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Health Literacy

A Manual for Clinicians

*Part of an educational program
about health literacy*

Barry D. Weiss, MD

The individuals involved with developing the content of this activity have no relevant financial relationships disclose.

Activity renewed: June, 2006

Expiration date: June, 2008

ISBN 1-57947-502-7

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*Part of an educational program
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Introduction

Communication, essential for the effective delivery of healthcare, is perhaps one of the most powerful tools in a clinician's arsenal. Unfortunately, there is often a mismatch between a clinician's level of communication and a patient's level of comprehension. In fact, evidence shows that patients often misinterpret or do not understand medical information given to them by clinicians. This lack of understanding can lead to medication errors, missed appointments, adverse medical outcomes, and even malpractice lawsuits.

There are many reasons why patients do not understand what clinicians tell them. Key among them is inadequate health literacy — an individual's ability to read, understand, and use healthcare information to make effective healthcare decisions and follow instructions for treatment. Clinicians can readily improve their patient's understanding of healthcare information by adopting a more patient-friendly communication style.

The need for today's patients to be health literate is greater than ever, because medical care has grown increasingly complex. We treat our patients with an ever-increasing array of medications, and we ask them to undertake more and more complicated self-care regimens. For example, patients with congestive heart failure were prescribed digoxin and diuretics in the past, while today's patients take loop diuretics, beta-blockers, angiotensin-converting enzyme inhibitors, spironolactone, and digoxin. In the past, these patients were simply instructed to decrease their physical activity, but now they weigh themselves daily, report weight gain to their clinicians, eat low-sodium and often low-fat diets, and participate in structured exercise regimens. Similarly, therapy for patients with asthma was once limited to

theophylline pills, but today these patients must learn to use inhalers with spacers and understand the difference between controller medications and rescue medications. They must also test their peak flow rates on a daily basis, take tapering doses of prednisone, and identify and eliminate allergens in their homes. Patients with diabetes may have the most difficult task of all, as they need to understand factors affecting blood glucose control so they can modify insulin regimens on a meal-to-meal basis in response to finger-stick glucose measurements.

Unfortunately, current data indicate that a large proportion of the US population — perhaps as many as half of American adults — lacks sufficient general literacy to effectively undertake and execute the medical treatments and preventive healthcare it needs. Inadequate health literacy affects all segments of the population, although it is more common in certain demographic groups, such as the elderly, the poor, members of minority groups, and recent immigrants to the United States. The economic consequences of limited health literacy are considerable, estimated to cost the United States between \$50 billion and \$73 billion per year.

In the pages that follow, this manual will discuss the problem of limited health literacy, its consequences for the healthcare system, and the likelihood that a clinician's practice includes patients with limited health literacy. The manual will then provide practical tips for clinicians to use in making their office practices more "user-friendly" to patients with limited health literacy, and give suggestions for improving interpersonal communication between clinicians and patients. Finally, the manual concludes with several case discussions based on vignettes in the accompanying videotape.

Health literacy

Health literacy is the ability to read, understand, and use health information to make appropriate healthcare decisions and follow instructions for treatment. There are many factors that contribute to an individual's health literacy, the most obvious being the individual's general literacy, or ability to read, write, and understand written material. Other factors include the individual's amount of experience in the healthcare system, the complexity of the information being presented, cultural factors that may influence decision making, and how the material is communicated.

Of these factors, perhaps the most important patient factor is the individual's general literacy. Most individuals with limited general literacy also have limited health literacy. This section discusses the general literacy aspect of health literacy.

General literacy skills: The National Adult Literacy Survey

The National Adult Literacy Survey (NALS) conducted by the US Department of Education in 1992 provides the most comprehensive view of the general literacy skills of American adults. The NALS tested a stratified national random sample of some 26,000 adults who were interviewed in their homes and asked to provide personal and background information and to complete a booklet of literacy tasks. The NALS results were reported by dividing the literacy skills of subjects into five levels of difficulty according to their ability to use and understand text and numbers (Table 1).¹

At the lowest level of literacy skill, termed NALS level 1, individuals can only perform basic tasks such as signing their name or finding a word or fact in a short written article. Individuals at NALS level 1 are often considered “functionally illiterate.” Although they can perform some reading and writing tasks, their limited literacy skills prevent full functioning in today's society. Individuals in NALS level 2 have somewhat more advanced skills but are still substantially limited in their ability to read and understand text. They are considered marginally literate.

In contrast, persons at NALS levels 3, 4, and 5 have sufficient literacy skills to permit full functioning in society. Those at NALS level 5, the most advanced literacy level, have well-developed literacy skills that enable them to perform complex tasks, such as writing lengthy documents and extracting data from tables and graphs (Table 1).

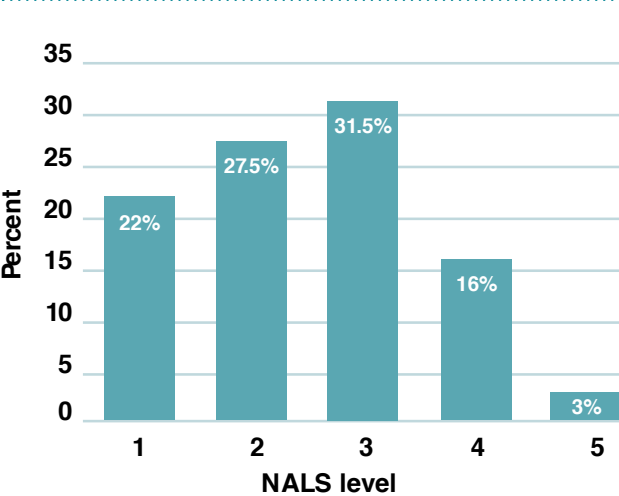
Table 1. Examples of tasks on the National Adult Literacy Survey (NALS)

Level	Sample tasks	Significance
1	<ul style="list-style-type: none"> • Sign name • Find a country in short article • Find expiration date on license • Locate one piece of information in a sports article 	<ul style="list-style-type: none"> • Functionally illiterate • Unable to perform level 2 tasks
2	<ul style="list-style-type: none"> • Enter background information on a Social Security application • Find intersection on street map • Locate two pieces of information in a sports article 	<ul style="list-style-type: none"> • Marginally literate • Unable to perform level 3 tasks
3	<ul style="list-style-type: none"> • Write a brief letter explaining an error on a credit card bill • Enter information into an automobile maintenance record • Identify information from a bar graph 	<ul style="list-style-type: none"> • Functionally literate • Unable to perform level 4 tasks
4	<ul style="list-style-type: none"> • State in writing an argument made in a lengthy newspaper article • Explain difference between two types of employee benefits • Compare two metaphors used in a poem 	<ul style="list-style-type: none"> • Functionally literate • Unable to perform level 5 tasks
5	<ul style="list-style-type: none"> • Summarize the way lawyers may challenge prospective jurors • Compare approaches stated in a narrative on growing up • Use table comparing credit cards to write about differences between them 	<ul style="list-style-type: none"> • High-level literacy

Source: Kirsch I, Jungeblut A, Jenkins L, Kolstad A. *Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey*. Washington, DC: National Center for Education Statistics, US Department of Education; September 1993.

Nearly all doctoral-level clinicians fall within NALS level 5, but fewer than 5% of all adult Americans have literacy skills at this level. In fact, more than 20% of American adults have only level 1 skills, and another 27% score at level 2. This means that nearly half of the US population is either functionally illiterate or marginally literate (Figure 1).

Figure 1. Results of the National Adult Literacy Survey (NALS)



Histogram bars represent the percentage of subjects at each literacy skill level. Level 1 is the most basic literacy level. Level 5 represents an advanced level of literacy skill.

Data from: Kirsch I, Jungeblut A, Jenkins L, Kolstad A. *Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey*. Washington, DC: National Center for Education Statistics, US Department of Education; September 1993.

Persons with NALS level 1 and level 2 literacy skills are found in all segments of society. In fact, most are white, native-born Americans. Nonetheless, limited literacy skills are much more common in certain segments of the population.

Table 2 shows the percentage of certain “high-risk” population groups that scored in NALS level 1. These groups include the elderly, persons with limited education, members of ethnic minorities, and recent immigrants to the United States. Unemployed persons and those with limited income are also more likely to score in NALS level 1. Interestingly, visual difficulties (7%) and learning disabilities such as dyslexia (3%) account for literacy deficits in only a small percentage of NALS level 1 subjects.

If your patient population includes many individuals in any of the groups mentioned above, it is likely that your practice includes persons with limited literacy skills. It is important, however, to keep in mind that persons with limited literacy skills do not fit into easy stereotypes. Indeed, one recent study of affluent individuals living in a geriatric retirement community found that 30% scored poorly on a test of functional literacy in healthcare situations.² And the cover article of a recent issue of *Fortune* magazine told the stories of several dyslexic billionaire executives.³ As with all poor readers, they had developed coping mechanisms that worked in their business and social lives but might not work well in an urgent healthcare situation.

