The Health Care Dilemma of Patients Who Can't Read

December 28, 1995 by Phyllis Schlafly

"Our health care system requires that patients be able to read." That ought to be a self-evident truth that is silly to enunciate, but it is actually the sensational revelation of a major problem just made public in the December JAMA (Journal of the American Medical Association).

The JAMA article reports on the first study ever made to test literacy using words combined with numbers that are in common use in health care. It was a cross-sectional research project conducted at two urban hospitals, one in Georgia, the other in California.

The massive National Adult Literacy Survey made by the U.S. government in 1993 concluded that 40 to 44 million adults are functionally illiterate and that another 50 million are only marginally literate. This new health literacy study specifically measured the ability of patients to read and understand medical instructions and health care information according to a test called TOFHLA (Test of Functional Health Literacy in Adults) and discovered that 33 percent of patients did not understand instructions for common procedures written at the fourth grade level.

This health literacy study measured the ability of patients to perform such tasks as reading labels on prescription bottles, instructions about how often to take medication, notices about when is the next doctor's appointment, informed consent forms, instructions about diagnostic tests, and how to complete insurance forms. The depressing conclusion is that a high percentage of patients simply can't read well enough to function in our health care system.

People with inadequate literacy skills are unable to read a thermometer, write down instructions by telephone, or read common medical terms such as "orally," "teaspoon," and "hours." They can't access useful messages from newspaper and magazine articles, educational materials, posters in supermarkets, or billboards about the importance of screening procedures or flu shots.

Health care standards require hospitals to provide patients with understandable health instructions, but do not require that the instructions be understood. Hospitals assume they are complying if they give patients a readable document, but a written instruction assumes that the patients can read.

Patients who can't read informed consent forms present doctors and hospitals with what the researchers call "a troubling ethical issue." Even if an effort is made to simplify the forms to the sixth grade level, that still will not reach the many who are functionally illiterate.

This health literacy project turned up other new and useful information not hitherto unearthed by previous literacy surveys made by educational institutions.

Neither appearance nor years of schooling adequately predicts illiteracy. This means that illiteracy is not just a problem for minority dropouts or recent immigrants, but is a handicap suffered by all races and classes of people who have no visible signs of disability and have spent many years in school.

Many illiterates do not realize that they have a problem. They are like myopic children who don't know that they are simply not seeing details that others see.

Ronald Reagan tells in his autobiography how, as a young boy riding in the back seat of an automobile, he picked up someone else's glasses and tried them on. Suddenly he was able to see the leaves on the trees and other landscape details for the first time. Until that moment of revelation, he hadn't known that other children had been seeing so many things that he did not see.

The predicament of illiterates is similar. Never having been able to communicate with the printed word, they have no comprehension of the vast world from which they are excluded.

Even more prevalent is the pervasive problem of shame. People with limited literacy skills try to hide their inability to read. The large majority of illiterates describe themselves as reading and writing "well" or "very well."

The health literacy study shows that, among patients with low literacy skills, 67.2 percent have never told their spouse, 53.4 percent have never told their own children, and 19 percent have never told anyone at all.

I can confirm this from my own experience. In counseling adults, I frequently hear such confessions as "I can't read big words" and "I just discovered that my husband can't read."

The health literacy study admits that patients' noncompliance with their medical instructions has been generally assumed by physicians and hospitals to be caused by poor motivation or different personal values. The study calls for a reevaluation of patients who have been labelled "uncooperative"; it is more likely that doctors and hospital personnel, to whom reading is as natural as breathing, never imagined that the patients just couldn't read their instructions.

The JAMA article recognizes that illiteracy is not a disease and its solution cannot be medicalized. Since doctors and hospitals can't provide the solution, and the schools have obviously failed in the task, parents will have to take on the responsibility of teaching their children how to read.