

The Crucial Link between Literacy and Health

Ruth Parker, MD, a practicing internist and researcher at Emory University School of Medicine, was years into her medical career before she discovered the importance of literacy in patient care. The revelation came when she was collaborating with a colleague on research in the early 1990s at Grady Memorial Hospital in Atlanta, Georgia, on waiting times in emergency departments. Much to her surprise, some patients completed the rather long surveys in just a few minutes.

"We began to think, there's no way that you could finish this thing so quickly. And it didn't happen just once or twice, it happened a good many times," Parker said. Confused, she started reading over the surveys with these patients, and she realized that they weren't reading them at all. Rather, they were just haphazardly answering the multiple-choice questions. Incredulous, she approached a hospital administrator and asked what he thought about the patients' ability to fill out surveys. He estimated that at least half of the hospital's patient could not read.

"I said, 'How did I get this far and not know this?' At that point I'd been in the medical field for a long time and taken care of thousands of patients without any idea of how many struggled with very basic literacy tasks," said Parker. She did a literature search that uncovered only a handful of studies addressing patient literacy in the health care system. When the results of the 1993 National Adult Literacy Survey (NALS) were published, they proved that the Grady hospital administrator's hunch was correct. The survey, the most thorough study on literacy ever conducted in the United States, showed that about half of adult Americans have literacy skills that are limited or even worse—meaning that they struggle to reliably complete many simple daily tasks, such as complete forms, read signs, or use transportation schedules. At least that many patients, then, must struggle with health care's many forms, educational materials, and direc-

tives. Parker collaborated with colleagues at Grady and Harbor-UCLA Medical Center to begin several years of work investigating how literacy affects the health and health care experience of patients.

In the past decade, a wave of research by Parker and others firmly established the link between health and literacy. Literacy skills predict an individual's health status more strongly than age, income, employment status, education level, and racial or ethnic group, according to an analysis of the research by the nonprofit organization Partnership for Clear Health Communication. Literacy directly affects patients' ability to follow instructions from physicians, take medication, understand disease-related information, learn about disease prevention and self-management, and understand their rights. Illiteracy affects patients' ability to access care, in particular because of difficulties completing application forms for insurance coverage. Most significant of all, it increases the chances of dying of chronic and communicable diseases.

Now health care researchers are working on fixing the problem through more accessible health care. The scope of the solution is big, but the potential savings are high. Poor adherence and high hospitalization rates among people with low literacy, along with related factors, add \$30 to \$73 billion to the annual health care bill—a figure similar to that of the annual cost of smoking. The issue is particularly relevant to internal medicine because low literacy is prevalent among core patient groups—the elderly and others with chronic conditions. "It's really bread-and-butter internal medicine," Parker said.

EVIDENCE OF THE LINK

Substantial evidence now exists on the link between literacy and health outcomes. Investigators use assessment tools like the TOFHLA (which is short for the Test of Functional Health Literacy in Adults) and REALM (which is short for Rapid Estimate of Adult Lit-

eracy in Medicine) to measure patients' ability to read and understand information that they need for their health care or health education. Patients who correctly answer fewer than half of the questions on the TOFHLA, for instance, are defined as having inadequate, or low, literacy that may hinder their ability to read pill bottle labels, appointment slips, educational brochures, informed-consent forms, and the like. In a study of 408 adults with type 2 diabetes, those with inadequate health literacy as measured by TOFHLA were less likely to achieve tight glycemic control and more likely to have poor glycemic control and to report having retinopathy than a group of more literate people with type 2 diabetes (1). Another study of 483 asthma patients found an association between reading ability and asthma knowledge. Among those patients reading below the third-grade level, 89% had poor metered-dose inhaler technique compared with 48% of patients reading at the high school level (2). In a study of 227 adults with HIV-AIDS, those with inadequate health literacy as measured by TOFHLA had significantly lower CD4 cell counts, were more likely to have been hospitalized for HIV-related conditions, and were more likely to perceive their health as poorer and the quality of care that they received as inadequate than a group of higher-literacy persons with HIV-AIDS. The lower-literacy group was also less likely to receive antiretroviral medications and had significantly higher viral loads than the higher-literacy group (3).

