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Literacy and Learning in Healthcare

Michael S. Wolf, MA MPH PhD^{1,2}, Elizabeth A.H. Wilson, MA¹, David N. Rapp, PhD^{1,2,3}, Katherine R. Waite, BA¹, Mary V. Bocchini, BA⁴, Terry C. Davis, PhD⁴, and Rima E. Rudd, PhD⁵

¹Health Literacy and Learning Program, Center for Communication in Healthcare, Division of General Internal Medicine, and Institute for Healthcare Studies, Feinberg School of Medicine at Northwestern University; Chicago, Illinois

²Department of Learning Sciences, School of Education and Social Policy at Northwestern University, Evanston, Illinois

³Department of Psychology, Northwestern University, Evanston, Illinois

⁴Department of Medicine-Pediatrics, Louisiana State University Health Sciences Center at Shreveport

⁵Department of Society, Human Development and Health, Harvard School of Public Health, Boston, Massachusetts

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 the 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 in order 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. We review the current health literacy definition and literature and draw upon 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*, referring to the broad constellation of cognitive and psychosocial skills patients or family members must draw upon to effectively promote, protect, and manage their own or a child's health. This new, related concept will ideally lead to more effective ways of thinking about health literacy interventions, including the design of health education materials, instructional strategies, and the delivery of healthcare services to support patients and families across the lifespan.

Address for Correspondence and Reprints: Michael S. Wolf, PhD MPH Associate Professor and Director Center for Communication in Healthcare Health Literacy and Learning Program Institute for Healthcare Studies & Division of General Internal Medicine Feinberg School of Medicine Northwestern University 750 N. Lake Shore Drive, 10th Floor Chicago, IL 60611 Voice: (312) 503-5592 Fax: (312) 695-4307 mswolf@northwestern.edu.

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Keywords

Health literacy; literacy; learning; cognition; education

The relationship between literacy skills and adult health outcomes is 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 more than 1,600 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 (IOM) and National Library of Medicine (NLM) 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 While 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 healthcare is likely to be an especially challenging environment for many Americans due to its changing nature and complexity. What an individual - be it a parent or adolescent - must do to promote, protect, and manage health may be more difficult or perhaps less familiar than what is typically required of a person 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 literacy may affect these outcomes are not entirely clear.¹⁶ Despite this incomplete understanding of cause, numerous interventions have emerged over the past decade. Early 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 multi-faceted 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 very 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 towards improving our understanding of the evidence uncovered in health literacy research studies.

Among adults, there is building evidence suggesting 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 impact 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 healthcare 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 in order to understand how difficult health tasks can either be eliminated or simplified.

We offer a new framework that draws upon 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 upon 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 families must draw upon to effectively promote, protect, and manage health. This will in turn 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) re-design health education materials, communication strategies, and the delivery of healthcare services to support patients, parents, and families.

Learning in Healthcare

At the individual level, health literacy involves one's ability to apply existing functional literacy skills towards learning and communicating effectively in the context of healthcare. 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 in order 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 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, to interactive video programs, electronic health record 'patient portals', and the internet.

In all of these scenarios, there is an assumption 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 readily aware of its meaning and utility, and to make the connections necessary for recalling health information at a later time to support actions (see Figure 1). The actual evidence base supporting 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 does 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 prominence. Health literacy is a broad concept that promotes public health and clear health communication, healthcare equity, safety, and quality. However, research is needed that further investigates the basic science behind how people learn within the context of healthcare. 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 two decades while health literacy was emerging as a new area of study, a parallel research inquiry was also 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*, as seminal investigations 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, 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 knowledge³¹, non-adherence to prescribed medication regimens³², physical and mental health³², 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 Figure 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 involved in the act of reading text (reading skills), and 3) semantic experience and verbal fluency to derive meaning during an oral 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 upon 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, anticipatory guidance, dosing out a prescribed drug at the appropriate intervals and based on a child's weight, or using a medical device. Clearly, the list of cognitive skills identified here is not exhaustive, as other aspects of memory, such as prospective memory (memory for future events, i.e. to remember to give a child medicine at bedtime), have also been viewed as highly important within the context of healthcare.

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 Figure). Pediatric patients and families must perceive themselves capable to readily seek out 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. Prior health and healthcare experiences, as well as broader societal and cultural factors will also influence current beliefs about health, the use of healthcare 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 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 out and understand health information and the ability to communicate effectively with healthcare 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 their established role and engagement in healthcare develops over time.

Healthcare as a Learning Environment

Adopting *health learning capacity* as a new construct for study is only of additional 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 as cognitive abilities are less modifiable.

