Patient Education and Literacy

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Introduction

This chapter describes two literacy problems plaguing the health care system at the turn of the millennium: hypoliteracy and hyperliteracy. *Hypoliteracy* (low literacy) refers to undeveloped or atrophied literacy skills. Hypoliteracy negatively affects health through lack of knowledge, resources, and empowerment. Hypoliteracy leaves patients unable to make sense of clinicians' instructions and unprepared to marshal the resources of an increasingly complex and technological health care system. *Hyperliteracy* refers to extremely high literacy, which can leave clinicians unable to communicate effectively with most patients. This chapter focuses on information necessary to clinicians to assist patients with low literacy levels while improving communication to all patients. After reading this chapter, providers will have:

- Explored communication gaps resulting from mismatches in logic, language and experience, that is, differences in the ways clinicians and patients think and talk about health and illness, and differences in their experience of the health care system;
- Considered universal precautions to bridge communication gaps and help all patients understand, recall, and act on information about their conditions, treatments, self-care, and self-management about their conditions, treatments, self-care, and self-management;
- Reviewed their legal responsibility and considered methods to communicate effectively with all patients in a language the patients can understand;
- Identified resources for managing education for patients of all literacy levels.

Literacy and Health

What is literacy?

The definition of literacy has evolved over the last two centuries from the ability to write one's name, to the ability to recite prose, to ability to read, and now to a new, broader concept. Around 1950, literacy was defined as the ability to read; a person was said to be literate or illiterate based on various standards related to comprehension. The United States Army was among the first to realize that illiteracy could be hazardous to health and designated a fifth-grade reading ability as the threshold for recruits' literacy. The U.S. Census Bureau recorded as literate persons who could read at a sixth-grade level, while the Department of Education said literate students read at the eighth-grade level.[1]

Literacy took on a new definition under the 1991 National Literacy Act. Congress defined adult literacy as the ability to:

- Read, write and speak *in English*
- Compute and solve problems
- Function on the job and in society
- Achieve one's goals
- Develop one's knowledge and potential[2]

The National Literacy Act both broadened and narrowed the concept of literacy in the U.S. Its new definition of literacy recognizes that life in the Information Age requires higher levels of basic skills (word recognition and comprehension) and expands the concept of literacy to include problem solving and higher level reasoning skills (synthesis, analysis).

In this broadened view, a person is no longer said to be literate or illiterate, but rather more or *less functionally literate*. An individual's skills my be adequate to function day-to-day at a satisfactory level in one's environment, e.g. a rural farming community, but inadequate in another environment, such as a university medical center. This line of thinking led to the concept of *health literacy*, described by Baker[3] as *ability to read and understand health-related materials*. Health literacy is discussed later in this chapter.

The 1991 National Literacy Act also narrowed the concept of literacy in the U.S. to English language proficiency. Following suit, at least 18 states have enacted "English-only" laws making English the official state language. For example, the Arizona constitution requires state employees to "act in English and not other language." The U.S. House of Representatives considered similar legislation in 1996. The proliferation of English-only statutes threatens the ability of persons with limited English proficiency (LEP) to access health care services and contradicts other laws requiring health care providers to bridge communication barriers. The constitutionality of these English-only laws has been challenged and their future remains clouded.[4]

Who is Literate?

Little was known about the literacy skills of American adults until 1993 when the U.S. Department of Education published results of the National Adult Literacy Survey (NALS). This monumental study interviewed 26,000 adults and tested their literacy skills in three areas, each reflecting a different type of literacy task. Reading tasks, such as finding information in a newspaper story, reflect *prose literacy. Document literacy* is demonstrated, for example, by completing forms. *Quantitative literacy*, also called *numeracy*, is reflected in tasks requiring computing or interpretation of charts and tables.

NALS makes clear that literacy is not something someone has or does not have. NALS measured literacy on a continuum divided in five *Functional Competency Levels*. Level 1 reflects the lowest skill level and Level 5 the highest. An individual may perform at different levels on different skills and under different conditions. (Figure 12-1).

NALS found about one in five American adults at Functional Competency Level 1. Although NALS levels are not designed to be comparable to school grades, Level 1 prose literacy is roughly equivalent to a fifth grade or lower reading level.[2] This means that about 40 to 44 million of the 191 million Americans over age 16 are hypoliterate – they have low function literacy. Of these, about 4% or 1.6 million cannot complete the most basic literacy tasks, such as finding one piece of information in a sports article. It is also notable that the vast majority of adults in Level 1 describe themselves as reading well or very well.

