Health Literacy: It’s Time To Take It Seriously!

Have you ever thought that the explanations you gave to patients and families were understood, only to find out later that they misunderstood what you said, and an error was made? Listen to what one patient experienced when she tried to hide her shame about her inability to read well.

“At the age of 30 or 31 I went into the gynecologist and complained that part of this was not working properly. And he said we can repair that. Great! I didn’t ask all the right questions. When I showed up two weeks later at the admissions office at the hospital, they put enough papers in front of me; I bet there were 5 papers that I needed to sign. I wasn’t going to say excuse me, but I don’t read very well and I certainly don’t read fast, and I’m concerned with some of these words. To me it was lines and circles over sheets, and sheets, and sheets, and I wasn’t going to reveal my sense of stupidity. So I signed where they told me to sign. Never read it. And a couple of weeks later in the office follow-up visit, the nurse said, “how do you feel since your hysterectomy?” Now I acted as normal as I could. Inside my mouth fell open and I thought to myself, “How could I be so stupid as to allow somebody take part of my body and I didn’t know?”

Mrs. C-S’s experiences, unfortunately, are not uncommon. To hear directly from additional patients who have low literacy as to what it is like to communicate with most health professionals, view the videotape Health Literacy: Help Your Patients Understand, produced by the American Medical Association Foundation (2003)

http://www.ama-assn.org/ama/pub/category/8035.html
What is general literacy?

Individuals with low general literacy skills have greater difficulty with health literacy than those who are more proficient readers. However, literacy varies by context and setting and is not necessarily related to years of education or general reading ability. A person who functions at home or at work may have marginal or inadequate literacy in a health care setting. The 2003 National Assessment of Adult Literacy (NAAL): http://nces.ed.gov/naal/resources/execsumm.asp defines general literacy as “Using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential.”

What is health literacy?

The Healthy People 2010 defines health literacy as “The ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Quite simply, health literacy is the ability to read, understand and act on health information to make informed decisions. http://www.healthypeople.gov

Why is health literacy important to you as a health professional?

Low health literacy is a serious threat to the well being of our patients and ultimately to the stability of the health care system. Chances are high that some of your patients are among the 43% percent of Americans that struggle to understand and act on health information. In fact, you may not even know that these patients exist because they are often too embarrassed or ashamed to admit they have difficulty understanding instructions, and they use well-honed coping means to effectively mask their problem.

These patients are often the ones who do not follow our instructions and we label them as being difficult or non-compliant. They often are those who are “repeaters” in our Emergency Departments or hospitals and they are sicker when they come to us. They require additional care that results in annual health care costs that are four times higher than for those with higher literacy levels.

Many of our regulatory agencies, such as the Joint Commission on Accreditation of Healthcare Organizations, have standards that specify the need for patient education and informed consent to be communicated in such as way that the patient understands. If these standards are not complied with, it will affect the accreditation status of the organization. Also, clinicians and hospitals can be held liable for adverse patient outcomes as a result of them not understanding important health information about their diagnosis, treatments, and self-care. Providing all patients with easy-to-understand health information, not just those with limited literacy skills, will ensure that the standards are met and that situations that could lead to litigation do not occur.
Attorneys estimate that a clinician’s communication ability, style, and attitude are major factors in nearly 75% of malpractice suits.

Malpractice lawsuits based on provider-patient communication usually results from:
- Inadequate explanation of diagnosis / treatment
- Patients feeling ignored or rushed
- Clinician fails to understand patient’s and family’s perspective or discounts / devalues their views

Why is health literacy important as a public health issue?

Low health literacy has been linked to less knowledge of disease and self-care, less health promoting behaviors, poor health outcomes, and more use of health care resources and costs.

