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ESSAY

# Following Doctor's Orders Isn't Hard, if You Can Read

By ERIN N. MARCUS, M.D.

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.

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