Tackling the Problems of Health Illiteracy

On paper, the instructions for someone facing a barium enema exam are not very complicated: follow the diet guidelines and take the medicine to help empty the lower intestine. The procedure is straightforward.

But for many patients, doctors say, the first hurdle is not the enema itself but the written instructions, which many people cannot fully understand.

"I was not aware how large this problem was when we started looking at it," said Dr. William H. Mahood, a gastroenterologist and the president of the American Medical Foundation, which has just begun a program to try to counter what it calls health illiteracy.

The foundation, the philanthropic arm of the American Medical Association, has raised $350,000 so far to develop ways to make sure that patients who cannot read, or who read poorly, clearly understand how to use the drugs they are prescribed or the treatments they are being given.

Foundation officials cited a recent study finding that 27 percent of English-speaking patients at a public hospital could not read their appointment slips and that 42 percent did not understand all the details on their prescription bottles.

The doctors also pointed to a 1992 national adult literacy study that found that 21 percent of Americans adults could not read the front page of the newspaper, and that 48 percent had trouble reading a bus schedule.
The Silent Epidemic — The Health Effects of Illiteracy

Erin N. Marcus, M.D., M.P.H.

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." 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.

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. 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

http://content.nejm.org/cgi/content/full/355/4/339
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. Some studies have found correlations between literacy and measures of disease such as glycated hemoglobin levels in people with diabetes. 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. "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

Dr. Marcus is an assistant professor of clinical medicine in the Division of General Internal Medicine at the University of Miami Miller School of Medicine, Miami.

References


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.
Consequences: Reading Skills Are Tied to a Longer, Healthier Life

By ERIC NAGOURNEY

Older people who lack "health literacy" — that is, they cannot read and understand basic medical information — may be paying a high price. A new study finds that they appear to have a higher mortality rate than more-literate patients.

As the authors note, education levels have long appeared to play a role in longevity: one study found that people who did not graduate from high school lived an average of nine years less than graduates.

The explanation, researchers have suggested, may be that better education tends to result in better jobs, housing, food and health care.

But, writing in the July 23 Archives of Internal Medicine, researchers say that one particular characteristic of a poor education, low reading skills, may alone account for much of the problem. The study was led by Dr. David W. Baker of the Feinberg School of Medicine at Northwestern University.

The researchers based their findings on a study of 3,260 Medicare patients over more than five years.

At the beginning of the study, the patients were asked about their health and backgrounds and given a health literacy test that required reading and some math.

More than 60 percent of the patients were described as having adequate skills. But about a tenth were described as having marginal skills and a quarter as not literate. They were more likely to be older and nonwhite, the study said.

In the following years, those with inadequate reading skills were the most likely to die, even when overall education and other social factors were taken into account.

The most common cause of death in the group was cardiovascular disease, with a rate of more than 19 percent. The rate for those described as health-literate was 8 percent.

Health Literacy and Mortality Among Elderly Persons

David W. Baker, MD, MPH; Michael S. Wolf, PhD, MPH; Joseph Feinglass, PhD; Jason A. Thompson, BA; Julie A. Gazmararian, PhD; Jenny Huang, PhD

Background Individuals with low levels of health literacy have less health knowledge, worse self-management of chronic disease, lower use of preventive services, and worse health in cross-sectional studies. We sought to determine whether low health literacy levels independently predict overall and cause-specific mortality.

Methods We designed a prospective cohort study of 3260 Medicare managed-care enrollees in 4 US metropolitan areas who were interviewed in 1997 to determine their demographic characteristics, chronic conditions, self-reported physical and mental health, and health behaviors. Participants also completed the shortened version of the Test of Functional Health Literacy in Adults. Main outcome measures included all-cause and cause-specific (cardiovascular, cancer, and other) mortality using data from the National Death Index through 2003.

Results The crude mortality rates for participants with adequate (n = 2094), marginal (n = 366), and inadequate (n = 800) health literacy were 18.9%, 28.7%, and 39.4%, respectively (P < .001). After adjusting for demographics, socioeconomic status, and baseline health, the hazard ratios for all-cause mortality were 1.52 (95% confidence interval, 1.26-1.83) and 1.13 (95% confidence interval, 0.90-1.41) for participants with inadequate and marginal health literacy, respectively, compared with participants with adequate health literacy. In contrast, years of school completed was only weakly associated with mortality in bivariate analyses and was not significant in multivariate models. Participants with inadequate health literacy had higher risk-adjusted rates of cardiovascular death but not of death due to cancer.