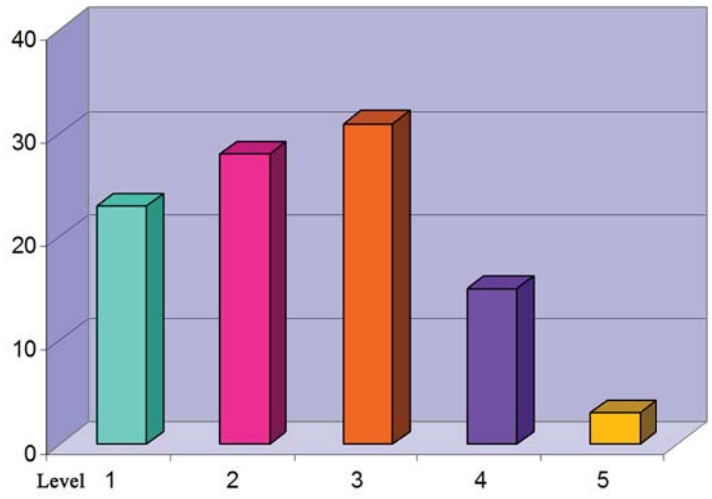

Figure 12-1. Percentage of U.S. adults in functional competency levels. (From U.S. National Adult Literacy Survey 1993, U.S. Department og Education, 1993.)

Hypoliteracy may result from lack of education or poor quality education; 62% of adults in NALS Level 1 did not graduate from high school. Hypoliteracy may also be attributable to atrophied skills among those unaccustomed to learning by reading and many years out of school; 71% of Level 1 adults are over age 60. Low functional literacy also may be the result of LEP, common among immigrant and refugee population; 25% of those in Level 1 are immigrants who have just begun to learn English.

Most Americans in Level 1 are white and U.S.-born. Disproportionately represented are people with low incomes, minorities, and inner city and rural populations. Since persons of low income, low education and advanced age carry the largest disease burden and have the highest need for health and medical information, literacy is a critical issue for the healthcare system, particularly for clinicians.

Although hypoliteracy crosses all social, economic, educational and political boundaries, it carries a significant stigma and is a source of shame, feelings of inadequacy, fear and vulnerability. Most hypoliterate persons are adept at hiding their difficulty from their spouses, children, friends, coworkers, and doctors.[5] Clinicians encounter hypoliterate patients daily without recognizing them.

NALS data have been variously interpreted and misinterpreted in the medical literature, sometimes confounding common sense. Recent journal articles have reported that adults in Level[1] "cannot read and write well enough to meet the needs of everyday living and working,"[3] and that "they are unable to assimilate information that could improve their

health."[6] Katz[7] describes illiteracy as a "permanent barrier to learning." Titles of several journal articles refer to "patients who cannot read" and "illiterate patients".[8,9]

NALS data show that hypoliterate persons are at a disadvantage in society. They do not have access to the full range of economic, social and personal options that are available to Americans with higher levels of literacy skills. However, researchers who developed NALS emphasize that persons in Level 1 are not "illiterate". They are able to perform a variety of literacy and other tasks that life may require of them. They may be highly functional in familiar surroundings. [10]

Most people with hypoliteracy have average intelligence and function quite well by compensating in other ways for lack of literacy skills. They can learn what they need to know to maintain their health or manage disease. The can learn from nearly any health instruction that is designed and presented in ways suitable to them.[11] (see Box 12-1)

The Health-Literacy Connection

However health is defined or measured, it is negatively affected by low literacy, both directly and indirectly. It is hardly surprising that failure to understand information about medications, health practices and safety risks can result in health problems. Three themes emerge from consideration of variables through which literacy affects health.

1. Lack of knowledge – about health and health services, about how to get information and assistance
2. Lack of resources – safe living conditions, food, medical care and supplies, and health services
3. Lack of empowerment and control – patients' limited self-advocacy and self efficacy, unemployment and low income, limited control over their own health.[12]

Box 12-1
Skill Levels of Adults at Functional Competency Level 1

Usually Can

- Sign one's name
- Identify a country in a short article
- Locate one piece of information in a sports article
- Locate expiration date on a driver's license
- Total a bank deposit

Usually Cannot

- Locate an intersection on a street map
- Locate two pieces of information in a sports article
- Fill out a social security application
- Total costs on an order form

From Reader, S. *The State of Literacy in America*. Washington, DC: National Institute for Literacy, 1998.

Direct impacts of hypoliteracy on health include not following medical instructions and incorrect use of medication, such as mixing up bottles. Similarly, infant health is directly impacted by parents' hypoliteracy when parents improperly administer infant formula. These occurrences are frequently mistaken for non-compliance.

Safety risks are another direct impact of hypoliteracy. Low-literacy workers often are limited to dangerous work environments and have higher than average rates of accidents, often owing to inability to read or understand warnings.[12] The major impact of low literacy on health status occurs indirectly and has significant implications for preventive services.

