

The Silent Epidemic — The Health Effects of Illiteracy

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He came in for a "tune-up." He was 64 years old, with a "history of noncompliance," according to the resident, and he hadn't taken his diabetes or cardiac medications for weeks. We weren't quite sure why. He was alert, he appeared to be intelligent and interested in getting well, and he was able to get his prescriptions filled at a reduced cost. Before he went home, we explained why he needed to take his medicines and reviewed the frequency and doses with him several times. He told us he would follow up with his doctor (though he couldn't remember the doctor's name or telephone number) and left the hospital with a handwritten discharge summary.

Five months later, he appeared at the community clinic. He said he was taking his medications, but he wasn't sure of their names or how often he took them. A medical student and I reviewed the regimen again. The student typed up simple instructions in big letters for him to follow, as well as a list of dates and times at which he should record his blood sugar levels. We asked him to come back in two weeks.

When he returned, the student saw him first — and made a diagnosis that no one else had considered: illiteracy. The clue lay in the jumbled mess of his glucose log. Many of the sugar values were written next to future dates. We quietly asked him to read his list of medications aloud. Haltingly, he told us he couldn't do it. Born in the rural South, he had left school in the second grade. He lived alone. He had been able to support himself as a gas-station attendant and handyman, but he had never learned to read.

We were stunned. We had tried to avoid jargon and to use simple language in explaining our instructions, and he had seemed to understand everything we had told him. He had seen scores of doctors, nurses, and social workers over the years without anyone's guessing he had a reading problem.

Although we had been blind to his illiteracy, our patient's problem is not uncommon. The [National Assessment of Adult Literacy \(NAAL\)](#), a large survey conducted by the National Center for Education Statistics, recently estimated that 14 percent of adults in the United States have a "below basic" level of "prose literacy" — defined as the ability to use "printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential."¹ The NAAL describes "below basic" skills as "no more than the most simple and concrete literacy skills," specifying that adults with this level of prose literacy range from being nonliterate in English to being able to locate easily identifiable information in short, commonplace prose text — able to find out, for example, "what a patient is allowed to drink before a medical test." They generally cannot, say, find "in a pamphlet for prospective jurors an explanation of how people were selected for the jury pool." Like my patient, 55 percent of those in the lowest prose-literacy group had not finished high school.

(Figure)

Prose Literacy Levels among U.S. Adults in 2003.

Percentages are based on a sample of 18,102 household respondents and 1156 prison inmates. Data are from the National Assessment of Adult Literacy.

On the basis of the NAAL results, 12 percent of U.S. adults are estimated to have below basic "document literacy," the ability to read and understand documents such as transportation schedules and drug or food labels — they may be able to sign a form, but they cannot use "a television guide to find out what programs are on at a specific time." In addition, 22 percent of adults are estimated to have below basic "quantitative literacy," the ability to perform fundamental quantitative tasks — they may be able to sum the numbers on a bank deposit slip, but they cannot compare the ticket prices for two events. Older adults fared poorest on the NAAL: 23 percent of those more than 64 years of age had below basic prose literacy, 27 percent below basic document literacy, and 34 percent below basic quantitative skills.

There is also a growing body of research on health literacy, the ability to comprehend and use medical information. Survey results indicate that more than a third of English-speaking patients and more than half of primarily Spanish-speaking patients at U.S. public hospitals have low health literacy. One analysis found that Medicare enrollees with low health literacy were more likely than enrollees with adequate health literacy to use the emergency room and to be admitted as inpatients.²

Patients with reading problems may avoid outpatient doctors' offices and clinics because they are intimidated by paperwork, according to Joanne Schwartzberg, director of aging and community health at the American Medical Association and editor of a textbook on health literacy. "Emergency rooms are user-friendly if you don't read," she pointed out, "because somebody else asks the questions and somebody else fills out the form."