Table 2. Percentage of adult population groups with literacy skills at NALS level 1

Group	Percent
Age	
16–54 years	15
55–64 years	28
65 years and older	49
Highest education level completed	
0–8 years	77
9–12 years	44
High school graduation (no college study)	18
High school equivalency diploma	16
Racial/ethnic group	
White	15
American Indian/Alaska Native	26
Asian/Pacific Islander	35
Black	41
Hispanic (all groups)	52
Immigrants to United States (various countries of origin)	
Arriving after age 12	>50

Average of prose and document literacy scores on the NALS.
Source: Tables 1.1A, 1.1B, 1.2A, and 1.2B in: Kirsch I, Jungeblut A, Jenkins L, Kolstad A. *Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey*. Washington, DC: National Center for Education Statistics, US Department of Education; September 1993.

Literacy in the healthcare setting

NALS level 1 and level 2 readers have the most difficulty with understanding healthcare information. Studies in healthcare settings have shown that persons with limited literacy skills often have a poor understanding of basic medical vocabulary and healthcare concepts. One study of patients in a general medical clinic found that many patients did not really understand the meanings of words that clinicians regularly use in discussions with patients — words like “bowel,” “colon,” “screening test,” or “blood in the stool” (Table 3).⁴ In another study, it was discovered that one out of four women who thought they knew what a mammogram was, did not.⁵

Table 3. Common medical words that patients with limited literacy may not understand

- Blood in the stool
- Bowel
- Colon
- Growth
- Lesion
- Polyp
- Rectum
- Screening
- Tumor

Source: Davis TC, Dolan NC, Ferreira MR, Tomori C, Green KW, Sipler AM, et al. The role of inadequate health literacy skills in colorectal cancer screening. *Cancer Invest.* 2001;19:193-200.

Lack of understanding is not limited just to medical terms. Several studies, all conducted in primary care practices in different parts of the United States, have shown that persons with limited literacy skills also do not understand, or are not aware of, *concepts* basic to common diseases. For example, fewer than half of low-literacy patients with diabetes knew the symptoms of hypoglycemia,⁶ and the majority of low-literacy patients with asthma could not demonstrate proper use of an asthma inhaler.⁷ Table 4 shows some other problems experienced by persons with limited literacy skills when they interact with the healthcare system.⁸⁻¹⁰

It is important to emphasize that limited understanding of health concepts and health information is not solely a problem of persons with low literacy skills. For example, even patients with average reading levels are unable to understand most of the content of consent forms used for research studies of cancer drugs.¹¹ Highly literate, well-educated individuals also report difficulty understanding information provided to them by clinicians because clinicians often use vocabulary and discuss physiological concepts unfamiliar to those who do not have a medical education. In a well-known anecdote, a prominent obstetrician once reported that he was unable to fully understand the explanation he received from an orthopedist about his upcoming orthopedic surgery.

Table 4. Some other health system problems experienced by persons with limited literacy skills

26%	did not understand when their next appointment was scheduled
42%	did not understand instructions to “take medication on an empty stomach”
86%	could not understand the rights and responsibilities section of a Medicaid application

Sources: (a) Williams MV, Parker RM, Baker DW, Parikh NS, Pitkin K, Coates WC, et al. Inadequate functional health literacy among patients at two public hospitals. *JAMA*. 1995;274:1677-1682. (b) Baker DW, Parker RM, Williams MV, Pitkin K, Parikh NS, Coates W, et al. The healthcare experience of patients with low literacy. *Arch Fam Med*. 1996;5:329-334; (c) *Fact Sheet: Health Literacy and Understanding Medical Information*. Lawrenceville, NJ: Center for Health Care Strategies; 2002.

Implications of limited literacy

A limited ability to read and understand information translates into poor health outcomes. Most clinicians are surprised to learn that literacy is the single best predictor of health status. In fact, all of the studies that have investigated the issue report that literacy skills are a stronger predictor of an individual's health status than age, income, employment status, education level, and racial or ethnic group.^{6,7,12,13}

Be aware that education level is a poor surrogate for literacy skills. Education level measures only the number of years an individual attended school, not how much the individual learned in school. Thus, asking patients how many years of school they completed does not help you predict their literacy skill. Indeed, fully 24% of NALS level 1 readers completed high school.¹

Literacy and health knowledge

Patients with limited literacy skills have less awareness of preventive health measures and less knowledge of their medical conditions and self-care instructions than their more literate counterparts. This knowledge deficit has been shown for a variety of health conditions, ranging from childhood fever to asthma to hypertension. Persons with limited literacy skills also exhibit less healthy behaviors (Table 5).^{6,7,14,15}

Table 5. Health knowledge deficits and risky behaviors of persons with limited literacy skills

Health knowledge deficits

- Patients with asthma less likely to know how to use an inhaler
- Patient with diabetes less likely to know symptoms of hypoglycemia
- Patients with hypertension less likely to know that weight loss and exercise lower blood pressure
- Mothers less likely to know how to read a thermometer

Less healthy behaviors

- More smoking, including during pregnancy
- More exposure to violence
- Less breastfeeding

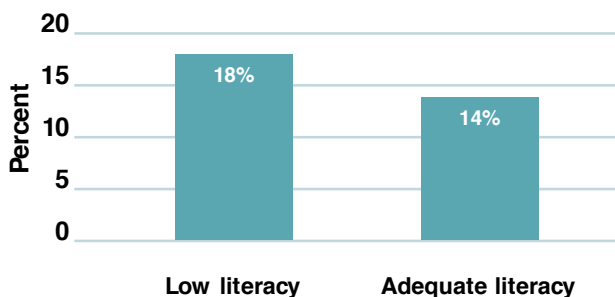
Sources: (a) Davis TC, Arnold C, Berkel HJ, Nandy I, Jackson RH, Glass J. Knowledge and attitude on screening mammography among low-literate, low-income women. *Cancer*. 1996;78:1912-1920; (b) Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension or diabetes. *Arch Int Med*. 1998;158:166-172; (c) Davis TC, Byrd RS, Arnold CL, Auinger P, Bocchini JA Jr. Low literacy and violence among adolescents in a summer sports program. *J Adolesc Health*. 1999;24:403-411; (d) Arnold CL, Davis TC, Berkel HJ, Jackson RH, Nandy I, London S. Smoking status, reading level, and knowledge of tobacco effects among low-income pregnant women. *Prev Med*. 2001;32:313-320.

Literacy and health outcomes

Persons with limited literacy skills have poorer health status than the rest of the population. Several studies in diverse settings have shown that even after controlling for sociodemographic variables, limited literacy skills and limited understanding of health concepts (ie, poor health literacy) are associated with worse health outcomes. This may be due to the aforementioned deficits in health knowledge as well as medication errors, poor understanding of medical instructions, and lack of self-empowerment.

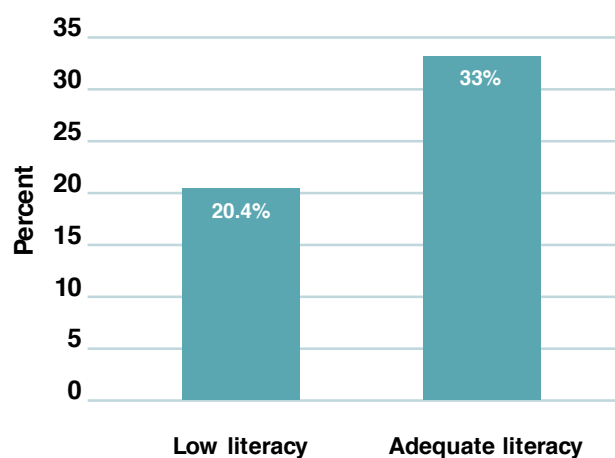
The relationship between limited literacy and poorer health is seen in all socioeconomic groups and in many disease states. For example, Medicare managed care enrollees (mostly older individuals) are 29% more likely to be hospitalized if they have limited literacy skills (Figure 2).¹⁶ Medicaid enrollees with diabetes (mostly individuals with limited income) are less likely to have good diabetes control if they have limited literacy skills (Figure 3).¹⁷ Persons with limited literacy skills also have more emergency department visits and generally worse health status than their more literate counterparts.^{12,13}

Figure 2. Percentage of Medicare managed care enrollees requiring hospitalization over a 3-year period



Data from: Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, et al. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *Am J Public Health*. 2002;92:1278-1283.