Literacy and Poverty

Documentation of links between poverty and ill health is extensive.[13] In turn, education and literacy are the primary factors in poverty.[4] Literacy is a critical determinant of employability. It is closely related to employment and income. According to the U.S. Department of Labor, about 40% of existing jobs can be done by unskilled workers, but only 27% of newly created jobs will be in that category.[1] Because hypoliteracy severely limits employment opportunities, it can "cause" poverty. Without literacy skills, chances of escaping poverty are slim.

In addition, people with low literacy are likely to live in low-quality housing and in unsafe areas with higher rates of pollution, traffic and crime. They are less likely to be in a position to install smoke detectors and other safety devices. For these reasons, accidents are more common among hypoliterate persons.[12]

Lifestyle Practices and Literacy

Hypoliteracy limits one's options to make lifestyle choices by limiting opportunities, knowledge, resources and control. People with low literacy are more likely than others to engage in unhealthy behaviors such as smoking, poor nutrition, inactivity, not using seatbelts and bicycle helmets, not breastfeeding and not obtaining blood pressure checks and Pap smears. Hypoliterate persons are less likely to be aware of the importance of healthy lifestyle practices.[15]

Stress, Lack of Control and Literacy

For someone who lacks literacy skills, coping with the literacy demands of a technologically advanced society is stressful by itself. In addition, hypoliteracy my introduce stress from unemployment, poverty, unsafe living and working conditions, uncertainty, lack of control over ones own life. At the same time, low literacy severely limits resources available to cope with these stressors.

Stress is recognized as a health problem in itself. For example, stress is a major factor in depression and other mental illnesses and can lead to other disease. Change is a source of stress for everyone but a severe disadvantage for persons with limited literacy who rely on routines, landmarks and set processes. In a stable environment they may function very well, but they are likely to suffer increased stress when environments change.

The stigma attached to low literacy leads to stress, shame and low self-esteem. Many persons with low literacy have invested a lifetime in hiding their disability.[15] Stress and shame related to low literacy have significant implications for preventive services. The stress involved in the process of obtaining care can discourage hypoliterate patients from seeking care, especially preventive services. Shame and low self-esteem interfere with efforts to change health-related behavior. According to Bandura[16] a feeling of confidence that one can do what is asked of him or her is the most important prerequisite for behavior change.

Health Affects Literacy

Clinicians need only observe themselves to notice that stress, hunger, fatigue, pain, illness and medication reduce ability to apply literacy skills. Newcomer [17] showed that stress affects cognitive ability and memory. Greater stress corresponds to greater impairment. Therefore, even persons with well-developed reading, reasoning and numeracy skills are likely to become less functionally literate when their condition warrants medical treatment, particularly hospitalization. Feeling stressed and lacking medical vocabulary, the patient may be unable to describe clearly his or her complaint, to answer or articulate questions, or to understand answers.

However health is measured, it is negatively impacted by hypoliteracy, both directly and indirectly. Conversely, poor health reduces literacy

skills, even among the most proficient. Hypoliteracy limits opportunities, knowledge, resources and control over one's own life. Persons with limited literacy are likely to have a high need for health care and to experience significant barriers to obtaining health information, locating health services and accessing care.

Literacy & Health Care

Communication gaps between hyperliterate clinicians and hypoliterate patients have been described as mismatches in logic, language and experience, that is, differences in the ways clinicians and patients think and talk about health and illness, and differences in their experience of the health care system.[11] The National Adult Literacy Survey found that about 20% of American adults are at Level 1 functional literacy, roughly equated to a fifth grade reading level or lower. Only 3% function at Level 5, the highest level of competence, roughly equivalent to a college graduate level of ability.

Because of their training and daily practice of advanced literacy skills, most, but not all, clinicians have Level 5 literacy skills and can be said to be hyperliterate. Although hyperliteracy – very high literacy- is generally considered an advantage, in healthcare delivery it leads to communication problems. Whereas hypoliteracy leaves patients unable to make sense of clinicians' instructions and unprepared to marshal resources of an increasingly complex and technological health care system, hyperliteracy can leave clinicians unable to communicate effectively with most patients.

Differences in How Persons Process Information

Although most people think of literacy in terms of reading comprehension, literacy skills also affect listening comprehension, the ability to understand verbal instructon.[3] There are significant differences in the ways hypoliterate and hyperliterate persons obtain information and learn. Clinicians typically are highly successful, life-long learners with a gourmet's taste for knowledge. In contrast, patients with low literacy skills typically have had negative learning experiences associated with failure and embarrassment. For them, learning leaves a bitter taste, so they approach it with apprehension.

