



Recognizing and overcoming inadequate health literacy, a barrier to care

MARK V. WILLIAMS, MD

Director, Hospital Medicine Unit, Emory University School of Medicine,
Atlanta, Georgia

"[The] new civil right in today's society is literacy...Imagine that in the greatest, wealthiest nation in the world, 7 out of 10 fourth graders in big cities and rural areas cannot read...It is our greatest failure as a nation. It is our failure as a people."

—ROD PAIGE, SECRETARY, US DEPARTMENT OF EDUCATION

■ ABSTRACT

Health literacy—the ability to understand and act on health information—is essential for high-quality care. Many people, especially the elderly, who bear the greatest burden of disease, have inadequate health literacy. This adversely affects their quality of care, and places increased cost burdens on society. Learning to recognize when a patient may have low literacy skills and understanding the common ways in which these people misinterpret medical information can help physicians develop strategies to improve patients' health literacy.

A SHOCKING NUMBER of patients cannot participate effectively in their own care for the simple reason that they cannot read adequately.

Compounding the problem, we physicians speak a specialized language ("medicalese") that is often unintelligible to outsiders. Moreover, many patients are expert at concealing their poor literacy skills.

Inadequate health literacy has measurable ill effects on health. Given the increasing complexity of health care, which requires increased involvement of patients, we need to

address this common but underappreciated problem and find ways to communicate with patients more effectively.

■ GOOD COMMUNICATION IS VITAL

Good communication between physician and patient is a cornerstone of good health care. Yet, many patients have difficulty understanding their doctors' instructions. Even immediately after leaving the physician's office or the hospital, patients may recall no more than 50% of the important information just given to them.

Furthermore, communication between physician and patient is becoming more difficult as health care becomes more complex. For example, 30 years ago there were only about 650 prescription drugs, and the average hospital stay for acute myocardial infarction was 4 to 6 weeks; today there more than 10,000 prescription drugs, and a hospital stay for acute myocardial infarction is typically 2 to 4 days.

In addition, with the increasing prevalence of chronic conditions such as diabetes, high blood pressure, and congestive heart failure, patients are required to know how to manage their own health care outside the clinic and hospital.

■ ONE FOURTH OF AMERICANS ARE FUNCTIONALLY ILLITERATE

In 1991, Congress defined literacy 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

**Do not assume
that your
patient
understands
you**

By this definition, millions of people living in the United States are functionally illiterate. According to the National Adult Literacy Survey (NALS), roughly one fourth of adults in the United States may lack the necessary skills to function adequately in modern society.² These people come from all types of backgrounds; however, functionally illiterate adults are more likely to be older, poorer, less educated, and have more health problems.

Health literacy is even lower

An individual's *health literacy*—"the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"—may be significantly worse than his or her general literacy, because functional literacy is context-specific.

The language of medicine is highly technical, and outsiders may not understand it. Gibbs et al³ reported a large variation among patients in their ability to comprehend commonly used medical terms: only 13% of the 125 participating patients understood the meaning of "terminal," 35% understood "orally," and 18% understood "malignant."

Other studies reported low comprehension in other critical areas of good health care, such as understanding written directions for taking medications, understanding clinical appointment slips, and informed consent forms. In a study of Medicare patients, Gazmararian et al⁴ found that:

- 48% did not understand the written instructions "take medicine every 6 hours"
- 68% could not interpret a blood sugar value
- 27% could not identify their next appointment
- 27% did not understand "take medicine on an empty stomach" (instructions written at 4th grade level)
- 100% could not understand a statement of Medicaid rights (written at a 10th grade level).

We tested more than 2,500 patients at two public hospitals and found that 35% of English-speaking patients and 62% of Spanish-speaking patients had inadequate or marginal health literacy.⁵

Patients over 60 years old have a particu-

larly high prevalence of inadequate health literacy: more than 80% at one of the public hospitals.

Physicians are often unaware that patients do not understand them. Patients, on their part, often feel shame over their lack of literacy skills and most often will not acknowledge this deficiency despite its interference with their care.⁶

INADEQUATE HEALTH LITERACY IS BAD FOR PATIENT HEALTH

A number of studies showed that inadequate health literacy has measurable adverse effects on patients' health.

Among low-income patients with prostate cancer,⁷ those with low literacy tended to be diagnosed later in the course of the disease, regardless of race.

Low health literacy has also been highly correlated with excessive hospitalization,⁸ which may suggest decreased knowledge of self-care, reduced compliance, and less ability to negotiate the health care system in people with marginal literacy.

Treatment compliance is yet another area affected by literacy skills. A study that looked at the significance of health literacy to other predictors of compliance to treatment for HIV and AIDS found that education and health literacy were significant independent predictors of adherence to treatment.⁹

Inadequate health literacy is estimated to cost the health care system from \$30 to \$73 billion annually.¹⁰

RECOGNIZING INADEQUATE HEALTH LITERACY

You may not know that your patient has inadequate or marginal health literacy. The patient's level of education does not guarantee that he or she can read. A study in five family practice clinics found that over 60% of patients tested had a reading skill that was at least three levels below the school grade they completed.¹¹ In the large Medicare survey previously described, 27% of the patients who had a high school diploma and 17% of those who had some college education had inadequate or marginal health literacy.⁴

Many people
conceal their
inadequate
health literacy



To help identify patients with low literacy skills, we developed the Test of Functional Health Literacy in Adults (TOFHLA).¹² Available in English and Spanish, the test uses common materials in the health setting that require reading skills (eg, pill bottles, standardized appointment slips, instructions for upper gastrointestinal preparation) and grades a patient's comprehension on a scale of 0 to 100. Patients who score lower than 60 points are considered to have inadequate health literacy, and often misread dosing instructions and appointment slips.