Figure 3. Patients with tight diabetes control



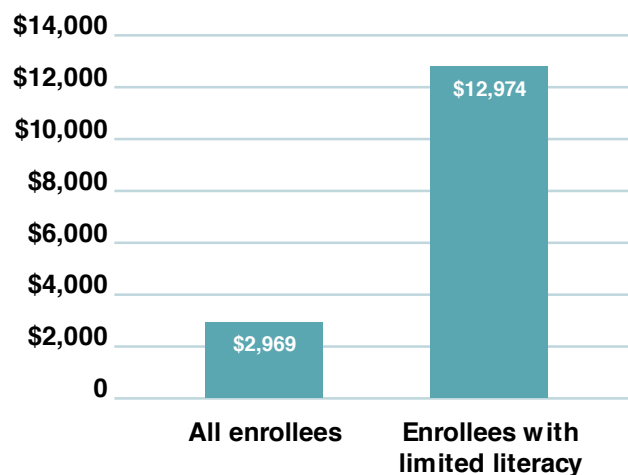
Tight diabetes control as defined as a glycated hemoglobin level $\leq 7.2\%$.

Data from: Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, et al. Association of health literacy with diabetes outcomes. *JAMA*. 2002;288:475-482.

Literacy and healthcare costs

The adverse health outcomes of low literacy translate into increased costs for the healthcare system. In one study, the average annual healthcare costs for all Medicaid enrollees in one state was \$3,000 per enrollee, but the annual cost for enrollees with limited literacy skills averaged \$13,000 (Figure 4).¹⁸

Figure 4. Annual healthcare costs of Medicaid enrollees



Derived from secondary analysis of the data from: Weiss BD, Blanchard JS, McGee DL, Hart G, Warren B, Burgoon M, et al. Illiteracy among Medicaid recipients and its relationship to health care costs. *J Health Care Poor Underserved*. 1994;5:99-111.

The combination of medication errors, excess hospitalizations, longer hospital stays, more use of the emergency department, and a generally higher level of illness results in an estimated excess cost for the US healthcare system of \$50 billion to \$73 billion per year attributable to low literacy alone.¹⁹ According to the Center for Health Care Strategies, this amount is equal to what Medicare pays for physician services, dental services, home healthcare, drugs, and nursing home care *combined*.²⁰

Literacy and the law

The Joint Commission on Accreditation of Healthcare Organizations and the National Committee for Quality Assurance have both adopted guidelines specifying the need for patient education information and consent documents to be written in such a way that patients can understand them.^{21,22} Accordingly, failure to provide understandable information to patients may be a negative factor in the accreditation status of a healthcare organization.

More compellingly, some legal experts indicate that clinicians and hospitals can be held liable for adverse outcomes suffered by patients who do not understand important health information needed for diagnosis and treatment.²³ This holds clinicians to the standard of providing patients with health information in a form that they can understand. For patients with limited literacy skills, clinicians need to deliver this information in a clear, plain-language format. In fact, clinicians can best serve their patient population by providing *all* patients with easy-to-understand information.

You can't tell by looking

You probably see patients every day who have trouble reading and understanding health information. Half of the adult US population has limited or marginal general literacy skills, and these individuals are likely to have limited health literacy skills as well. In addition, even persons with adequate literacy skills may have trouble understanding and applying healthcare information, especially when it is explained in technical, unfamiliar terms. Patients may be verbally articulate and appear well educated and knowledgeable yet fail to grasp disease concepts or understand how to carry out medication regimens properly.

Patients with limited health literacy can be difficult to identify. Even patients with limited general literacy skills do not always fall into predictable groups. The population groups listed in Table 6 are certainly at higher risk for limited literacy skills, but keep in mind that many patients within these groups actually have well-developed literacy skills. Conversely, many patients with limited literacy skills do not fall into any of the population groups listed in Table 6.

The important message is that you can't tell by looking whether someone has sufficient skills to adequately understand health concepts and carry out healthcare instructions. Because you can't tell just by looking, clinicians and medical practices can best deliver effective medical care by providing easy-to-understand information to all patients. Later in this manual, we will show you how you can do this.

Table 6. Key risk factors for limited literacy

- Elderly
 - Low income
 - Unemployed
 - Did not finish high school
 - Minority ethnic group (Hispanic, African American)
 - Recent immigrant to United States who does not speak English
 - Born in United States but English is second language
-

How can I tell if an individual patient has limited health literacy skills?

Red flags

While you can't tell by looking, some of your patients may drop clues, or "red flags," that they have limited health literacy skills. If your patients have ever filled out their registration forms or health questionnaires incompletely or incorrectly, or taken their medications the wrong way, they may have done so because of limited literacy skills or because they were not familiar with the medical terms and concepts in these forms. Other clues to limited literacy are listed in Table 7.

It important to understand, however, that the absence of such clues *does not* indicate that a

patient has adequate health literacy. Most individuals with limited health literacy go undetected by the healthcare system. In fact, patients with limited general literacy skills go to great lengths to hide this from others, even going so far as to bring decoy reading materials with them to the clinician's office or handing articles about medications or treatments to their clinician. The majority of patients with limited literacy skills have never told anyone in the healthcare system, and most have never even told family members (Figure 5 on page 16).²⁴ Similarly, patients with well-developed literacy skills who fail to understand health information may also avoid asking questions for fear of appearing "stupid" or annoying the clinician.

In other words, you can't tell by looking *and* you can't expect your patients to tell you.

Table 7. Behaviors and responses that may indicate limited literacy

Behaviors

- Patient registration forms that are incomplete or inaccurately completed
- Frequently missed appointments
- Noncompliance with medication regimens
- Lack of follow-through with laboratory tests, imaging tests, or referrals to consultants
- Patients say they are taking their medication, but lab tests or physiological parameters do not change in the expected fashion

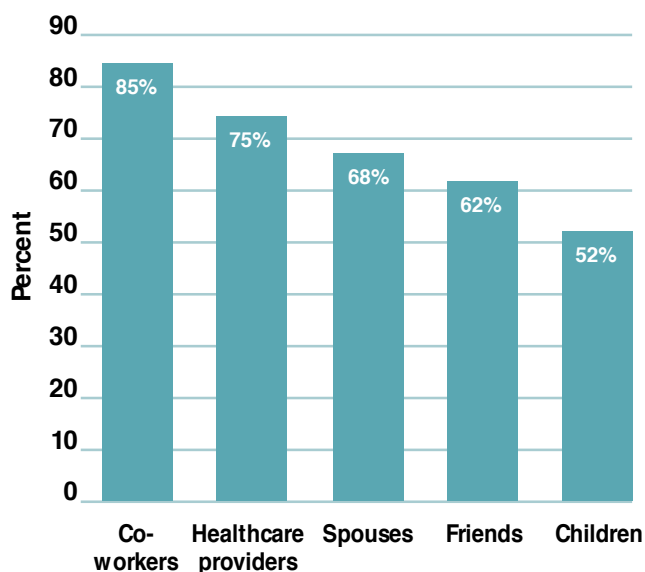
Responses to receiving written information

- "I forgot my glasses. I'll read this when I get home."
- "I forgot my glasses. Can you read this to me?"
- "Let me bring this home so I can discuss it with my children."

Responses to questions about medication regimens

- Unable to name medications
 - Unable to explain a medication's purpose
 - Unable to explain timing of medication administration
-

Figure 5. Nondisclosure of limited literacy



Histogram bars represent the percentage of persons with limited literacy skills who had never told coworkers, healthcare providers, spouses, friends, or their children about their limited literacy.

Data from: Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. Shame and health literacy: the unspoken connection. *Patient Educ Couns*. 1996;27:33-39.

Social history

Some physicians have found it effective to add a question about literacy skills when taking a patient's social history. After asking about occupation and education, they add, "How happy are you with the way you read?" This question gives patients an opportunity to "open up" and discuss the issue if they desire.

The discussion that follows can lead the patient and clinician to agree on the importance of understanding health information, and on the need to find alternate ways for patients to learn what they need to know to care for themselves. It is essential that such discussions and, indeed, any questions about reading skills be conducted in a safe and supportive environment, and that all questions are asked in a neutral, nonjudgmental fashion.

Medication review

One of the most effective ways to identify patients who have limited health literacy skills is the "brown-bag medication review." At the time an appointment is made, ask the patient to bring in all medications (prescription and over-the-counter medications, nutritional and herbal supplements, etc). When the patient comes to the office, the clinician or medical assistant can conduct the medication review by asking the patient to name each medication and explain its purpose and how it is taken.

As patients respond to these questions, note whether they identify medications by reading the label or by opening the bottle and looking at or pouring the pills into their hand. Identifying the medication by looking at the pills may be a clue to limited literacy skills. When responding to questions about how to take the medication, the patient may have

memorized instructions, such as “Take one pill three times per day.” However, when you probe further with questions such as “When was the last time you took one of these pills?” and “When was the time before that?” the patient’s confusion may become apparent.

Measuring health literacy

Although it is not practical to formally measure the health literacy skills of your patients, there are ways to do so. The following two measures are frequently used in health literacy research.