Even when highly motivated to learn, a hypoliterate patient may read or hear all the words in an instruction and still obtain little or no meaning. While most clinicians, as skilled learners, are adept at interpreting meaning, patients with low literacy skills take words literally without interpreting them for new situations.[11] Therefore, as the cartoon illustrates, a patient who appears noncompliant in fact may be highly motivated to follow instructions to the letter, even if the instructions make no sense. (Figure 12-2)

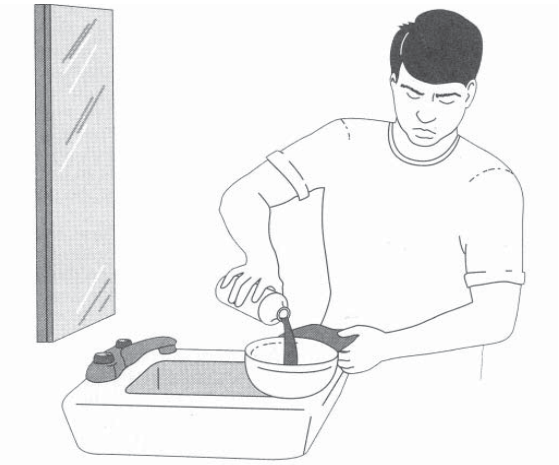

Figure 12-2. One capful every 4 hours.

Where hypoliterate persons read and listen with fluency and draw on broad vocabulary, hypoliterate persons often read and listen to one word at a time. When listening to verbal instruction, they may not hear the second half of a sentence because they are still digesting the first part, especially if

terms are unfamiliar. This may lead them to appear uninterested or distracted. Similarly, when people read one word at a time, they may easily forget the beginning of the sentence by the time they get to the end, particularly if the sentence is long. Even when they can read and understand all the words, unskilled readers can miss the meaning of sentence or paragraph.[11]

Although skilled readers are accustomed to deciphering the meaning of uncommon words, looking them up in a dictionary or asking clarifying questions, unskilled readers typically skip over unfamiliar terms and avoid asking questions out of fear of revealing their low literacy or of appearing ignorant.

Unskilled readers may miss the context. For example, a person with low literacy skills may not infer from a brochure or discussion that the facts about a particular disease and how it affects other people also relates to his or her own life, unless the connection is specifically explained. Although most people with hyperliteracy have adequate intelligence, their skills at decoding words and meaning, and in analyzing and synthesizing information tend to be inadequate to understand unfamiliar terms or complex presentation of facts.

The Role of Logic, Language & Experience

Additional communication problems arise in health care settings out of mismatches in clinicians' and patients' logic, language and experience (LLE).[11] Humans learn by adding new information to what they already know – their logic, language and experience. The cartoon on page 7 illustrates what can happen when new information does not fit into the patients' LLE. In the cartoon the patient adds new information – instructions to "take one capful" of medicine- to his existing LLE, which tells him that "cap" is his hat, and that he can drink from it in a pinch. So being motivated to follow instructions, he pours the elixir in his cap.

Because of their training, clinicians think about illness and treatment in ways foreign to persons outside the medical professions. For, example, most patients take medication to feel better. In this manner of thinking, it is logical to stop taking medication when symptoms abate; it does not make sense to continue taking antibiotics when feeling fine.

This mismatch in logic is particularly problematic in preventive services and with patients from certain cultural backgrounds. For example, Hispanic women view pregnancy as a normal, healthy condition, and view the health care system as a place to seek treatment for serious injury or disease. Another characteristic of Hispanic culture is fatalism, a sense that health and disease -including fetal and infant health- are divinely ordained and unlikely to be changed by human efforts. Further, in some Hispanic cultures, only a woman's husband can properly touch or examiner her.[18] From this cultural background, seeking early prenatal care is illogical. It should not be surprising then, that utilization of prenatal care services is low among Hispanic women in the U.S.

Consider also the mismatch in experience of health care settings between clinicians and patients with low literacy levels. Whereas clinicians have daily experience in the medical office or hospital and so feel at home and in control in that setting, for patients, a visit to the doctor is by definition a stressful event. For many immigrants, a trip to the hospital may represent their first encounter with an institution of any kind.

The medical encounter may be particularly difficult for hypoliterate and LEP patients, who may experience significant difficulties just locating the facility. The usual signage, forms, questions and instructions that are daily routine for health care professionals can be overwhelming to persons

with low literacy. They may hesitate to ask for help, either because they do not speak English well, or out of fear of discovery of their low literary and the attendant shame and potential for discriminatory treatment. By the time the clinician sees the patient, the patient's stress level can be high enough to prevent effective application of whatever literacy skills he or she may possess. Newcomer[17] showed that stress level affects cognitive ability and memory. Greater stress corresponds to greater impairment. Feeling stressed and lacking medical vocabulary, the patient may be unable to describe clearly his or her complaint and answer or articulate questions. Such a situation is ripe for missed or delayed diagnosis and inappropriate or unnecessary testing and treatment.

