

The Role of Health Literacy in Patient-Physician Communication

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Background and Objectives: *Patients' health literacy is increasingly recognized as a critical factor affecting patient-physician communication and health outcomes. We reviewed research on health literacy, examined its impact on patient-physician communication, and offer recommendations to enhance communication with patients who have poor health literacy.* **Methods:** *We conducted a literature review using the MEDLINE database for January 1966 through July 2001. The keywords "literacy" and "health literacy" were searched independently and in combination with the medical subject headings (MeSH) "physician-patient communication," "communication," and "reading."* **Results:** *Poor health literacy is common, especially among elderly patients. More than 33% of patients ages 65 and older have inadequate or marginal health literacy, as do up to 80% of patients in public hospital settings. Patients with poor health literacy have a complex array of communication difficulties, which may affect health outcomes. Such patients report worse health status and have less understanding about their medical conditions and treatment; they may have increased hospitalization rates. Professional and public awareness of the health literacy issue must be increased, beginning with education of medical students and physicians and improved patient-physician communication skills.* **Conclusions:** *Future research needs to address identification of optimal methods for communicating with patients who have low literacy skills. This should focus on the effect of poor health literacy on patients' ability to communicate their history and physicians' ability to solicit information, as well as identifying the most-effective techniques to educate patients.*

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Communication is a core skill for physicians, yet many patients have difficulty understanding what physicians tell them.¹⁻³ Even immediately after leaving their physicians' offices, patients are able to recall 50% or less of important information just given to them.² Patients with inadequate literacy skills, particularly those with a poor understanding of common medical terms³⁻⁵ and written health materials,⁶⁻⁹ probably account for a substantial portion of these patients. Indeed, the concept of poor "health literacy" has been coined to describe patients with an inability to "obtain, process, and understand basic health information and services needed to make appropriate health decisions"^{10,11}

With the number of Americans who have limited literacy estimated at more than 40 million,¹² the ramifications of poor health literacy, and the associated lack of understanding of written or oral health communication, are many. They include difficulties navigating the health care system, inaccurate or incomplete histories, missed doctors' appointments, pills taken at incorrect times or in inappropriate dosages, and lack of "informed" consent.^{3,9,13-18}

This article reviews evidence documenting the prevalence of inadequate health literacy in America, the effect of limited literacy on patient-provider communication, identification of patients with low literacy, and research on interventions to enhance the outcomes of patients with inadequate health literacy. After a review of research examining the issue, we provide recommendations for how clinicians can optimize communication with patients who have limited health literacy.

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Methods

We searched MEDLINE for English-language articles published between October 1966 and July 2001. The keywords "literacy" and "health literacy" were searched independently and in combination with the medical subject headings (MeSH) "physician-patient relations," "communication," and "reading." Subject headings were "exploded" to expand the search. After reviewing the title and abstract of all articles retrieved, one author identified pertinent publications. The reference lists of the articles obtained through the MEDLINE search were reviewed to identify additional articles. Results from previously conducted literature searches^{10,11} and systematic reviews on patient-doctor communication were also reviewed.^{1,2}

These search strategies yield a total of 66 salient articles and books. In this paper, we categorized these publications into those addressing (1) prevalence of the problem, (2) effect of health literacy on patient-physician communication, (3) association of health literacy to outcomes, and (4) interventions to enhance communication with patients who have inadequate or marginal health literacy.

Results

Literacy and Health Literacy in America—Prevalence of the Problem

According to the National Adult Literacy Survey (NALS),¹² considered the most accurate portrait of literacy in the United States, about one fourth of American do not have the ability to "read, write, and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society."¹² Persons with inadequate literacy skills come from a variety of backgrounds, including all races and socioeconomic classes. These functionally illiterate adults are more likely to have health problems, live in poverty, and have fewer years of education.¹² Of note, lack of adequate literacy is twice as common for older Americans and inner-city minorities, the primary users of Medicare and Medicaid.

