Chapter 9: Health Literacy

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Summary

Health literacy reflects both individual capabilities and the complexity of demands placed on the individual by the health care system. Over the past two decades, an extensive body of research has linked various functional literacy and numeracy skills to a range of health outcomes. The literature is summarized in this chapter, as are some practical steps for addressing known health literacy barriers in the larger context of health communication.

Introduction

In 2004, the Institute of Medicine (IOM) convened an expert panel to review the evidence, generating a seminal report entitled Health Literacy: A Prescription to End Confusion. The agreed on definition of health literacy put forth by the IOM was that it 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.” In a similar yet slightly different perspective of the topic, the World Health Organization (WHO) recognized a definition presented earlier by Don Nutbeam, referring to health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.” Both the IOM and WHO therefore recognize health literacy as comprising cognitive and psychosocial abilities that serve as antecedents to health behavior.

Both Nutbeam and Wolf and colleagues acknowledge that despite these accepted definitions, there is often disagreement among health professionals and researchers in this field as what health literacy truly means. For some, it is a broad public health agenda to promote clear health communication and individual engagement in health care. And to others, health literacy is an underlying clinical risk factor for misunderstanding medical instructions, worse self-care, and poorer health — the latter view being derived from the body of evidence that has served as the foundation for the field of health literacy. Early studies linking health literacy to health knowledge and outcomes have assessed and continue to assess the construct using crude measures of vocabulary, reading fluency, or numeracy. More recent, but less-used, tools have relied on
subjective assessment or even the use of population data to derive individual skills.° 7 Clearly, there is a disconnect between the findings manifested in the literature and the broad interpretations and implications set forth by some. However, all can agree that health literacy is a multifaceted concept; reading ability and numeracy as measured by the most commonly used tests in the field are just a few of the fundamental components.

**What does the science say about health literacy?**

According to the National Assessment of Adult Literacy (NAAL) of 2003, approximately 14% of U.S. adults possess skills in the lowest level of prose and document literacy (below basic), and 22% are at the lowest level for quantitative literacy.° These individuals can perform only the most simple and concrete tasks associated with each of these domains. However, those with only basic literacy proficiency have limited abilities and are likely to be hindered in routine daily activities. When considering individuals with basic and below basic skills combined, as many as 34% to 55% of U.S. adults have limited literacy skills. Those who are older, less educated, belonging to racial or ethnic minority groups, socioeconomically disadvantaged, and from rural areas of the country have higher rates of limited health literacy. Similar population estimates and associations have been found in the United Kingdom, throughout Europe, Australia, and Canada.°

As health information and tasks may be more difficult and unfamiliar to many, estimates of health literacy using general literacy assessments in these national surveys may under-estimate the problem. Therefore, the NAAL included a health literacy component.° The report showed the average health literacy scores of Americans to be lower than average general literacy scores of adults, although general literacy proficiency is strongly correlated with health literacy.

The methods for assessing adult literacy and health literacy skills follow traditional approaches used in education for evaluating basic reading and numeracy skills. All of the current tools used in the health literacy literature rely on individuals pronouncing words, retrieving information, and/or making inferences from print materials, including prose text and tables. By far the most common measures of literacy in health care include the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Short Test of Functional Health Literacy in Adults (S-TOFHLA).° ° Other measures have emerged to improve the timeliness of assessment or to provide opportunities for measuring literacy across languages.° ° All of these new tools, whether they leverage technologies or expand assessment tasks, fall back on the same premise: that mainly reading fluency and/or numeracy skills are to be evaluated to determine health literacy.
Extent and associations. Although the relationship between literacy and health outcomes is not entirely clear, there are plausible mechanisms by which literacy could directly affect health behaviors, compliance with medications, and other pathways to health.\textsuperscript{1,14,15} Empirical data collected over the past two decades support these links.\textsuperscript{5} It is this body of literature demonstrating associations between measures of reading skills and numeracy with outcomes (>1,000 related studies to date) that has driven the formation of the health literacy field. Specifically, lower literacy has repeatedly been associated with less health knowledge, worse self-management skills, higher hospitalization rates, poorer health, and greater mortality.\textsuperscript{5,16,17} In prospective analyses, literacy is more strongly associated with these outcomes than years of education.\textsuperscript{5,17}