Perhaps the most apparent mismatches in health care settings are mismatches in language. Medicine has its own terminology, which is rarely heard outside the professions. Few English-speaking Americans understand even basic medical words such as, void, laceration, or tumor. Communicating risk information is particularly challenging, since hypoliterate persons have difficulty with fractions and statistics and may not connect facts about risks to others to themselves.[11]

Few English-speaking patients understand even basic medical words

Universal Precautions for Hypoliteracy

Patient education enables patients to:

- Make informed decisions
- Engage in self-care to survive and recover
- Recognize problems
- Seek timely, appropriate assistance
- Get information and find resources[19]

Half the adult population needs easy-to-read materials and the other half who do not need them want them anyway.[20] People at all literacy levels can better understand simply written materials. [21, 22]

College-educated readers report increased recall of key messages and express extreme satisfaction with fifth-grade level health information materials. [23] A study comparing a simplified sixth grade level brochure to a tenth grade level brochure on the same topic demonstrated that patients of all reading levels and socioeconomic levels preferred the shorter, simpler material. [24]

Hypoliteracy affects more than just reading. Information that is incomprehensible in writing is still incomprehensible when presented in person, in audio or video tape. Whether reading, viewing or listening and regardless of their literacy skills, people under stress have limited ability to understand, and otherwise able learners prefer their information brief, clear, picturesque and accurate.

Therefore, it makes sense to approach low literacy in health care settings with universal precautions. Universal precautions are principles and practices applied to all patients to prevent or mitigate the effects of literacy mismatches in health care settings.

A universal precautions approach recognizes that all patients' literacy skills are reduced by the physical and mental effects of illness and the stress associated with needing medical care. In addition, since low literacy is associated with factors that increase need for health services, such as poverty, advanced age, and lack of education, it is likely that the majority of patients have low functional literacy.

A universal precautions approach further recognizes that most people outside the health and medical

professions have low "health literacy," since medical topics are increasingly complex, technological, anxiety-producing, and unrelated to people's lives until they become patients – an occurrence most seek to avoid. Medical terms are rarely used in everyday conversations and are unfamiliar, even to the highly literate. Since a universal precautions approach anticipates that all patients will have difficulty understanding the language of medicine, it begins to position clinicians for a multicultural future and for treating increasing numbers of patients with LEP.

Because the same strategies that help patients with low literacy also help highly literate patients,[25, 26] there is no need to identify individuals with low literacy. There is no need to rate patients' "health literacy", and no need to provide printed information at various reading levels. Successful clinicians and health care systems are those who develop skills for communicating orally and in writing with persons with low functional literacy and lower health literacy, and who practice those skills with all patients.

Clinicians cannot change some factors in the effectiveness of health communications, such as cultural beliefs and values, formal education, socioeconomic status, language differences, and intellectual ability. However, research on patient education, patient satisfaction, adult learning, memory, and compliance indicates that the clinicians can improve patients' comprehension of health messages. With the universal precautions described hereafter, clinicians can expect to achieve gains in patients' recall (knowledge), satisfaction, compliance, and outcomes. [23, 27-29]

Joseph Pulitzer's formula for prize-winning writing serves as a succinct and memorable statement of principles that can mitigate mismatches in literacy in health care settings:

Put it before them briefly so they will read it, clearly so they will appreciate it, picturesquely so they will remember it, and above all, accurately so they will be guided by its light.

—Joseph Pulitzer

Pulitzer offers an elegant guide to preparing or selecting materials for patients and planning educational interventions. The formula is applicable to all types of materials—printed, audio, video—as well as face-to-face communications.

At least 22 factors are known to affect suitability and effectiveness of materials. Detailed assessment instruments are available, notably the Suitability Assessment of Materials (SAM).[11] Clinicians who rigorously apply Pulitzer's formula will address most factors covered in more complex instruments.

Now consider each element of Pulitzer's advice and its implications for practice.

Put it before them briefly so they will read it…

Brief means short. Here it refers not only to the length of materials, but also to all aspects of the information package.

- Short words—one- or two-syllable common words
  Quick test: Hold your chin as you say the word. It moves once per syllable.
- Short sentences in writing and speaking—less than 15 words, one idea
- Short paragraphs—two to five sentences, one topic
- Short lists—not more than 5 items

Put it before them…clearly so they will appreciate it…

Clearly means clear to the reader, not open to interpretation. Appreciate does not mean grateful, although patients will be grateful for clear information and instruction. Appreciate means to understand and value the information so they can act on it.

To speak or write clearly:

- Focus on behavior not facts.

In other words, do not describe a condition the way clinicians are taught in medical school. Patients do not need to know the etiology, incidence, and prevalence of a disease. They need practical how-to information to make informed decisions, engage in self-care, recognize problems, seek timely and appropriate assistance, and get information or resources.

- Use the learners' LLE—logic, language, and experience—not yours.

