

Literacy and Learning in Health Care

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KEY WORDS

health literacy, literacy, learning, cognition, education

The views presented in this article are those of the authors, not the organizations with which they are affiliated.

www.pediatrics.org/cgi/doi/10.1542/peds.2009-1162C

doi:10.1542/peds.2009-1162C

Accepted for publication Jul 20, 2009

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

abstract

The relationship between literacy and health outcomes are well documented in adult medicine, yet specific causal pathways are not entirely clear. Despite an incomplete understanding of the problem, numerous interventions have already been implemented with variable success. Many of those who proposed earlier strategies assumed the problem to originate from reading difficulties only. Given the timely need for more effective interventions, it is of increasing importance to reconsider the meaning of health literacy to advance our conceptual understanding of the problem and how best to respond. One potentially effective approach might involve recognizing the known associations between a larger set of cognitive and psychosocial abilities with functional literacy skills. Here we review the current health literacy definition and literature and draw on relevant research from the fields of education, cognitive science, and psychology. In this framework, a research agenda is proposed that considers an individual's "health-learning capacity," which refers to the broad constellation of cognitive and psychosocial skills from which patients or family members must draw to effectively promote, protect, and manage their own or a child's health. This new, related concept will lead, ideally, to more effective ways of thinking about health literacy interventions, including the design of health-education materials, instructional strategies, and the delivery of health care services to support patients and families across the life span. *Pediatrics* 2009;124:S275–S281

The relationship between literacy skills and adult health outcomes has been well documented. Specifically, lower literacy has been linked to problems with the use of preventive services,¹ delayed diagnoses,^{2,3} understanding of one's medical condition,⁴⁻⁶ adherence to medical instructions,^{7,8} self-management skills,^{9,10} physical and mental health,¹¹ increased mortality risk,¹² and higher health care costs.¹³ This growing body of research, with >1600 related publications to date, has led to the formation of a new field of study, referred to as health literacy.

Health literacy has been defined by the Institute of Medicine and National Library of Medicine in the United States 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.'¹⁴ Although this definition clearly suggests that health literacy is a multifaceted concept, reading ability has implicitly, if not explicitly, been viewed as its most fundamental component. An individual's ability to read, comprehend, and take action based on health-related material is closely related to the ability to read, comprehend, and take action based on other types of materials.^{14,15} However, the context of health care is likely to be an especially challenging environment for many Americans because of its changing nature and complexity. What individuals (be they parents or adolescents) must do to promote, protect, and manage health may be more difficult or perhaps less familiar than what is typically required of people in other settings, with far more serious consequences associated with inadequate performance.

Although the associations between health literacy, patient behaviors, and health outcomes are evident, the specific pathways by which low health lit-

eracy may affect these outcomes are not entirely clear.¹⁶ Despite this incomplete understanding of cause, numerous interventions have emerged over the past decade. Those who implemented earlier strategies rushed to address the health literacy problem in a limited manner by rewriting health materials at a simpler level or following other design principles to enhance reading comprehension.^{17,18} In recent years, a small number of trials have tested more comprehensive interventions to mitigate the impact of low health literacy on various knowledge, behavior, and health outcomes with promising results.^{19,20} However, these broad strategies used multiple approaches to address system complexity, making it difficult to elucidate the true cause for any reduction in the effect of health literacy on outcomes. Concerns also remain with regard to the ability to sustain and/or translate these interventions to other settings. Given the limitations of previous interventions, it is of increasing importance to advance our conceptual understanding of the problem and how best to respond. Maintaining a specific focus on reading and reading difficulties alone may be too restrictive and may not foster novel approaches to address problems of health literacy. Yet, broad definitions of health literacy that include health knowledge, motivation, and behavior together can be equally problematic if they diffuse our thinking on the matter. An appropriate starting point might be to recognize the known associations between a larger set of cognitive abilities and functional literacy skills. Developing these links might serve as the first step toward improving our understanding of the evidence uncovered in health literacy—research studies.

Among adults, there is building evidence to suggest that measures of literacy, and health literacy, are strongly

correlated with specific and global tests of cognitive function.²¹⁻²⁴ The consideration of cognitive abilities in the act of learning about and managing one's health may better clarify how individual skills subsequently affect health behaviors and outcomes. Beyond the individual, unnecessary complexity of a particular health task can be a root cause of misunderstanding medical information. This is the greater public health challenge of health literacy: the widening gap between the average skills of the individual user of health care and the corresponding demands of the typical health system that are placed on patients and families attempting to access services.^{14,15} The goal for future health literacy interventions should always target health system complexity, but to do this we must first deconstruct what is actually asked of young patients and their families to understand how difficult health tasks can either be eliminated or simplified.