Health-Related Knowledge:
Persons with limited literacy skills often do not understand basic health concepts associated with knowledge of diseases. Patients with inadequate literacy and chronic conditions were less likely to:
- share in the decision-making about prostate cancer treatment.
- know how to use an inhaler for asthma, how to avoid allergic substances, and to see a doctor even if they do not have an attack.
- know about one’s HIV status, and AIDS disease and treatment
- know how to read a thermometer
- know about exercise and weight loss if they have high blood pressure

Health-Promoting Behaviors:
- Less use of preventive services (flu and pneumovax vaccine, mammography, Pap smear)
- More likely to present with late stage prostate cancer
- If pregnant, less knowledge and concern about the effects of smoking on the baby
- Less likely to be tested for gonorrhea
- Less likely to initiate and continue breastfeeding during the first 2 months

Health Outcomes / Status:
- Poor glycemic control and higher rates of complications in patients with diabetes
- Lower medication compliance rates
- Worse skills using a metered dose inhaler
- More likely to be non-adherent with HIV/AIDS therapy
- Five times more likely to misinterpret prescriptions
- 42% did not understand instructions to “take medicine on an empty stomach.”

Use of Health Care Resources:
- 52% higher risk of admission to the hospital
- More emergency department visits

Literacy skills are a stronger predictor of an individual’s health status than age, income, employment status, educational level, and racial or ethnic group.
- Over 25% did not understand when their next appointment was scheduled
- Over 85% misunderstood the rights and responsibilities of a Medicaid application
- Lack the needed skills to effectively navigate the complex health care system

**Health Care Costs:**
Poor health outcomes and health status translate into increased costs for the health care system through medication errors, re-admission rates, more hospitalizations with longer stays, more use of emergency departments and doctor visits, extra tests, procedures and prescriptions.
- The impact of low health literacy skills on annual health care expenditures in 2001 was estimated to be an additional $32 to $58 billion.
- Annual health care charges for persons enrolled in Medicaid with literacy skills of 3rd grade or below were $10,688 per year, but only $2,891 for those with better literacy levels of 4th grade and above.
- Low functional literacy results in 3 to 6% greater health care expenditures. Specifically, adults whose functional literacy was in the bottom 20% were more likely to have:
  - 6% more hospital visits
  - 2 day longer hospital stay
  - 1.5 times more likely to visit a physician
  - 3 times as many prescriptions

**What is the scope of the low literacy problem?**

The 2003 National Assessment of Adult Literacy (NAAL), conducted by the National Center for Education Statistics and published in 2005, is the most accurate portrait of literacy in the U.S. to date. The general literacy skills of a representative sample of about 21,000 American adults were measured in three functional areas or domains:

- **Prose**: Knowledge / skills needed to understand and use information from texts (books, newspapers, etc.)
- **Document**: Knowledge / skills needed to find and use information from documents such as job applications, maps, charts, etc.
- **Quantitative**: Knowledge / skills required to read, interpret and apply math to calculate or reason numerically (balance a check book, figure a tip, change a recipe, etc.)

The degree of difficulty for the required literacy tasks in these three domains was divided into four levels. The tasks ranged from the Below Basic Level, which were very easy, to Proficient Level, the most difficult. People who were determined to be in the Below Basic Level were non-literate in English or had the most simple and concrete literacy skills to those who were Proficient and had skills necessary to perform the most complex and challenging literacy activities. The prose literacy results for everyday reading tasks were higher than those for document and quantitative results. Literacy professionals, not the researchers assigned the relative grade abilities for skills at each level.

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<thead>
<tr>
<th></th>
<th>Prose</th>
<th>Document</th>
<th>Quantitative</th>
<th>Grade Level</th>
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<tbody>
<tr>
<td>Below Basic</td>
<td>14%</td>
<td>12%</td>
<td>22%</td>
<td>about 5th grade &amp; below</td>
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<tr>
<td>Basic</td>
<td>29%</td>
<td>22%</td>
<td>33%</td>
<td>about 8th grade</td>
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<tr>
<td>Intermediate</td>
<td>44%</td>
<td>53%</td>
<td>33%</td>
<td>about 10th - HS</td>
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<td>Proficient</td>
<td>13%</td>
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The National Center for Educational Statistics has produced estimates of the percentage of adults lacking Basic Prose Literacy Skills for all states and counties in the U.S. http://nces.ed.gov/naal/estimates/index.aspx. These estimates are based on statistical models, using data from the actual assessments of the 2003 NAAL study and the 1992 National Adult Literacy Survey (NALS) related to county characteristics, such as race/ethnicity and educational levels. Although the margins of error for these estimates is large, they are the best predictions that can be made from the national survey data, and provide a general picture of literacy for all states and counties.

