

# Health Literacy: A Review

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Illiteracy has become an increasingly important problem, especially as it relates to health care. A national survey found that almost half of the adult population has deficiencies in reading or computation skills. Literacy is defined as the basic ability to read and speak English, whereas functional health literacy is the ability to read, understand, and act on health information. Up to 48% of English-speaking patients do not have adequate functional health literacy. The consequences of inadequate health literacy include poorer health status, lack of knowledge about medical care and medical conditions, decreased comprehension of medical information, lack of understanding and use of preventive services, poorer self-reported health, poorer compliance rates, increased hospitalizations, and increased health care costs. The medical community must acknowledge this issue and develop strategies to ensure that patients receive assistance in overcoming the barriers that limit their ability to function adequately in the health care environment. (Pharmacotherapy 2002;22(3):282-302)

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Illiteracy in the United States has become an increasingly important problem, especially as it relates to health care. Although children in this country have the opportunity for a free education, a large proportion of adults have considerable limitations with functional literacy.<sup>1,2</sup> Deficiencies in basic reading, computation, and comprehension skills significantly affect the lives of many people in the United States. Illiteracy affects the quality of medical care, as patients are not able to perform necessary functions in the health care environment such as reading an appointment slip or following the directions on a prescription label. The most accurate assessment of this problem is reflected in the National Adult Literacy Survey (NALS) published in 1993.<sup>1</sup> The

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National Center for Education Statistics surveyed more than 26,000 randomly selected Americans and provided a detailed picture of their literacy skills to represent the country as a whole. The intent of the survey was not to measure literacy by reading level or last grade completed, but to assess how literacy skills affect the ability to function in everyday life situations. It included assessments of prose literacy (the ability to understand prose), document literacy (the ability to interpret documents), and quantitative literacy (the ability to perform mathematical tasks).

The NALS found that 40–44 million Americans, or approximately one-quarter of the population, were functionally illiterate. Another 50 million U.S. citizens had marginal literacy skills. This indicates that nearly half of the adult population in our country has inadequacies in reading or computation skills. Although 5% of this group have learning disabilities and 15% were born outside this country, most are Caucasian, native-born Americans.<sup>1</sup> The survey was a random selection of Americans and was weighted to represent all ethnic groups equally. African-Americans were more likely to score lower, but, overall, Caucasians made up a large percentage of those with inadequate literacy. The mean reading level of adults in the United States was 8th grade, although Medicaid enrollees had a mean reading level of 5th grade. The problem of inadequate literacy was particularly prevalent in the elderly, with 44% of those aged 65 years or older scoring in the lowest reading skill level in the NALS. Other subgroups with a high percentage of persons scoring in the lowest literacy levels included those who were living in poverty, had fewer years of education, had health problems, or were imprisoned. As health care professionals, we must work to increase the awareness of health illiteracy and begin to identify and implement solutions to improve the health care needs of these patients.

### Definitions

Literacy, in the United States, is defined as the basic ability to read and speak English.<sup>3</sup> Functional literacy is the ability to use reading, writing, and computation skills at a level of proficiency necessary to meet the needs of everyday life situations, function on the job and in society, achieve one's goals, and develop one's knowledge and potential.<sup>3, 4</sup> The lack of functional literacy skills in the United States raises serious concern about the ability of

Americans to function adequately in the health care setting.<sup>1</sup> The number of years of school completed measures the amount of education attempted but does not necessarily measure what individuals can do with that education or their ability to apply it to their daily lives.<sup>5</sup> Functional literacy, however, does measure what was learned during those years and the ability to read and comprehend new information.<sup>2, 5</sup>

Functional health literacy is the ability to read, understand, and act on health information. This includes such tasks as reading and comprehending prescription labels, interpreting appointment slips, completing health insurance forms, following instructions for diagnostic tests, and understanding other essential health-related materials required to adequately function as a patient.<sup>2–5</sup> Functional health literacy varies by context and setting and may be significantly worse than one's general literacy.<sup>3</sup> An individual may be able to read and understand materials with familiar content at home or at work but struggle when presented with medical material of the same complexity that contains unfamiliar vocabulary and concepts.<sup>3</sup> Even well-educated patients can be functionally health illiterate at times, when they do not comprehend the meaning of health information. Patients with inadequate health literacy are at great risk of misunderstanding diagnoses, directions for administering drugs, and self-care instructions.<sup>2, 5</sup> Illiteracy can have a tremendous impact on all areas of a person's life. If illiteracy is not identified and addressed and opportunities for disease prevention or treatment are missed, the effects can be detrimental to one's health and well-being.