When planning an educational intervention, start by inviting a group representative of the learners to tell you about their condition, what they think caused it, what it means in their lives, how they cope, and their experience of seeking treatment. This will allow you to think about the condition as the patients do and to recognize their concerns and questions. It will give you specific words and phrases to use when discussing the condition that will make sense to them.

When administering a formal education intervention or initiating an informal teaching conversation, start with a learning needs assessment.[19] This can be a quick step that saves time and frustration for both patient and clinician. Informal conversation is an effective and unintimidating method of assessment.

- Set the stage by reminding patients that learning is part of treatment and recovery, that they should expect teaching from clinicians, and that their job is to understand and to ask questions when they do not.
- Find out what the learner knows already. Reinforce desired behaviors and correct misperceptions. Listen carefully to the patient's words and use them in your response.
- Determine the patient's readiness to learn. Ask directly what the patient wants to know and why it is important to him or her. Whatever that is, address is first. The patient is ready to learn about that topic.
- Find out what the patient believes. Tailor instruction for this patient by framing the conversation around his or her beliefs. Keep the focus on the critical minimum that the patient needs to know (despite your urge to teach something else).
- Recognize when you are not getting through. Any resistance is a "red flag" that tells you to stop teaching and check for mismatches between your LLE and the patient's. Are you lecturing? Are you talking to the right person—should you be addressing the caregiver instead of the patient? Does the information conflict when something the patient already knows or believes? Does the advice seem irrelevant, impractical, or impossible in the patient's situation? In each case, stop and ask a question to refocus on what the patient needs to know to make an informed decision, engage in self-care, recognize problems, seek assistance, or get information and resources.
- In each sentence, start with what the patient already knows and believes. To get information into memory where it can become knowledge, the brain needs a place to put it. By starting with what the patient/learner already knows, you put

the information on an established pathway into memory. Construct sentences with the known information first, followed by new information. For example, say "When you have a stomach ache" (the part the patient knows), "call the doctor" (the new information). This construction is especially important to unskilled readers who may forget the first part of the sentence by the time they work through to the end.

- Replace or explain value judgment terms. Instructions that require patients to make a judgment are unclear. Rephrase to be specific and not open to interpretation. For example, instead of "heavy bleeding," say "bleeding that soaks a pad in 2 hours." Instead of "large clots," say "clots the size of a golf ball or larger"—unless your learners do not play golf. Then you might say "the size of a walnut." Instead of "a fever" say "a temperature higher than 100 degrees."
- Review, repeat, summarize. Adults learn by repetition. Say the most important thing three times. Do not be concerned about repeating yourself. Ask the patient to summarize the discussion about one topic before going onto the next.
- Test readability. Readability, the relative difficulty of decoding the words, typically is expressed as a school grade reading level required to recognize most of the words in a text. For example, materials with an eighth-grade readability rating require reading skills equal to those of the average middle school student. Formulas that rate readability are based on syllables (or characters) per word and words per sentence. Some include a vocabulary list. A too-high rating readily identifies materials that exceed most patients' literacy skills.[30]

Readability is only one of many factors that make materials more or less useful for patients. Readability rating has well-known shortcomings.[31] Since it is quite possible to recognize all the words and still miss the meaning, a good (low) readability score cannot stand alone as a predictor of easy reading and understanding.

Clinicians who apply Pulitzer's formula as described in this section will likely achieve an appropriate readability level. Still, the importance of this factor warrants a policy requiring readability testing of all materials for patients. Several software programs, including Microsoft Word, apply one or more of the more than 40 readability formulas in existence, and when properly applied, these formulas produce a rating that is accurate within a grade or two.[11]

For most patient populations, a fifth to sixth grade reading level is a reasonable standard. Materials at this level that are otherwise well designed can be independently understood by about 80% of the U.S. adult population. Patients with low literacy skills may stretch their capacity in order to understand information that is immediately applicable to a problem they have now.

Put if before them…picturesquely so they will remember it…

Picturesque means attractive. We do judge books by their covers. Patients/learners will decide whether or not to read your instructions in a few seconds. The appearance of materials communicates loudly and clearly the importance the clinician places on the information. If it's only worth a quick and dirty photocopy, maybe it's not worth reading and following.

Picturesque also means the words paint a picture in the learner's mind. This returns to the issue of clarity and LLE. Familiar words make meaningful mental pictures. Technical terms, acronyms, and other jargon make static.

Replace this:	*With this:*
limbs	**arms and legs**
ambulate	**walk**
bacteria	**germs**

Put it before them…accurately so they will be guided by its light.

A rigorous expert review process is appropriate for all information on which patients rely. Clinicians typically are content experts. Content must be current, evidence-based, and independently reviewed for adherence to national guidelines as well as to local conventions.

