

Challenges and strategies to improve patient health literacy and competencies

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Abstract: Health literacy continues to be a significant public health problem with more than a third of Americans having difficulties understanding basic health information. While a number of factors are associated with health literacy, in light of soaring health care costs, further examination of ways to identify and reduce the impact of poor health literacy are essential. To this end, this review of health literacy includes details on numeracy, summarizes why health literacy is crucial in the health care setting, the impact of poor health literacy, and the correlates of poor health literacy. In addition, ways to identify poor health literacy are discussed and summarized and successful methods in reducing the impact of health literacy are provided. Given that successful management of many acute or chronic health conditions is influenced by patients' understanding of relevant health information, providing additional support to individuals who have difficulty understanding this information can positively influence health outcomes.

Keywords: low literacy, numeracy, behavioral intervention, chronic disease, patient-physician communication

Introduction

The Institute of Medicine issued a report on health literacy in 2004 defining health literacy as “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions”.¹ This report estimated that over 90 million adult Americans lack the literacy skills to effectively function in the current health care environment – a number that has not significantly improved in the past 10 years.² More than one third of US residents have low health literacy, such that for example they are unable to determine medication timing based on a common prescription drug label;³ therefore the Institute of Medicine has named this issue as a priority area of national action.¹

Discussion

Low health literacy is found in many different health care settings^{4,5} and is most common in older patients, those with lower education levels, immigrants, and racial/ethnic minorities.^{6,7} Among seniors enrolling in Medicare Managed Care plans, 33.9% of English-speaking and 53.3% of Spanish-speaking enrollees had inadequate or marginal health literacy.⁵ Many individuals do not admit they have reading problems.⁸ The National Work Group on Literacy and Health⁹ cautioned health care providers not to assume they can recognize patients with poor literacy, and research shows that physicians often have difficulty identifying patients with low health literacy.¹⁰

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The prevalence of limited literacy can vary widely between demographic groups, but also may vary depending on the clinical setting. In a systematic review, the prevalence of low health literacy ranged between 0% and 68% depending on the clinical setting with higher prevalence of low health literacy in public health care settings.⁷ This pooled analysis of over 300 studies found that 26% of patients had low literacy, and an additional 20% had marginal health literacy. These estimates reflect over sampling from health care settings serving patients with lower socioeconomic status and education, and therefore may overestimate the prevalence in different health care settings. In a large study of patients at public hospitals, approximately 20% of patients with at least a high school education had inadequate or marginal health literacy.⁴

In a recent multisite study, the ability of primary care patients to understand and demonstrate instructions found on container labels of common prescription medications were examined. Approximately half (46%) of the patients in the study were unable to read and correctly state one or more of the label instructions on five common prescriptions. Rates of misunderstanding were higher among patients with marginal and low literacy (63%), yet more than one third (38%) of patients with adequate literacy skills misunderstood at least one of the label instructions.¹¹ Misunderstanding information at this stage of adherence can have a negative impact on later stages by leading to plans that do not correspond to the instructions and ultimately, nonadherence with treatment.

A component of health literacy is numeracy, which is defined as the ability to understand and use numbers in daily life. Much health information includes quantitative information, making numeracy an important component of health literacy.¹² Numerical competence is needed to understand and weigh the risks and benefits of treatment, to decipher survival and mortality curves, and to navigate medical insurance forms and informed consent documents.¹³ Many patients cannot perform the basic numeric tasks required to function in the current health care environment. Inadequate numeracy is even more common than inadequate reading ability according to the 2003 National Assessment of Adult Literacy; 22% of adults had below-basic numeracy compared to 14% who were below-basic for reading prose.¹⁴

Researchers have measured numeracy using objective math tests and self-reported perceptions of math ability.¹⁵ Based on the National Adult Literacy Survey, almost half of the general population has difficulty with relatively simple numeric tasks.¹⁶ In another study, 26 percent of participants were unable to understand information about when an appointment was scheduled.⁴

