

MIEC Claims Alert

Number 41
March 2009

Health literacy: A national dilemma

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Health literacy can be defined as the degree to which individuals have the capacity to obtain, process, understand and act upon basic health information and services needed to make appropriate health decisions.¹

National data on health literacy is alarming; a recent study estimates the cost of low health literacy to be between \$106-236 billion annually.² Another study concluded that a large percentage (53%) of patients are functionally illiterate and are unable to comprehend consent forms; cannot follow written directions, such as advice to take medications on an empty stomach; and are unlikely to understand what physicians say, prescribe, and advise.³ A third study found that approximately 50% of patients have problems understanding health literature, forms, medication instructions, medical literature, and disease management.⁴ These three studies reinforce what the medical community has known for decades: low health literacy will continue to harm patients, expose physicians to liability and compromise the nation's health care system unless physicians and patients take

proactive steps to improve patient understanding. This newsletter will discuss why physicians should attempt to determine patients' health literacy levels, review closed claims in which health literacy played a role in the outcome, and will offer suggestions and resources on improving health literacy and patient safety.

National Data

According to the 2003 National Assessment of Adult Literacy report, more than 90 million Americans have below basic or basic health literacy, making it difficult for them to comprehend most medical information. Fourteen percent (14%) had below *basic* literacy (can identify the date and time of an appointment on a confirmation slip); 22% had *basic* literacy (can explain why a test should be performed based on reading a disease-specific pamphlet); 53% had *intermediate* literacy (can determine the healthy weight range and BMI for a person based on a height and weight graph); and 12% had *proficient* literacy (can determine the potential risks of a procedure based on a multi-page consent form).

Moreover, adults 65 and older had lower average health literacy than adults in younger groups, and nearly

Special Report Claims Alert

A publication of the Loss Prevention Department, Medical Insurance Exchange of California, 6250 Claremont Ave, Oakland, CA 94618. Articles do not constitute legal advice.

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1 "Low Health Literacy: Implications for National Health Policy," University of Connecticut. October 2007
 2 "The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy," The US Department of Education. <http://nces.ed.gov/pubs2006/2006483.pdf>
 3 "Health Literacy: A Prescription to End Confusion," 2004 Institute of Medicine.
 4 *ibid.*

half of the adults who never attended or did not complete high school had a *below basic* health literacy. Literacy levels may be low for those patients for whom English is a second language.

Assessing Health Literacy:

What if your patient can't read?!

Low health literacy affects a person's health status more than any other factor, including income, education, employment or nationality. People may speak English well, but still have low health literacy because their ability to read and comprehend English is inadequate. Low health literacy and poor adherence to medical advice may increase liability exposure and the potential for patient injury.

Many patients take medications incorrectly because they don't remember what was discussed during the encounter. Other patients may identify sounds, shapes and colors more readily than numbers and letters which may be problematic because

many drugs look alike and have names that sound similar.

During an encounter, your patient with *basic* literacy skills remembers less than half of what you try to explain. For example, if patients routinely forget their glasses at home or can't read the small print on a medication label when asked, they may be embarrassed to admit that they have difficulty reading and/or comprehending the medication label. These patients need help but may be reluctant to ask because they fear embarrassment, making it nearly impossible for you to determine whether they appreciate the importance of following your medical advice.

Gerald Moore slouched into the doctor's office clutching his John Deere cap to his chest, gray hair semi-obscuring his eyes. He stood in front of the receptionist's window until she looked up and asked him if he had an appointment. He assented with a murmur and a nod. Carol, the receptionist, politely asked Gerald to add his signature to the sign-in sheet, which he did slowly, his work-thickened fingers making

the task look difficult. Then Carol handed Gerald a clipboard with a list of ten questions about his demographics and his health history. Gerald accepted the clipboard, sat down, and stared at the questionnaire.

Ten minutes passed. Carol noticed that Gerald's questionnaire remained free of responses to the questions. "Mr. Moore," said Carol. "Do you have questions about the form?"

Gerald startled, said gruffly, "All I want to do is see Dr. Santana. I don't want to answer all these questions."

"Dr. Santana asked me to give you the form to fill out," Carol said softly.

"I don't care. I just want to see him."

"Please cooperate, Mr. Moore. You need to fill out the form before you see the doctor."

"Don't tell me what to do. I have an appointment with the doctor, and I want to see him." Carol sighed heavily, turned from the

COULD THIS HAPPEN TO YOU? The 54-year-old Middle Eastern-born, poorly-educated patient presented to the ED with what appeared to be symptoms of appendicitis. He was appropriately evaluated, the diagnosis was equivocal, and his symptoms improved before he was released from the ED. He was given a patient education handout that specifically cited the symptoms that "should they occur within the next twelve hours" would require that he return to the ED. The symptoms occurred, he did not return for another 48 hours, and by the time he did, his abdomen was severely compromised. Ultimately, the complications lead to loss of the patient's testis and a portion of his inner thigh. The patient denied being told to return with increased symptoms, and denied he was given a handout.