Clinicians rarely are experts on materials development or specialists in health education, so presentation (format, design, graphics, typography) must be reviewed for adherence to health education theory separately from evaluation of design and graphics factors that affect readability, comprehension, and persuasiveness.

Patients themselves are the only reliable experts on the suitability and effectiveness of particular content and presentation. Information can be accurately stated and inaccurately interpreted. Misinterpretation may be due to the patients' low literacy skills, but more likely it is a problem of the writers failure to adequately consider the patients' LLE. Only patients/learners can tell you if information is attractive, understandable, and persuasive to them.

Brief interviews with 10 representative patients will be sufficient to reveal weaknesses in materials and suggest remedies. (Doak, Doak, and Root[11] offer details on how to involve patients in review and revision of materials.) Only when materials and planned oral presentations are pretested with patients and revised according to their suggestions are materials ready to be put before them as Pulitzer suggests.

Put it before them…

Briefly reviewing materials with each patient increases the proportion of patients for whom the materials are useful. This practice improves understanding and reinforces the key messages for readers at all literacy levels. Reviewing materials adds the motivating power of the clinician's endorsement. In the process, the materials cue the clinician to reinforce key messages.[29]

Give the patient a pen to write his or her name on the materials to demonstrate the importance of the information and of the patient's role. Refer to the materials to answer questions. Use a highlighter to point out areas of particular importance to the patient, such as warning signs to report and how to report them. This makes materials more useful when patients refer to them later or share them with a caregiver.

Reviewing printed information with the patient also gives the clinician opportunities to assess understanding by asking a question such as "What will you do if you have trouble breathing?" Do not ask "Do you understand?" No one wants to appear ignorant, so almost everyone will respond positively. Instead, take responsibility for the communication by asking "Is there something you'd like to go over again?"

Assuring Linguistic Access to Care

Clinicians' Legal Responsibilities

Before 1975 only a few languages could be heard in the U.S. Since then, immigration patterns have changed dramatically. Now, U.S. residents speak at least 328 languages in addition to English. About 32 million U.S. residents, in both urban and rural areas, speak a language other than English at home.[32]

Increasingly, clinicians encounter patients who are immigrants or refugees unfamiliar with English. While these patients may be well educated and proficient in another language, by U.S. standards and for practical purposes they are hypoliterate owing to LEP—limited English proficiency. Many may have limited literacy skills in their primary language, or no literacy skills. According to the U.S. Department of Health and Human Services, non-English speakers face substantial communication barriers at almost every level of the health care system.[33]

When communication barriers prevent health care professionals from understanding their patients' symptoms, proper medical care and informed consent can be nearly impossible. Lack of appropriate linguistic services to facilitate communication between clinicians and patients with LEP is associated with failure to use preventative care.[36] In addition, cost of care may be increased by unnecessary testing,[35] extended treatment times,[36] delayed diagnosis, and increased chances of patients' inability to follow instructions.[37]

In most cases, providers have the means to overcome language barriers. Still, according to a report from the National Health Law Program,[4] current practice in most communities reflects an assumption that the providers have no obligation to bridge language barriers, or that it is the patients' obligation to make themselves understood. In most instances, this assumption is wrong as a matter of law. Federal and state laws and accreditation standards require access to linguistically appropriate care.

Federal Law

No person in the United States shall, on the grounds of race, color or national origin, be excluded from participation in, be denied benefits of, or assistance, or be subjected to discrimination under any program or activity receiving Federal financial aid.

—Title VI of the 1964 Civil Rights Act

Nondiscrimination language similar to that of Title VI in the Hill Burton Act and in Medicaid laws provides an additional base for requiring clinicians to overcome language barriers. In addition, the Health Care Financing Administration (HCFA), the agency in charge of Medicaid at the federal level, specifically requires states to communicate orally and in writing in a language understood by the beneficiary.[38]

The Office for Civil Rights has consistently taken the position that these federal laws place the burden of ensuring effective communications with LEP patients on the recipient of federal funds.[4] The obligations of Title VI and its implementing regulations apply to all recipients of federal funding, without regard to the amount of funding or the number of non-English speakers in a program. Since federal funding of medical care is so pervasive, nearly every health care provider is bound by Title VI.[4]

Liability for Negligence

Clinicians who fail to overcome language barriers run the risk of malpractice claims arising from injuries suffered as a result of miscommunication.[39] Providers also face potential claims that failure to ensure their understanding of the patient's complaints is a breach of professional standards of care.[4] Failure to ensure that the patient understands treatment options, risks, and benefits is a breach of informed consent requirements.