Clues that a patient may have inadequate health literacy include bringing a family member to the clinic visit or wanting to discuss materials with family, claims of forgetting reading glasses, or incompletely or inadequately filling out forms.

■ TOWARD BETTER COMMUNICATION

Physicians can improve their communication with patients with low literacy skills by learning to recognize the particular ways in which these patients deal with communication.

Patients with low literacy skills tend to interpret words literally (eg, thinking hypertension means "being hyper") and often have difficulty identifying key concepts (or prioritizing or distinguishing them from minor details). This difficulty with language is the most frequent area of miscommunication between physician and patient. Several types of words that physicians commonly use are difficult for these patients to comprehend, such as words denoting concepts (eg, normal range), categories (eg, ACE inhibitors), or value (eg, excessive bleeding).

Another area of miscommunication is related to the lack of training in science and medicine in most patients, which can lead to logic problems. This problem can be particularly exacerbated in patients with low literacy skills because of their tendency not to acknowledge when they don't understand something.

For example, it may seem logical to patients to stop a 10-day course of antibiotics once they feel better, even though they've been instructed to take the full

TABLE 1

Ways to improve understanding in patients with low health literacy

Slow down

Take time to assess patients' health literacy skills

Use "living room" language instead of medical terminology

Use language that patients can understand

Show or draw pictures

Visual aids 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

Ask patients to demonstrate their instructions to ensure that instruction has been adequate

Never ask "do you understand?" Typically, patients will say yes even if they don't understand

Be respectful, caring, and sensitive

This attitude reassures patients and helps them to improve participation in their own health care

course. Physicians understand the science and medical implications of stopping antibiotics mid-course, but this is not clear to many patients (even those with higher levels of literacy).

Ways to improve health literacy include simplifying or clarifying patient education materials, with particular focus on the use of visual aids such as videos, pictographs, and cartoons. Studies show that visual aids improve comprehension, compliance, and retention.^{13–15} Physician involvement in delivering these materials and educating the patient are critical for enhancing health literacy.

Including family and friends in helping deliver health information is also important, as patients with inadequate health literacy often go first to people they know for explanation. **TABLE 1** lists a number of key points to help enhance health literacy in the clinical setting. To help educate physicians on health literacy, the American Medical Association's Foundation has launched an initiative in this area; see www.ama-assn.org/ama/pub/category/3119.html.

Patients may misunderstand many medical terms





REFERENCES

1. National Literacy Act, 20 USC Section 1201 (1991).
2. **Kirsch I, Jungeblut A, Jenkins L, Kolstad A.** Adult literacy in America: a first look at the findings of the National Adult Literacy Survey. Washington, DC: National Center for Education Statistics, US Dept of Education; 1993.
3. **Gibbs R, Gibbs P, Henrich J.** Patient understanding of commonly used medical vocabulary. *J Fam Pract* 1987; 25:176–178.
4. **Gazmararian JA, Baker DW, Williams MV, et al.** Health literacy among Medicare enrollees in a managed care organization. *JAMA* 1999; 281:545–551.
5. **Williams MV, Parker RM, Baker DW, et al.** Inadequate functional health literacy among patients at two public hospitals. *JAMA* 1995; 274:1677–1682.
6. **Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV.** Shame and health literacy: the unspoken connection. *Patient Educ Couns* 1996; 27:33–39.
7. **Bennett CL, Ferreira MR, Davis TC, et al.** Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *J Clin Oncol* 1998; 16:3101–3104.
8. **Baker DW, Parker RM, Williams MV, Clark WS.** Health literacy and the risk of hospital admission. *J Gen Intern Med* 1998; 13:851–851.
9. **Kalichman SC, Ramachandran B, Catz S.** Adherence to combination anti-retroviral therapies in HIV patients of low health literacy. *J Gen Intern Med* 1999; 14:267–73.
10. **Friedland R.** Understanding health literacy: new estimates of the costs of inadequate health literacy. Presented at the 3rd Annual Health Literacy Conference on Health Literacy. 1998.
11. **Davis TC, Mayeaux EJ, Fredrickson D, Bocchini JA, Jackson RH, Murphy RW.** Reading ability of parents compared with reading level of pediatric patient education materials. *Pediatrics* 1994; 93:460–468.
12. **Parker RM, Baker DW, Williams MV, Nurss JR.** The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med* 1995; 10:537–541.
13. **Houts P, Bachrach R, Witmer J, Tringali C, Bucher J, Localio F.** Using pictographs to enhance recall of spoken medical instructions. *Patient Educ Couns* 1998; 35:83–88.
14. **Houts PS, Witmer JT, Egeth HE, Loscalzo MJ, Zabora JR.** Using pictographs to enhance recall of spoken medical instructions II. *Patient Educ Couns* 2001; 43:231–242.
15. **Jacobson TA, Thomas DM, Morton FJ, Offutt G, Shevlin J, Ray S.** Use of a low-literacy patient education tool to enhance pneumococcal vaccination rates. A randomized controlled trial. *JAMA* 1999; 282:646–650.

SUGGESTED READING

Baker DW, Parker RM, Williams MV, et al. The health care experience of patients with low literacy. *Arch Fam Med* 1996; 5:329–334.

Council on Scientific Affairs for the American Medical Association. Health literacy. Report of the AMA Council on Scientific Affairs. *JAMA* 1999; 281:552–557.

Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest* 1998; 114:1008–1015.

Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension or diabetes. *Arch Intern Med* 1998; 158:166–172.

ADDRESS: Mark V. Williams, MD, Department of Medicine, Emory University School of Medicine, 69 Butler Street SE, Atlanta, GA 30303.