The exact relation between literacy and health is still unclear, but people with low literacy are more likely to report having poor health, and are more likely to have diabetes and heart failure, than those with adequate literacy.^{3,4} Some studies have found correlations between literacy and measures of disease such as glycated hemoglobin levels in people with diabetes.³ Of course, factors other than literacy (such as educational level, income, primary language, sex, and age) affect the management of many conditions, and whereas "some studies have attempted to control for income and social circumstances . . . many didn't," according to Darren DeWalt, an internist at the University of North Carolina who has reviewed the evidence for the Agency for Healthcare Research and Quality.

Many researchers describe low literacy as a silent epidemic: despite its high prevalence, many physicians and other health care workers remain unaware that their patients may have reading problems. "I think most doctors are blind to the problem," said Barry D. Weiss, a professor of family and community medicine at the University of Arizona. "It's hard for them to believe."

Patients with poor literacy skills often are ashamed of their problem and are adept at hiding it. In one study, more than two thirds of patients with low literacy in public hospitals said they had never told their spouses about it. Nearly a fifth said they had never told anyone. Forty percent of the patients with low literacy said they felt shame about it.⁵ "A clinical psychologist once told me that **the shame experienced by people with literacy problems is comparable to the shame experienced by incest victims**," said Ruth Parker, a professor of medicine at Emory University, who coauthored the study. "In our society, it is very embarrassing not to know. Nobody wants to look dumb, especially not in front of their doctor."

Weiss advocates routine screening for **literacy as a new "vital sign."** He has created a brief, bilingual literacy-screening test that entails asking patients six questions about a nutrition label. He recommends that physicians screen some of their patients to assess literacy levels and then tailor the way they talk with patients accordingly. "The average doctor who's thinking he or she is talking in simple, plain language probably isn't," he said. "It may be more practical to screen a sample of patients to see what's needed."

But routine screening is controversial. Some worry that it takes too long, embarrasses patients, and could stigmatize those with low literacy. Moreover, in an era of "pay for performance," physicians might avoid low-literacy patients, viewing them as time-consuming and difficult to treat. Many literacy experts say that physicians often perceive inquiring about reading ability as opening Pandora's box, releasing a sprawling, unwieldy problem that they haven't been trained to handle and that is beyond the scope of a 15-minute office visit. "Physicians are not prepared to know what [their] immediate response should be," said Dean Schillinger, an internist at San Francisco General Hospital who has conducted several studies of physicians and health literacy. He added that the health care system does not help physicians who treat low-literacy patients.

Some experts advocate an approach to communication similar to universal precautions for preventing HIV infection. Health care workers, they say, should assume that all patients have a limited understanding of medical words and concepts, whether or not they have passable general-reading skills. Schwartzberg advocates that physicians organize their discussions with patients around three key points per visit and use a teach-back approach, asking patients to explain what they have been told.

Parker, a general internist, routinely carries an empty pill bottle in her pocket when she works in the clinic. "I tell patients, 'This is not your medication, but if it were, tell me how you would take it,'" she said. "It's never been validated [as a screening test], but I pick up a lot of people who can't do it, and it's an immediate way for me to know, does this patient need help?"

Other interventions such as educational videotapes, simplified brochures, and color-coded medication schedules have had mixed results in improving the health of patients with low literacy, according to Michael Pignone, an internist and associate professor at the University of North Carolina. Pignone and other researchers have shown that disease-management programs specifically designed for low-literacy patients with diabetes and congestive heart failure — approaches involving simply written educational materials or reminders, individualized educational sessions, and teach-back methods — can be effective in reducing symptoms and improving disease markers such as glycohemoglobin levels. A variety of professional groups

have launched initiatives to improve patients' health literacy — as well as physicians' skills in communicating with low-literacy patients.

With the help of a social worker, our patient enrolled in an adult reading program, which he attends regularly. Three years later, it's not clear that he always takes his medications as prescribed. But he feels that the literacy program has been useful in helping him to decipher his pill labels and to function in the world. And these days, I think twice whenever I explain anything to a patient — or jot down instructions on a pad of paper.

Source Information

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