### Measuring Literacy and Health Literacy

Health care professionals cannot assume that all patients know how to read, but direct questioning about reading level may not be effective, as illiteracy often causes shame and embarrassment.<sup>2, 6–8</sup> Assessing a patient's reading skills in the clinical setting can be helpful to health care professionals by providing insight into an individual's ability to function adequately in the health care environment. Generally, only aggregate testing is recommended in order to provide profiles of the reading ability of groups of patients.<sup>2, 9</sup> For example, a random sample of a specific practice population can provide an average reading level that then can be used as a guide in the selection and development of patient

**Table 1. Literacy and Health Literacy Tests**

Variable	WRAT-R <sup>9, 12, 14-15</sup>	REALM <sup>3, 9, 12, 16</sup>	MART <sup>14</sup>
Description	Word recognition test	Medical word recognition test	Medical word-recognition test using prescription bottles
Age	5-74 yrs	Adults only	High-school age
Administration time (min)	3-5 <sup>a</sup>	2-7 <sup>a</sup>	3-5 <sup>a</sup>
Scoring	Raw score of 1-57, converted to grade equivalent	Approximated grade level: 3rd and below, 4th-6th, 7th-8th, or 9th and above	Raw score converted to grade equivalent
Advantages	Quick	Quick, uses medical terminology	Nonthreatening, quick
Limitations	Difficult test	Assigns only grade-range equivalents	No clinical experience published
Correlation with other tests (r value)	PIAT-R 0.62-0.91	WRAT 0.88, SORT-R 0.96, PIAT-R 0.97, TOFHLA 0.84	WRAT 0.98

education materials.<sup>10</sup> Some practitioners advocate routine testing of all adult patients during their first visit to a new medical facility to identify those with certain needs and to develop strategies to address these needs.<sup>9-12</sup> If this approach is chosen, it must be conducted privately and with great sensitivity to avoid embarrassment to patients.<sup>9, 10</sup> Some recommend that reading grade levels not be recorded in medical records because of concerns that this information could be discovered by employers and impose adverse consequences on the patient.<sup>2, 9</sup> However, all health care professionals must be aware of any deficiencies in a patient's ability to read or understand instructions, as standard approaches to care and patient education materials may need to be revised and tailored to each individual patient. The implications on patient dignity and variations in treatment when low literacy is identified and documented in medical settings have not been adequately researched.<sup>13</sup> To date, assessment tools are primarily used in clinical research to further explore the relationship among illiteracy, health illiteracy, and poor health outcomes.<sup>13</sup>

Many clinicians have developed informal methods of determining whether patients can read.<sup>9</sup> This often is done by asking open-ended questions to assess understanding of written materials. For example, patients might be asked to read a prescription label or asked to answer specific questions about instructions they have received.<sup>9</sup> Another common technique is to give

patients written material upside down while discussing it and observe whether they turn it right side up.<sup>6-8</sup> It is also important to recognize strategies commonly used by patients in an attempt to hide their illiteracy.<sup>6, 10</sup> These include statements such as, "I forgot my reading glasses," "I'll read through this when I get home," "I'd like to discuss this with my family first," or "May I take the instructions home?"<sup>6, 7, 10, 14</sup> Other signs include an inability to keep scheduled appointments, follow medical instructions, or adhere to prescribed therapies.<sup>6, 8</sup>

What follows is a brief overview of some of the more commonly used assessment tools for evaluating literacy and health literacy. These tools are categorized as word recognition tests, reading comprehension tests, and functional health literacy tests. A summary of the tests is presented in Table 1. Information on ordering the tests can be found in Appendix 1.