RECOGNIZING THE LOW-LITERACY PATIENT

Although it's probably not surprising that people with reading problems struggle in the health care system, the prevalence of low literacy—and therefore the widespread effect that it has on health care—is hard to believe. "Many physicians still ask me 'Are you sure?'" Parker said. Patients with low literacy

Getting the Most from a Doctor Visit

Earlier this year, a large coalition of health-focused groups formed the Partnership for Clear Health Communication. Their Web site (www.askme3.org) provides simple advice for patients about managing their own care. The advice encourages patients to follow these guidelines every time they talk with a doctor, nurse, or pharmacist:

- I will ask the 3 questions.
 1. What is my main problem?
 2. What do I need to do?
 3. Why is it important for me to do this?
- I will bring a friend or family member to help me at my doctor visit.
- I will make a list of my health concerns to tell my doctor.
- I will bring a list of all my medicines when I visit my doctor.
- I will ask my pharmacist for help when I have questions about my medicines.

More detailed information about getting the most from a doctor visit is available in an article by Lawren H. Daltroy, DrPH, on the Harvard School of Public Health's Health Literacy Studies Web site: www.hsph.harvard.edu/healthliteracy/talk_drvisit.html.

are usually difficult to identify on a casual basis, and physicians should never presume that a patient is literate, according to Dean Schillinger, MD, a primary care physician at San Francisco General Hospital and clinical researcher at University of California, San Francisco. Patients typically cover up by faking it, avoiding situations that require reading, "leaving" their glasses at home, and asking family and friends for help. Even the most poised and articulate patients may have trouble reading, and people with reading problems are unlikely to step forward and ask for help. One study at a women's health clinic found that, among patients considered to have low literacy, physicians identified only 20% (4).

Most adults with poor literacy are white, native-born Americans, Parker notes. The likelihood of low literacy, however, is generally higher among racial and ethnic minorities, often as the result of cultural barriers, language variations, and differing educational opportunities. Physicians can expect to see low literacy more commonly in certain hot spots, such as urban settings and public hospitals and clinics. Poor and physically and mentally disabled

persons are most likely to have poor literacy skills, according to the NALS data.

Low literacy is also common among the elderly, and it may become worse over time as a result of failing eyesight, diminished hearing, and declining mental alertness. In an assessment of the literacy skills of 299 emergency department patients age 60 years or older, researchers found that 4 out of 5 were unable to read and understand basic medical instructions, such as directions on how to take medication on an empty stomach (5). A recent paper by Parker and colleagues focused on the importance of declining literacy occurring at the same time that many people become more reliant on medical care (6). About 80% of all people older than 65 years of age have at least 1 chronic condition, and half have at least 2, Parker notes.

Because identifying literacy problems can be difficult without administering a reading examination—something that is rarely practical or desirable in the patient care setting—experts advise approaching all patients as if they have a lower level of functional health literacy and communicating accord-

ingly. "There's no reason to call people out and embarrass them. But because they typically don't know how to ask for help, the system has to be better at helping them," said Seth C. Kalichman, PhD, a health literacy researcher at University of Connecticut.

WRITTEN MATERIALS UNREADABLE TO MANY

One obvious step toward improving accessibility of health information is making written materials less complex. The U.S. Food and Drug Administration's overhaul of over-the-counter drug labeling simplified medication decisions by allowing consumers to compare nonprescription products easily, much in the same way standardized information on packaged foods helps people to compare nutrition information. Visual-based materials appear to be particularly accessible. For example, most of the materials used to help HIV-positive persons stay on their demanding antiretroviral regimens involve a written form. In addition, "People with low health literacy know much less about HIV-AIDS and much less about their disease status, and they are more likely to miss doses of their antiretroviral medications and therefore increase their risks for the development of HIV treatment resistance," according to Kalichman, who has conducted community-based AIDS behavioral research at the AIDS Survival Project of Atlanta for the past 8 years. He and colleagues have designed a 4-part brochure for people with HIV that features pictures instead of words, stickers shaped and colored to look like specific pills, and charts to track viral load and CD4 cell count. Kalichman is currently pilot-testing the new brochure and has had positive results.