We offer a new framework that draws on relevant research from the fields of education, cognitive science, and psychology to provide a more in-depth explanation of the various requisite individual abilities called on when obtaining, processing, and understanding health information and making health decisions. We introduce a new concept, health-learning capacity, to more accurately reflect the constellation of cognitive and psychosocial skills from which families must draw to effectively promote, protect, and manage health. This, in turn, will better inform the health system in its efforts to (1) develop more effective strategies for identifying and responding to individuals who will struggle to learn and apply health information and (2) redesign health-education materials, communication strategies, and the delivery of health care services to support patients, parents, and families.

LEARNING IN HEALTH CARE

At the individual level, health literacy involves one's ability to apply existing functional literacy skills toward learning and communicating effectively in the context of health care. Within a clinical encounter, the physician seeks to elicit information, answer questions, explain diagnoses, provide anticipatory guidance, and offer instructions for possible medical or behavioral intervention. The parent and pediatric patient, in turn, are expected to be able to provide an accurate account of behaviors or symptoms, and both raise and answer pertinent questions within a medical and social history-taking process. Beyond the physician visit, the parent must remember what transpired during the interaction with the physician to make appropriate decisions. In addition to the interpersonal communication, information about recommended health behaviors, promotion for self-care, treatment decision-making, or even directions for navigating a particular health system are conveyed by using various health technologies. Families are expected to be able to use available communication tools, which may range in complexity from print forms, brochures, and telephone contact to interactive video programs, electronic health record 'patient portals,' and the Internet.

In all of these scenarios, there is an assumption that the parent or caregiver and young patient can successfully perform the various tasks, implement medical instructions, and follow anticipatory guidance in their family's daily life outside of the doctor's office. Yet, individuals must have more than the motivation to want to engage in their or their child's health and the specific activities in question. They must also possess the cognitive skills necessary to encode all of the new health information into memory, be

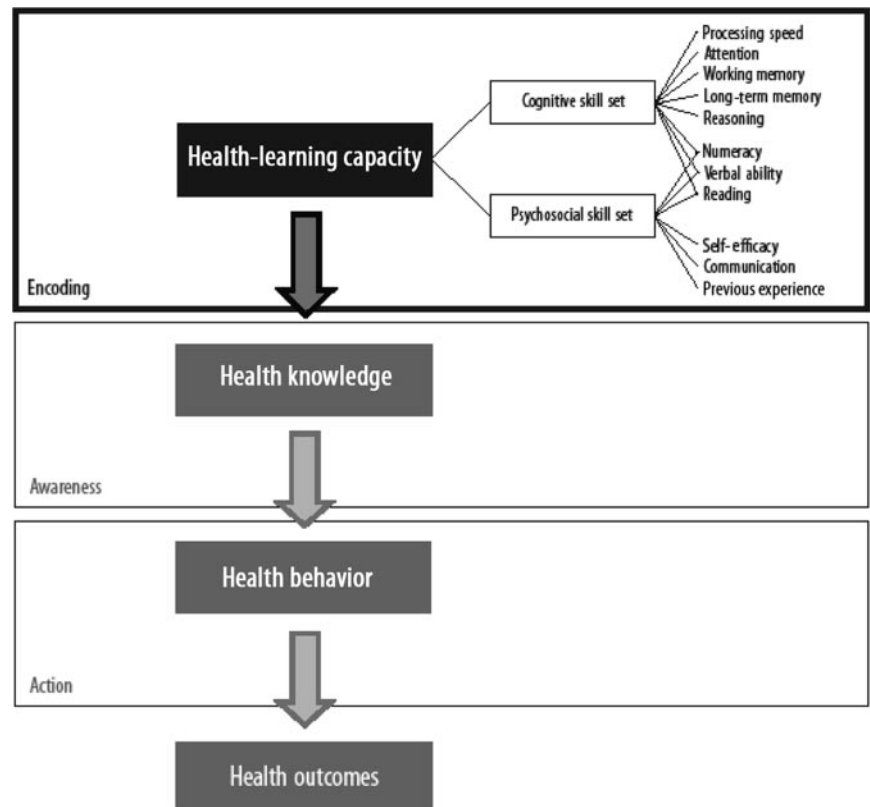


FIGURE 1
Conceptual model of health learning.

readily aware of its meaning and utility, and make the connections necessary for recalling health information at a later time to support actions (see Fig 1). The actual evidence base that has supported health literacy research to date has used measures that are likely tapping into this early act of encoding and processing health messages in the formation of health knowledge.²⁵