REALM

A patient’s literacy level can easily be measured in about two minutes with an instrument called the Rapid Estimate of Adult Literacy in Medicine (REALM).²⁵ The REALM is a word recognition test, in which subjects read from a list of 66 medical words arranged in order of complexity by the number of syllables and pronunciation difficulty. Patients are asked to read aloud as many words as they can, beginning with the first word and continuing through the list as far as possible until they reach words they cannot pronounce correctly. The REALM yields a score that estimates a patient’s reading level (ie, grades 0–3, grades 4–6, grades 7–8, grade 9 and above). Patients who score in grades 0–3 and 4–6 have literacy skills that correspond approximately to NALS levels 1 and 2, respectively. Because the REALM uses medical words, the test provides not just an assessment of general reading skills, but also an indication of the individual’s health literacy. The main limitations of the REALM are that it is available only in English and that it tests word recognition, not reading comprehension.

TOFHLA

The Test of Functional Health Literacy in Adults (TOFHLA), which is available in both English and Spanish,²⁶ is widely used in health literacy research. The TOFHLA provides patients with medical information or instructions (eg, instructions on a prescription label or instructions for preparing for a diagnostic procedure). Patients then respond by answering questions that test their understanding of the information or instructions they have received. Scores on the TOFHLA categorize patients into those with low, marginal, or adequate health literacy skills. The TOFHLA takes longer to administer than the REALM. A short form of the TOFHLA is available, however, and an ultrashort version is under development.

Strategies to enhance your patient's health literacy

While there is little that clinicians can do to boost the general literacy skills of their patients, there are strategies they can carry out to enhance their patients' health literacy. By making their practices more patient-friendly, communicating in easy-to-understand language, and creating and using patient-friendly written materials, clinicians can deliver more effective care to all of their patients.

Making your practice patient-friendly

Imagine that you are one of the nearly 50% of adults in the United States that has NALS level 1 or level 2 literacy skills. You can't read and understand an article in a newspaper. You can't fill in a government application for Social Security, Medicare, or Medicaid benefits. You can't follow a bus schedule or a map. You don't really understand what a cancer-screening test is, or the meaning of words like "rectum," "tumor," "prostate gland," or "mammogram." Perhaps English is your second language.

Imagine also that you, the patient, are coming to visit *your* practice for the first time today.

- What will you find there?
- What paperwork will the staff ask you to produce or complete?
- What rules and procedures will they ask you to follow?
- What kinds of paperwork will you receive if you are referred for ancillary tests or consultations with other clinicians, and how will you find your way to those tests and consultations?
- Will you receive handouts and consent forms?
- If so, will you be able to understand them (Figure 6)?
- What do you know about your medical insurance coverage, assuming, of course, you are not one of the 42 million Americans without medical insurance?

Figure 6.

Your naicisyhp has dednemmocer that
you have a ypocsonoloc. Ypocsonoloc
is a test for noloc recnac. It sevlovni
gnitresni a elbixelf gniweiv epocs into
your mutcer. You must drink a laiceps
diuqil the thgin erofeb the noitanimaxe
to naelc out your noloc.

The text above, which provides basic information about colonoscopy, provides a sense of what it might be like for a person with limited literacy skills to read a handout similar to those you may give to patients in your office.

Individuals with limited literacy skills prefer information that has short words and short sentences and that contains only essential

information. Long or unfamiliar words (written backwards in the example above) are often difficult to decipher. Difficult words slow down reading speed and, as a result, decrease understanding. Similar concerns apply to oral communication — simple, plain language is the best way to communicate.

Table 8. Checklist for patient-friendly office procedures

- Exhibit a general attitude of helpfulness.

 - When scheduling appointments:
 - Have a person, not a machine, answer the phone.
 - Collect only necessary information.
 - Give directions to the office.
 - Help patients prepare for the visit. Ask them to bring in all their medications and a list of any questions they may have.

 - Use clear and easy-to-follow signage.

 - Ask staff to welcome patients with a general attitude of helpfulness.

 - During office check-in procedures:
 - Provide assistance with completing forms.
 - Collect only essential information.
 - Provide forms in patients' languages.
 - Provide forms in an easy-to-read format.

 - When referring patients for tests, procedures, or consultations:
 - Review the instructions.
 - Provide directions to the site of referral.
 - Provide assistance with insurance issues.

 - When providing patients with information:
 - Routinely review important instructions.
 - Provide handouts in an easy-to-read format.
 - Use nonwritten modalities.
-

This section of the manual provides suggestions and tips for making your practice more patient-friendly. These tips are summarized in Table 8. While the paragraphs above portray a patient with limited general literacy skills, the tips in this section will benefit *all* the patients in your practice.

Attitude of helpfulness

A general attitude of helpfulness from you and other members of your staff can go a long way towards helping your patients feel comfortable in your practice. This attitude starts from the top. Through example, clinician leaders and office managers can encourage all employees to help patients feel comfortable asking questions about office procedures and their medical care. Although everyone is involved, one of the most important individuals is the person the patient encounters first — the receptionist.

To advertise an attitude of helpfulness to your patients, it may be useful to have all members of the office staff — including the clinicians and clerical staff — wear a button that states, “Ask me I can help” (Figure 7).

Figure 7. “Ask me I can help” pin



Scheduling appointments

When patients call the office to make an appointment, a person should answer the phone — not a machine asking the patient to select numerical options. Ideally, the person answering the phone should be able to converse with the patient in the patient’s preferred language.

Information collected on the phone should include only what is needed to process the appointment and expedite office flow. It should omit nonessential information that duplicates what others will ask later.

Ask if the patient needs directions to the office. For first-time patients, offer to mail, fax, or e-mail directions to the office.

Finally, help patients prepare for the visit by asking them to bring in all their medications and to make a list of the questions they wish to ask. Let them know that they are welcome to have someone accompany them to the visit and be a part of the discussion.

Office check-in procedures

Office check-in procedures — particularly the completion of registration forms and health questionnaires — often present an obstacle for patients with limited general and health literacy skills. The next time you receive a patient registration form that is incomplete or incorrectly completed, consider that the patient may have had difficulty completing the form.

The solutions to this problem are simple and beneficial to *all* patients who have difficulty completing registration forms (persons with limited literacy, as well as persons with vision deficits, tremors, etc). They are summarized in Table 9.

Table 9. Tips for assisting patients with registration forms

<ul style="list-style-type: none">• Routinely offer all patients assistance in completing their forms.• Collect only information that is essential.• Collect information and/or provide assistance in the patient’s preferred language.• Be sure forms are designed in a reader-friendly format.

First, and perhaps most importantly, office staff should routinely offer all patients the opportunity to have someone assist them in completing registration forms. This can be done by stating, “Some of these forms can be difficult to fill out. If you need help with them, please don’t hesitate to ask me.” Assistance should be provided in a confidential manner. Patients should be brought to a cubicle or empty exam room so that they will not have to discuss their health problems, financial status, or other personal matters aloud in the waiting area.

Second, registration forms should be simple and request only necessary information. For example, if a nurse or physician will later ask a patient about medication allergies, there may be no added value in having the patient provide this information on the registration form. Similarly, if office staff asks for and photocopies an insurance card, there may be no reason to have the patient complete insurance information on a registration form. Asking patients for unnecessary information serves no good purpose and intimidates patients who find it difficult to provide this information.

Third, information should be collected in a patient’s preferred language whenever possible. Forms should be provided in the patient’s preferred language, or someone who speaks the patient’s preferred language should be available to provide assistance.

In addition to the three aforementioned recommendations, make certain that the physical appearance and format of the registration form comply with the principles of easy-to-read patient materials. These principles are presented later in the manual (page 31).

Referrals and ancillary tests

When patients are sent for blood tests and imaging studies, or are referred to other clinicians for consultations, treatments, or procedures, they are often handed a piece of paper and told to “make an appointment.” For many patients, and especially those patients with limited literacy skills, making that appointment can be a daunting task. Again, imagine you are the patient with limited literacy skills. You, as the patient, must read the referral instructions, then call and make an appointment in another practice that may have its own registration system and forms to complete. You also need to determine if insurance coverage will pay for this service, and complete additional paperwork for the insurance company. Then you will need to follow preappointment instructions, which could include bowel preparation for a colonoscopy or proper adjustment of medications before a procedure. Finally, you will need to find your way to the site of the consultation or procedure and arrive at the correct time.

Most clinicians have dealt with tasks such as these and know they can be frustrating. For a patient who is a NALS level 1 reader, these tasks may be overwhelming.

The solutions to this problem are straightforward. Any written instructions should be clear, simple, and, as directed in the next section (page 31), written in easy-to-understand language and format. Office staff should verbally review instructions with patients and check that patients understand them. It is a good idea to read written information aloud rather than assume that your patients can read and understand the information on their own.

Complicated procedures (eg, bowel preparation) should be reviewed in detail, as should directions to the referral site. It can be useful to have a map on the back of referral forms, appointment notices, and test requisition slips, so that the directions can be highlighted and reviewed with the patient. Business office staff should be available to assist patients with issues related to insurance coverage.

Improving interpersonal communication with patients

Clinician-patient communication is an important factor in health literacy. Good communication is crucial for a successful clinician-patient relationship and effective exchange of information. Breakdowns in communication can lead to confusion for patients, poor health outcomes, and even malpractice lawsuits against clinicians.