The case may have resolved in the doctor's favor had the RN documented: she gave the patient the handout; reviewed the information with him; the patient verbalized understanding; and, she advised him to review the handout a second time with a friend or family member who could read English. (There was no evidence in the chart that the patient was given written information, received an explanation or that the patient's literacy level had been assessed.)

window and went to Marsha, the office manager to explain what was happening. Marsha went into action, and marched to the reception area with a determined look on her face.

She repeated a similar exchange with Gerald, a little more firmly but with as little luck, and in exasperation she told him that she was going to have to tell the doctor that he was uncooperative with them. "All I want to do," said Gerald stubbornly, "is talk to the doctor." Marsha gave up and took Gerald to the exam room. The deliberate stamp of his feet down the hall was audible evidence of his displeasure.

Forty-five minutes later, Dr. Santana called Marsha aside and asked her what had happened to anger Mr. Moore. When Marsha had described what had taken place, Dr. Santana sighed. "You don't know his story, Marsha. He grew up on a hard-scrabble farm. His parents were uneducated and poor, and somehow, between work, responsibility, and his parents' lack of sophistication, Gerald only went to school sporadically, and he never learned to read. He's done unskilled labor all his life, and I'm sure he's embarrassed that he is an adult who can't read. Now he's angry, he's been shamed, and he's got some medical problems that frighten him. We have to find a strategy to address all his issues in order to get him to cooperate in his care."

You can't tell by looking

Low health literacy poses a problem for the majority of physicians because they may not notice until a patient is injured. Most patients lack physical characteristics that indicate illiteracy, and most patients will not disclose that they cannot read or write. Here are some cues that could play an important role in assessing patients' health literacy levels:

- Incomplete or inaccurate registration forms;
- Frequently missed appointments;
- Lab results not consistent with prescribed medication use;
- Problems "remembering" medication information;
- Inability to comprehend a consent form;
- Inability to follow written directions;
- Failure to keep appointments with specialists;
- Use of emergency departments for non-emergent or routine care; and
- Reference to medication by color, size, or shape.

The Agency for Healthcare Research and Quality offers physicians numerous tools to measure and aides to improve health literacy. (See **Figure 1**)

You need to identify, assess and accommodate health literacy in order to obtain optimal results when discussing treatment options (e.g., whether or not to have surgery); reading health information (e.g., understanding a consent form); and calculating when and how to take medications (e.g., three times a day on an empty stomach with a glass of milk).

The task of assessing patients' healthy literacy level needn't be your responsibility alone. Enlist properly trained staff to personalize communication in an effort to improve comprehension and compliance. Consider the following:

1. Don't overwhelm patients; most can only absorb two or three key messages in a visit. Tailor your communication to make it easier for patients to understand and comply with your advice.
2. Ask patients to tell you what they heard you say.
3. Check your listening skills to make sure you are actively listening.
4. Ask patients to show you what medications they take, why they take them, and how they take them.
5. Keep forms simple. Use large print when appropriate.
6. Ask staff to help patients fill out forms or read educational materials.

COULD THIS HAPPEN TO YOU? Dr. Chang spent considerable time explaining the risks, benefits, and alternatives of knee replacement surgery to Mrs. Lee, his 65-year-old patient. Mrs. Lee was a retired seamstress who lived alone. He then gave her a pamphlet that explained thoroughly all the highlights of what he had said orally. He advised her to read it carefully and ask questions if she had any.

The written information went into exquisite detail about the possible risks of surgery, including infection, blood clots, loosening of the prosthesis, numbness, bleeding, loss of motion, and more. When Mrs. Lee's knee regained no more than 50% of her anticipated range of motion, she sued Dr. Chang, saying that not only had he incorrectly conducted the surgery, but if she had known her range of motion was going to be impaired to that degree, she would never have consented to the surgery.

Much to Dr. Chang's surprise, the jury was sympathetic to the patient when her attorney informed them that Mrs. Lee had never read the handout her doctor gave her. She spoke English well, but did not read it at all, and Dr. Chang had not asked her if she could read. She swore under oath that he had not mentioned the possibility of the immobilization she experienced; he had no documentation to the contrary even though his chart reflected that he told her to read the handout.

