

Health Literacy

Report of the Council on Scientific Affairs

Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association

LITERACY IN THE UNITED STATES has been defined as “an individual’s 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, to achieve one’s goals, and develop one’s knowledge and potential.”¹ The 1992 National Adult Literacy Survey (NALS),² the most accurate portrait of English-language literacy in the United States, found that 40 to 44 million Americans, or approximately one quarter of the US population, are functionally illiterate, and another 50 million have marginal literacy skills. This means that almost half of our adult population has deficiencies in reading or computational skills. Of these, 5% have learning disabilities and 15% were born outside the United States. However, the vast majority of adults with poor literacy are white, native-born Americans. Inadequate literacy is especially prevalent among the elderly, with almost half scoring in the lowest reading skill level in the NALS.

The NALS raises serious concerns about the ability of many Americans to function adequately in health care settings. An individual’s functional health literacy—the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient—may be significantly worse than their general literacy, because functional literacy is context spe-

Context Patients with the greatest health care needs may have the least ability to read and comprehend information needed to function successfully as patients.

Objective To examine the scope and consequences of poor health literacy in the United States, characterize its implications for patients and physicians, and identify policy and research issues.

Participants The 12 members of the Ad Hoc Committee on Health Literacy, American Medical Association Council on Scientific Affairs, were selected by a key informant process as experts in the field of health literacy from a variety of backgrounds in clinical medicine, medical and health services research, medical education, psychology, adult literacy, nursing, and health education.

Evidence Literature review using the MEDLINE database for January 1966 through October 1, 1996, searching Medical Subject Heading (MeSH) *reading* combined with text words *health* or *literacy* in the title, abstract, or MeSH. A subsequent search using *reading* as a search term identified articles published between 1993 and August 1998. Authors of relevant published abstracts were asked to provide manuscripts. Experts in health services research, health education, and medical law identified proprietary and other unpublished references.

Consensus Process Consensus among committee members was reached through review of 216 published articles and additional unpublished manuscripts and telephone and Internet conferencing. All committee members approved the final report.

Conclusions Patients with inadequate health literacy have a complex array of communications difficulties, which may interact to influence health outcome. These patients report worse health status and have less understanding about their medical conditions and treatment. Preliminary studies indicate inadequate health literacy may increase the risk of hospitalization. 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. Future research should focus on optimal methods of screening patients to identify those with poor health literacy, effective health education techniques, outcomes and costs associated with poor health literacy, and the causal pathway of how poor health literacy influences health.

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cific. That is, an individual may be able to read and understand materials with familiar content but struggles to comprehend materials written at the same level of complexity if that material contains unfamiliar vocabulary and concepts. The NALS did not specifically test health literacy.

In the largest study of functional health literacy in the United States,³ one third of English-speaking patients at 2 public hospitals could not read and understand basic health-related materials (ie,

they had inadequate functional health literacy). Overall, 42% of patients in that study were unable to comprehend directions for taking medication on an empty stomach, 26% could not understand information on an appointment

Author Affiliations: A complete list of the members of the Ad Hoc Committee on Health Literacy and the members and staff of the Council on Scientific Affairs appears at the end of this article.

Correspondence and Reprints: Linda B. Bresolin, PhD, Council on Scientific Affairs, American Medical Association, 515 N State St, Chicago, IL 60610 (e-mail: Linda_Bresolin@ama-assn.org).

See also p 545.

slip, and 60% could not understand a standard consent form.³ Moreover, functional health literacy was worse among the elderly and individuals who reported poor overall health. Thus, groups with the highest prevalence of chronic disease and the greatest need for health care had the least ability to read and comprehend information needed to function as a patient.

Recognizing that poor literacy is both common and complex, the American Medical Association (AMA) Council on Scientific Affairs asked an ad hoc committee of experts to investigate the subject. Committee members were selected by a key informant process and represented expertise in clinical medicine, medical and health services research, medical education, psychology, adult literacy, nursing, and health education. This report describes (1) the consequences of poor literacy in health care settings; (2) the implications of the problem for practicing physicians; (3) important research issues; and (4) the ramifications of poor literacy for the US health care system.