The findings of the NALS have been corroborated in health care settings. For example, an evaluation of more than 2,500 patients at two public hospitals, using the patients' native language (English or Spanish), revealed that 42% could not understand directions for taking medication on an empty stomach, 26% could not understand an appointment slip, and 60% could not understand a standard informed consent document.⁹ The prevalence of inadequate or marginal functional health literacy was more pronounced among older persons, with more than 80% of those older than 60 having inadequate health literacy.⁹ Similar findings were noted in a cross-sectional survey of 3,260 community-dwelling Medicare enrollees in a managed care plan from three different states. That study revealed that 34% of

English-speaking and 54% of Spanish-speaking respondents had inadequate or marginal health literacy.¹⁹

Effect of Health Literacy on Patient-Provider Communication

Understanding the Physician's Vocabulary. The terminology or "language" that health care providers use to communicate with patients is a barrier for patients with inadequate health literacy. Multiple studies document that physicians' use of medical terms, combined with patients' limited health vocabulary, results in inadequate and even confusing communication,^{3-5,20,21} and patients commonly complain that physicians do not explain their illness or treatment options to them in terms they can understand.³ An older, yet still relevant, study assessed 125 hospitalized patients' comprehension of 50 of the most common health words found in transcripts of physician-patient interviews.²⁰ While almost all (98%) understood the word "vomit," only 35% of patients understood the word "orally," 22% understood "nerve," 18% comprehended "malignant," and just 13% understood "terminal."

A more recent study revealed confusion and lack of understanding of medical terms used in describing colon cancer screening. Many participants did not know the meaning of commonly used terms such as polyp, tumor, lesion, screening, or blood in the stool. None knew what or where the colon or bowel was, and many were not clear about the rectum.⁵

(1) *Understanding Patient Education Pamphlets.* Patients' ignorance of medical terms interferes with the usefulness of written patient education pamphlets. Numerous studies have documented that standard patient education materials are frequently written at levels exceeding patients' literacy skills.²² Studies in the mid-1990s found that only 19% of health education pamphlets written for parents of pediatric patients were written below a ninth-grade level, and only 2% were written below a seventh-grade level—placing them beyond the reading comprehension of most US adults, for whom average reading skills are at the eighth-grade level.²³

In the last few years, some health education materials have been written in simpler language. Yet, current studies show that much health educational material is still written with wording too difficult for patients with inadequate or marginal health literacy.²⁴⁻²⁶

(2) *Understanding On-line Information.* The Internet is a potentially attractive method for patients to get specific health information. However, current formats are not suitable for audiences with low literacy skills. A recent study conducted by Rand found that 100% of the English-language Web sites evaluated presented health information at a ninth-grade level or higher, and six of seven Spanish-language sites presented information on at least a high-school level.²⁷ Additionally, the

National Cancer Institute found that although more people are going on-line for health information, most users cannot find the information they are looking for.²⁸

(3) *Understanding Instructions from Clinicians.* Insufficient comprehension of health vocabulary, limited health knowledge, and impaired ability to assimilate new information and concepts play varying roles in low-literate patients' ability to communicate with health care providers.^{3,4,9,13,14,20,29} A study in senior citizens' public assistance housing complexes found that subjects with the poorest literacy skills reported greater difficulty understanding information given to them by health care providers.³⁰ Simple instructions such as take medicine orally, on an empty stomach, or three times daily are daunting to many low-literate patients. They commonly do not understand the context, detail, or significance of their diagnoses,³¹⁻³³ and hospital discharge instructions are often too complex for them.^{32,34}

Such concerns are validated in studies documenting that patients with chronic diseases, such as diabetes, hypertension, asthma, or HIV infection are also less likely to understand their disease and its treatment.³⁵⁻³⁷ Low-literate patients may feel overwhelmed with information about their illness and ask fewer questions than their more-literate counterparts.³ Moreover, providers give too much detailed information or information that is not relevant to these patients or their cultural backgrounds.^{1,3,29,38-40}

Compliance. It has been suggested that limited literacy may be related to poor compliance with recommended treatments.³ Indeed, patients with poor literacy skills may take medications at the wrong dosage or frequency and are not always cognizant of treatment side effects or the need for follow-up testing.^{15,41}

Validity of the Medical History. A total of 60%–80% of diagnostic information physicians acquire is from what patients say (ie, from the history).⁴²⁻⁴⁵ Patients with low literacy may not realize what information doctors need, may lack the health vocabulary to report symptoms accurately, or may relate information in an illogical or out-of-sequence fashion. Checking to ensure that information gathered from patients is accurate and confirming that patients understand questions being asked are among the most important—but least used—interviewing skills a physician has.⁴⁶ In one cross-sectional study of audiotaped encounters between patients and their internists or family physicians, physicians assessed patients' understanding only 2% of the time.⁴⁷

Validity of Medical Tests. Low health literacy may interfere with the validity of instruments used to screen for cognitive impairment. In particular, scores on the Mini-mental State Examination (MMSE)⁴⁸ are influenced by a patient's literacy skills.⁴⁹⁻⁵¹ Patients may

score in the demented range because they cannot read or count well enough to accurately complete some of the items on the test such as writing a sentence, following instructions to “close your eyes,” or serial subtraction by sevens.