7. Provide patients with a pill card that includes simple instructions for taking medications. (See the *Resource* section for pill card development.)
8. Use analogies when possible; patients are more likely to understand the comparison of something familiar to something unfamiliar. For example, when explaining how the heart works, consider: "The heart is like a pump," or "An aneurysm is like a bulge in a garden hose."⁵
9. Avoid medical jargon. In some cases, it is not possible to simplify your language; however, asking a patient, for example, "Have you ever had irregular heart beats?" rather than "Have you ever been diagnosed with cardiac arrhythmia?" may be easier for patients to understand and accurately answer.

Create a safe environment

Your practice culture may influence patients' willingness to ask for additional information or assistance. The prudent physician will create a safe environment that invites patients to ask questions without the fear of appearing "dumb."

Health literacy is a crucial factor in patient safety; patients who understand your instructions are more compliant and less likely to become injured as a result health illiteracy. Make a commitment to assist all patients, including those with low health literacy:

- Speak slowly and clearly;
- Convey warmth and make eye contact during patient encounters;
- Wait for a response before moving on to the next topic;
- Encourage questions and open discussion of health care issues;

- Encourage patients to take notes during the encounter;
- Help patients color-code or organize their medication for daily consumption;
- Invite family members to participate in the management of chronic conditions;
- Offer group educational workshops to patients with chronic medical conditions;
- Use audio-visual aids to assist in educational efforts (e.g., posters, videos, tapes, CDs, DVDs);
- Provide written instructions to supplement oral instructions in patients' primary language; and
- Educate patients on how to spot problems with medications, wound appearances, etc.

⁵ The Altoona List of Medical Analogies, <http://www.altoonafp.org/analogies2.htm>

Literacy resources:

The following resources offer information and tools for improving your patients' health literacy:

For a free comprehensive on-line learning tool that will help you improve your communication with patients, and help you implement effective communication practices visit: www.train.org.

Agency for Health Research and Quality

<http://www.ahrq.gov/qual/pillcard/pillcard.htm#How>

<http://www.ahrq.gov/populations/sahlsatool.htm>

AMA Foundation Health literacy

<http://www.ama-assn.org/ama/pub/category/8115.html>

Institute of Medicine

<http://www.iom.edu/CMS/3775/3827/19723.aspx>

National Institute for Literacy

<http://www.nifl.gov/>

Network of Libraries of Medicine

<http://nnlm.gov/outreach/consumer/hlthlit.html>

U.S. Department of Education

<http://nces.ed.gov/naal/>

U.S. Department of Health and Human Services

www.health.gov/communication/literacy/default.htm

<http://www.hrsa.gov/healthliteracy/training.htm>

U.S. Department of Health & Human Services Office of Disease Prevention & Health Promotion

<http://www.health.gov/communication/literacy/default.htm>

U.S. Government Interagency LEP Work Group

<http://www.lep.gov/>

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Explanation: The agency for Healthcare Research and Quality, Rockville, MD, developed this measuring tool to aid physicians in assessing patients' literacy levels. MIEC encourages you to follow the instructions below to determine the health literacy levels of your patients. Once a patient's literacy level is determined, you and your staff can tailor your oral and written communication to improve patients' compliance to your medical advice, increase patient safety, and reduce your liability exposure.

Rapid Estimate of Adult Literacy in Medicine--Short Form (REALM-SF)

Patient name _____ Date of birth _____ Reading level _____

Date _____ Examiner _____ Grade completed _____

Menopause	
Antibiotics	
Exercise	
Jaundice	
Rectal	
Anemia	
Behavior	

Instructions for Administering the REALM-SF

1. Give the patient a laminated copy of the REALM-SF form and score answers on an unlaminated copy that is attached to a clipboard. Hold the clipboard at an angle so that the patient is not distracted by your scoring. Say: "I want to hear you read as many words as you can from this list. Begin with the first word and read aloud. When you come to a word you cannot read, do the best you can or say, 'blank' and go onto the next word."
2. If the patient takes more than five seconds on a word, say "blank" and point to the next word, if necessary, to move the patient along. If the patient begins to miss every word, have him or her pronounce only known words.

Figure 1

Before filling in the REALM-SF:

Some patients are embarrassed and ashamed of their lack of education and/or reading skills. Tools to assess patients' health literacy, when diplomatically introduced, can assist you to determine what you will need to do to ensure that patients understand your explanations, advice, and directions. One tactful approach might be:

"I (doctor) want to be as effective as possible in communicating with you (patient). In order to help me help you, I'd be grateful if you would go through this little exercise with me. Your responses will help me understand what I should say and how I should say it when I give you information about your illness / medication / treatment, etc."

After filling in the REALM-SF:

"Thank you. I appreciate your help. Please ask me questions if you have any. Medical terms are not everyday words for most people, and I now have a better idea of how I should choose my words when we talk. The better we communicate, the better collaborators we are in your health care."