Health knowledge. The large number of relevant empirical studies have most often linked limited literacy with less health knowledge.\textsuperscript{18,19} Early work by Williams and colleagues found patients presenting to an emergency room with low health literacy had poorer asthma knowledge.\textsuperscript{20} In a similar study, lower literate patients with hypertension and diabetes were also reported to have poorer understanding of disease.\textsuperscript{21} Other research studies have since confirmed this relationship in a multitude of contexts. Among individuals living with HIV/AIDS, those with limited literacy were less able to define CD4 lymphocyte count and viral load and to identify antiviral medications in their regimen even with the aid of pictures.\textsuperscript{22,23}

A great deal of attention has also highlighted the association between low health literacy and treatment misunderstanding, including medication names, indications, and instructions. Davis, et al., conducted two multi-site studies among adults and found those with limited literacy had higher rates of misunderstanding their directions for medications provided by either the physician or pharmacist.\textsuperscript{24,25} The problem extended to text and icons used for medication warnings and precautions. Wolf and colleagues most recently reported that lower literate patients would over-complicate multi-prescription drug regimens, taking medicine at more times a day than necessary.\textsuperscript{26} Finally, in perhaps one of the most indicting studies linking literacy skills to medical understanding, Gazmararian, Williams, Peel, and Baker interviewed patients with asthma, hypertension, diabetes, or congestive heart failure and found that low health literacy was an independent predictor of poor functional understanding across each of these chronic conditions.\textsuperscript{18}

Self-efficacy and health behaviors. Fewer studies have directly examined the relationship between literacy skills and individual health-related self-efficacy and behaviors, and some of the evidence on these outcomes is conflicting. For self-efficacy, Wolf and colleagues examined self-efficacy, knowledge, and medication adherence among a sample of patients living with HIV/AIDS in Chicago and Shreveport, LA.\textsuperscript{27} Those with limited literacy had lower self-efficacy to engage in treatment. Self-efficacy was found to mediate the literacy-medication adherence association. Yet DeWalt and colleagues did not find an
association between literacy skills and self-efficacy among a sample of diabetic patients.28

Research on health literacy and health behaviors offers some insights and, similarly, a lack of concordant findings. In a single sample, Arnold, Davis, Berkel, and colleagues reported on an association between smoking and health literacy.29 However, Wolf, Gazmararian, and Baker found no significant associations between literacy skills and health risk behaviors (smoking, alcohol use, physical activity, body mass index) in a large multi-site sample of Medicare managed care enrollees.30 Findings are more conclusive with regard to the significance of the association between literacy and health promoting behaviors, including cancer screening and vaccinations. Schillinger and colleagues presented seminal evidence of the relationship between limited literacy and inadequate self-care for diabetes, although recent studies have not been able to replicate these findings.31 In addition, there are an equivalent number of studies that document associations between literacy and medication adherence as those that report this relationship to not be significant.23,27,32

Clinical outcomes and mortality risk. Individuals with limited health literacy experience poorer health. Baker, Parker, Williams, and Clark examined the relationship between literacy and self-reported health among patients at two urban public hospitals.33 Patients with low literacy were more than twice as likely to self-report poor health, even after adjusting for demographic and socioeconomic factors. Wolf, Gazmararian, Baker investigated the relationship between low literacy and self-reported functional health status among older adults.16 Those with low literacy had a higher prevalence of diabetes and congestive heart failure, reported worse physical and mental health, greater difficulties with activities of daily living, and limitations due to physical health. Likewise, Mancuso and Rincon reported that among adult asthma patients, limited health literacy was associated with poorer physical health, worse quality of life, and a greater number of emergency department visits.34 Two studies by Baker and colleagues had previously reported that patients with inadequate health literacy had a greater risk of hospital admission—compared to those with adequate literacy.33,35

Most recently, research has identified low health literacy as a significant risk factor to greater mortality. Sudore and colleagues reported that low health literacy was associated with a 75% increased risk for all-cause mortality, compared to those with adequate health literacy.36 Similarly, Baker, Wolf and colleagues found low health literacy to be significantly and independently associated with a 51% greater mortality risk; the association was found to be significant for cardiovascular causes but not for cancer.17

Limitations of available evidence. Among the hundreds of studies that have evaluated the literacy–health relationship, only a limited number to date have gone beyond cross-sectional investigations to report on prospectively
collected outcomes, thereby truly being able to comment on causality. Also, as the far majority of the research examines individual comprehension of health information and instructions, without the extended connection to actual clinical outcomes, many have criticized the legitimacy of health literacy as a true risk factor to poorer health.