This effort might include orienting families to the healthcare system and the tasks they must complete to manage their health, or training young patients and parents on how to more effectively communicate with healthcare providers through modeling encounters or giving explicit guidance on what questions patients should ask.⁴⁴⁻⁴⁶ Either activity builds upon one's healthcare schema and has the potential to increase one's self-efficacy to seek and obtain health information in a more productive manner. For younger patients in particular, they may have impressive cognitive abilities and potential to learn, yet lack prior knowledge to support the development of strategies to handle new healthcare 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 in order to increase their familiarity 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 healthcare 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, whether they are oral or written. Cognitive demands can also be addressed by incorporating more effective communication strategies when imparting health skills, such as confirming understanding using the 'teachback' 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

We may find that even after simplifying health tasks and further modifications to the health system 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 should therefore be considered.⁵² However, current controversies remain on 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 approaches described previously to reduce extraneous cognitive burden have been implemented, and individual differences by 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. This 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 prior 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 lifespan, throughout all levels of the education system.⁵⁶ This endeavor will require united efforts among the fields of education, medicine, and public health. For instance, 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 healthcare 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 healthcare simplified, the impact of low health literacy should be reduced.

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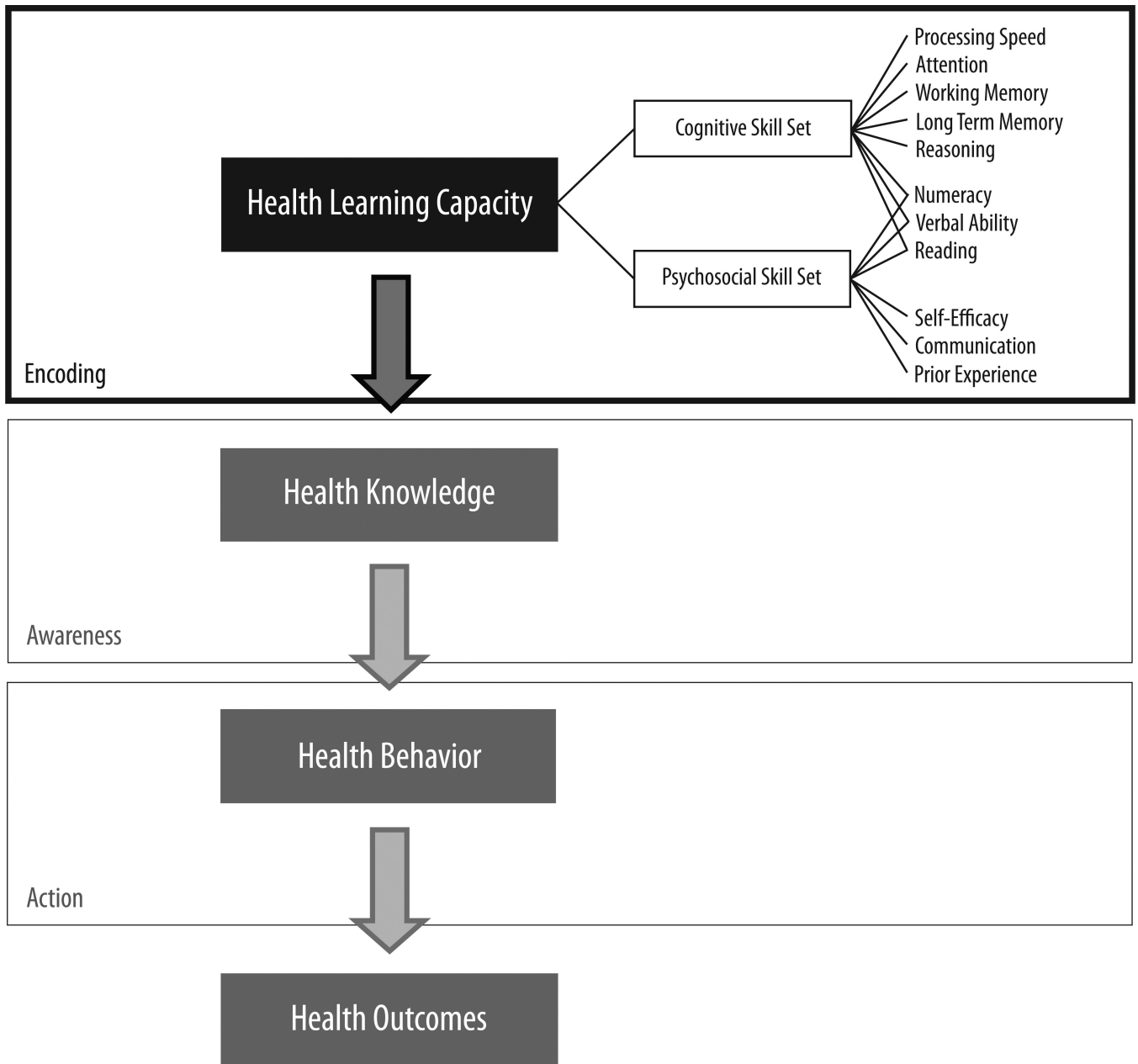


Figure.
Conceptual Model of Health Learning