METHODS

The ad hoc committee met via telephone and Internet conferences. After agreeing on the scope of the report, subject areas were assigned based on individual expertise. One member assumed primary responsibility for the initial search of medical literature, and designated committee members reviewed relevant literature from this search. All committee members reviewed and approved the final report, which was then reviewed and approved by the Council on Scientific Affairs, and the recommendations of the council were adopted as AMA policy in June 1998.

The literature review involved a search of the MEDLINE database for English-language articles published between January 1966 and October 1996. The search combined (using *and*) the Medical Subject Heading *reading* with a text word search using *health*. Results of this search were then combined (using *or*) with the text word *literacy* to expand capture of articles. A subsequent MEDLINE

and PsycINFO search used the Medical Subject Heading *reading* for articles published between 1993 and August 1998. After reviewing the title and abstract of all articles, 1 committee member identified pertinent publications. Experts in health services research, health education, and medical law were consulted to identify proprietary and other unpublished references. Authors of relevant published abstracts were asked to provide manuscripts under review. The reference lists of all articles obtained were reviewed to identify additional articles.

This search process yielded 1425 articles. Preliminary review of these articles identified 217 that were appropriate to consider in preparing this report. These included 44 articles on epidemiology of illiteracy, 55 on readability of patient education materials, 63 on associations of literacy with health-related parameters, 38 on how to communicate with low-literacy populations, and 17 on development or implementation of interventions to improve patients' knowledge or outcomes, of which 1 was a randomized controlled trial.⁴ Representative articles from each category are cited in this report.

HEALTH LITERACY

Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment. Patients with adequate health literacy can read, understand, and act on health care information. There is disparity, however, between the skills needed for adequate health literacy and the literacy skills of many Americans. Numerous studies document that health materials, such as patient education brochures,⁵⁻⁷ discharge instructions,^{8,9} contraception instructions,^{10,11} and consent forms,¹²⁻¹⁵ are often written at levels exceeding patients' reading skills. This problem is magnified by the increasing multicultural and multilingual diversity of the US population. Issues of culture, language, and learning are interrelated, and to be effective, health education must be conducted in both culturally and linguistically appropriate formats.¹⁶

Despite the difficulties in providing effective health education across all languages, cultures, and reading skills, health care professionals routinely expect patients to have adequate health literacy. But, how well do patients understand health messages? Can they understand instructions on their medication bottles? Do parents know how to dose medications for children? Can patients comprehend and adhere to the necessary preparations for diagnostic studies or procedures? Do patients understand informed consent documents? Based on what is known about the health literacy skills of the US population, the answers to these questions are almost certainly "no" for many patients.

CONSEQUENCES OF INADEQUATE HEALTH LITERACY

Literacy is an important and well-known correlate of health status and health-promoting behaviors in nonindustrialized nations.¹⁷⁻¹⁹ Despite this, research on the relationship between literacy and health in industrialized countries has been limited by difficulties in disentangling complex factors that covary with literacy. These factors include education level, socioeconomic and other demographic factors, self-efficacy, and cultural background.²⁰⁻²³

Several recent studies, however, indicate that even after adjusting for these covariables, literacy is related to multiple aspects of health, including health knowledge, health status, and use of health services.²⁴⁻²⁸ For example, a study in general medical clinics at 2 public hospitals²⁴ evaluated 402 patients with hypertension and 114 with diabetes mellitus and found patients' functional health literacy (measured in English or Spanish)²⁹ strongly correlated with knowledge of their illness. Among patients with diabetes, only half of those with inadequate literacy knew the symptoms of hypoglycemia compared with 94% of patients with adequate literacy. Similarly, fewer patients with hypertension and inadequate literacy knew that blood pressure can be lowered with weight loss and exercise. Another study of 483 patients

with asthma showed poor literacy skills correlated with less knowledge of asthma and improper metered-dose inhaler skills.²⁵ When statistical adjustments were made for education and other sociodemographic covariables, literacy level was the strongest correlate of health knowledge and disease management skills.