Accreditation Standards

Additional requirements to overcome language barriers are imposed by accrediting organizations. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards require hospitals to offer education to patients and families to enable them to meet patients' ongoing health care needs. Explanations and instructions must be presented in ways that are understandable to patients and their families, taking into account their culture and language.[40]

The National Committee for Quality Assurance (NCQA) accredits managed care organizations (MCOs) and produces the Health Plan Data and Information Set (HEDIS) to enable health care purchasers to evaluate the performance of MCOs. HEDIS asks MCOs to report how many doctors and staff serving Medicaid patients speak a language other than English, and the availability of out-of-plan interpreters for all members. HEDIS also asks for an inventory of all materials in languages other than English.

Many of the federal and state laws requiring health care providers to take steps to understand and be understood by LEP patients are relatively unknown and infrequently enforced. However, MCOs are dealing with language problems because of government regulation and to compete for market share. In an attempt to assure that MCOs prepare adequately for multicultural populations, states are including requirements for culturally sensitive services, translated written materials, use of interpreters, and multilingual staff in managed care contracts and requests for grant proposals.[4] Clinicians can anticipate growing pressure to comply with federal, state, and private mandates to ensure linguistic access to services and information for immigrant and refugee populations.

Steps to Bridge the Communication Gap with LEP Patients

- Increase data collection

Lack of data on the language and health needs of LEP patients makes it difficult to determine what specific steps clinicians should take to overcome language barriers, determine costs of linguistic services, and monitor provisions of services. A logical first step for clinicians is to advocate for data collection in their services areas. At the same time, clinicians should consider involving consumers and their advocates in designing and implementing solutions.

- Translate patient education materials

For cost-conscious clinicians and organizations, translating printed materials is a particularly attractive method of communicating with LEP patients. Materials can be reproduced and reused easily. Member service information and informed consent forms are now translated with some frequency. However, patient care instructions, satisfaction surveys, grievance forms, and bills are rarely available in any language other than English.

Availability of translated materials of any kind is limited. The quality of available materials varies widely. Straight translations that do not take into account differences within cultures and subtleties in language are likely to confuse and alienate

readers. Since most of these materials exceed the literacy skills of most Americans,[11] translations of these materials are likely to be unsuitable for LEP patients. Certified professional translators should translate materials. Before use with patients, translated materials must be tested with representatives of the target audience, revised according to their recommendations, and retested. Clinicians can bridge language barriers, increase understanding and compliance, and reduce liability exposure by using quality materials to guide discussions and reinforce key messages.

- Hire bilingual staff and qualified interpreters

Recruitment and hiring of bilingual and bicultural physicians, nurses, and health aides may be vital to delivering language-appropriate services to LEP patients. Professionally trained staff interpreters or a shared pool of contract interpreters can also improve services. Experts emphasize the need for interpreters to demonstrate skill in medical interpretation.

Clinicians should not rely on family, friends, or health care workers untrained for interpretation. Children should never be asked to translate. Untrained interpreters are prone to omissions, additions, substitutions, volunteered opinions, and semantic errors that can distort care.[41] Patients may speak less freely when family members, especially children, interpret.[42] Family interpreters might not translate accurately out of fear of the impact on the patient.[41] They rarely know medical terminology and may be uncomfortable discussing sensitive conditions (see Box 12-2).

Box 12-2
The Use of Family and Friends as Interpreters

- Results in omissions, substitutions, and semantic errors that distort care
- Breaches confidentiality
- Creates barriers to the provider/patient relationship
- Upsets family relationships and hierarchies that are deeply rooted in culture
- Is particularly problematic in areas of gynecology, reproductive health, and sexually transmitted diseases
- Inhibits mental health treatment

How to Locate Qualified Interpreters

To locate medical interpreter services in your area, consult the telephone directory under Translators and Interpreters. Also, professional organizations specifically for medical interpreters are emerging around the country and can help clinicians locate services. These include the National Council on Interpretation in Health Care, the Massachusetts Medical Interpreter Association, the California Healthcare Interpreters Association, and the American Translators Association. For more information on these and other interpreters' organizations, visit the DiversityRX website at http://www.diversityrx.org/HTML/MOASSO.htm.

Clinicians who do not have ready access to qualified interpreters can obtain telephone interpretation services from English into 140 languages through AT&T Language Line Services. Call 1-877-886-3885, or see http://www.languageline.com.

Conclusion

According to the 1990 census, U.S. residents speak more than 300 languages. Approximately 32 million persons, in both urban and rural areas, speak a language other than English at home. One in five U.S. adults are hypoliterate, medical conditions reduce functional literacy for all learners, and, since virtually all patients have low "health literacy" – little understanding of health and medical concepts and terminology—universal precautions are appropriate to mitigate communication problems in health care settings. Universal precautions for low health literacy recognize that strategies to assist low literacy patients help all patients, and, consequently, there is no need to identify patients with low literacy or to design educational interventions to particular literacy levels. Joseph Pulitzer's formula for prize-winning writing serves as an elegant guide to developing materials, planning education interventions, and engaging in informal teaching conversations with patients.

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