Which populations are most at risk for having low general literacy skills?

Health literacy affects everyone. Even well educated adults, including clinically trained professionals, report high levels of misunderstanding in stressful circumstances. However, there are certain groups of individuals who are more vulnerable to limited general literacy, and specifically health literacy.

- **Elderly**: They tend to have fewer years of schooling. More than 60% of U.S. adults age 65 and over have either below basic or basic reading skills, and these skills decrease as age increases. *(For more information see Teaching the Elderly)*
- **Poverty**: About 90% of those who are not employed are in the below basic and basic levels for prose literacy.
- **Immigrants**: English, as a second language, is a tremendous problem. For those who only spoke Spanish before starting school, 86% read at the two basic levels. The result for those speaking other languages only before starting school was 59%. Keep in mind that some people may not read their native language.
- **Minority groups**: Generally, 46%-74% of those in minority groups read at the below basic and basic levels.
- **Chronic mental and/or physical health conditions**: Forty-six (46%) percent of adults with below basic prose literacy had one or more disabilities.

What are the 2003 NAAL survey results for the health literacy of America’s adults?

The NAAL health literacy results were published in September 2006 and can be found at http://nces.ed.gov. The health literacy scale and tasks were guided by the definition of health literacy used by the Institute of Medicine and Healthy People 2010, and represent a range of literacy activities adults are likely to face in their daily lives. The NAAL health tasks were distributed across three domains of health and health care information and services: *clinical, prevention, and navigation of the health system*. Each health literacy task was classified as prose, document, or quantitative, and the health literacy tasks were analyzed together to create a health literacy scale.

- **Overall**: Fifty three percent (53%) of adults had Intermediate health literacy and 12% had a Proficient level. Adults with Basic health literacy were 22% and Below Basic at 14%.
- **Gender:** Women had a higher than average health literacy than men. Only 12% of women compared to 16% of men were in the Below Basic health literacy category.
- **Race / Ethnicity:** Hispanic adults had lower average health literacy than Black, American Indian/Alaska Native, and multiracial adults. Whites and Asian/Pacific Islander adults had higher average health literacy than all these groups.
- **Age:** Adults in the 65 and older age group had lower average health literacy than those in younger age groups.
- **Education:** Average health literacy increased with each higher level of education obtained, starting with high school graduates or those with a GED. Below Basic health literacy comprised 49% of adults who had never attended or completed high school, compared with only 15% of high school graduates and 3% of those with a bachelor degree.
- **Language:** Those who spoke only English before starting school had higher average health literacy than adults who spoke only other languages or other languages and English before school.
- **Poverty:** Adults living above the poverty line had higher average health literacy than those who live in poverty.
- **Insurance:** Adults had higher average health literacy if they received health insurance from any source than those who received Medicare, Medicaid or no health insurance. Twenty seven (27%) of those on Medicare and 30% on Medicaid had Below Basic health literacy.
- **Sources of Health Information:** Adults with Below Basic health literacy were less likely to get health information from any written sources (newspapers, magazines, books, brochures, Internet) than adults in the other categories. A higher percentage of adults with Below Basic and Basic health literacy than those at the Intermediate and Proficient levels got health information from radio and TV. A higher percentage of adults got health information from family members, friends, and coworkers as the level of health literacy increased.