Communication and malpractice lawsuits

Poor communication between patients and clinicians is a major factor leading to malpractice lawsuits. In fact, attorneys estimate that a clinician’s communication style and attitude are major factors in nearly 75% of malpractice suits.²⁷ The most frequently identified communication errors are inadequate explanations of diagnosis or treatment and communicating in such a way that patients feel that their concerns have been ignored (Table 10).²⁸⁻³⁰

Table 10. Clinician-patient communication problems involved in malpractice lawsuits

- Explanation of diagnoses is inadequate.
- Explanation of treatment is inadequate.
- Patient feels ignored.
- Clinician fails to understand perspective of patient or relatives.
- Clinician discounts or devalues views of patients or relatives.
- Patient feels rushed.

Sources: (a) Vincent C, Young M, Phillips A. Why do people sue doctors? A study of patients and relatives taking legal action. *Lancet*. 1994;343:1609-1613; (b) Hickson GB, Clayton EW, Githens PB, Sloan FA. Factors that prompted families to file medical malpractice claims following perinatal injuries. *JAMA*. 1992;267:1359-1363; (c) Hickson GB, Clayton EW, Entman SS, Miller CS, Githens PB, Whetten-Goldstein K, et al. Obstetricians’ prior malpractice experience and patients’ satisfaction with care. *JAMA*. 1994;272:1583-1587.

Communication and medical outcomes

Studies have shown that effective communication with patients has a beneficial effect on medical outcomes. These benefits include lower rates of anxiety, pain, and psychological distress, and higher rates of compliance and symptom resolution.³¹

In particular, it has long been known that compliance is heavily influenced by communication style. Specifically, clear and concise instructions delivered to patients by clinicians the patients trust are associated with improved rates of compliance with therapy.³²

Steps to improve communication with patients

There is little research to guide us on how best to communicate with patients who have limited literacy skills. Nonetheless, there is general consensus among health literacy and communication experts that six basic steps can help you improve communication with patients (Table 11).^{33,34}

Slow down

Communication is improved — and the risk of malpractice claims is decreased — when clinicians spend more time with patients. Only a small amount of time is needed to make a difference. Data from multiple states in the United States indicate that primary care physicians who have been the target of malpractice liability claims spend an average of 15 minutes per patient on routine visits, while physicians who have never had a malpractice claim against them spend an average of 18 minutes. This is a difference of a mere three minutes.³⁵

Table 11. Six steps to improve interpersonal communication with patients

1. Slow down.	Communication can be improved by speaking slowly and by spending just a small amount of additional time with each patient. This will help foster a patient-centered approach to the clinician-patient interaction.
2. Use plain, nonmedical language.	Explain things to patients as you would explain them to a family member.
3. Show or draw pictures.	Visual images can improve the patient’s recall of ideas.
4. Limit the amount of information provided, and repeat it.	Information is best remembered when it is given in small pieces that are pertinent to the tasks at hand. Repetition further enhances recall.
5. Use the teach-back or show-me technique.	Confirm that patients understand by asking them to repeat back your instructions.
6. Create a shame-free environment.	Make patients feel comfortable asking questions. Enlist the aid of others (patient’s family, friends) to promote understanding.

In addition to spending more time, clinicians can optimize the use of this time by creating a “patient-centered visit.” In a patient-centered visit, the clinician focuses on addressing the patient’s concerns. Such patient-centered visits take no longer than “traditional” visits, in which the agenda is set by the clinician.³⁶ Behaviors, such as sitting rather than standing, listening rather than speaking, and speaking slowly, can further create an impression that you are focused on the patient. Patients may respond to these behaviors by perceiving that you have spent more time with them. These and other useful behaviors are listed in Table 12.

Table 12. Behaviors that improve communication

<ul style="list-style-type: none">• Use orienting statements: “First I will ask you some questions and then I will listen to your heart.”• Ask patients if they have any concerns that have not been addressed.• Ask patients to explain their understanding of their medical problems or treatments.• Encourage patients to ask questions.• Sit rather than stand.• Listen rather than speak.

Clinicians often express concern that a patient-centered approach results in a substantial increase in the duration of office visits; research shows otherwise. In one important study, patients who were allowed to talk without interruption for as long as they liked spoke for an average of only one minute and 40 seconds.³⁷ In another study, patients were permitted to voice their initial concerns at the beginning of an office visit, again for as long as they wished without interruption. The mean spontaneous talking time was only one minute and 32 seconds, with a median value of 59 seconds.³⁸

While patient-centered visits do not take substantially longer than traditional visits, they create an atmosphere in which patients feel that their needs have been met. This aids in the development of an effective patient-clinician alliance, with potential benefits such as increased patient compliance and decreased risk of malpractice suits.

Use plain, nonmedical language

You should always seek to use plain, nonmedical language when speaking to patients. Words that clinicians use in their day-to-day conversations with colleagues may be unfamiliar to the majority of nonmedically trained persons. A good approach is to explain things to patients in language that you might use when talking to your own family member. This is sometimes called “living-room language,” “the language of the family,” or conversational language. Table 13 gives some examples of plain-language alternatives to medical words. Conversational language creates opportunities for dialogue between the clinician and patient, rather than limiting communication to a monologue by the physician.

Table 13. Medical terms that patients may not understand

Medical term	Translation into plain language
• Analgesic	Pain killer
• Anti-inflammatory	Lessens swelling and irritation
• Benign	Not cancer
• Carcinoma	Cancer
• Cardiac problem	Heart problem
• Cellulitis	Skin infection
• Contraception	Birth control
• Enlarge	Get bigger
• Heart failure	Heart isn't pumping hard enough
• Hypertension	High blood pressure
• Infertility	Can't get pregnant
• Lateral	Outside
• Lipids	Fats in the blood
• Menopause	Stopping periods, change of life
• Menses	Period
• Monitor	Keep track of, keep an eye on
• Oral	By mouth
• Osteoporosis	Soft, brittle bones
• Referral	Send you to another doctor
• Terminal	Going to die
• Toxic	Poisonous

Show or draw pictures to enhance patient understanding and recall

The expression “A picture is worth a thousand words” is particularly true when communicating with patients who may have trouble understanding medical concepts delivered in words. It has long been known that visual images are remembered better than letters and words.³⁹ That is why we often recall a person’s face but not a name, or the picture on a book’s cover but not the name or author of the book.⁴⁰

The most effective pictures are simple ones. For example, if you are trying to explain that an aortic valve needs to be replaced, the illustration should display a heart, an aorta, and an aortic valve. Additional details, such as coronary arteries and other heart valves, should not be included if they are irrelevant to the patient’s health problem. Inclusion of irrelevant details distracts the patient and diminishes the effectiveness of the picture as a teaching tool.

Limit the amount of information given at each visit — and repeat it

Another key to effective communication is to limit the amount of information provided to patients at each visit. This does not mean you should withhold important information. Rather, it means you should focus your communication on the one or two most important things a patient needs to know at the time of the visit. The principle behind this approach is that advice is remembered better, and patients are more likely to act on that advice, when it is given in small pieces and is relevant to the patient’s current needs or situation.⁴⁰

For example, at a patient’s first visit following a diagnosis of type 2 diabetes, the most important message is that “the sugar level in your blood is high, and you must start taking medicine to lower the sugar level.” Information about the physiology of glucose control, while ultimately important for the patient’s ability to self-regulate diabetes control, is not important at the first visit and should not be discussed at that time. Information about potential complications of diabetes might be mentioned, but they are not the focus of the visit. The focus of the first visit should be the initiation of treatment.

After discussing the key information with a patient, the information should be reviewed and repeated, because repetition is the key to learning and memory. Ideally, the information will be reviewed and repeated by multiple members of the healthcare team, perhaps by a physician, nurse, pharmacist, dietitian, and others.

Repetition can be achieved even after the patient’s visit through handouts to reinforce the information provided in person. Consider reading handouts to patients to emphasize the importance of the information. If the handout is too long to read aloud, it may be too complex. Preparation of reader-friendly handouts will be discussed later in more detail (page 31).

Some experts suggest calling patients several days after delivering important information to further reinforce learning.⁴¹ While not routinely necessary, such phone calls can be helpful for reinforcing particularly important information. When making this phone call, try not to make it seem that you are calling only to repeat the instructions. Rather, make it clear that you want to help by stating, “I am calling to check that everything I told you was clear, and to find out how are you doing with the treatments I recommended.”

Use the teach-back and show-me techniques

The teach-back and show-me techniques are methods for ensuring that patients understand what you have told them (Table 14). These techniques involve asking patients to explain or demonstrate what they have been told. For example, you can say, “Now I want you to explain to me how you will take your medication, so I can be sure I have explained everything correctly,” or, “Please show me how you will use the asthma inhaler, so I can be sure I have given you clear instructions.”