Conclusions Inadequate health literacy, as measured by reading fluency, independently predicts all-cause mortality and cardiovascular death among community-dwelling elderly persons. Reading fluency is a more powerful variable than education for examining the association between socioeconomic status and health.

Author Affiliations: Division of General Internal Medicine (Drs Baker, Wolf, and Feinglass and Mr Thompson), Institute for Healthcare Studies (Drs Baker, Wolf, and Feinglass), and Department of Preventive Medicine (Dr Huang), Feinberg School of Medicine, Northwestern University, Chicago, Illinois; and Rollins School of Public Health, Emory University, Atlanta, Georgia (Dr Gazmararian).
By ERIN N. MARCUS, M.D.
Published: July 24, 2007

Last year, the community clinic where I work began requiring patients with managed-care insurance to go elsewhere for their blood and urine tests. The managed-care plans had signed contracts with private laboratories to perform these tests, and the clinic, which serves low-income patients, could no longer do the lab work.

Most of my patients have been able, with some time and effort, to navigate their way to the private laboratory. For others, figuring out how to go elsewhere for part of their medical care has been a seemingly insurmountable task, for reasons they haven't always wanted to share.

One patient, compulsive about keeping his appointments with me, routinely waits on a hot sidewalk to catch the bus that brings him and his rumpled grocery bag of pills to the public clinic. But whenever I’ve asked him to see a specialist or to have tests done elsewhere, he has had an excuse about why he couldn’t do it. He lost his appointment slip. He forgot the date. He couldn’t find the place.

And then one day, because of his Medicaid managed-care plan, he could no longer get his routine tests done at our clinic.
Knowing his history, I did what I could to help him locate the private laboratory. I looked it up on the Internet and printed a map. I even called the place and handed him the phone so that he could get verbal directions.

But when he returned for his next appointment, he still had not had the tests done. And so I was stuck with a pleasant, but complicated, patient and no way to monitor the effects of the medicines I had prescribed.

Some people might blame the patient for being "noncompliant." But I think the reason he never got those tests done is something else, something he will never admit: He can't read.

The Department of Education's 2003 National Assessment of Adult Literacy estimates that 14 percent of adults in the United States, or 30 million people, have "below basic" prose literacy, meaning they generally cannot read and understand information in a short, simple text when tested. Twelve percent of adults demonstrate below basic "document skills," meaning they generally cannot read and understand information in simple documents, including maps, when tested.

Although I've never formally tested my patient's literacy, he shows several signs that suggest a problem. He never earned a high school diploma, and the plastic bag he carries with him is usually a mess of pill bottles and papers. Whenever I've written down his medications and asked him to read the list, he has begged off, saying he doesn't want to do it. But whenever I've asked him if he has problems reading, he has denied it.

This isn't surprising, because research indicates that low literacy is associated with high levels of personal shame. One study of low-literacy patients found that a majority had never told their spouses that they could not read, and nearly one in five had never told anyone. Forty percent said they felt ashamed about their reading problem.

"If high-quality health care is to be provided to all patients, changes need to be made in the health care delivery system to accommodate low-literacy patients," the authors, writing in the journal Patient Education and Counseling, concluded.

But we live and work in an increasingly disjointed health care system that presumes patients are quite literate. Health educators commonly recommend that patient materials be written at or below an eighth-grade level, within reach of the average American adult. Yet surveys have found that handouts, informed consent documents and Hipaa forms — those long, legalistic papers detailing patients' privacy rights — are often written at much higher levels. And many literacy experts believe that when it comes to health information and prescription labels, an eighth-grade level is too high for many adults to understand.

Most medical schools don't spend much, if any, time teaching their students how to cope with low-literacy patients, and most doctors aren't particularly adept at detecting reading problems — or knowing what to do when they identify someone who can't read. And with the specter of "pay for performance," in which doctors' reimbursement will be tied to meeting certain quality goals, there is concern that physicians will shun low-literacy patients, seeing them as too tough to treat.

For us to take good care of these patients, we need to be given more time for office visits and more support from nurse educators, social workers and reading specialists. And our patients need a simpler, one-stop shopping approach to their health care, like easily accessible, comprehensive community clinics that perform — and get reimbursed fairly for — simple tests.

Otherwise, I worry that many people simply won't be able to navigate the system, and more doctors will be left without the basic diagnostic information they need to provide good treatment.

Erin N. Marcus is a general internist and associate medical director of the Institute for Women's Health at the University of Miami Miller School of Medicine.

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