**What are the barriers to adequate health communication?**

Many barriers or gaps in understanding occur that can result in an ineffective patient or consumer response to the literacy demands in health care. Some of the factors that contribute to problems with health literacy may include:

**Patient Barriers:**
- Limited general literacy skills
- Lack of understanding of health care terms, body systems, and how the health care system works
- Distrust of health care providers
- Complexity of the information about “high tech” medicine
- Being elderly
- Disability, illness and stress / fear related to the health problem
- Stress level at the time information is given
- Increased demands for self-care management
- Social and cultural factors, such as language, that influences information processing and decision-making
- Ability to ask questions
Health Care Provider Challenges:

- Feel the need to give an overwhelming amount of information at once; less time for teaching
- Poorly communicated health information or inadequate teaching
- Power imbalance with health professionals
- Lack of support or information availability
- Competing information from other people or sources such as internet
- Overuse of printed word in giving health care information and lack of non-printed methods for instruction

What are the reading levels of most health materials?

There have been many studies in the past 20 years clearly documenting that the average American adult does not easily understand many health promotion and patient education materials, informed-consent forms, patient rights, business forms, signage, and directions for self-care and medications. Considering that the most widely used method for providing patient education is the use of written materials, these identified discrepancies between the reading level of materials and the reading level of most patients is a huge problem in providing quality health care.

Only 13% of the population is proficient in reading. However, even this group of readers often finds health information difficult. The language and concepts of health care and how the health care system works are confusing for most people, regardless of ability to read. Only recently, has there been a concerted effort to develop health education materials that are easy-to-read for people of all levels of literacy skills.

Study Results

The studies indicated that there is a significant gap or mismatch between patients’ reading and comprehension levels and the reading difficulty of printed education materials. Some of the results from these studies reveal:

- Most patient education materials were written above the 8th grade level, with the average level falling between 10th and 12th grade.
- Most people typically read at least 2 grade levels below their highest level of education obtained.
- Proficient readers also prefer patient education materials in simplified, plain language when ill and even when not ill, due to their busy schedules.
- Standard informed consent documents require college-level reading comprehension
- Education materials from public sources, such as government, professional associations, universities, and industries are written above the reading ability of a majority of adults.
• Much of the medical information targeted for the general public on the internet is written at a reading level higher than is easily understood by much of the general population.

How can I identify patients with low health literacy?

Low health literacy is a hidden problem. Many adults with low literacy have developed coping skills that enable them to function quite well in most situations. The American Medical Association's first health literacy videotape was titled “Low Health Literacy: You Can't Tell By Looking”, and indeed, this is so true! Knowing that your patient has limited health literacy skills is very important if you are going to match the readability level of materials to the reading skills of patients. Also, it is important to know when non-printed teaching materials, such as videotapes, audiotapes, demonstration, models, and other visuals are essential for giving effective instructions.

Keep in mind that how well a person communicates does not indicate a lack of intelligence, but that the skills of speaking, reading, writing, and comprehension have not been developed at the same level as good readers. People with low-literacy skills often have the capability to develop these skills; they have not had the opportunity.

You cannot depend on appearances to determine if one has low literacy. In one study, physicians could identify only 20% of their patients who were at the lowest literacy level (less than 3rd grade). Shame and stigma has resulted in 67% of those with low literacy never telling their spouses, and 85% have never told their co-workers.

Red Flags

Some of the red flags that should alert you that your patient might have low literacy include:

• Resists filling out forms, takes a long time filling them out, or fills them out incorrectly; overwhelmed by too many forms and printed materials
• Not asking questions
• Signs forms without reading the information
• Eyes wonder over the page
• Shows lack of interest or frustration and impatience
• Looks at pills for color, size and shape rather than reading the label to identify
• Uses excuses, such as “I forgot my glasses…my eyes are tired…I’ll take this home to read it later…I want my family to read this…can you read it to me?”
• Reacts to complex learning situations with withdrawal / avoidance
• Has difficulty following directions
• Listens and watches attentively to try to memorize information
• Acts confused or talks out of context about the information
• Discrepancies between what is heard and what is written
Assessment Questions
Assessing Reading Ability

In addition to looking for clues that your patient may have limited reading ability, you can ask questions that may reveal a problem. Note that the questions are asked in such a way that the person is not embarrassed or “put on the spot,” but shows that the health provider understands that health information is difficult to read and understand.

