Part VI
Future Directions

Chapter 17

Cognitive Informatics and Health Behaviors: The Road Ahead

Thomas G. Kannampallil and Vimla L. Patel

Abstract The transformation of healthcare can be partly attributed to the rapid development of technology. This started with the use of technology in the clinical arena; now, consumer-based devices and applications are being used by patients to record and manage their own health.

Devices such as activity trackers and monitors, and communication technologies, such as smartphones and wireless communication, have changed how modern healthcare is practiced.

Although these capabilities are expanding, the goals that drive our excitement about innovations in health programs are the improvements that focus on wellness and health promotion more globally. Looking forward, public health workers, clinical providers, and patients are likely to have greater access to support tools that enable proactive health management. Our challenge will be to ensure that these approaches are scalable and address the diverse needs of the patients in various communities. The marriage of health-related technologies to health behavior changes will lessen the burden not only on providers and patients by providing key information more precisely and readily, but also support the caregivers who assist these patients.

Keywords Cognitive informatics • Health behavior change • Health behavior measurement • Tracking devices

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The last decade has seen significant growth and development in the healthcare industry. Part of this shift has been spurred by a paradigmatic shift towards the use of health information technology in clinical settings, spurred both by necessity and by external federal mandates (Patel and Kannampallil 2015). These changes in healthcare practices have also translated into how patients understand and manage their health. From trackers that record physical activity to devices that monitor blood sugar levels, technology support for managing and maintaining one's health is ubiquitous. Developments in sensor-based applications related technology have enabled clinicians to remotely monitor and manage their patients. Similarly, technological advancements in the realm of electronic health records (EHR) allow clinical providers to directly interact with their patients, outside of their clinic visits, through patient portals that allow direct messaging using emails or texts.

Of these advances, the increasing role of the patients in managing their health is probably the most notable. The role of the patient has been transformed from a "passive" client to an "active" consumer. This transformation has been afforded by the development of tools and applications that promote healthy behaviors, provide contextual information, or play the role of a health coach. Some of the chapters in his volume highlight these applications and their potential value (see Chap. 14 by Mamykina, and Chap. 12 by Czaja and Taha). Much of this development has been centered around mobile or handheld devices (Patel and Kannampallil 2015). These applications can track human activity, physiological variables, and emotional states.

Although all these hold considerable promise in improving the quality and effectiveness of care, it also creates new challenges. For example, how much do the patients understand the appropriate use of these new tools and applications? What is the appropriate role of the clinician in using such data? How much should the clinicians be involved? How often should the clinicians be monitoring the patients? Are indirect interactions with text-based or messaging applications effective? What about the user interfaces for these applications? Are patients able to identify abnormalities? How does patient literacy and clinical understanding play into such an understanding? Some or most of these questions do not have concrete answers. However, these are the some of the opportunities for researchers in the realm of cognitive informatics—in the design, development, and evaluation of consumer-facing tools that align with the cognitive needs and abilities of its users. In this concluding chapter, we look in to the future and discuss some of the opportunities and challenges for CI researchers in this emerging discipline.

The growth of activity trackers has transformed the notions of tracking and has provided opportunities for large amount of possibly useful data. In the realm of healthcare, such tracking has been a boon for patients with chronic conditions who require continuous monitoring and management. For example, patients who have diabetes or heart disease need monitoring in terms of the physical activity, diet, sleep, and blood glucose levels. The onus previously was on the patient to manually track these observations of daily living. With devices that simplify these processes, tracking is made easy. During clinic visits, such patient generated health data are often used for making changes in the patient's disease management plans. One distinguishing feature of such data is that they are essentially patient-initiated and driven (Cohen et al. 2016).

Given the infancy of this technology, the integration of such data into clinical practice introduces several challenges. First, the data is "messy"—given the ease of generating such data, considerable amount of data is generated with limited context and situatedness. For example, number of steps taken by a patient over a 3-month period is likely to have significant variations in a day-to-day basis. Similarly, blood pressure readings can have significant variations over time. How does a physician integrate such data into their decision making process? How does the physician comprehend the "important" data points? Does such data go into the patient's care record? What are the tools available for physicians to visualize and understand the data in a nuanced manner to make more effective decisions? Finally, what are the challenges of adopting such technology by clinicians in to their routine practice?

