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HEALTH LITERACY AND A PATIENT'S RIGHT TO UNDERSTAND

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The 2005 White House Conference on Aging (WHCOA) Mini-Conference on Health Literacy and Health Disparities focused on the role of limited literacy and low understanding of health information as a cause at the root of health disparities and poor health outcomes in the United States.

In their executive summary, the conferees stated: *“Patients have the right to understand healthcare information that is necessary for them to safely care for themselves and to choose among available alternatives. Healthcare providers have a duty to provide information in simple, clear and plain language and to check that the patients have understood the information before ending the conversation.”*

ADVERSE OUTCOMES

In the last quarter-century, research has repeatedly shown that patients leaving a physician’s office are unable to recall or explain between 46% and 63% of the medical information they have been given. These misunderstandings have been shown to lead to adverse clinical outcomes. The early responses to these distressing studies were to concentrate on the patients—exhorting them to become more involved and activated, ask questions, participate, share in decision making and manage their own care. Only after the publication of the National Adult Literacy Survey (NALS) in 1993, with its startling revelations of the functional literacy levels of Americans, did educational and health researchers begin to look more deeply into the effectiveness of oral and written healthcare communications and the barriers poor communication created for patients.

Although the average American reads at the eighth-grade level (at or below level two of the five-level NALS scale), most healthcare information has been written at a college level. Also, most informed-consent documents are written at a 17th-grade level. Of particular concern are the difficulties encountered with numeracy: The approximately one-half of Americans falling into the NALS level-one and level-two categories (around 90 million adults in the United States) demonstrated great difficulty in answering questions based on their reading and interpretation of bar graphs or charts, such as train or bus schedules.

All healthcare directions involve numeracy. For example, “Take 1 teaspoon four times a day.” Directions that use simple words and seem very clear to the health professional can be very confusing to people who try to carry them out and realize at home that they do not have enough information to confidently follow the instructions correctly. In this case, how do you divide a 24-hour day by 4? Do you count night as “day”? Do the instructions mean to take the medicine every six hours, or every three-and-a-half hours while awake? Does the interval have to be spaced out? Could one take two teaspoons in the morning and two at night, or one dose every hour? And is a teaspoon a regular spoon or a soup spoon?

In addition, what happens to older adults who take multiple medications with differing instructions and schedules throughout the day? Over the years, many studies have reported that up to 30% of hospital admissions for people 65 or older are caused by “medication misadventures.”

90 MILLION AT RISK

According to the Institute of Medicine 2004 report “Health Literacy: A Prescription to End Confusion,” 90 million Americans are at risk for medical misunderstandings, errors, poorer health outcomes

and higher medical costs because of their limited literacy skills.

While the majority of those people are white, native born and educated in American schools, minority populations face additional barriers. More than 10% of the U.S. population has limited English proficiency, but more than 50% of the patients who enter healthcare facilities in New York City, for example, don't speak English. In some situations, English speakers are the minority.

Most of the studies looking at low literacy and limited English proficiency have concentrated on the Latino population. Literacy levels for U.S. Spanish-speaking patients tested in Spanish were lower than the average English-speaking American tested in English. Although 47% of the English speakers had inadequate or marginal literacy skills, fully 62% of the Spanish speakers had inadequate or marginal literacy skills in their primary language.

Data published in December 2005 from the 2003 National Assessment of Adult Literacy (NAAL) identified a big decline in the Latino population's English-reading skills over the last decade (since the NALS). Only Hispanics who could read English were tested in both the NALS (1993) and the NAAL (2003), but whereas 35% fell into the lowest level in 1993, that segment increased to 44% in 2003.

This rapidly growing population may be very difficult to identify: They may be very articulate in spoken English but their literacy skills in English may be at a basic level that is inadequate for understanding complex health information. For example, one study of patients who felt their English was adequate enough that they did not need an interpreter revealed that 36% of those surveyed could not describe their diagnosis correctly and 31% could not describe their medication directions accurately.

SHORTAGE OF INTERPRETERS

There is a tremendous shortage of trained medical interpreters (as well as very limited funding for them), so untrained staff and family members are often called in to interpret for patients. One study of the use of untrained interpreters found an average of 31 mistakes per visit—and 60% of those errors had negative clinical consequences. Poor, untrained interpretation has been correlated with a greater probability of hospital admission, longer times in the emergency department, a 39% increase in healthcare charges, poorer health outcomes and reduced compliance with medication regimens.

The WHCOA Mini-Conference on Health Literacy and Health Disparities recommended, *“Training and certification programs for interpreters should be developed, and these health professionals should be recognized as an essential part of the healthcare team, and payment should be provided for their services.”*

The training of interpreters and the health professionals who must rely on them needs to include information about low health literacy and the importance of translating information from medical jargon into lay language. Interpreters and professionals need to encourage patients to “teach back” the information they provide them. Professionals must learn to say, for example, “Tell me or show me how you are going to do this when you get home.” This step is an essential part of every healthcare encounter. All interpreters need to be familiar with eliciting and evaluating this kind of teachback.

Although many recommendations from the WHCOA mini-conference called for specific actions by the U.S. Congress, the Centers for Medicare and Medicaid Services, the Food and Drug Administration and other agencies, several overarching recommendations were directed to all health and social service professionals:

- Training in communication strategies (to include giving clear instructions and assessing patient understanding) should be implemented for all professional and administrative staff to ensure that all patients or clients can accurately summarize the information they need in their own words and demonstrate how the information can be applied in their daily life.
- Public health messages and community outreach should use simple, clear, plain language. Messages should be field-tested with consumers for accuracy and understanding. Special attention should be paid to multicultural media such as radio, local newspapers, and community and faith-based organizations. In addition, health literacy efforts should include working with social service agencies, libraries, adult education and local literacy programs.
- Simplify and standardize written and oral communications to improve patient understanding, increase patient safety and reduce medication misuse. ❖

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