Having lower numeric skills is associated with lower comprehension and less use of health information. Low numeracy has been associated with misunderstanding risk information,¹⁷ fewer self-management behaviors¹⁸ and misinterpretation of medication labels.¹⁹ Even many highly educated individuals struggle to understand risk information presented as proportions or percentages.¹⁵

Limited basic numeracy would probably not matter so much if all health care providers were able to explain to patients what the percentages mean, assuming they have the time. For both patients and health care providers, understanding health statistics involves more than basic numeracy. For instance, 27% of British women believe that, among 1000 women who participate in screening, 200 will be saved from dying of breast cancer. The randomized trials, in contrast, suggest a reduction from about 5 to 4 in 1000 women.²⁰ As another example, one study suggests that 16 percent of highly educated people incorrectly answered straightforward questions about risk magnitudes (eg, which represents the larger risk: 1%, 5%, or 10%?).²¹ If these errors occur in highly educated people, then it is important to ensure proper understanding of risks and benefits in patients who may have somewhat lower cognitive ability due to disease, low education levels, or the aging process.

Understanding risk-benefit information is also an important dimension of health literacy, and a hierarchy of skills is needed to comprehend and use this information. First, patients must be able to acquire accurate and timely information from tables, charts, text, or orally. Then patients often must make calculations and inferences. For example, given survival rates for chemotherapy versus hormone therapy, a cancer patient must calculate the difference between therapies and infer the meaning of that difference. Next, patients must remember information either for a short period (if the decision is made quickly) or after an extended delay (if the decision is made after an extended period of time), and memory ability differs across patient populations. Finally, the patient must be able to weigh factors to match his/her needs and values to arrive at a health decision.

In summary, patients are required to read medical information and comprehend what to do and when to do it. Patients may be required to perform numeric tasks including calculating the number of tablets for a single dose of medicine. In the case of medication, potentially the most common health behavior, individuals are expected to monitor themselves for both beneficial and adverse effects, know what to do if they miss a dose of medication, and master when, if, and how to obtain refills of their medication.²² Chronic illnesses in the

elderly population often require following an intensive and complex medical regime (medications, daily monitoring, routine physician visits, tests, etc.) such that the adverse consequences of low health literacy in the elderly population may be particularly pronounced and require serious consideration.²³

Poor health literacy and outcomes

In a recent meta-analysis, it was reported that lower levels of health literacy are associated with poorer global health status, higher rates of hospitalization, decreased use of preventive and early detection procedures (eg, mammography), poorer adherence to medications regimens, poorer disease management (eg, poor glycemic control), and lower levels of knowledge about chronic disease, health outcomes, and health services.²⁴ Individuals with lower health literacy have a nearly twofold higher mortality rate^{25,26} and are more likely to experience disparities in health and health care access.²⁷ Low health literacy also has a negative affect on doctor-patient communication. Patients with low health literacy more often use a passive communication style with their physician, do not engage in shared decision making, and report that interactions with their physician were not helpful or empowering.^{28–30} The additional health care expenditures associated with low health literacy is estimated at \$50 to \$73 billion annually.³¹

While there is evidence of poor relationships between literacy and outcomes, a significant amount of research has focused on examining the relationship between literacy and medication use. Prior research has shown that only 50%–60% of patients are adherent to taking prescribed medications during a 1-year period.^{32,34} Medication nonadherence is an important public health issue, particularly in chronic disease management. It costs an estimated \$100 billion annually in the US and accounts for 10% hospital admissions.³⁴ Evidence suggests that health literacy is an independent predictor of medication adherence and medication knowledge.^{35–38}

