

Low Literacy Increases Risk Of Death And Misunderstanding Of Medical Consent Forms

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Literacy at less than a ninth-grade level almost doubles the five-year risk of mortality among elderly people, regardless of education, socioeconomic status, or health, according to a study led by a researcher at the San Francisco VA Medical Center.

"From a public health standpoint, this has important implications," says lead author Rebecca Sudore, MD, a staff physician at SFVAMC and an assistant professor of medicine at the University of California, San Francisco. "Poor literacy appears to have long-lasting effects on patients' health. This is yet just one more reason why improving the educational system in the US is so important."

The study appears in the August 2006 issue of the Journal of General Internal Medicine, a special issue devoted to the topic of health literacy.

In another study led by Sudore that appears in the same issue, findings showed that only 28 percent of adults understood a highly simplified medical consent form the first time they encountered it, even after extensive modification of the consent process in order to improve understanding. The form, written at a sixth-grade reading level, was read aloud to subjects in English or Spanish as they read it for themselves.

"We cannot make the assumption that anyone, even highly literate native English-speakers, will understand medical consent information," asserts Sudore.

The literacy and mortality study analyzed data on 2,512 participants in the Health, Aging, and Body Composition Study that was conducted by the National Institute on Aging from 1999 to 2004. Study subjects, aged 70 to 79, lived independently in the community in Memphis, Tennessee or Pittsburgh, Pennsylvania. The study excluded participants with dementia or poor physical functioning.

Among participants with limited literacy - defined as a reading level of less than ninth grade - the death rate was 20 percent. Among all others, the death rate was 11 percent. After taking into account gender, race, socioeconomic status, education, health status, health care access, and health-related behaviors, the authors concluded that limited literacy increased the risk of death by a factor of 1.75.

Only two other factors had a stronger association with mortality, according to the study. Self-reported poor health increased mortality risk 2.17 times (Sudore notes that self-reported health status is a robust measure of actual health). Being a current smoker increased the risk of death 3.09 times.

Given the observational nature of the study, says Sudore, the researchers could not ascertain why low literacy increased the risk of death. She offers a number of possible reasons, including a link between illiteracy and poverty.

"Many studies have shown that people with lower socioeconomic status have higher mortality rates," she notes. "It could be that people with limited literacy have fewer economic opportunities, lower paying jobs, and lower socioeconomic status overall. There may have been socioeconomic factors and combined lifetime effects of lower socioeconomic status that we could not assess in this study."

In addition, says Sudore, "limited literacy might be the result of poorly controlled chronic disease over time - that is, your disease burden is so high that it interferes with cognitive processing."

Finally, she adds, "Our health care system places high literacy demands on patients, so limited literacy likely impedes access to health care and chronic disease management. Poor understanding of how to take medication or how to manage chronic disease, not to mention being unable to navigate through the complex health care system, could also cause increased mortality."

Sudore warns that low literacy might have profound implications for public health. "The elderly population is growing, chronic disease is on the rise, and we know that the socioeconomic disparities

associated with poor health and death persist into old age. Is there any better reason to redesign our health care system so that our patients actually understand health related information and are empowered to manage their disease processes?"

The study was part of an actual trial of advance directives, the name given to the forms that allow patients to state their wishes ahead of time with regard to medical treatment and end-of-life care.

"We did not design the modified consent process in order to write a paper, but because we wanted to protect patients who were enrolling in our trial," says Sudore. "Studies have shown that up to 80 percent of patients don't understand some aspect of consent information, and that low literacy is probably a factor. Most consent forms are written at a 12th grade level or beyond. We were concerned that a vulnerable, possibly illiterate patient population would not be able to understand the sensitive nature of end-of-life issues associated with our trial if we used conventional consent forms."

The researchers recruited 204 adult subjects, fluent in English or Spanish, with a mean age of 61 years. Forty percent had limited literacy. The subjects were given a consent form written in English or Spanish at a sixth grade-reading level, and asked to read along slowly while native speakers read the form aloud to them. The speakers stopped frequently to ask if the subjects understood what was being read to them. They then asked the subjects seven true-or-false questions designed to probe comprehension.

"If they missed any of the seven questions, we'd go back to the form, read aloud the sections of the consent form they misunderstood, then go back to the questions they missed and ask a second time," recounts Sudore. "We did this until they got all the questions right, or until they required more than six passes through this consent process."

Only 28 percent of subjects got all questions right on the first pass.

Fifty-two percent needed a second pass and 20 percent needed three or more passes before they fully understood the consent form. Two percent of subjects did not understand the form completely after six passes.

"The good news is that only two passes were required for 80 percent of people," Sudore notes. "The bad news is that most subjects had poor comprehension on the first pass - in spite of the form being written at a sixth-grade reading level and read aloud, and also in spite of participants being asked frequently if they had any questions."

After taking into account age, race, education, gender, language, and literacy, the researchers found that only low literacy and minority status were associated with requiring two or more passes through the consent form.

According to Sudore, "Among blacks as opposed to whites, the odds of requiring more passes were 2.5."

Sudore speculates the reasons might have to do with an already-existing high level of distrust of medical studies among African Americans.

She cites the Tuskegee Study, in which the United States Public Health Service withheld syphilis treatment from a group of 399 African-American men for 40 years, from 1932 to 1972. "A history like that is not going to engender an atmosphere of trust and openness," she says, noting that the study could not assess the affects of potential mistrust of black versus non-black research staff because none of the research assistants were African American.

Sudore also notes that language was very important. Among subjects who stated they were fluent in English or Spanish but were native in another language, "every single one required more than one pass, regardless of literacy level," she says.

Sudore concludes that modifying the medical consent process "has now become a matter of ethics. It's easy to shove a consent form under a patient's nose and tell them to sign it. This happens with clinical and research procedures all the time - rarely does someone actually read the consent form to the patient and assess understanding before the procedure or study. The results of our study indicate that most patients probably don't know what they're signing. But if we modify the consent process by simplifying the consent language, reading the information to patients, and formally assessing

understanding in order to clarify any misunderstanding, most patients will be able to give informed consent."

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Co-authors of the literacy and mortality study were Kristine Yaffe, MD, of SFVAMC and UCSF; Suzanne Satterfield, MD, of the University of Tennessee; Tamara B. Harris, MD, of the National Institute on Aging; Kala M. Mehta, DSc, of SFVAMC and UCSF; Eleanor M. Simonsick, PhD, of NIA; Anne B. Newman, MD, and Caterina Rosano, MD, of the University of Pittsburgh; Ronica Rooks, PhD, of Kent State University; Susan M. Rubin, MPH, and Hilsa N. Ayonayon, PhD, of UCSF; and Dean Schillinger, MD, of UCSF and San Francisco General Hospital.

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