#### Word Recognition Tests

Word recognition tests are useful predictors of general reading ability and typically require an individual to read aloud from a list of words.<sup>9</sup> These tests do not measure reading comprehension or interpretation but assess the ability to recognize or read and pronounce individual words. These literacy tests offer the advantage of being quick and easy to administer and score, but they do not offer an assessment of functional literacy. If patients have difficulty with word

**Table 1. Literacy and Health Literacy Tests (continued)**

SORT-R <sup>9, 12, 17</sup>	PIAT-R <sup>12, 18-19</sup>	IDL <sup>9, 20</sup>	TOFHLA <sup>4, 20-21</sup>
Word recognition test	Reading recognition and comprehension test	Reading comprehension test	Functional health literacy test
4 yrs and older	All ages	All ages	Adults only
5–10	60	20–30	22 (7 for short version)
Results converted to age and grade equivalents	Comprehension subtest score determines grade level	0–8, 0 = failure at 1st-grade level, 8 = 8th-grade level or above	Inadequate, marginal, or functional health literacy
Quick	Assesses comprehension	Available in Spanish	Measures functional health literacy, available in a shortened form and in Spanish
Small print and many items intimidating, not recommended for poor readers	Long	Long	Long version is time consuming, timed test can be frustrating
PIAT-R 0.83–0.90	Not available	0.65–0.70 with other English assessments	WRAT 0.74, REALM 0.84

WRAT-R = Wide Range Achievement Test-Revised; REALM = Rapid Estimate of Adult Literacy in Medicine; MART = Medical Terminology Achievement Reading Test; SORT-R = Slosson Oral Reading Test-Revised; PIAT-R = Peabody Individual Achievement Test-Revised; IDL = Instrument for the Diagnosis of Reading; TOFHLA = Test of Functional Health Literacy in Adults.

<sup>a</sup>Includes time required to administer and score test.

recognition, which is a beginning-level reading skill, they also are likely to have difficulty comprehending written information.

The Wide Range Achievement Test-Revised (WRAT-R) is a nationally standardized achievement test consisting of three subtests: reading recognition, spelling, and arithmetic.<sup>9, 15</sup> The reading subtest, for example, consists of letter reading (naming 15 letters of the alphabet) and word reading (pronouncing 42 words). The words are presented in ascending order of difficulty, and the individual must continue saying words aloud until they have missed 10 consecutive items.

The Rapid Estimate of Adult Literacy in Medicine (REALM) screening instrument is a word recognition test commonly used in health care settings.<sup>9, 16</sup> The tool is a laminated sheet containing 22 common medical words or layman's terms for body parts and illnesses and is arranged in three columns. The words are written in large font and arranged in order of difficulty. Patients are asked to pronounce each word aloud. If they are unable to pronounce several consecutive words, they are asked to look down the list and pronounce as many of the remaining words as possible.

The Medical Terminology Achievement Reading Test (MART), modeled after the WRAT-R, was developed to measure medical literacy in a

way that is nonthreatening to patients.<sup>14</sup> It places a variety of medically related words in small font on a label that is then placed on a prescription bottle. The bottles are covered with a glossy finish that produces a glare typical of an actual prescription bottle. Examiners explain that the print is small and that the glare may make words difficult to read, in an effort to make this test less intimidating to patients.

The Slosson Oral Reading Test-Revised (SORT-R) is often used in educational settings, but it is appropriate for use in medical settings as well.<sup>9, 17</sup> It contains 20 core words representing each grade level from kindergarten to high school. The examiner decides which list to start with, which is generally three to four grade levels behind the last grade completed. All words must be pronounced correctly, or the individual must move back to the previous list. Words are counted as incorrect if they are mispronounced or omitted, if the individual takes longer than 5 seconds to pronounce the word, or if more than one pronunciation is given.

#### Reading Comprehension Tests

Word recognition tests can be useful in determining the basic literacy level of many patient populations. They are generally quick and easy to perform and provide a general

assessment of reading ability. The limitation is that they do not test comprehension of written information. The assumption could be made that those who cannot recognize written words will have difficulty comprehending written instructions. Several tests are available that assess reading comprehension, rather than strict word recognition.

The Peabody Individual Achievement Test-Revised (PIAT-R) is widely used by schools, industry, and other community agencies. It consists of a reading recognition test and a reading comprehension test.<sup>18,19</sup> The recognition subtest contains 84 items that range in difficulty from preschool through high school. The comprehension subtest contains 66 items and is given only if the subject completes a majority of the preschool items on the recognition test. Individuals are asked to read a sentence silently and then choose, from among four pictures, the one that best represents the meaning of the task. The sentences become progressively more difficult, and the test is stopped when five of seven consecutive items are answered incorrectly.