Establishing a direct link between literacy and chronic disease control, such as blood pressure, has been elusive, although prior investigators have demonstrated this in diabetes and asthma.^{39,40} In addition to the association with health beliefs, behaviors, and outcomes, Rothman et al⁴¹ suggested that literacy may be an important predictor of response to health service interventions. Low literacy may be one of the mechanisms underlying the relationships between participant demographic characteristics and poor health outcomes due to inaccurate recall of instructions.⁴² The degree to which literacy causally mediates adverse effects or is a surrogate for

more direct mediating variables is not known. In addition, it is not yet clear under what set of conditions literacy is relevant to health outcomes.⁴³

Correlates of health literacy

An extensive review of the health literacy literature found that the most consistent correlates of health literacy were age, education, ethnicity, and income.⁷ Some chronic conditions require better patient self-management skills than others to achieve adequate disease control. For example, a patient with diabetes or asthma may require a higher level of self-monitoring and regular medication adjustment to achieve adequate control than a patient with hypertension or hyperlipidemia. Even within an individual illness, varying degrees of severity may interact with literacy (eg, the diabetic patient on four shots of insulin a day with a sliding scale may depend more on adequate literacy than one who can be controlled on metformin only). It may be that literacy becomes increasingly important as the disease complexity and requirements from the patient increase.

If adequate literacy is required for a patient to successfully navigate encounters with a health care delivery system, there may be specific health care provider and health system organizational factors that exacerbate or mitigate the impact of low literacy. Literacy may matter more for patients who are cared for in a chaotic and discontinuous system that is not organized around delivering high quality care in a multidisciplinary setting. It is also interesting that while low literacy is prevalent in many different health care settings, most studies reporting a significant association between low literacy and health outcomes have been conducted in public hospitals or clinics.⁴⁴

Measurement of literacy

Health care providers are often unaware of patients' literacy levels, despite its important health implications. Physicians tend to overestimate their primary care patients' health literacy level^{45,46} and fail to recognize literacy as a risk factor for health outcomes.⁴⁷ There are a number of measures available to assess health literacy. A basic vocabulary is a necessary prerequisite for understanding and applying health information.

The two mostly commonly used measures of assessing health literacy are the Test of Functional Health Literacy in Adults (TOFHLA, or the shortened S-TOFHLA)^{48,49} and the Rapid Estimate of Adult Literacy in Medicine (REALM).⁵⁰ The two measures correlated with one another and with various health-related measures.²⁴ However, the administration methods for these measures have some practical limitations for use in clinical settings. TOFHLA involves written

tests that are self-administered but require 22 minutes to complete; although shorter, the S-TOFHLA typically still requires around 7 minutes. REALM only requires about 2 minutes to complete; however, it is not self-administered. REALM requires patients to read a list of words aloud, and a practitioner must be present to score accurately. The Medical Term Recognition Test (METER) is a newly developed, short, self-administered measure of health literacy. Individuals are required to read a list of words and identify which ones are real words. It takes 2 minutes to complete and was correlated with the REALM ($r = 0.74$).⁵¹ A more recent screening instrument, the Newest Vital Sign (NVS), has been developed to assess level of health literacy.⁵² The NVS takes approximately 3 minutes to administer. The NVS assesses maths, reading, and comprehension skills as well as abstract reasoning.

In the REALM, the patient reads and pronounces 66 medical words arranged in ascending order of difficulty. Scores (0–66) are correlated with reading grade estimates with accepted cut points of <61 corresponding to <9th grade reading level and <45 corresponding to <6th grade reading level.⁵³ While the ability to correctly pronounce a list of words does not ensure understanding, the REALM is easy to administer and is strongly correlated with other measures of literacy⁴⁹ as well as clinical outcomes.²⁴