In a study involving low-level readers enrolled in adult basic education classes,²⁶ 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 were made for confounding sociodemographic factors. Similarly, a study of 2659 patients at 2 public hospitals found that those with inadequate functional health literacy were more than twice as likely to have poor self-reported health status as were subjects with adequate literacy.²⁷ 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. This is not surprising because literacy abilities of adults cannot be accurately predicted from their education level.³⁰ Another recent preliminary study found that low literacy was a better predictor than race or age of metastatic disease at presentation of prostate cancer.³¹

Patients with low literacy may also have higher health care costs. A study of English- and Spanish-speaking Medicaid participants revealed that those who read at the lowest grade levels (grades 0-2) had average annual health care costs of \$12 974 compared with \$2969 for the overall population studied.^{32,33} Finally, in a study of 958 low-income patients followed up for 2 years, patients with inadequate literacy were nearly twice as likely to have been hospitalized during the previous year (31.5% vs 14.9%), a relationship that persisted after adjustment for health status and various socioeconomic indicators.²⁸

These consistent results link literacy to various health indicators. The relationship between health literacy and outcomes is likely mediated through both

indirect (ie, poverty or employment in hazardous jobs) and direct effects (ie, patients not properly caring for chronic medical conditions). However, the actual causal pathways have not been elucidated.

IMPLICATIONS FOR PRACTICING PHYSICIANS

Twenty-five years ago, patients with newly diagnosed asthma were instructed to take theophylline. Today, patients are asked to monitor asthma with a peak flow meter, select and correctly use inhalers, sometimes augment therapy with tapering dosages of steroids, and avoid triggers that exacerbate their asthma.³⁴ Additionally, they are expected to properly use but not overuse the emergency department, their primary care physician, and subspecialists. To meet these expectations, patients need information and must have sufficient reading, computational, and self-management skills to use that information. Unfortunately, current practice environments provide physicians with little time for "information giving."³⁵ Not surprisingly, a gap often exists between what patients actually understand and what health care professionals expect them to know or think they know.

Health literacy is not only important for self-management of chronic conditions. It also affects the spectrum of health care, from prevention and screening to history taking and explaining diagnoses and treatment. For example, women with inadequate health literacy have poorer understanding of mammography and more negative attitudes toward breast cancer screening.³⁶ Less than half of the adult US population understands many commonly used medical words, which likely interferes with a clinician's ability to obtain an accurate and complete medical history.^{37,38}

After visiting a physician, patients expect and physicians hope they share a common understanding of both a diagnosis and treatment plan. However, patients with low literacy often do not understand physicians' instructions.^{3,39,40} Finally, people with poor literacy skills are less likely to understand and remem-

ber medication advice. Patients with poor health literacy may take medications at the wrong dosage or frequency and may not understand adverse effects or the need for follow-up monitoring.⁴¹ Physicians almost never (only 2% of the time in 1 recent study⁴²) assess patients' understanding of their instructions. Moreover, the signature of a low-literacy patient on a consent form for research, treatments or surgery may not indicate informed consent,⁴³ because in most cases the readability level of consent forms is at the college or graduate-school level, far above the 8th-grade reading level of the average US adult.^{3,12-14}

These limitations on patients' ability to understand information about disease management, prevention, and informed consent send a clear message to physicians: physicians are not successful in communicating essential health care information to their patients, particularly to those with inadequate health literacy.

COMMUNICATING WITH PATIENTS

Nearly all patients prefer medical advice that is simple and easy to understand.^{41,44-46} Thus, strategies for communicating with all patients, including those with well-developed reading ability, should rely on simple, straightforward methods.^{16,47} In many cases, advice can be simplified by reducing the content to what the patient truly needs to know to follow essential instructions, because adult education theory points out that adults are most (and often only) interested in information that helps solve their problems, rather than in background information.⁴⁸ For example, most patients are more interested in learning what they need to do to manage their diabetes so they can resume their daily activities, and less interested in disease pathophysiology.

Physicians can learn skills for effective communication with low-literacy patients through continuing education activities.⁴⁹ They can also make their instructions interactive by having patients do, write, say, or show something to demonstrate their understand-

ing.¹⁶ For example, physicians can show patients a pill bottle and ask, "If this were your medicine, tell me or show me how you would take it?" This simple task provides a measure of health literacy. Application of these communication skills, even in busy practice settings, is practical and characterizes effective clinicians and health care systems.

RESEARCH ISSUES

As outlined above, much has been learned about the magnitude and consequences of the health literacy problem. Inadequate health literacy is common,^{3,8,32,50-52} associated with worse health status and poorer understanding of medical information,^{15,24-27,46,53} and is likely associated with increased health care costs.^{28,33} Research efforts in health literacy need to focus on (1) literacy screening; (2) methods of health education; (3) medical outcomes and economic costs; and (4) understanding the causal pathway of how health literacy influences health.