The Instrument for the Diagnosis of Reading (IDL) is a bilingual (English-Spanish) tool.<sup>20</sup> Subjects are presented text at different grade levels and asked to read it silently in a private room before returning to the examiner.<sup>9,20</sup> The examiner then asks the subject a series of multiple-choice questions, of varying difficulty, that pertain to the text.

### Functional Health Literacy Test

Reading comprehension tests move a step beyond word recognition and measure the ability to comprehend information. Although these tests can be very helpful, they have limited usefulness in measuring functional literacy or the ability to comprehend and apply information to one's own life. The Test of Functional Health Literacy in Adults (TOFHLA) moves beyond comprehension to assess how well patients not only comprehend, but also act on real-world examples of health care situations.<sup>4,21</sup> This test has utility for health care professionals because it provides an assessment of an individual's potential or ability to function in the health care environment. The test includes an assessment of both reading comprehension and numeracy comprehension. The reading comprehension section contains 50 items that measure one's ability to read and one's ability to complete missing sections of selected passages about an upper gastrointestinal series, a Medicaid

application, and a procedure informed consent form. The numeracy section contains 17 items that assess one's ability to understand numbers, such as directions on prescription labels, blood glucose values, and appointment slips. The original TOFHLA, while comprehensive, can be time consuming to both administer and score; therefore, a shortened version of this test was developed and is now available.

### Applicability to Pharmacy

Published literature on the use of these tests specifically in pharmacy practice or by pharmacists is not available, although some studies are under way. The REALM is a relatively quick test that uses medical words and can easily be used by pharmacists in any practice setting. The MART is also a quick test that relies on prescription labels to test word recognition. Since the original TOFHLA can be time consuming to administer, the shortened version is a reasonable test for pharmacists to use in a variety of settings. These tests can assist pharmacists in determining patient-specific functional health literacy needs for appropriate implementation and monitoring of drug therapy recommendations and nonpharmacologic interventions. The tests also allow pharmacists to tailor their education and interventions based on these needs. In addition, these tools can be useful in conducting clinical research in the area of pharmacy practice.

### Prevalence of Illiteracy

The prevalence of illiteracy is well documented. It pervades all patient populations, medical conditions, socioeconomic classes, and age groups. This is particularly alarming because many studies have confirmed that patients read on a lower level than their last grade completed, which often is used as an estimate of reading ability.<sup>22-28</sup>

A large study of patient reading ability was conducted in a population of 528 indigent patients in seven outpatient clinics who were insured by Medicare or Medicaid, or had no health insurance.<sup>22</sup> Reading levels were assessed using the PIAT-R. Patients read on an average of 4.6 grade levels below their last grade completed in school ( $p < 0.001$ ). The mean reading comprehension of all patients was 5th grade 4th month, or grade 5.4 (SD = 3.9), whereas the mean self-reported educational level was 10th grade (SD = 2.8). Of all patients tested, 40%

reported completing the 12th grade, yet more than 58% read at or below the 5th grade level and could be considered functionally illiterate. Additional studies in specific patient populations demonstrate similar findings.

A second study used the REALM to assess the reading ability of patients with cancer.<sup>23</sup> The mean reading level of the 63 patients tested was 6th–7th grade. Over half of these patients read below their stated education levels. In another study, the prevalence of low literacy in 40 patients taking warfarin was assessed by using the REALM with a cross-sectional design.<sup>24</sup> Only 47% had a REALM score correlating to a high school reading level, and 30% had scores at or below the 6th grade level; however, 83% of this sample had completed high school.

In a study of 100 patients with systemic lupus erythematosus, REALM scores correlated with a mean reading level of 7th–8th grade in a university clinic and 9th grade in a private clinic.<sup>25</sup> The mean education level completed for these patients was 12th grade. Likewise, in an indigent psychiatric population, REALM testing revealed that 76% of a sample of 45 patients read at or below the 7th–8th grade reading level.<sup>26</sup> Only 24% of the low-literacy group in this study reported they did not read well.