Comprehension of health information is a highly important outcome and a necessary 'precondition' for the later adoption of sustainable health behaviors; it is often described as such in the most prominent health-behavior theories.^{26,27} However, encoding health information and possessing knowledge alone do not always directly link to recommended behaviors.²⁸ Rather, intrinsic and extrinsic motivational influences and beliefs that are not actually measured with the current tools used in health literacy research take prom-

inence. Health literacy is a broad concept that promotes public health and clear health communication, health care equity, safety, and quality. However, research is needed to further investigate the basic science behind how people learn within the context of health care. We frame health-learning capacity as the component within the larger construct of health literacy that addresses how patients or parents actually obtain, process, and comprehend health information.

A Cognitive Skill Set

During the past 2 decades while health literacy was emerging as a new area of study, a parallel research inquiry was being initiated in the field of psychology with reports of significant associations between measures of cognitive function and health outcomes. This work became known as cognitive epidemiology, because seminal investiga-

tions were able to link more traditional measures of psychometric intelligence with life expectancy, spanning from early childhood experiences to older adulthood.²⁹ Other clinical research studies have further examined the association between more intermediary health outcomes and specific cognitive domains by using neuropsychological tests to better pinpoint which cognitive skills are associated with poorer health.³⁰ Not surprisingly, this growing body of empirical evidence has demonstrated likely common causal pathways with health literacy research. Specifically, individual differences in certain cognitive abilities have been linked to health knowledge,³¹ non-adherence to prescribed medication regimens,³² physical and mental health,³² and mortality risk.^{33,34} Both cognitive epidemiologists and health literacy researchers seek to dissect the skills required to perform routine health tasks, but measures of health literacy have been mostly limited to more crude cognitive assessments of reading fluency, health-related vocabulary, and numeracy. The cognitive skill set activated when engaging in a vast array of common health-learning tasks most likely includes many more skills than reading and numeracy, such as one's ability to (1) quickly and efficiently recognize and process new information (processing speed), (2) focus available mental resources and avoid distraction (attention), (3) hold and manipulate information so that it can be actively considered (working memory), (4) encode, store, and retrieve information over extended time periods (long-term memory), and (5) engage in inferential processes and the retrieval of background knowledge (reasoning) (see Fig 1). These skills, in turn, support higher-order mental tasks such as (1) understanding numerical systems, performing arithmetic operations, and comprehending probabilities and risk information (numeracy), (2) basic phonological and decoding processes in-

involved in the act of reading text (reading skills), and (3) semantic experience and verbal fluency to derive meaning during a verbal exchange or from print communications (verbal ability).

Each of these cognitive activities may be engaged when attending to a particular health task. In fact, it is likely that most health tasks require individuals to draw on a combination of these skills, such as determining the need to seek out medical care, locating a health service within a health system, completing a consent-and-authorization form, comprehending and recalling a diagnosis or medical instructions, following anticipatory guidance, dosing out a prescribed drug at the appropriate intervals and on the basis of a child's weight, and using a medical device. Clearly, the list of cognitive skills identified here is not exhaustive, because other aspects of memory, such as prospective memory (memory for future events [ie, to remember to give a child medicine at bedtime]), have also been viewed as highly important within the context of health care.

A Psychosocial Skill Set

The act of encoding, or processing, health information to form new knowledge also requires a formidable, broader set of psychosocial skills that connect to cognitive abilities (see Fig 1). Pediatric patients and families must perceive themselves as capable to readily seek and obtain health information, such as asking questions and giving an organized history (self-efficacy).³⁵ However, this likely depends on having effective communication skills that fall back on one's reading fluency, listening and speaking skills, and numeracy ability. Previous health and health care experiences, as well as broader societal and cultural factors, will also influence current beliefs about health, the use of health care services, and if, when, and

how one retrieves health information. Experience ultimately leads to the formation of expectations of how the health system works, the roles and responsibilities that adolescent patients and families must assume within it, and health-related knowledge, ranging from a greater familiarity with health terms to a more accurate, functional understanding of pediatrician instructions.¹⁴

Self-efficacy to seek and understand health information and the ability to communicate effectively with health care professionals have been found to significantly influence the quality of physician-patient relationships, patient motivation and understanding of personal health issues, treatment decision-making, medical adherence, and health outcomes.³⁶⁻⁴² Among adults, low health literacy has already been linked with inadequate health information-seeking strategies, which is also related to poor satisfaction with care, maladjustment to disease, and health outcomes.^{6,43} Both weaker cognitive abilities and limited health literacy have been extensively studied and found to be associated with deficits in health knowledge in support of decision-making.^{5,31}

From a pediatric perspective, both cognitive and psychosocial abilities are increasing from early childhood through adolescence. The unique challenge for families is the gradual inclusion, supervision, and eventual fostered independence of the pediatric patient to co-manage their health. Ultimately, a child or adolescent's health-learning capacity will be influenced, and increased, as his or her established role and engagement in health care develop over time.