Table 14. The teach-back/show-me techniques

<ul style="list-style-type: none">• Do not simply ask a patient, “Do you understand?”• Instead, ask patients to explain or demonstrate how they will undertake a recommended treatment or intervention.• If the patient does not explain correctly, assume that you have not provided adequate teaching. Reteach the information using alternate approaches.

Using these techniques, clinicians take responsibility for adequate teaching. If patients cannot explain or demonstrate what they should do, the clinicians must assume that they have not provided patients with an adequate explanation or understandable instructions. The result should be new efforts to ensure that patients learn what they need to know. It is important not to appear rushed, annoyed, or bored during these efforts — your affect must agree with your words.

The teach-back and show-me techniques should replace the more common practice of simply asking a patient, “Do you understand what I have told you?” Experience shows that patients often answer “yes” to such questions, even when they understand nothing.

Incorporating these techniques into patient counseling and education creates the opportunity for dialogue in which the physician provides information, then encourages the patient to respond and confirm understanding before adding new information.

Create a shame-free environment:

Be respectful, caring, and sensitive

As discussed earlier, patients with limited literacy are often ashamed of this limitation and rarely speak of it.²⁴ Even patients with well-developed literacy skills may feign understanding material to avoid seeming “stupid” or annoying to the clinician. To foster effective communication with patients, it is essential to create a shame-free environment in which patients feel comfortable asking questions about what they do not understand.

This can be accomplished by letting patients know that “many people have difficulty reading and understanding the medical information I give them, so please feel comfortable asking questions if there’s something you don’t understand.”

Make certain to follow up on this by answering any questions your patients may have.

Another strategy is to ask patients during the visit if they would like a family member or friend to be with them during discussions about diagnoses and options for treatment. Research shows that patients with limited health literacy often seek the assistance of family or friends after visits with clinicians to interpret what their clinicians told them.⁴² By asking your patients in a routine, nonjudgmental way, you can help them feel comfortable about bringing others into the examination room to help at the time of the visit.

Creating and using patient-friendly written materials

Written consent forms and patient education handouts

The readability of consent forms and patient education handouts has received more attention than perhaps any other health literacy issue. Countless studies have shown there is a mismatch between patients' reading skills and the reading skills needed to comprehend the consent forms and handouts they are given.⁴³⁻⁴⁶ The reality is that most consent forms and patient education handouts are written at a difficulty level that far exceeds the reading skills of average Americans. In fact, most consent forms and handouts are written at 10th grade to graduate school level, even though the average US adult reads at an 8th grade level.

Medical practices should ensure that the reading difficulty level of their patient materials matches the reading skills of their patients. Clinicians can use a variety of approaches to reach this goal. One approach is to develop practice-specific written materials. The principles for how to do this are discussed and shown in Table 15 (page 32).

Alternatively, clinicians can purchase materials that have already been developed on the basis of these principles. Such reader-friendly written materials may be found through the list of useful resources on page 44.

Whatever written materials are used, their effectiveness may be increased if the clinician or staff member reads them aloud and highlights, underlines, circles, or numbers key points for the patient to remember. Drawing supplemental pictures and writing out steps and directions for individual patients can also be helpful.

Principles for creating patient-friendly written materials

Written materials that are easy for patients to read and understand are beneficial to *all* patients. Evidence indicates that all patients — not just those with limited literacy skills — prefer easy-to-read materials to more complex or comprehensive materials.

The basic principles (Table 15 on page 32) for creating patient-friendly written materials involve attention to:

- a) the depth and detail of the content
- b) the complexity of the text itself
- c) the format in which the material is prepared
- d) user testing

Table 15. Formatting checklist for easy-to-read written materials

General content

- Limit content to one or two key objectives. Don't provide too much information or try to cover everything at once.
- Limit content to what patients really need to know. Avoid information overload.
- Use only words that are well known to individuals without medical training.
- Make certain content is appropriate for age and culture of the target audience.

Text construction

- Write at or below the 6th grade level.
- Use one- or two-syllable words.
- Use short paragraphs.
- Use active voice.
- Avoid all but the most simple tables and graphs. Clear explanations (legends) should be placed adjacent to each table or graph and also in the text.

Fonts and typestyle

- Use large font (minimum 12 point) with serifs. (Serif text has the little horizontal lines that you see at the bottom of letters, as in the title of this table.)
- Don't use more than two or three font styles on a page. Consistency in appearance is important.
- Use uppercase and lowercase text. ALL UPPERCASE TEXT IS HARD TO READ.

Layout

- Ensure a good amount of empty space on the page. Don't clutter the page with text or pictures.
 - Use headings and subheadings to separate blocks of text.
 - Bulleted lists are preferable to blocks of text in paragraphs.
 - Illustrations are useful if they depict common, easy-to-recognize objects. Images of people, places, and things should be age appropriate and culturally appropriate to the target audience. Avoid complex anatomical diagrams.
-

The practical application of these principles is reviewed in the paragraphs that follow. Readers who desire more detailed information on creating easy-to-read written materials for patients can consult standard textbooks⁴⁷⁻⁴⁹ on creating effective patient-education information, or attend seminars or workshops offered by experts in the field. (See Useful resources on page 44.)

Depth and detail of the message

Effective patient materials focus on instructions for key behaviors that the patient must put into action — not lengthy and unnecessary background information about physiology and pathology. Many patient education brochures are ineffective because they begin with a review of anatomy and physiology rather than with clear statements about what a patient needs to do.

Figure 8A. Inappropriate detail and prioritization of information in a patient education handout

Streptococcal pharyngitis (strep throat)

Your doctor has diagnosed you as having streptococcal pharyngitis, or “strep throat.” Strep throat is caused by Group A beta hemolytic streptococcus, a common bacteria in the nose and throat that can cause sore throats (pharyngitis) and skin infections. Symptoms of strep throat include pain and redness in the throat, difficulty swallowing, fever, and swollen glands in the neck. Sometimes there is a rash going along with the sore throat, in which case patients are said to have “scarlet fever.” Strep throat occurs most commonly in children.

The symptoms of strep throat go away by themselves, even without treatment. Without treatment, however, a small percentage of patients with strep throat will develop rheumatic fever, a serious disease of the heart and heart valves. When patients get rheumatic fever, heart valves may be damaged and in the future, the patient may need open heart surgery to replace a heart valve. Although rheumatic fever is uncommon, in recent years there have been more cases reported.

The treatment for strep throat involves taking penicillin, an antibiotic that kills the streptococcus bacteria. The reason for treating strep throat is not to make the sore throat get better quicker. Rather, the reason for treating strep throat is to prevent the development of rheumatic fever. Treatment with penicillin for 10 days almost always prevents rheumatic fever. It is important that you take the penicillin for the full 10 days, even if you are feeling better before the medicine is used up. That’s because taking the penicillin for less than 10 days may not protect you against rheumatic fever. Patients allergic to penicillin can take one of several other medications.

(274 words; 10th grade reading level)

Examples of appropriate and inappropriate detail for patient education handouts are shown in Figures 8A (page 33) and 8B.

Figure 8B. More appropriate detail and prioritization of information in a patient education handout

Treating strep throat

- Take your pills two times each day (once in the morning and once in the evening).
- Take the medicine every day for 10 days, even if you feel better before then.
- Stopping the pills before 10 days can result in serious heart problems.

(43 words; 6th grade reading level)

Note that the more reader-friendly text in Figure 8B is not an example of “dumbing down” the information. Rather, it is an example of effective application of the principles for creating written patient education materials in a form that all patients prefer (ie, focusing on what the patient needs to know and put into action, while avoiding medical terminology and unnecessary background information).

Complexity of text

Written materials should ideally be created for readability at the 5th or 6th grade level, thus ensuring readability by the majority of adults. The reading level should be even lower — ideally at the 3rd to 5th grade level for practices with a high percentage of patients at risk for limited literacy. The average reading skill of Medicaid enrollees, for example, is at the 5th grade level.

Text written at the 5th or 6th grade level typically is constructed of short words, all or most of which are one or two syllables long. Sentences should be as short as possible, and complex or multipart sentences should be avoided. Paragraphs should contain no more than two or three sentences. Many healthcare professionals find it difficult to construct text at such a basic level, but as shown in the example in Figure 8B, it is possible to do so.

Most word processing programs on personal computers contain grammar checking programs that include a tool for measuring readability. A widely used tool is the Flesch-Kincaid readability score, which is integrated into the grammar checker of Microsoft Word. The Flesch-Kincaid reports readability as a grade equivalent reading level and is a useful guide for measuring complexity of text. However, two caveats must be considered:

- First, the Flesch-Kincaid score is based on the physical characteristics of the text. Specifically, the score is based on word length (ie, the number of characters between spaces) and sentence length (ie, the number of words between periods). Thus, the Flesch-Kincaid will compute a reading level even for nonsensical text such as “Xxx xxxxx x xxxxx. Xxx xxxx xxxx xxxxxxxx xxx xxxxxx.” Furthermore, the program counts anything before a period as a sentence, thus skewing results if one is not careful. For example, “Dr.” is counted as one sentence.
- Second, the readability score does not consider content. An individual with medical training may easily understand medical text written at a certain grade level, but that same text may be incomprehensible to someone with similar reading skills but no medical training.

