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Functional Health Illiteracy: What patients don't know can hurt them! By: James L. Holly, MD

Health literacy -- the ability to understand and act on health information -- is essential for high-quality healthcare. Many people, especially the elderly, who bear the greatest burden of disease, have inadequate health literacy. This adversely affects their quality of care. Learning to recognize when a patient may have low literacy skills and understanding the common ways in which these people misinterpret medical information can help physicians develop strategies to improve patients' health literacy.

In order to identify patient's at risk of not getting the maximum benefit from their health care, Southeast Texas Medical Associates is adopting the *Test of Functional Health Literacy in Adults (TOFHLA)* to help patients know if they understand what their healthcare provider tells them. Patients who score lower than 60 points on the *TOFHLA* are considered to have inadequate health literacy, and often misread dosing instructions and appointment slips. If a patient's *TOFHLA* is low, special attention can be given to helping all patients understand their role in their own health.

A 2002 study reported in the *Journal of the American Medical Association*, stated "for each 1 point decrease in the *Test of Functional Health Literacy in Adults (TOFHLA)*, the glycosylated hemoglobin (HbA_{1c}, a measure of blood glucose levels over time) increased by 0.02. Patients with inadequate health literacy were less likely than patients with adequate health literacy to achieve tight glycemic control and were more likely to have poor glycemic control and to report having retinopathy (eye disease)." The study concluded, "After adjusting for other socioeconomic and clinical factors affecting glycemic control, patients with inadequate health literacy had nearly one-half the odds of patients with adequate health literacy of achieving tight glycemic control (hemoglobin HbA_{1c} of 7.2 percent or less) and a two-fold greater odds of having poor glycemic control (HbA_{1c} of 9.5 percent or more) and to report having retinopathy."

The more a patient knows about his/her illness, the better healthcare outcome the patient will have with chronic diseases such as diabetes, congestive heart failure, asthma, headaches, high blood pressure, metabolic syndrome and others.

Language Illiteracy Promotes Health Illiteracy

A shocking number of patients cannot participate effectively in their own care for the simple reason that they cannot read adequately. Compounding the problem, physicians speak a specialized language (“medicalese”) that is often unintelligible to outsiders. Moreover, many patients are expert at concealing their poor literacy skills. Inadequate health literacy has measurable ill effects on health. Given the increasing complexity of health care, which requires increased involvement of patients, we need to address this common but underappreciated problem and find ways to communicate with patients more effectively.

Good communication between physician and patient is a cornerstone of good health care. Yet, many patients have difficulty understanding their doctors’ instructions. Even immediately after leaving the physician’s office or the hospital, patients may recall no more than 50% of the important information just given to them.

Furthermore, communication between physician and patient is becoming more difficult as health care becomes more complex. For example:

- 30 years ago there were only about 650 prescription drugs, and
- the average hospital stay for acute myocardial infarction was 4 to 6 weeks;
- today there more than 10,000 prescription drugs, and
- a hospital stay for acute myocardial infarction is typically 2 to 4 days.

In addition, with the increasing prevalence of chronic conditions such as diabetes, high blood pressure, and congestive heart failure, patients are required to know how to manage their own health care outside the clinic and hospital.

Health Literacy

The sentiment that “what I don’t know can’t hurt me” was clearly never true in the area of health, and the increasing complexity of medicine has made what the patient doesn’t know ever more dangerous. Health care providers are often unaware of the shocking ineffectiveness of our communication of basic information to patients about their diseases and treatments. Patients often walk out of a medical office newly burdened with diagnoses they don’t understand, armed with powerful and dangerous drugs and with precious little to help them in case something goes wrong.

An individual’s *health literacy* – “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” -- may be significantly worse than his or her general literacy, because functional literacy is context-specific.

Teaching Methods Obsolete

At least in the case of chronic diseases, it may be time to recognize that the traditional one-on-one method by which a physician teaches a patient about the disease has become obsolete. While face-to-face time with the physician is certainly necessary, it may be beneficial to supplement this with more formal classroom teaching by professional educators as part of a team approach to patient care. Patient education has become a discipline in itself, with its own scientific basis, and physicians need to take better advantage of it.