Adequate health literacy also requires the ability to understand and apply written material, including numerical information. While the ability to read and pronounce words is a prerequisite for reading comprehension, comprehension requires higher cognitive functions for contextualizing and applying written material. The TOFHLA with a Spanish version (TOFHLA-S) measures comprehension of written instructions and numerical information.⁴⁹ The test consists of three prose passages followed by a 50-item reading comprehension section that uses a modified Cloze procedure (ie, patients fill in omitted words from a passage based on multiple choice options). The passages are taken from instructions to prepare for an upper gastrointestinal tract radiograph series, the patient “Rights and Responsibilities” section of a Medicaid application, and a standard hospital informed consent document. There is also a 17 item numerical ability test that assesses the ability to comprehend prescription labels, blood glucose test results, clinic appointment slips, and financial information forms. Each numeracy item is multiplied by 2.941 and the sum of the two sections of the TOFHLA is scored from 0–100. Scores from 0–59 are considered inadequate functional health literacy; scores from 60–74 are considered marginal functional health literacy;

and scores from 75–100 are considered adequate functional health literacy.

A shortened version of the TOFHLA (S-TOFHLA), requiring only 7–12 minutes to administer, has been adapted, with 36 items from two prose passages and four items assessing numerical ability.⁴⁸ The S-TOFHLA raw scores are weighted in order to create a 0–100 score, similar to the complete TOFHLA, with inadequate literacy categorized as 0–53, marginal literacy 54–66, and adequate literacy 67–100.⁴⁸ Many investigators omit the four numerical ability items and score the S-TOFHLA reading passages according to the raw score between 0–36. Conventional scoring with this method categorizes scores of 0–16 as inadequate functional health literacy; scores of 17–22 indicate as marginal health literacy; and scores of 23–36 indicate as adequate literacy.

The NVS uses an ice cream nutrition label that the patient holds and reviews; then, six questions based on that nutrition label are given orally. Four or more correct answers indicate adequate literacy; two to three correct answers indicate limited literacy is possible, and none to one correct answers indicate limited health literacy is likely.^{52,54} The NVS demonstrated high sensitivity for detecting limited literacy and moderate specificity (area under the receiver operating characteristic [AUROC] curve 0.71–0.73). The NVS was less effective than the S-TOFHLA for predicting health outcomes.⁵⁵

Patients who score below an accepted threshold on health literacy reference standards are described variably as having low, limited, or inadequate literacy. One of the challenges in understanding the relationship between literacy and health is determining what level of literacy is truly “adequate” to navigate the health care system such that a patient’s reading ability poses no limitations. In particular, the complexity of health tasks and the attributes of the health care system may influence the relationship between literacy and health, making inadequate health literacy a dynamic state.^{56,57}

Nearly one-half of patients with limited literacy were ashamed of their inability to read and are likely to attempt to conceal this information from others.^{8,58} Although education attainment is strongly associated with literacy, it is an inadequate proxy for literacy because patients often read several grade levels lower than the highest grade achieved in school.^{59–62} Thus, there is a need for quick and accurate assessments of literacy that can be conducted in the clinical setting.

In a recent systematic review of the accuracy of brief screening instruments for limited health literacy, articles on health literacy, numeracy, reading ability, and reading skill were examined. Where appropriate, a meta-analysis of the

diagnostic test characteristics for screening instruments was performed. Nine studies using 6 different screening instruments met inclusion criteria. Several single item questions about confidence with filling out medical forms, use of a surrogate reader, and self-rated reading ability performed moderately well in identifying patients with inadequate or marginal health literacy. For identifying patients with inadequate or marginal health literacy, asking “How confident are you in filling out medical forms by yourself?” is associated with a summary likelihood ratio (LR) 5.0 (95% confidence interval [CI]: 3.8–6.4) for an answer of “a little confident” or “not at all confident”; a summary LR of 2.2 (95% CI: 1.5–3.3) for an answer of “somewhat confident”; and a summary LR of 0.44 (95% CI: 0.24–0.82) for answers of “quite a bit” or “extremely confident”. Combinations of screening questions and demographic information did not perform better than single item screening instruments.⁶³ The Newest Vital Sign was effective for ruling out inadequate or marginal health literacy, but significantly less practical than the single item measures. However, one strength of the Newest Vital Sign is that the provider can immediately see challenges patients may be having using health information. The authors of the review concluded that asking patients about their confidence with filling out medical forms, use of a surrogate reader for health information, and their self-rated reading ability were all effective methods for identifying patients with limited health literacy. Screening for inadequate health literacy is easy and can be performed accurately with a single question. However, before screening for literacy, clinicians should be able to recognize and respond appropriately to patients with limited literacy.⁶³