Paasche-Orlow and Wolf previously proposed certain causal pathways in which it would be plausible to assume how limited literacy and health literacy skills affect health outcomes, (see Figure 1), although further research is needed to elucidate these connections.14 For instance, it has been proposed that individuals with limited literacy may face greater difficulty in accessing health information in a timely manner, engaging with health care practitioners during spoken encounters, and following through on medical instructions and the everyday problem-solving required to promote, protect, and maintain optimal health. In addition, those with low literacy may feel shame and consequently lack the self-efficacy to seek out clarification or acquire information elsewhere.37-39 Over time, these factors contribute to poorer health as a result of inadequate use of health services, negative health behaviors, and poorer self-care. While this conceptual framework is logical, the evidence reviewed above has shown that there is evidence supporting and also refuting a few of these pathways, making the big picture not entirely clear as of yet. On a final related note, unlike longstanding public health research into health behavior and health education, the field of health literacy continues to lack a unifying theory. Regardless of these limitations, the evidence that continues to be gathered on the topic demands considerable attention.

Figure 1. Proposed causal pathways linking health literacy to health outcomes

Adapted from Paasche-Orlow and Wolf (2007)14
What general practice advice can the science support?

Although there are a multitude of research studies that have examined the problem of limited health literacy, only a fraction currently report on viable solutions to address known mitigating effects in various health contexts.40,41 Most of the early interventions that have been published began by solely rewriting health materials at a simpler reading level or following other design techniques to improve comprehension.42,43 Further research is necessary to fully understand how to reduce known health literacy disparities, however, a few studies have highlighted some approaches that could be very promising. Specifically, identified targets for health literacy interventions include (1) the content and design of health materials, including print and multimedia communications; (2) counseling skills of health care practitioners and allied health professionals; and (3) the delivery of health care services.

Numerous longstanding resources and related references already exist that can inform best practices for designing health care materials, whether it be a print brochure, web site, or educational video. The Table describes some key techniques identified by prominent practitioners in the field. Studies have shown that the majority of audiences, regardless of literacy level, prefer health materials that are clear and concise. What may vary is the depth of information desired, therefore limiting and layering content is essential. This means that materials should both provide individuals with triage, need-to-know information on a topic, but also opportunities to seek out more detailed background content.

<table>
<thead>
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<th>‘Best Practices’ for Rx labeling</th>
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<td><strong>Organize label components</strong></td>
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<td><strong>Emphasize patient content</strong></td>
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<td><strong>Simplify language</strong></td>
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<td><strong>Give explicit time periods</strong></td>
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<td><strong>Include purpose for use</strong></td>
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<td><strong>Limit auxiliary information</strong></td>
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<td><strong>Address English proficiency</strong></td>
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<td><strong>Select appropriate font</strong></td>
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Some evidence is available that suggests the use of visual aids may help lower literate patients attend to, process, and remember health information. One study demonstrated that subjects who listened to medical instructions accompanied by a pictograph remembered 85% of what they heard in contrast to 14% for patients who did not receive a visual aid.44 Wolf and colleagues also found the inclusion of patient-centered icons on auxiliary drug warning labels significantly improved comprehension, compared to concordant text messages without the icons. Those with lower literacy benefited the most.45 As described by Webb and colleagues, visual aids can be optimized for individuals across all literacy levels so long as the picture or symbol matches mental representations held by the intended viewer.46 Therefore, the target audience should be included in the development and evaluation of visual aids.

Beyond health materials, limited research is available describing efforts to improve how health care providers verbally communicate to effectively engage with patients. There are some initial evaluations of interactive communication strategies, such as confirming understanding using the teach back technique, or through guided imagery approaches during clinical encounters with patients that support the efficacy of these methods.

The teach back technique is a particularly useful and simple way to confirm patient understanding during the encounter.47 After describing a diagnosis and or recommending a course of treatment, the health care practitioner asks the patient to reiterate what has been discussed by reviewing the core elements of the encounter. If a patient provides incorrect information, the practitioner can review the information again and give the patient another opportunity to demonstrate understanding. In this manner, the practitioner gains assurance that the patient has adequately understood instructions and information. In contrast, guided imagery requires the patient to not only reiterate content of a spoken encounter, but to describe how a recommended behavior should be performed in the specific context of the individual’s personal situation. This might include explicitly asking a patient when they will take a prescribed medicine, where they will store the medicine, and how they will remind themselves of the activity. In essence, the practitioner is requiring the patient to perform a dress rehearsal of the behavior. Park and colleagues found the use of guided imagery to significantly improve adherence.48

A final health literacy strategy, and perhaps the most daunting, is that of practice redesign. The interventions that have demonstrated the greatest effectiveness in closing the health literacy gap have been intensive care management strategies among patients with certain chronic conditions, such as heart failure and diabetes.40,41,49 These include minimizing, whenever possible, the patient’s role and responsibilities in managing health. For instance, health care practices can streamline tasks, more closely track and follow-up chronically ill patients, use navigators or other forms of care coordination to
deliver preventive services or set action plans for disease management. These broad strategies have incorporated several of these approaches to address system complexity, unfortunately, making it difficult to elucidate the true cause for any reduction in the effect of health literacy on outcomes. It is also unclear whether these comprehensive interventions involving system change can be sustained and/or translated to other settings.

