

A Silent Epidemic

By Sandra G. Boodman
Washington Post Staff Writer
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Toni Cordell recalled feeling reassured when her gynecologist said her problem could be fixed with an "easy repair" involving surgery. She readily agreed, she said, barely glancing at the consent forms because reading was difficult for her. She said she didn't ask any questions because she didn't know what to say.

During a routine postoperative checkup several weeks later, Cordell vividly remembers, she was stunned when the nurse asked, "How are you since your hysterectomy?"

"All I could think of was how could I have been so stupid?" Cordell said of that day 30 years ago. "I just wanted to scream. I really didn't know I was surrendering part of my body."

Similar events occur every day in every hospital around the country, medical experts say, a consequence of the pervasive and largely unrecognized problem known as low "health literacy." Cordell, who lives in Charlotte and received remedial reading instruction as an adult, said she believes her case was typical: She graduated from high school reading at a fifth-grade level, a deficiency she long sought to hide. She attributes her poor reading skills to a combination of dyslexia and a childhood medical condition.

In a 2004 report, the Institute of Medicine defined health literacy as the ability to obtain and understand basic health information and services needed to make informed decisions. Low health literacy, the institute noted, affects an estimated 90 million Americans, who struggle to understand what a doctor has told them or to comply with treatment recommendations as essential as taking the proper dose of medication. A 1999 report by the American Medical Association found that consent forms and other medical forms are typically written at the graduate school level, although the average American adult reads at the eighth-grade level.

Earlier this month a Chicago-based organization known as the Joint Commission, which accredits the nation's hospitals and clinics, unveiled a list of 35 recommendations to address the problem, which is estimated to cost taxpayers \$58 billion annually. Among the recommendations developed by a panel of experts: adoption of communication techniques proven to be effective with patients, simplification of jargon-laden consent forms, and development of patient-friendly navigation signs, which may include the use of pictures or icons that are also recognizable to non-English speakers.

Low health literacy "is a silent epidemic that threatens the quality of health care," said Dennis O'Leary, commission president. Too many physicians and administrators, he said, fail to grasp the dimensions of a problem that affects every aspect of medical care and is a major impediment to patient safety. In some cases, cultural and language differences are a barrier, but experts emphasize that the majority of those with low health literacy are native-born and white.

Interest in health literacy comes at a time when Americans are expected to assume ever-greater

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responsibility for their care and are discharged from hospitals sicker and quicker, experts agree. Many patients are expected to comply with sophisticated drug regimens, to adjust or calculate medication doses or to manage complicated equipment with little training and less supervision. A comprehensive national assessment of adult literacy conducted in 2003 by the U.S. Department of Education found that 43 percent of adults have basic or below-basic reading skills -- they read at roughly a fifth-grade level or lower -- and 5 percent are not literate in English, in some cases because it is not their first language.

The picture is even more dismal when it comes to numerical skills: Fifty-five percent of adults have basic or below-basic quantitative abilities; many are unable to solve simple arithmetic problems, including addition.

The statistics don't differ much from the literacy assessment conducted a decade earlier. That survey found that many Americans could not determine the difference between two prices using a calculator or were unable to write a brief letter explaining a credit card billing error. Studies of health literacy have found that a surprisingly large number of adults were perplexed by the meaning of the term "orally," didn't know the difference between a teaspoon and tablespoon and were unable to calculate the proper dose of medicine. Low health literacy is more common among elderly or low-income patients and those with a chronic illness, researchers say.

A study published in the Journal of the American Medical Association in 1995 found that more than 80 percent of patients treated at two of the nation's largest public hospitals could not understand instructions written at the fourth-grade level for the preparation of gastrointestinal X-rays known as an upper GI series. A 1999 study of more than 3,200 Medicare recipients found that one in three native-born patients could not answer a question about normal blood sugar readings even after being given a paper to read that listed the correct answer. And a study of 2,500 elderly patients published last year in the Journal of General Internal Medicine reported that patients with low health literacy were twice as likely to die during a five-year period as those with adequate skills, regardless of age, race or income.

Sometimes language is a factor. In Spanish, for example, the word "once" means 11, not "once" as is often written on prescription labels. Patients have been treated for accidental overdoses of blood pressure medication and other drugs as a result of such linguistic confusion, said Ronald M. Davis, president-elect of the American Medical Association, who chaired the Joint Commission panel.

"You still have physicians who use medical jargon too much," Davis added, citing the use of "hypertension" instead of "high blood pressure" and "febrile" rather than "fever." Because doctors are rushed, he noted, they tend to lapse into medical jargon because it is what they are used to.

O'Leary said that the Joint Commission's interest in the issue should serve as a signal to hospitals to ramp up their efforts to communicate better with patients. Literacy improvements might be included in future standards hospitals must meet, he said, because they are inextricably linked to patient safety. At the Washington Hospital Center, the largest hospital in the District and health-care provider for many low-income and elderly patients, spokeswoman Paula Faria said administrators are aware of the problem and are examining admission forms and other documents to see whether they are intelligible as well as culturally sensitive. "We want to make sure that people understand what they're reading and, if they can't read, what they're hearing," she said.

Faria said that some departments are using a technique endorsed by the Joint Commission known as "teach back." Instead of asking a patient, "Do you have any questions?" -- which will probably elicit little in the way of a useful response and puts the patient on the spot -- doctors are taught to ask, "What is the most important thing you learned from our visit today?"

"You never want to put a patient in a situation where they feel like they're dense," Davis said.

Another effort regarded as promising, underwritten by drug manufacturer Pfizer, is called Ask Me 3. Designed by the Partnership for Clear Health Communication, a coalition of national health and literacy groups, the program encourages patients to ask three simple questions and to be sure they understand the answers: What is my main problem? What do I need to do? Why is that important?

Cordell, who has worked with the Ask Me 3 program as a patient advocate, said she also advises patients never to go to a doctor or to a hospital alone. Having another person present makes it more likely that necessary questions will be asked, she said.

Anyone who doesn't understand what a doctor or other health-care worker has said should speak up, Cordell said. "You can say, 'Look, you're giving me stuff I can't manage,' " she advised.

Comments: boodmans@washpost.com

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