To ensure that the content of written materials is understandable, the text must use words that are well known to readers. Authors should avoid technical words or jargon, and use and define medical words only when they are essential. Table 13 (page 27) presents some common medical terms and jargon, along with suggestions for “plain language” alternatives. Additional examples are shown in Table 16 (page 36). While most of the suggested alternate wording seems obvious, clinicians regularly use the medical terms in conversations with patients.

Format

Format is one of the most critical characteristics of reader-friendly patient education materials. Written material is difficult to read when it contains text that is dense, small, or presented in long, uninterrupted paragraphs. Material is easier to read when text is larger and interspersed with blank space.

Readability is further enhanced when information is presented or supplemented with bulleted lists and clear illustrations. Table 15 (page 32) presents a checklist of important formatting suggestions that should be considered when creating written information for patients. The examples shown, in Figures 8A (page 33) and 8B give a sense of what constitutes good and bad formatting.

User testing

After creating written material for patients according to the guidelines in Table 15 (page 32), it is useful to have the materials reviewed by patients — ideally patients with limited literacy skills — to ensure that what you have prepared can be understood.

The user-testing process is more than simply asking patients, “Do you like it?” or “Does it make sense?” Rather, it involves asking patients, “After reading this, can you tell me what you are supposed to do?” and “What does this word or phrase mean to you?” and then adopting the patient’s language in the text. Appropriate modifications should be made in response to reviewer feedback before the written material is put into use.

Table 16. More examples of common medical terms and jargon and suggestions for alternate wording

Medical terms or jargon	Alternate wording
• Cardiologist	Heart doctor
• Catheterize	Put in a tube where your urine comes out
• Chemotherapy	Drugs to treat cancer
• Echocardiogram	Pictures of your heart
• Fractured femur	Broken hip/leg
• GI specialist	Stomach doctor
• Malignancy	Cancer
• Metastatic	Cancer has spread
• Noninvasive	Without surgery, needles, or cutting skin
• Pulmonary embolism	Blood clot in your lung
• Radiology	X-ray department
• Tap your knee	Put a needle in your knee to remove fluid

Nonwritten patient education materials

While a great deal of attention focuses on written materials suitable for low-literacy audiences, nonwritten materials can also be effective patient education tools. These nonwritten materials include graphic illustrations, such as pictures, pictographs, and models, along with audiotapes, videotapes, and various forms of computer-assisted learning applications (Table 17). There is increasing research to support the effectiveness of these nonwritten modalities, which may even be superior to written materials for patients with limited literacy.

Table 17. Alternatives to written handouts for patient education handouts

- Graphic illustrations
 - Pictures
 - Pictographs
 - Models
- Audiotapes and compact disks
- Videotapes
- Information-only computer modalities
 - CD-ROMs
 - Downloadable Internet sites
- Interactive computer modalities
 - Interactive CD-ROMs
 - Interactive Internet sites

Graphic illustrations (pictures, pictographs, models)

Research has shown that using models and pictures, including cartoons or pictographs with verbal explanations, can greatly increase patient understanding and retention of information. In one study, mean correct recall of information was 85% with pictographs and 14% without.⁵⁰ Another study found that patients receiving wound-care instructions with cartoons were able to answer questions correctly 46% of the time three days later, compared to only 6% of patients who received only written instructions.⁵¹

Audiotapes and compact disks

Most patients own an audiocassette or compact disk (CD) player. Providing patients with audiocassettes or CDs is often an easy way to repeat and reinforce healthcare messages given during office visits. For example, patients who have just been diagnosed with a disease or who are embarking on a new treatment can be given an audiotape or CD that provides a brief summary of their disease or treatment.

Audiotapes and CDs should be no more than a few minutes long. They can be recorded by individual clinicians or purchased from companies that prepare such recordings. If prepared by the clinician, it is essential to practice the principles discussed earlier. In other words, the recording should use plain language and focus on only one or two key topics. There should be an emphasis on what the patient needs to know to execute the clinician's recommendations.

Videotapes

A quick search on the Internet reveals that there are hundreds, perhaps thousands, of patient education videotapes available for purchase from commercial and noncommercial sources. Many pharmaceutical companies have prepared patient education videotapes about their key products, and these tapes are often available at no charge to clinicians or patients. Similarly, many professional organizations have created educational materials pertinent to specific diseases and treatments. While it is beyond the scope of this manual to review the quality of the thousands of available videotapes, many are worth exploring.

Computer-assisted education

Computer-assisted education has been created for patients with asthma, diabetes, heart failure, cancer, and many other diseases. Some of these computer-assisted modalities are provided to patients via Internet downloads or CD-ROMs they can use in home computers. Others are available for use by patients in a clinician's office. Of note, they have been used successfully by patients who have no prior experience using computers.

As an example, one computer-based program is an interactive diabetes simulator that patients use to learn the effects of diets and insulin on blood glucose profiles.⁵² Over 74,000 visits have been logged to the site, and 20,000 copies of the free program have been downloaded by users, most of whom rated the simulator favorably.

Another program uses CD-ROM technology to help patients with prostate cancer decide on the preferred treatment for their disease.⁵³ When the program was tested with a group of patients who had limited literacy skills, more than two thirds of the patients were able to select a treatment for their cancer. There was, however, some question about how effectively the program improved the knowledge of patients with the very lowest level of literacy skill.

Still other programs have been used to provide patients with information about colonoscopy,⁵⁴ asthma,⁵⁵ and heart failure.⁵⁶ Yet another program teaches patients who have had malignant melanoma about skin protection and identification of new skin lesions.⁵⁷

While results are not uniformly positive, most studies find a benefit to using interactive educational tools. Some patients may even learn better with computer-assisted modalities than with standard modalities. Clinicians should be aware that these new tools are available and consider them viable alternatives to standard written materials. It is important, however, to confirm that patients have correctly understood information obtained from these sources, as much online information is written at advanced reading levels.

Final comments

When working with patients, you must use your communication skills to ensure that each patient provides you with the information you need to formulate a treatment plan, and that he or she has all the information needed to execute this treatment plan. There are five main categories of information, each of which is listed in Table 18 (page 40). If your patients can answer all of these questions when they leave your office, you have done a good job.

As we have discussed in this manual, the patient's limited literacy and the clinician's communication skills are both important factors in health literacy. By being aware of this and applying the principles of good communication, clinicians can be "good doctors" to *all* patients. As stated by an adult with limited literacy skills:

"A good doctor is not too busy to help, doesn't use big words, sits down and listens, asks how you are doing and what is your problem. The doctor asks how you want to be addressed, and doesn't read the chart in front of you (if he does, it shows he hasn't prepared for your visit, which is rude and demeaning). Good doctors tell you things in plain English and break them down into what's really important. If you don't understand what the doctor says, you are comfortable asking him to repeat the explanation. When the doctor repeats and you still don't understand, the doctor goes out of his way to make sure you do."

Table 18. Checklist for patient understanding

At the end of each office visit, a patient should be able to answer the following questions:

- What health problems do I have and what should I do about them?
- Where do I go for tests, medicine, and appointments?
- How should I take my medicine?
 - When do I take it?
 - What will it do?
 - How do I know if it is working?
 - Whom do I call for if I have questions?
- Other instructions
 - What to do?
 - How to do it?
 - When to do it?
- Next steps
 - When do I need to be seen again?
 - Do I have another appointment? If so, what are the date and time of the appointment?
 - Are there phone numbers to call?

Case discussions

This section offers a series of study questions based on the vignettes on the accompanying videotape and CD-ROM.

Case 1: Mr. Day

Patient who misunderstands the term hypertension



Mr. Day clearly misunderstands the meaning of the word hypertension, believing it refers to a state of behavioral

hyperactivity rather than to elevated blood pressure. His physician takes responsibility for this misunderstanding and explains the meaning of hypertension to the patient.

Issues for discussion:

1. How could you explain the meaning of hypertension to Mr. Day in easy-to-understand language? How could you make certain he understands the meaning?
2. What other common diagnoses or medical terms could easily be misunderstood by patients?
3. What did Mr. Day's physician achieve by accepting responsibility for his misunderstanding?

Case 2: Mrs. Cordell-Seiple

Patient who discusses her hysterectomy



Mrs. Cordell-Seiple talks about her experience signing a surgical consent form without reading it and then undergoing surgery —

only to find out after the surgery that she has had a hysterectomy. Dr. Williams points out that when patients sign surgical consent forms they do not understand, then undergo procedures that result in adverse outcomes, there is potential for medicolegal liability.

Issues for discussion:

1. Is it reasonable to assume that when patients sign consent forms, they have read and understood them? Why or why not?
2. What could Mrs. Cordell-Seiple's physician have done to ensure that she understood her treatment?
3. If you were the patient's malpractice attorney, what arguments would you make in developing a case against the patient's surgeon and the hospital?