Health Literacy Screening

Screening instruments, such as the Rapid Estimate of Adult Literacy in Medicine (REALM), can quickly (<3 minutes) assess patients' word recognition skills and provide an approximate grade level of reading ability.^{51,54} The REALM correlates well with the Test of Functional Health Literacy in Adults (TOFHLA),²⁹ a shortened version of the TOFHLA (S-TOFHLA),⁵⁵ and other more sophisticated reading assessment instruments that take longer to administer. Further studies are necessary to determine the relative advantages and disadvantages of the S-TOFHLA and the REALM. Some have suggested the REALM be used to screen patients in clinical settings,⁵⁶ but the S-TOFHLA is the only instrument for measuring functional health literacy.⁵⁵ However, patients may not be willing to have their reading ability measured and recorded in their chart. Many low-literacy patients do not recognize their inadequate literacy² or are ashamed and hide it.^{41,57} Research is needed to determine if screening and identifying patients with poor health literacy has an effect on patient-clinician relationships or improves patient outcomes.

Improving Communication With Low-Literacy Patients

Research is needed to determine the best ways to communicate with low-literacy patients. Current efforts focus on revising written educational material to a simpler level, and a few studies have shown that simpler written materials can improve knowledge.^{39,58-60} However, no published studies have shown a beneficial effect on patients' health outcomes from using such simplified materials. Even though simple materials may increase appeal and satisfaction,^{46,61} they may not be understood by individuals who have very limited literacy. Thus, important questions include (1) What is the best way to communicate medical information to patients? (2) What is the minimum content required for patients to achieve their self-management goals and what is the literacy demand of the task(s) we are asking the patient to carry out? (3) Can visual aids, videotapes, and multimedia technologies improve patients' understanding of medical information and can they do so more effectively than simplified written materials? (4) How should clinicians approach decision making with patients who do not understand informed consent? (5) What is the most cost-effective way to enhance compliance when patients have poor health literacy? Studies of interventions to enhance communication and patient education should measure outcomes such as patient satisfaction, changes in quality of life, and objective disease-outcome parameters. Importantly, researchers and providers must involve patients—the real experts on health literacy—in developing and testing interventions.^{53,61,62}

Cost and Outcomes of Poor Literacy

Although preliminary research suggests that poor literacy is associated with poorer health and higher health care costs, definitive studies using national data are needed to clarify the magnitude of these relationships. The Prudential Center for Health Care Research, Atlanta, Ga, is currently studying the relationship between literacy and health

services use by 3000 Medicare managed-care enrollees, a population with a substantial burden of chronic disease. Results should provide information about the interactions between literacy and health services use and insight into the higher prevalence of inadequate literacy among the elderly, which may be due to cohort effects (education), atrophy of reading ability, or a manifestation of general cognitive decline with aging. Additional research is needed to clarify the effect of poor literacy on specific health policy sectors (eg, Medicare, Medicaid, Veterans Affairs) and the relationship of poor health literacy with treatment, costs, and outcomes of specific diseases.

Causal Pathways

The causal pathways by which poor literacy is associated with poorer health, higher health care use, and higher costs need elucidation.⁶³ Patients with inadequate health literacy probably have a complex array of problems, including difficulty with oral as well as written communication,^{16,64} limited problem-solving abilities,^{65,24,25} lack of self-empowerment,⁶⁶ trouble following instructions and complying with treatments, and distrust of new information. Until the relationship of these and other factors is understood, it will be difficult to develop rational interventions to improve health outcomes in populations with poor health literacy.

HEALTH LITERACY AS A POLICY ISSUE

Why has the issue of health literacy failed to register in the minds of health policymakers? There are likely several reasons. First, highly educated physicians and nurses, all with adequate health literacy, rarely think about patients' ability to read. There has been no compelling reason to study and recognize the policy implications of health literacy because it is intuitively obvious that not being able to read causes problems for patients. Second, low literacy in the health care setting is perceived to be a problem of the educational system, and the health sector is reluctant to devote its

time, energy, or resources to dealing with problems that are not specifically in the domain of medicine. Finally, there is no constituency for health literacy. Without a group of consumers to call attention to their "problem," a group of health care professionals whose livelihood depends on dealing with the problem, or a government agency charged to address the issue with appropriate resources, health literacy will remain tangential to the US health care system.