Perhaps the biggest challenge the health literacy field has brought to light is finding a way to incorporate a long-term objective in health care pertaining to orienting people to the health care system and their role and responsibility within it. This will likely require standard training and education early in life (i.e., through schools) that deconstructs everyday tasks across the life course, how to more effectively communicate with health care practitioners, or giving explicit guidance on typical questions one should always ask. This equates to providing anticipatory guidance to individuals and families to convey typical expectations and experiences when interacting with health care practitioners and systems. The intention would likely be to increase self-efficacy to seek and obtain health information in a more productive manner and to develop effective health and health care problem solving skills.

How does one evaluate communications implementing this advice?

Addressing health literacy in practice can refer to a range of activities, many of which can be performed easily with minimal orientation and at little or no cost. For instance, health systems and practitioners should review the manner in which they communicate with patients and families and take steps to ensure that distributed materials can be understood by patients with more limited literacy. For print tools, the readability of materials can be analyzed using several different formulas and internet tools. One recommended assessment includes Lexile analysis, which can be accessed with a free subscription on the internet. Davis and colleagues previously found that readability as determined by Lexile scores was a significant independent predictor of patient comprehension of drug warning information. Doak, Doak, and Root’s Suitability Assessment of Materials (SAM) is another more comprehensive procedure for systematically critiquing materials for low literate audiences. In general, there are a multitude of available options that can offer an initial, although crude, assessment of the quality and comprehensibility of print content, whether conveyed via print tools or the web.

Another inexpensive approach to evaluating the extent of health literacy concerns within a health system or community is to use demographic data to gain estimates of limited health literacy. Algorithms that include age, race or ethnicity, and educational attainment have considerable predictive power in determining the likelihood of low literacy and could be used to promote the need for health literacy interventions in more resistant corporate cultures and systems. Some currently recommend performing basic surveys that include a
literacy assessment among a representative sample within a practice setting, albeit this would be at a nominal cost.

With modest funds, patient and practitioner surveys could be performed to determine and identify with more precision any health literacy concerns and needs. Surveys of patients might go beyond a literacy assessment; the use of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey developed by the Agency for Healthcare Research and Quality (AHRQ) includes health literacy-related questions pertaining to patient satisfaction with practitioner professionalism and spoken communication. This could be performed periodically after a baseline has been established to evaluate any ongoing efforts to improve communications, particularly among patients with limited literacy. Other tools similar to the CAHPS are available. More costly, but informative for continuing education opportunities, would be to video-record clinical encounters before and after any training activities and engage in fidelity assessments of any new strategies to improve patient access to health information. For instance, a practice may seek to confirm that patients are receiving mailings, phone calls, emails, and requests from patient portals embedded in electronic health records.

In all, a standard uniform approach to delivering health information is necessary and practitioners and health systems should coordinate their efforts to ensure patients and families have multiple access points to receive the same content. A recent example in the health literacy literature has been with medication education and labeling. The use of a universal medication schedule (UMS) has been proposed to standardize the way physicians prescribe medicines in the most patient-centered manner and to equally request pharmacies to use the same instructions and information when labeling and dispensing medicines (see Figure 2).\textsuperscript{52}

**Figure 2. Universal medication schedule**

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Source: IOM Workshop summary\textsuperscript{52}
Conclusion

In its seminal 2004 health literacy report, A Prescription to End Confusion, the IOM recognized that patients’ health-related knowledge, skills, and behaviors are primarily shaped by: (1) cultural background, (2) health system demands, and (3) prior learning opportunities.1 This report aptly frames limited health literacy not as an individual problem, but as a challenge to health care practitioners and health systems to reach out and more effectively communicate with those they serve. Long-term health literacy interventions must engage communities to develop sustainable health promotion strategies. The educational system must support public health efforts by imparting relevant skills and familiarizing learners to the U.S. health care system and their role within it. Most important, steps can be taken now to increase the quality of and access to meaningful health information and simplify the health care experiences of those in greatest need.

Endnotes