Q: Medical terms are complicated and many people find the words difficult to understand. Do you ever get help from others in filling out forms, reading prescription labels, insurance forms, and health education sheets?

Q: “A lot of people have trouble reading and remembering health information because it is difficult. Is this ever a problem for you?”

Q: What do you like to read? (Newspapers are 10th grade reading level and news magazines are at 12th grade)

Q: How often do you read?

Q: When you have to learn something new or unfamiliar to you, what ways do you prefer to learn the information? (read, watch TV or videotape, listen to tapes or CDs, use the computer, talk to other people, or practice how to do something?)

Q: How happy are you with the way you read?

Q: Ask patient to read prescription bottle and explain how to take their medicines

How can I improve communication with my patients?

In the AskMe3 program http://www.askme3.org/, The Partnership for Clear Health Communication encourages providers to discuss these 3 questions with their patients:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?
10 Tips for Clear Health Communication with Your Patients
(See 10 Tips Poster for 8.5X11 flyer for your office)

1. Establish a trusting, safe, shame-free environment where patients feel comfortable talking. Give instructions to family members.

2. Plan with your patient what is possible for them to do. Consider that they may not be able to do what you ask. Plan together what is realistic for them to do.

3. Speak slowly to allow patients time to absorb the information and ask questions. Ask “what questions do you have?” rather than “do you have any questions?” The latter usually results in a No answer.

4. Limit, organize, and repeat the 3 most key points. Break down complex instructions into smaller parts and teach one step at a time. Repetition enhances recall at a later date.

5. Use everyday language and avoid medical jargon. Use short sentences, 1 to 2 syllable words, and active voice. Define any medical terms.

6. Give specific, concrete, and vivid instructions, rather than general advise or abstract ideas. Use real world examples and analogies to make key points.

7. Frame the message first by telling them what you are going to cover, and then give them the specific information. Provide the context for the new information. Try to “hook” new information to prior knowledge.

8. Use a variety of teaching methods (tailoring, cuing, simplifying regimens, providing reminders) and teaching tools (pictures, models, videos, posters, audiotapes, color coding medicines). Principles of Teaching; Top Ten Teaching Tips

9. Provide easy-to-read written materials at a 5th - 6th grade reading level as a back up. Materials are only a supplement to personal contact and should not be solely used. Write It In Plain Language; Plain Language Checklist

10. Check for understanding using the “teach-back” method. Ask them to tell you or show what they are supposed to do for self-care. Example: “I want to make sure that I’ve been clear in my instructions and that I haven’t left out anything, please tell me in your own words what you will do.” Avoid asking, “Do you understand?” because the answer is usually “yes” even when they do not understand. Use problem-solving situations to see if they can apply the information to their situation.
What benefits does clear health communication bring to my practice?

- Better patient – health care practitioner relationship with increased satisfaction for both parties
- Less possibility of litigation
- Patients who are more able to follow medical advise and self-manage their care
- Less broken appointments
- Less need to re-schedule tests and procedures due to poor patient understanding of instructions
- More patient recruitment to the practice or facility
- Less phone calls for clarification of instructions
- Less patient errors in following treatment plan
- Less use of health care resources and cost

Conclusion

Clear health communication is a basic foundation of health care. Recent health care reform efforts have focused on empowering patients through helping them become an active partner in their health care decisions. Empowerment begins with understanding health information, and that is done through clear health communication. Patients with low health literacy face barriers at every step when accessing and receiving health care. If we are unaware of their problem, we can interpret their coping mechanisms as being inappropriate, hostile, or difficult. Our inability to handle these reactions often results in our withdrawal, which only adds to the patient’s problem. Helping the patient understand health information and manage their health will result in fewer medical errors, better health outcomes, and a reduction in healthcare disparities. Understanding health information is everyone’s right, and providing clear health communication is everyone’s responsibility!

References


Williams, MV; Baker, DW; Parker, RM; et al. (1998). Relationship of functional health literacy to patients’ knowledge of their chronic disease. *Arch Intern Med*, 158(2), 166-172.