SETMA recognizes these problems and addresses them

At the very least, patients should be given written information about self-management of their illness at each visit. In subsequent visits, the patient's understanding of that material should be tested. That is why at SETMA, we not only have developed an education department for diabetes, metabolic syndrome, hypertension, congestive heart failure and weight management, but we also have the capacity to give every patient precise and useful educational information on their illness each time they attend clinic.

How Can Healthcare Providers Help?

Do not assume that the patient understands what they are being told. The language of medicine is highly technical, and outsiders may not understand it. Studies have reported a large variation among patients in their ability to comprehend commonly used medical terms:

- only 13% of the 125 participating patients understood the meaning of “terminal,”
- 35% understood “orally,” and
- 18% understood “malignant.”

Other studies reported low comprehension in other critical areas of good health care, such as understanding written directions for taking medications, understanding clinical appointment slips, and informed consent forms. A study of Medicare patients found that:

- 48% did not understand the written instructions “take medicine every 6 hours”
- 68% could not interpret a blood sugar value
- 27% could not identify their next appointment
- 27% did not understand “take medicine on an empty stomach” (instructions written at 4th grade level)
- 100% could not understand a statement of Medicaid rights (written at a 10th grade level).

More than 2,500 patients tested at two public hospitals and found that 35% of English-speaking patients and 62% of Spanish-speaking patients had inadequate or marginal

health literacy. Patients over 60 years old have a particularly high prevalence of inadequate health literacy: more than 80% at one of the public hospitals.

Physicians are often unaware that patients do not understand them. Patients, on their part, often feel shame over their lack of literacy skills and most often will not acknowledge this deficiency despite its interference with their care.

Recognizing inadequate health literacy

A healthcare provider may not know that his/her patient has inadequate or marginal health literacy. The patient's level of education does not guarantee that he or she can read. A study in five family practice clinics found that over 60% of patients tested had a reading skill that was at least three levels below the school grade they completed. In the large Medicare survey previously described, 27% of the patients who had a high school diploma and 17% of those who had some college education had inadequate or marginal health literacy.

Toward Better Communication

Physicians can improve their communication with patients with low literacy skills by learning to recognize the particular ways in which these patients deal with communication. Patients with low literacy skills tend to:

- interpret words literally (e.g., thinking hypertension means “being hyper”) and
- often have difficulty identifying key concepts (or prioritizing or distinguishing them from minor details).

This difficulty with language is the most frequent area of miscommunication between physician and patient. Several types of words that physicians commonly use are difficult for these patients to comprehend, such as:

- words denoting concepts (e.g., normal range),
- categories (e.g., ACE inhibitors), or
- value (e.g., excessive bleeding).

Another area of miscommunication is related to the lack of training in science and medicine in most patients, which can lead to logic problems. For example, it may seem logical to patients to stop a 10-day course of antibiotics once they feel better, even though they've been instructed to take the full course. Physicians understand the science and medical implications of stopping antibiotics mid-course, but this is not clear to many patients (even those with higher levels of literacy).

Ways to improve health literacy include:

- simplifying or clarifying patient education materials,

- with particular focus on the use of visual aids such as videos, pictographs, and cartoons.
- Studies show that visual aids improve comprehension, compliance, and retention.

Physician involvement in delivering these materials and educating the patient are critical for enhancing health literacy. Including family and friends in helping deliver health information is also important, as patients with inadequate health literacy often go first to people they know for explanation.

Patients May Misunderstand Many Medical Terms

The following are ways to improve understanding in patients with low health literacy

- **Slow down** -- Take time to assess patients' health literacy skills
- **Use "living room" language instead of medical terminology** -- Use language that patients can understand
- **Show or draw pictures** -- Visual aids enhance understanding and subsequent recall
- **Limit information given at each interaction and repeat instructions**
- **Use a "teach back" or "show me" approach to confirm understanding** -- Ask patients to demonstrate their instructions to ensure that instruction has been adequate. Never ask "do you understand?" Typically, patients will say yes even if they don't understand
- **Be respectful, caring, and sensitive** -- This attitude reassures patients and helps them to improve participation in their own health care

And, for the patient, the charge is always to ask and keep asking until you are clear and sure you understand. Remember, it is your life and it is your health.