Recommendations to improve health literacy

Low health literacy is so prevalent among older adults that a “universal precautions” approach has been recommended versus implementing specific screening measures.⁶⁴ A “universal precautions” approach means that clinicians make it routine practice to use language and written communication materials that are appropriate for individuals with limited health literacy, without trying to determine the literacy level of each individual.⁶⁴ While a universal approach has been proposed and while good communication among providers is essential, there are questions regarding the advantages and practicalities of screening all patients for low literacy.

Health care providers often use words that patients don’t understand.⁶⁵ Clinicians should reflect on their communication and interview styles and ensure that they are using lay language

as much as possible and avoiding or explaining terminology that may be unfamiliar to patients and families. Keep in mind that caregivers may also have limited health literacy. Communication methods such as the “teach back”, asking patients or surrogates to repeat key information in their own words, is a useful strategy for ensuring that patients and families have heard and processed the information appropriately.

Reasonable measures a clinician can take may mitigate the negative impacts of illiteracy. Prior work has evaluated the impact of alternative methods of communicating health information including low-literacy written material, verbal communication for low literacy patients, and video presentations targeting patients with limited literacy. A systematic review of interventions for patients with limited literacy found mixed results and several methodological limitations that did not allow definitive conclusions about the effectiveness of these interventions.⁶⁶

Beyond adapting the reading level of print material, however, there may be additional services to offer patients with limited literacy that enhance the value of rapid and accurate literacy screening. A disease management intervention in patients with diabetes, for example, was especially effective for the patients with limited literacy, suggesting literacy may be an important marker for a positive response to intensive disease management.⁴¹ An efficient screening tool for the medical setting would enable providers to rapidly identify adults with limited literacy skills and allow the provider to adapt their communication style and consider supplemental services such as disease management for these patients.

Common mistakes that clinicians make in communication include overwhelming the patient with too much information, using jargon and technical terminology, relying on words alone, and failing to assess patient understanding.^{29,67,68} Employing effective communication techniques may be one of the most important interventions to reduce health disparities related to low health literacy.

Recommendations for the provider to improve health communication include employing patient-centered communication, clear health communication techniques, confirmation of understanding, and reinforcement.⁶⁹ Clinicians should also attempt to prioritize and limit the number of key points discussed to three or less.⁷⁰ At the system level, helpful interventions for patients with low health literacy include designing and offering easy-to-understand health education materials, improving medication drug labeling, designing and offering chronic disease management programs, creating an empowering environment, and offering communication training to clinicians.⁶⁹

Summary

Low health literacy is prevalent and is associated with many poor health outcomes. While the explanatory pathways for these relationships are complex, many of the poor outcomes associated with low health literacy may be caused or exacerbated by inadequacies in both clinician-patient and system-patient communication. Feasible interventions at the clinician-patient level (eg, patient-centered communication, clear communication techniques, teach back methods, and reinforcement), and at the system-patient level (eg, clear health education materials, visual aids, clear medication labels, tailored self-management support programs, and creating shame-free clinical environments) can improve care for patients with low health literacy. Given that successful management of many acute or chronic health conditions is influenced by patients' understanding of relevant health information, providing additional support to individuals who have difficulty understanding this information can positively influence health outcomes. Because most of these strategies can benefit all patients regardless of health literacy level, clinicians, health system planners, and health policy leaders should promote the uptake of such strategies as part of routine health care.

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