Association of Health Literacy With Medical Outcomes

While there is abundant research documenting the prevalence of inadequate health literacy and its correlation with health knowledge, research on the association of health literacy with medical outcomes is less developed. Most studies have focused on general health outcomes and health care costs. A few preliminary studies have evaluated disease-specific health outcomes. Overall, these studies indicate that patients' health literacy is associated with less-optimal health outcomes, health status, and hospitalization rates.

General Health Outcomes and Costs. In a study involving low-level readers enrolled in adult basic education classes,⁵² subjects with the lowest reading skills had poorer physical and psychological health than those with better reading skills. These relationships persisted, even after statistical adjustments for confounding sociodemographic factors. A study of 2,659 patients at two public hospitals found that those with inadequate functional health literacy were more than twice as likely to have poor self-reported health status than subjects with adequate literacy.⁵³ Literacy was a stronger correlate of health status than education level and other sociodemographic variables. In fact, after adjustment for literacy, education level had no significant association with health status.^{19,22,53}

Patients with limited literacy skills may also have higher health care costs. A study of English- and Spanish-speaking Medicaid participants revealed that among those enrolled in Medicaid because of medical need or indigence, those reading at the lowest grade levels (grades 0–2) had average annual health care costs of \$12,974, compared with \$2,969 for the overall population studied.^{54,55} Finally, in a study of 958 low-income patients followed for 2 years, patients with inadequate literacy were nearly twice as likely to have been hospitalized during the previous year (31.5% versus 14.9%), a relationship that persisted after adjustment for health status and various socioeconomic indicators.⁵⁶ Inadequate health literacy has also been confirmed as an independent risk factor for hospital admission among elderly managed care enrollees.⁵⁷

Disease-specific Health Outcomes. One study found that low literacy was a better predictor than race or age of metastatic disease at presentation of prostate cancer.⁵⁸ Another study, which examined breast-feeding practices, found that first-time mothers with lower

health literacy were less likely to initiate and continue breast-feeding than women with higher literacy (23% versus 54%).⁵⁹

Interventions to Enhance Communication

Written Materials. A variety of techniques are recommended for preparing simplified written patient education materials to use with low-literacy populations.⁶⁰ Some studies have demonstrated these techniques to be successful in improving patients' understanding of health-related information,³² but other studies have not.⁷ An encouraging recent study by Jacobson demonstrated in a controlled trial that a simple one-page low-literacy handout written at a less than fifth-grade level increased pneumococcal vaccination rates five-fold in an elderly low-literate minority population.⁶¹

Research suggests that the benefit of written handouts depends considerably on how they are organized and used. Studies in family practice settings have shown that it makes a difference whether or not patients are given health information directly from physicians. In practices that "stockpiled" written patient education materials, physicians were unfamiliar with the materials and tended not to recommend or give them to patients. In contrast, physicians were most likely to use written health materials when they took responsibility for selecting and maintaining a small collection of materials. Physicians could then select a familiar handout, use it as a teaching tool, and tailor its message to the patient's needs.⁶²⁻⁶⁴

If written materials are used, evidence indicates that they should be written following recommendations from experts in the development of brochures.⁶⁰ Patient acceptance of written materials is also enhanced if development of the materials includes review by focus groups consisting of patients from the target audience.⁶⁵

Non-written Materials. International health experts have long known that visual aids can help communication with nonliterate persons.^{66,67} Recent studies have shown such aids to be effective in industrialized nations. One study showed that use of video, in comparison to written materials, increased comprehension by low-literate patients.⁶⁸ Another study showed that pictographs (ie, pictures that represent ideas) enhanced recall of spoken medical instructions from 14% to 85% among literate individuals,⁶⁹ and similar findings were noted with low-literate individuals, including long-term retention of information.⁷⁰ Cartoon illustrations also improve comprehension of and compliance with health care instruction in most, though not all, studies.⁷¹⁻⁷³ Finally, interactive computer-based multimedia represents an approach that appears successful in educating patients with inadequate health literacy.^{74,75}