HEALTH CARE AS A LEARNING ENVIRONMENT

Adopting health-learning capacity as a new construct for study is only of addi-

tional value if it offers more direct guidance for helping families better comprehend health information, make appropriate decisions, and take action. The health system, whether the setting is a hospital, doctor's office, or community health center, should view itself as a dynamic learning environment with an educational directive. In review of the components detailed within our model, it seems most plausible to initially seek improvement in the health-learning capacity of a patient, parent, or family by targeting improvement in psychosocial skills, because cognitive abilities are less modifiable.

This effort might include orienting families to the health care system and the tasks they must complete to manage their health, or training young patients and parents how to more effectively communicate with health care providers through modeling encounters or giving explicit guidance on what questions patients should ask.^{44–46} Either activity builds on one's health care schema and has the potential to increase one's self-efficacy to seek and obtain health information in a more productive manner. Younger patients, in particular, may have impressive cognitive abilities and potential to learn yet lack previous knowledge to support the development of strategies to handle new health care experiences. Children may be unintentionally shielded from the formation of new health experiences and subsequent knowledge when a parent or caregiver assumes a managing role in their care. Guided by initiatives such as the American Academy of Pediatrics' *Bright Futures*, pediatricians already are recommended to seek ways to actively involve children in their care.⁴⁷ Efforts should continue to be directed at finding the best ways to support clinicians in providing anticipatory guidance and explaining diagnoses, processes, and treatment to pediatric patients to increase their famil-

ilarity with health, the health system, and their role within it.

The goals for cognitive interventions might begin by decreasing the extraneous cognitive strain placed on patients and families by a health care system. For example, such demands can be lowered by optimizing the layout of health materials to reduce visual clutter and distraction, providing more explicit instructions, or chunking new concepts into related groups.^{48,49} These strategies organize health information in a way that recognizes limitations of working memory, thereby freeing mental resources to more efficiently process new messages regardless of whether they are verbal or written. Cognitive demands can also be addressed by incorporating more effective communication strategies when imparting health skills, such as confirming understanding using the 'teach-back' technique or through guided-imagery approaches.^{50,51} Both of these approaches make the patient a more active participant and promote deeper encoding of health information.

A LONG-TERM STRATEGY

Even after simplifying health tasks and further modifications to the health system, we may find that different remediation strategies are necessary to effectively and efficiently meet the needs of families at risk for low health literacy or, more specifically, limited health-learning capacity. The need for clinical screening, therefore, should be considered.⁵² However, current controversies remain regarding whether there is sufficient evidence to support the clinical screening of health literacy. Opposition to screening programs has primarily been based on the potential for inducing shame and stigma, coupled with a lack of viable responses.⁵³ However, many of the previously described approaches to reducing extraneous cognitive burden have been implemented, and individual differences

according to literacy level still remained among the outcomes under study.^{54,55} Acceptable screening tools and methods that more comprehensively assess the full cognitive and psychosocial skill set would still need to be created before this could be a possibility. A clinical screening program would also require a clear plan for incorporating this information into clinical decisions and establishing robust interventions. In the meantime, clinical guidelines such as *Bright Futures* should incorporate strategies for informally identifying parents, caregivers, and children who may have literacy and learning difficulties. Incomplete health forms and previous parental education may offer some insights.

A long-term goal should be to support programs that advance the health literacy of future generations by increasing patient skills across the life span, throughout all levels of the educational system.⁵⁶ This endeavor will require united efforts among the fields of education, medicine, and public health. For instance, the primary and secondary educational curriculum should include content for building health-learning capacity. The pertinent psychosocial skill set can be taught by training younger learners on common terminology, practical health care–navigation skills, and age-related health issues. Ideally, this course of action will lead to more accurate expectations of one's current and future roles and responsibilities to manage personal health. If the quality of early education can be improved and health care can be simplified, the impact of low health literacy should be reduced.

ACKNOWLEDGMENT

The model presented in this article was developed with support from the National Institute on Aging (grant R01 AG030611 to Dr Wolf).

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Pediatrics 2009;124;S275

DOI: 10.1542/peds.2009-1162C

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