As with HIV-AIDS, most disease-specific materials are written at a reading level that is higher than that of the average reader. The Internet is now a main source of medical information for patients, and physicians are doing a better job of helping patients find reliable sites, such as www.cdc.gov, www.medlineplus.gov, www.medem.com, www.mayoclinic.com, and [876 | 18 November 2003 | Annals of Internal Medicine | Volume 139 • Number 10](http://www.health</p>
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finder.gov. But most of the medical information on the Internet is written at a 12th-grade level. Proponents of health literacy are advocating for more of the health-related information on the Internet to be written at a level that more readers could understand. (The 1993 NALS found that the average American reads at an eighth- or ninth-grade level and the average Medicaid recipient reads at a fifth-grade level.) The U.S. National Work Group on Literacy and Health, a group of professionals from the education, health, and related fields, recommend that physicians reduce their reliance on written material and that written communication be created at a fifth-grade level or lower.

COMPREHENSION MATTERS, TOO

Some studies have linked medication adherence with the readability of informational materials given to patients. But other studies have found that matching the reading level of materials to the reading ability of patients had little effect on comprehension. The mixed results may stem from the fact that literacy skills have implications that reach beyond simply being able to read. Studies have shown that people with low literacy often struggle to comprehend oral communication as well, and they may be more reticent to express themselves. Researchers have started to use the term “health literacy” to encompass not only reading ability but also ability to understand and communicate important medical and health information.

Just as written materials containing long sentences, formal language, and unfamiliar words can heighten literacy problems, so can similar information when presented in the one-on-one patient-physician encounter, according to Schillinger. A study of 408 diabetes patients assessed the quality of physician-patient communication among patients with adequate and poor literacy (determined by a short-form version of the TOFHLA reading comprehension test). Patients with inadequate literacy reported more problems understanding physicians' explanations of

Strategies for Physicians

Various sources offer doctors information about communicating clearly with patients. Among these is the Harvard School of Public Health's Health Literacy Studies Web site. One article by Sally Ebeling, titled “Lessons and Tips for Addressing Health Literacy Issues in a Medical Setting” (www.hsph.harvard.edu/healthliteracy/insights.html), is available on the Web site and includes the following advice.

- Communicate with all patients on a basic level, without jargon.
- Give the patient a chance to tell his or her story uninterrupted.
- Limit new concepts to a maximum of 3 per visit.
- Use pictures, graphics, and real devices for demonstration.
- Ask questions beginning with “how” and “what” to ensure comprehension.
- Convey information orally and use written material mostly as a backup.

their condition, of self-care guidelines, and of the process of care, among other problems. In particular, these patients struggled with the technicality of the information communicated by their physician and the speed at which it was delivered (7).

Schillinger's research on patient comprehension, which has shown that patients often comprehend as little as half of what physicians tell them, has led him to encourage more physicians to use a communication method called “closing the loop.” Whenever a physician introduces a new health concept to a patient, the physician asks the patient to restate the message in his or her own words. By using this teach-back method, the physician knows if the communication between the patient and the physician is clear, and if it is, the patient may be more likely to remember and adhere to the message. But if the patient's view is discordant with the physician's, either because of poor comprehension or disagreement with the plan, the physician has the

chance to re-explain the information in a way that the patient can understand or tailor the plan to meet the patient's needs. Schillinger noted that patients in a diabetic study were more likely to achieve good glycemic control when physicians used this teach-back method; however, few physicians used the method (8).

Schillinger is also currently testing the effectiveness of weekly automated phone messages and of group medical visits in which patients with diabetes meet with health care professionals to discuss health-related questions, concerns, and solutions. Other alternative methods to convey health messages to patients have been tested, with mostly inconclusive results, according to a review by Rima E. Rudd, ScD, and colleagues at Harvard University. The review summarizes some of the approaches that have been tried, including videotape presentations, focus groups, games, incentives, and cartoons. The effectiveness of these approaches is little studied, and the re-

The American College of Physicians Foundation's second national health communication conference, “Strategies To Improve Health Care by Removing Communication Barriers,” took place on 17 November 2003. It was co-sponsored by the Institute of Medicine and focused on operational programs in the private and public sector that are seeking to reduce barriers to effective communication.

view's authors concluded that "more research is needed on strategies that complement or replace the use of written material." Suggested strategies for addressing low literacy included engaging a surrogate reader; computer-assisted, interactive technology; and health-focused pictorial presentations, such as photo essays and photo novels (9).