Discussion

A marked expansion in patient education requirements has paralleled the recent growth in medical technology. For example, patients with an acute myocardial infarction are now typically hospitalized for just 2 to 4 days (compared to 4 weeks about 30 years ago), will probably be discharged on five or more medications (β blocker, aspirin, anti-platelet agent, ACE inhibitor, lipid-lowering agent), and given detailed dietary and exercise instructions.^{76,77}

Such demands on patients' medical knowledge, combined with their limited health vocabulary and frequent use by physicians of medical terms, represent a major source of miscommunication between patients and physicians. Although physicians frequently believe they speak to patients in layman's terms, patients and nurses do not perceive this.⁷⁸ Indeed, Waitzkin found that physicians used nontechnical language in only 12% of explanations to patients.⁷⁹ Not surprisingly, therefore, patients—especially those with limited health literacy—commonly report that physicians do not adequately explain illness or treatments in understandable terms.³

Identifying Patients With Limited Health Literacy

Unfortunately, it is difficult to identify patients with low health literacy skills because they do not fit a stereotype.¹² Many well-groomed, articulate, intelligent-sounding individuals have limited health literacy. Further, most individuals with limited literacy try to hide this limitation from others because of shame.⁸⁰ A previous study found that 67% of patients with low literacy had not told their spouse, more than half had not told their children, and 19% never told anyone.⁸⁰

Clinicians often attempt to assess patients' literacy by asking how far they went in school, but there is a poor correlation between educational attainment and literacy skills. A study of five family practices in a southern city found that more than 60% of patients had reading skills at least three levels below the highest school grade they attended.²⁰ The previously mentioned survey of Medicare managed care enrollees found that 27% of those who graduated from high school had inadequate or marginal health literacy, as did 17% of those with some college education.¹⁹ Thus, one cannot predict literacy level simply by inquiring about a patient's education level.

Tests such as the Rapid Estimate of Adult Literacy in Medicine (REALM)⁸¹ and the Test of Functional Health Literacy in Adults (TOFHLA)⁸² can identify patients with low literacy skills, the former in as little as 90 seconds. The literature does not, however, support using these instruments to test patients' literacy skills unless health care providers are willing to tailor communication and health education to the needs of low-literacy patients identified by testing.⁸³

However, certain clues to limited literacy skills, if present, should not be ignored. Specifically, patients may have limited literacy skills if they claim to be unable to read something because "I forgot my reading glasses," regularly bring family members with them to office visits, or fill out intake forms incompletely or inaccurately. Individuals who did not graduate from high school are also likely to have limited literacy.

Dealing With Limited Health Literacy. Dealing with a patient who has limited literacy takes time—a commodity in short supply in most medical offices.⁷⁷ Office systems must be developed to help patients complete forms. Relatives must be invited to participate in medical interviews or patient education sessions. Clinicians must verify that patients have understood essential information.

Based on published research and our experience serving on a health literacy working group, we recommend six simple steps for communicating with patients who have inadequate and marginal health literacy (Table 1). Further, the American Medical Association has developed an inexpensive videotape that can be used in teaching students, trainees, and practicing health care providers about the issue of health literacy.⁸⁴ The videotape can be ordered by calling 312-464-5355.

Conclusions

Poor health literacy is common, especially among poor and elderly patients. Patients with poor health literacy have a complex array of communications difficulties that may affect health outcomes. Such patients report worse health status and have less understanding about their medical conditions and treatments; they may have increased hospitalization rates.

While a variety of methods have been recommended and studied for communicating with patients who have limited literacy skills, our search of the literature found little experimental research to determine which method(s) is optimal and leads to the best health outcomes. Such research is needed.

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Table 1

Six Steps to Enhance Understanding Among Patients with Low Health Literacy

- Slow down and take time to assess patients' health literacy skills.
- Use "living room" language instead of medical terminology.
- Show or draw pictures to enhance understanding and subsequent recall
- Limit information given at each interaction and repeat instructions
- Use a "teach back" or "show me" approach to confirm understanding. This approach involves having clinicians take responsibility for adequate teaching by asking patients to demonstrate what they have been told (ie, teach back to you how to take their medications) to ensure that education has been adequate.
- Be respectful, caring, and sensitive, thereby empowering patients to participate in their own health care.

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