The reading ability of 396 parents and caregivers of pediatric outpatients was tested by using the REALM and WRAT-R.<sup>27</sup> The mean reading level was 6th–8th grade, and the majority (65–73%) were reading at less than a 9th grade reading level, despite a mean self-reported last grade completed of 11th grade. In a study of 646 parents and caregivers, the mean reading grade ability was 8.7, and parents tended to read approximately four to five grade levels below their last grade completed.<sup>28</sup>

Low literacy rates are of particular concern in the elderly, who often have a greater burden of chronic disease than the younger population. The literacy skills of 177 low-income, community-dwelling, older adults were assessed using the IDL.<sup>29</sup> The overall reading grade level was 5.5 (SD = 2.5), but 32.2% of subjects had reading skills at or below the 4th grade level. Among the 177 subjects, 25.6% reported difficulty reading written medical information or having to seek assistance from someone to read the material to them. In a second study, the PIAT-R was used to assess the reading level of 272 outpatients aged 30 years or older.<sup>19</sup> The mean objective reading comprehension was 2nd grade 9th month in patients aged 60 years or

older. This was significantly lower than their younger counterparts, whose mean reading comprehension was 5th grade 8th month ( $p < 0.0001$ ). Of the 75 patients aged 60 years or older, 73% read at less than a 4th grade level, although 39% reported graduating from high school. Older patients also completed significantly fewer years of school. Analysis of variance for four age categories confirmed a decline in reading ability and education status with increasing age.

### **Prevalence of Inadequate Functional Health Literacy**

The prevalence of inadequate functional health literacy, or the inability to function effectively in the health care environment, is also widespread.

In a study conducted before the development of the TOHFLA, functional literacy was assessed among 400 emergency department patients.<sup>30</sup> Two sets of standard written instructions were chosen from among those used in an inner-city university hospital emergency department. The investigators wrote five questions based on information taken directly from each set of discharge instructions. Each participant was given 5–10 minutes to read a set of instructions and then was asked to answer five questions while referring back to the written instructions. Patients with an education beyond high school consistently did better than those with a 12th grade education or less ( $p < 0.01$ ). A trend was noted, which demonstrated that younger patients performed slightly better than older patients. Four of the five questions were answered correctly by 76% of those aged 18–39 years, 72% of those aged 40–59 years, and 64% of those older than 59 years.

A second study in an urban emergency department assessed patients' comprehension of their own discharge instructions.<sup>31</sup> A total of 217 patients were asked the following questions: "What did the doctor tell you was wrong with you," "Did the doctor tell you to take any medications, and, if so, how did he or she tell you to use each of them," and "Were you told to return to the emergency department or to see another doctor." Patients were encouraged to read from their discharge instruction sheet. Literacy levels were assessed using the WRAT. Two independent physician reviewers compared the patients' responses to the actual instructions. Twenty-three percent of patients had no understanding of at least one component of the

instructions, and 4% had no understanding of at least two components of the instructions. Patients with low literacy scores were more likely to have lower levels of comprehension. The preprinted discharge instruction sheet was calculated to have an 11th grade reading level, whereas the mean patient reading level was 6th grade.

A much larger study of functional health literacy included 2659 predominantly indigent and minority patients at two urban public hospitals located in Atlanta and Los Angeles.<sup>32</sup> English-speaking patients completed the standard TOHFLA, and Spanish-speaking patients in Los Angeles completed the Spanish version. Most of the patients were poor, had no health insurance, and had not completed high school. The results demonstrated that 35% of English-speaking patients in Atlanta, 42% of Spanish-speaking patients in Los Angeles, and 13% of English-speaking patients in Los Angeles had inadequate functional health literacy. When patients with marginal health literacy skills were included in this category, the percentage of patients who would have difficulty functioning in the health care setting was 48%, 62%, and 22%, respectively. As many as 33% of study patients did not adequately understand instructions for radiographic procedures written at a 4th grade level, 24–58% did not understand directions to take drugs on an empty stomach, 20% could not understand information on a routine appointment slip, and approximately 75% did not comprehend a standard informed consent document. Age and education were highly correlated with literacy skills for all three groups of patients ( $p < 0.001$ ), but the number of years of school alone did not reliably predict functional health literacy.

In a study of 3260 Medicare enrollees aged 65 years or older at four different locations around the country, more than one-third of participants were found to have inadequate or marginal health literacy.<sup>33</sup> Health literacy was assessed using the shortened version of the TOHFLA. The majority of patients included were Caucasian women with at least a high school education currently earning more than \$15,000/year. Almost half were taking three or more drugs/day, and 67% had at least one chronic disease. Overall, 24% of English-speaking patients and 34% of Spanish-speaking patients had inadequate health literacy. Another 10% and 20%, respectively, had marginal health literacy. Almost half of all participants did not understand a Medicaid application, 37% could not interpret

blood glucose values, and 22% could not calculate the correct timing for dosing drug therapy. Characteristics associated with higher rates of inadequate health literacy included African-American race, older age, fewer years of school completed, and having a work history in “blue collar” occupations ( $p < 0.001$ ). There was a trend toward an inverse relationship between health literacy and age. Adjusting the data for level of education and cognitive impairment still indicated that age was strongly correlated to inadequate health literacy: nearly 16% of those individuals aged 65–69 years exhibited inadequate literacy, compared with 58% of those 85 years or older. This is particularly disturbing as elderly persons often have comorbid disease states, take numerous drugs, and need adequate health literacy skills to actively participate in their care.