Cognitive informatics has a central role in making the data more accessible and comprehensible to physicians through translational tools that help in transforming and visualizing patient-generated data. From early studies on diagnostic reasoning with EHR's (Patel et al. 2000, 2013) to more recent studies on the use of EHR-based visualization tools and applications, there has been a strong history of CI research in this domain (Patel and Kannampallil 2015).

Another important, category of patient information is Patient Reported Outcomes (PRO) measures—which are data generated by patients based on standardized surveys that are designed to understand the patients' health conditions. As opposed to patient-initiated data from trackers or devices, PRO measures are intended to provide a more situated perspective regarding one or more health-related conditions. The role of PRO in patient care activities is gaining prominence with initiatives from the National Institutes of Health that have led to the development of frameworks for integrating PRO's in to EHRs (e.g., see NIH PROMIS). More recent efforts are underway to integrate PROMIS in prominent EHRs.

However, what is still unanswered, similar to the issues related tracking is how PRO measures can be integrated into the workflow of the physician such that it can provide significant benefits to the patient. In other words, although research has shown potential benefits of PRO, its realization in a real-world clinical setting requires an understanding of the complex cognitive, social, organizational, and pragmatic issues. A number of these open issues are best addressed by cognitive informatics researchers, both from a patient's and physician's perspective. From the patient's side, the issues related comprehension, usability, and interaction are key aspects; from a physician's perspective, additional issues arise with regards to reasoning and decision-making with respect to the available data. These issues are also exacerbated for physicians when they are dealing with at-risk populations or older adults.

Although the capabilities of expanding communication methodologies such as smartphones and wireless communication, the goals that drive our excitement and enthusiasm about innovations in health programs, the areas for improvement must focus on wellness and health promotion than on disease management. Looking forward, public health workers, clinical providers, and patients are likely to have greater access to support tools that enable proactive health and disease management. Our challenge will be to ensure that these approaches are scalable and address the diverse needs of the patients in various communities (Chap. 7). The marriage of health-related technologies to health behaviors will lessen the burden not only on providers and patients by providing key information more readily, but also support the care givers who assist these patients (see Chap. 12).

An important aspect in relating health behaviors to biomedical informatics is the design of innovative tools that can be adapted to each community's economic resources and needs (Shortliffe and Patel 2016). For example, there is "one stop" access to health clinics in large cities in the US and the implementation of communication networks in remote areas in developing countries, where there are healthcare kiosks and the use of portable health monitoring devices. For example, *Swasthya Slate* 2016 is an innovative mobile platform that supports various diagnostic tests on an inexpensive tablet computer. Developed in India, the platform offers 33 diagnostic and health-monitoring tests, including a digital thermometer, a BP monitor, a heart rate sensor, an ECG system, a blood sugar monitor, and a water quality unit. The platform is connected via Bluetooth to a mobile network that sends the data through a telephone network. The device helps frontline health workers to assist in care with an affordable, easy-to-use, solar-powered mobile device. However, reproducible evaluations must be conducted to show its technical and pragmatic feasibility (see Chap. 10).

Similarly, the use of games for supporting behavior change is becoming a significant area of research. By providing, timely, and contextual feedback these have the potential to directly reach the people in an effective manner. Amresh and his colleagues (Chap. 16) look specifically at game-based interventions to promote behavior change by increasing awareness (attitudes, knowledge and acceptance).

Finally, the lay public's understanding of what constitutes good health concepts affects their behavior and decisions. Such a conceptual understanding allows for explaining health related phenomena, leading to more efficient and informed decisions. The role of social media, where a proportion of the population gather their health-related information, is also becoming significant. With increasing information availability, Facebook, Twitter, and related social media sites are being increasingly used to gather health information, or act as support infrastructure for patients. However, the research in this domain is still in its infancy, and studies in this space is likely to exponentially increase over the next decade.

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