Nonetheless, there are 5 principal reasons why health policymakers should care about the health literacy issue. First, low-literacy patients, by definition, cannot be empowered consumers in a market-driven health care system. Second, patients who do not understand health care professionals' instructions will not receive quality medical care. Third, evidence in case law documents health care professionals' and hospitals' medicolegal liability for adverse outcomes by patients who do not understand important health information.⁶⁷ Fourth, clinical management problems related to poor health literacy problems probably result in substantial but avoidable costs for the US health care system, for individual health plans and providers, and for patients and their families. Finally, health literacy problems are more common in certain populations (eg, Medicare beneficiaries, Medicaid recipients, and uninsured individuals) that are heavily dependent for their health care on public policymakers.

For the reasons cited herein, health policymakers should be alerted to the broad problem of poor physician-patient communication. Both the Joint Commission on Accreditation of Healthcare Organizations and the National Committee for Quality Assurance have developed guidelines on patient communication and the readability of informed consent documents and patient education materials.^{68,69} The US Congress and the US Food and Drug Administration have long recognized the need to improve patients' knowledge and understanding of prescription drugs.⁷⁰ However, awareness of the importance of literacy and comprehension has not,

for the most part, extended to other areas of medical care or other parts of the federal legislative or regulatory apparatus.

A broad policy agenda on health literacy is needed, and it should involve both public- and private-sector decision-makers in the health system. Fortunately, the *Healthy People 2010 Objectives: Draft for Public Comment* notes that health literacy is "increasingly vital to help people critically evaluate health information."⁷¹ In building a constituency for health literacy, organized medicine can play an essential role. Physicians are at the fulcrum of this issue: they see patients, give them instructions, and see them again if the patients do not understand those instructions. In advancing solutions to dealing with health literacy, including identification of financial resources to further investigate the health literacy problem, medical organizations need to work to involve other professional organizations and consumer groups.

RECOMMENDATIONS

The following statements, recommended by the Council on Scientific Affairs, were adopted as AMA policy at the AMA Annual Meeting in June 1998.

1. The AMA recognizes that limited patient literacy is a barrier to effective medical diagnosis and treatment.

2. The AMA will work with members of the Federation [ie, specialty, state, and local medical societies] and other relevant medical and nonmedical organizations to make the health care community aware that approximately one fourth of the adult population has limited literacy and difficulty understanding both oral and written health care information.

3. The AMA encourages development of undergraduate, graduate, and continuing medical education programs that train physicians to communicate with patients who have limited literacy skills.

4. The AMA encourages the US Department of Education to include questions regarding health status, health behaviors, and difficulties communicating with health care professionals in the National Adult Literacy Survey of 2002.

5. The AMA encourages the allocation of federal and private funds for research on health literacy.

Ad Hoc Committee on Health Literacy: Ruth M. Parker, MD (chair); Mark V. Williams, MD (assistant chair); Barry D. Weiss, MD (assistant chair); David W. Baker, MD, MPH; Terry C. Davis, PhD; Cecelia C. Doak, MPH; Leonard G. Doak, BS, PE; Karen Hein, MD; Cathy D. Meade, RN, PhD; Joanne Nurss, PhD; Joanne G. Schwartzberg, MD; Stephen A. Somers, PhD.

Members and Staff of the Council on Scientific Affairs: Ronald M. Davis, MD, Detroit, Mich (chair); Joseph A. Riggs, MD, Haddon Field, NJ (chair-elect); Hunter C. Champion, New Orleans, La (report liaison); John P. Howe III, MD, San Antonio, Tex (report liaison); Roy D. Altman, MD, Miami, Fla; Scott D. Deitchman, MD, MPH, Decatur, Ga; Myron Genel, MD, New Haven, Conn; Mitchell S. Karlan, MD, Los Angeles, Calif; Mohamed Khaleem Khan, MD, PhD, Boston, Mass; Nancy H. Nielsen, MD, PhD, Buffalo, NY; Michael A. Williams, MD, Baltimore, Md; Donald C. Young, MD, Iowa City, Iowa. Staff: Joanne Schwartzberg, MD, Linda B. Bresolin, PhD (secretary), Barry D. Dickinson, PhD (assistant secretary), Chicago, Ill.

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