A study of 131 urban African-American patients with diabetes was conducted to evaluate functional health literacy status using the TOFHLA.<sup>34</sup> The patient population included 63 patients from a diabetes outpatient clinic, 20 from a general medicine clinic, and 48 from two satellite clinics. Overall, patients’ mean functional health literacy level was inadequate to marginal. More than half of new patients and three-quarters of established patients had inadequate or marginal functional health literacy. Of the patients with inadequate functional health literacy, 43% reported no difficulty reading medical forms.

These findings are important because patients are routinely expected to perform many of the tasks tested in these studies. Patients frequently are discharged from a clinic or hospital with prescriptions and appointment slips and only provided brief verbal instructions. Assuming that patients can read and understand materials that are given to them may result in poorer health outcomes among patients, especially those with low literacy skills.

### **Readability of Patient Education Materials and Dosing Instructions**

The discrepancy between patient literacy levels and readability and comprehension of written materials is well documented. In a study of 151 adult primary care patients, reading comprehension was assessed with the PIAT-R.<sup>35</sup> The readability of patient education materials and informed consent documents was tested using two computer programs. The mean reading comprehension ranged from grade 5.4 in a community clinic to

grade 10.8 in a private practice. Forty percent of all public clinic patients tested read at the 5th grade level or below. The written education materials used in this study required an average reading comprehension of 11th–14th grade, and the readability required of the informed consent documents ranged from the 13th–31st grade level. Over 60% of all patients were reading at least three grade levels below their last grade completed. In a study discussed previously that documented the prevalence of illiteracy in a Medicare, Medicaid, and uninsured population, four institutional informed consent forms, 275 patient education brochures, and one state-approved living will document were analyzed for readability.<sup>22</sup> The mean reading level necessary to comprehend the patient education brochures was 12th grade (SD = 2.6 grades, range 5th–22nd grade), and the informed consent and living will forms required post-college-graduate reading levels for comprehension. These results are consistent with the results of other studies that have examined the relationship between literacy level and the readability of written education materials.<sup>10, 14, 25, 27, 30, 36–39</sup>

In addition to struggling with education materials, patients often are unable to correctly interpret dosing instructions. A study was conducted to compare patient interpretation of prescription labels with health professionals' assumption of the message conveyed.<sup>40</sup> Three hundred twenty-one individuals were asked to explain how they would take a product labeled with one of six different common instructions. Responses were rated as technically correct, incorrect, or unknown. The only instruction that was understood consistently (96.8%) was "Take 1 tablet daily." The instructions, "Take 1 tablet three times a day," "Take 1 tablet twice daily," and "Take 2 tablets daily," were deemed correct in only 6.7%, 12.9%, and 9.0% of respondents. Multiple daily dosages were judged as correct only if dosages were 8 or 12 hours apart. Many responses were evaluated as incorrect because of associations with daily terms (e.g., morning, noon, bedtime), meals, or unevenly spaced dosing intervals. Correct responses were much higher for the specific instructions, "Take 1 tablet every 8 hours" (56.3%) and "Take 1 tablet every 12 hours" (56.9%). Although the strict interpretation of directions used in this study may not be relevant and applicable to all drugs, some drugs do require attention to dosing intervals and patients should be aware of this. A portion of patients (0.3–6.6%) chose an incorrect

number of doses/day, which is particularly alarming. The reading difficulty of these common instructions, after testing with two readability forms, was found to be at a 3rd–5th grade reading level.