Case 3: Mr. Bell

Patient who hides his illiteracy



Mr. Bell speaks about his fear of having others find out he is illiterate, and about his anger and tendency to blame others for not

respecting him. He sometimes walks out of the doctor's office to hide the fact that he cannot read.

Issues for discussion:

1. If you had not heard Mr. Bell's story, would you have considered him a "difficult" patient?
2. Do you see patients like Mr. Bell in your practice? How do you and your staff respond to them?
3. How could you change your office practices to support patients like Mr. Bell and help defuse their anger and frustration?

Case 4: Mrs. Grigar

Patient who is unable to fill out a satisfaction questionnaire



Dr. Alvarez has a discussion with Mrs. Grigar about how she was unable to fill out the satisfaction questionnaire. Some

patients may be able to fill these forms out but may do so incorrectly or incompletely.

Issues for discussion:

1. What might you see on a registration form or health questionnaire when a patient with limited literacy skills fills in the blanks?
2. Have you ever seen forms in your practice filled out in this way?
3. If you received a form completed in such a way as to suggest the patient had limited literacy skills, would you discuss it with the patient?
4. If so, how would you open the discussion with the patient?

Case 5: Mrs. Tilsley

Discussion of the brown-bag medication review



In a brown-bag medication review, the clinician asks the patient to take each pill bottle and explain the name of the pill,

its purpose, and how it should be taken.

Issues for discussion:

1. What responses, besides those noted, would you expect when conducting a brown-bag medication review with a patient who has limited literacy or limited health literacy?
2. How can you and your staff help your patients keep track of their medications and use them correctly?
3. How much time do you think a brown-bag medication review might take? Do you think this is a feasible amount of time for you and your staff to spend? What benefits might accrue to you or the patient from spending this time?

Case 6: Dr. Alvarez and Mr. & Mrs. Grigar

Explanation of arthritis



Dr. Alvarez avoids medical terminology when he describes osteoarthritis to Mrs. Grigor and her husband. Instead, he

uses the analogy of a creaky door hinge to illustrate the pathophysiology of arthritis.

Issues for discussion:

1. How might you explain to a patient, using no medical terms, the cause and treatment of the following medical conditions and their treatments?
 - Aortic stenosis
 - Pancreatitis
 - Duodenal ulcer caused by *Helicobacter pylori*
 - Epilepsy
2. How might you explain to a patient, using no medical terms, the following procedures?
 - First pelvic examination on a teenager
 - Coronary angioplasty and placement of an intracoronary stent
 - Placement of tympanostomy tubes
 - Lumbar puncture
 - Total knee replacement
3. What pictures or models might aid in the aforementioned explanations?

Useful resources

Guides to teaching and writing for patients who have limited literacy skills

- Doak CC, Doak LG, Root JH. *Teaching Patients with Low Literacy Skills*. 2nd ed. Philadelphia, Pa: JB Lippincott Company; 1996.
- National Literacy and Health Program. *Easy Does It: Plain Language and Clear Verbal Communication*. Ottawa: Canadian Public Health Association; 1998
- Osborne H. *Overcoming Communication Barriers in Patient Education*. New York, NY: Aspen Publishers; 2001.
- Centers for Medicare and Medicaid Services. *Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies*. Available by fax at 410-786-1905.

Sources for easy-to-read patient education materials

- *Health and Literacy Compendium*. Boston, Mass: World Education; 1999. Available at <http://www.worlded.org>.

Educational programs, workshops, and institutes

- Cancer, Culture, and Literacy Institute
H Lee Moffitt Cancer Center, Tampa, Florida
<http://www.moffitt.usf.edu/promotions/cclinstitute/index.htm>
- Health Literacy Center, University of New England, Biddeford, Maine
<http://www.une.edu/hlit>
- Clear Language Group
<http://www.clearlanguagegroup.com>
- Health Literacy Consulting, Natick, Massachusetts
<http://www.healthliteracy.com>

Organization Web sites

- American Medical Association Foundation Health Literacy Initiative
<http://www.amafoundation.org>
- National Institute for Literacy
<http://www.nifl.gov>
- Pfizer Health Literacy Initiative
<http://www.pfizerhealthliteracy.com/>
- Reach Out and Read
<http://www.reachoutandread.org/>
- Center for Health Care Strategies
Fact sheets on health literacy
<http://www.chcs.org>

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CME Questionnaire

Health Literacy: Help Your Patients Understand

A Continuing Medical Education Activity Sponsored by the American Medical Association.

Instructions:

The educational program *Health Literacy: Help Your Patients Understand* (including the video, the manual, and the case studies at the end of the manual) contains the correct answers for the following 10 questions. Select your answer(s) to each question and write the corresponding letter in the answer space provided.

Please return the form to:

Division of Continuing Medical Education
American Medical Association
515 North State Street
Chicago, IL 60610
Fax: 312-464-4567

A certificate documenting your participation in the CME activity will be forwarded to you upon successful achievement of a score of 70%. The American Medical Association designates this educational activity for up to 2.5 hours in Category 1 credit towards the AMA Physician's Recognition Award. Each physician should claim only those hours of credit that he/she actually spent in the educational activity.

CME Questions

1. According to the 1992 National Adult Literacy Survey (NALS), what percentage of adult Americans are functionally illiterate?
a) 8% b) 15% c) 21% d) 37%
2. Literacy is a stronger correlate of self-reported health status than educational level and other sociodemographic variables.
a) True b) False
3. Patients who experience difficulty reading, understanding, and acting on healthcare information may cope in which of the following ways:
a) Bringing someone who can read with them to their physician appointment
b) Watching and copying others' actions
c) Asking help from the medical staff and/or other patients
d) b and c
e) a, b, and c
4. According to results of previous studies, how many patients did not understand directions to take medicine on an empty stomach?
a) 42% b) 35% c) 25% d) 10%
5. Low literacy is often associated with which of the following:
a) Higher healthcare costs
b) Poorer health status
c) Higher probabilities of hospitalization
d) a and c
e) a, b, and c
6. The average informed consent and living will forms are written at the _____ reading level.
a) 6th grade
b) 8th grade
c) 12th grade
d) postcollege
7. Which of the following strategies might be useful when communicating with a patient who has low health literacy skills?
a) Present 1 to 3 concepts at a time and check for understanding
b) Overuse technical jargon
c) Review written instructions and have patients repeat them in their own words
d) a and c
e) a, b, and c
8. Patients with low health literacy may have difficulty with which of the following:
a) Understanding medication directions
b) Completion of medical forms
c) Self-management of chronic conditions
d) a, b, and c
9. An individual who is able to read and understand materials with familiar content will be able to read and comprehend materials written at the same level of complexity even if the vocabulary and concepts are unfamiliar.
a) True b) False
10. Most of the people with health literacy are white native-born Americans.
a) True b) False

CME Answer Sheet

Please return the form to:

Division of Continuing Medical Education
American Medical Association
515 North State Street
Chicago, IL 60610
Fax: 312-464-4567

Exam Response

Circle your response, one response per question

Q 1.	a	b	c	d	
Q 2.	a	b			
Q 3.	a	b	c	d	e
Q 4.	a	b	c	d	
Q 5.	a	b	c	d	e
Q 6.	a	b	c	d	
Q 7.	a	b	c	d	e
Q 8.	a	b	c	d	
Q 9.	a	b			
Q 10.	a	b			

What change(s) do you plan to make in your practice as a result of studying the materials in the *Health Literacy* educational program?

Comments

Please print and include all information requested

Name

Address

City

State

Zip

Phone

Fax

Medical School

Year of Graduation

ME#*

Signature

* The Medical Education Number (ME#) is an 11-digit number assigned to every physician in the US by the AMA. It is found on your AMA membership card, the mailing labels of your *JAMA*, *American Medical News*, or *Archives Specialty Journal*, or you can obtain your ME# by calling the AMA at 800-262-3211.

Program Evaluation

	Excellent	Above	Good	Below	Poor
Overall quality of the material	5	4	3	2	1
Content of the program	5	4	3	2	1
Usefulness in my practice	5	4	3	2	1
Would recommend it to my peers	5	4	3	2	1
Would recommend it to my office staff	5	4	3	2	1
Would recommend the CME program to my peers	5	4	3	2	1

An AMA Continuing Medical Education Program

The American Medical Association (AMA) is accredited by the Accreditation Council for Continuing Medical Education (CME) to provide continuing medical education for physicians.

The AMA designates this educational activity for a maximum of 2.5 AMA PRA Category 1 Credits™. Physicians should only claim credit commensurate with the extent of their participation in the activity.

The enclosed materials will enable physicians to:

- Understand the scope of the health literacy problem
- Recognize health system barriers faced by low literacy patients
- Improve methods of verbal and written communication
- Incorporate practical strategies to create a shame-free environment

Sponsored in part by an educational grant from Pfizer Inc