LITERACY BECOMES A PRIORITY

More strategies to help low-literacy patients are in the works as interest in the field grows. Health literacy experts are also calling for sweeping reforms, including adding health literacy to the training of health professionals, assessing health literacy to become part of provider systems and quality analysis, and advocating for federal funding of health literacy research and interventions (5). The Institute of Medicine (IOM), U.S. Health and Human Services, and Centers for Medicare & Medicaid Services, among others, have made the issue a priority. The American Medical Association Foundation has formed the Health Literacy Coalition, which provides grants for health literacy research and education. The American College of Physicians Foundation has made its focus the Health Communication Initiative, which encompasses an annual conference addressing health literacy and other issues. The IOM's Committee on Health Literacy plans to release a report in spring 2004 outlining the root problems and recommending solutions. The issue is not singular to the United States, and the World Health Organi-

zation also recently named health literacy a global priority.

Meanwhile, health education leaders are developing new health education programs, emphasizing skills that students can learn to advocate for their own health as well as that of their families and community. In addition to advocacy skills, students should learn how to access valid health information, products, and services; how to make healthy decisions; how to set health-related goals and communicate with others; and how to analyze the influence of culture, media, and technology on health, according to Regina A. Galer-Unti, PhD, a health educator at Purdue University (10). Underlying all of this is the school system, which is working to create future generations of students who grow up with strong reading skills.

Addressing literacy problems may result in system-wide changes in government services, patient education, and prescription monitoring. For now, however, physicians are left to rethink their interactions with their patients. Before Parker really understood health literacy, for instance, she said that she used to talk with patients about a new diabetes diagnosis by describing the pathophysiology of the disease. Now she focuses on discussing how they can take care of themselves. "Knowing what we now know, there's so much that we can do—and need to do—in order to provide patients with information that they can use. Ensuring that patients understand has become my goal, and that is a real shift for me in how I approach practicing medicine."

—Jennifer Fisher Wilson

References

1. Schillinger D, Grumbach K, Piette J, et al. Association of health literacy with diabetes outcomes. *JAMA*. 2002;288:475-82. [PMID: 12132978]
2. Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest*. 1998;114:1008-15. [PMID: 9792569]
3. Kalichman SC, Rompa D. Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *J Acquir Immune Defic Syndr*. 2000;25:337-44. [PMID: 11114834]
4. Lindau ST, Tomori C, Lyons T, Langseth L, Bennett CL, Garcia P. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. *Am J Obstet Gynecol*. 2002;186:938-43. [PMID: 12015518]
5. Williams MV, Parker RM, Baker DW, et al. Inadequate functional health literacy among patients at two public hospitals. *JAMA*. 1995;274:1677-82. [PMID: 7474271]
6. Parker RM, Ratzan SC, Lurie N. Health literacy: a policy challenge for advancing high-quality health care. *Health Aff (Millwood)*. 2003;22:147-53. [PMID: 12889762]
7. Schillinger D, Bindman A, Wang F, Stewart A, Piette J. Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Education and Counseling*. In press. Accessed at www.sciencedirect.com/science/journal/07383991 on 8 October 2003.
8. Schillinger D, Piette J, Grumbach K, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. *Arch Intern Med*. 2003;163:83-90. [PMID: 12523921]
9. Rudd RE, Moeykens BA, Colton TC. Health and literacy: a review of medical and public health literature. In: Comings J, Garners B, Smith C, eds. *Annual Review of Adult Learning and Literacy*. New York: Jossey-Bass; 1999.
10. Tappe MK, Galer-Unti RA. Health educators' role in promoting health literacy and advocacy for the 21st century. *Journal of School Health*. 2001;71:477-82.