A study was conducted to examine the readability of 21 common over-the-counter drug labels.<sup>41</sup> Only one product was found to require less than a 7th grade reading level for interpretation. The study also evaluated the visual acuity required to read over-the-counter drug labels. The majority of labels required a 20/50 visual acuity at a reading distance of 16 inches, and some packaging had print so small that a 20/20 visual acuity was required. Nearly 100 million people in the United States have some type of refractive vision disorder requiring correction, and many of these will have difficulty reading the small print found on drug labels.<sup>41</sup>

These findings reaffirm that pharmacists and other health care professionals cannot assume that written instructions or verbal messages are consistently clear and understandable, or that they will be implemented as intended. Pharmacists should be aware that many patients may not correctly interpret written dosing instructions and may need verbal explanations, open-ended questioning, demonstration techniques, or other interventions to ensure understanding and appropriate implementation. Furthermore, these studies, along with many others, confirm that the last grade completed does not provide an accurate estimate of literacy or health literacy, and that many patients may not be able to adequately comprehend much of the written information and instructions given to them in the health care setting.

### Cultural Literacy

Cultural literacy is defined as an understanding of the values and views of those in other social classes and ethnic groups in the mosaic of cultures that exist in the United States.<sup>2</sup> Language differences often create huge barriers between patients and providers. In the NALS, African-Americans, Hispanic-Americans, American Indians, Alaskan Natives, and Asian-Pacific Islander adults were more likely than Caucasians to score in the lowest two literacy levels.<sup>1</sup> Even though overall United States mortality rates have declined over the past several decades, the inverse relation between mortality and socioeconomic status remains.<sup>42</sup> The disparity among mortality rates according to income and

economic status actually increased between 1960 and 1986.<sup>42</sup> These disparities could be related to many things, including limited functional literacy and lack of information or access to information. Cultural barriers to receiving optimal health care services may exist, but some of these barriers can be overcome or modified to increase quality of care and affect health outcomes.<sup>43, 44</sup> Inadequate knowledge about chronic diseases and preventive services, existing language and communication barriers, and inadequate knowledge about how and where to seek care are but a few of the more recognized and potentially modifiable barriers. Those barriers that require attention and are more sensitive to change are core cultural beliefs and values regarding medical care.<sup>2</sup> Nevertheless, it is our responsibility to work with individual patients to identify such barriers and seek ways to address those that may be adversely affecting their health.<sup>43, 44</sup>

There are cultural differences apart from language and patient-held beliefs that may affect the delivery of optimal health care. Nonverbal cues vary from culture to culture, such as differences in eye contact, personal space, touching behaviors, and customs.<sup>2</sup> An unintentional disrespect or unwillingness to acknowledge and appreciate such cultural norms may itself be a hindrance to communication beyond that of language.

Hospitals and health care facilities are seeing an increasing number of non-English-speaking patients. Effective communication is often limited, with hand signals and gesturing replacing verbal communication and interaction. The literature suggests that more diagnostic tests are performed than might be necessary because limited communication does not allow for the appropriate verbal dialogue that often is necessary to adequately assess symptoms and medical conditions. Although translation services are available, and in some centers interpreters are present, the provider-patient relationship becomes compromised and it is difficult to establish a trusting relationship between provider and patient.<sup>2</sup>

Written materials are available in several different languages, but illiteracy rates among non-English-speaking Americans remain high. Various estimates indicate that 56% of Hispanic-Americans cannot read and 34% of Native Americans read at the 5th grade level or below.<sup>2</sup> Providing written materials in their native language appears to be of little use for many of these patients. In addition, even patients who are

bilingual may not feel comfortable discussing sensitive issues or approaching an emergency situation using the English language. Many of these patients may not have a telephone, so even a toll-free telephone number may not be effective.<sup>2</sup>

Cultural differences also exist among different English-speaking age groups. The prevalence of inadequate health literacy in the elderly population was discussed, but other sectors, such as the teenage population, can present their own challenges. Teenagers are not routinely reached with written information, but with other forms of communication such as television, radio, and their peers.<sup>2</sup> Written information may be ignored, and teenagers may feel threatened or uncomfortable in the health care system, especially if they have an embarrassing medical problem.

Communication also can be difficult with patients who are deaf or hearing impaired.<sup>2</sup> Adequate literacy skills are often essential for these patients to function in the health care environment. Any disability that affects communication can affect health literacy.

Solutions to these problems are not thoroughly discussed in the literature. Many of the solutions described later in this review should be considered and applied, where appropriate, in an effort to overcome cultural literacy barriers that affect health care.

### **The Health Care Experience of Patients with Inadequate Functional Health Literacy**

The prevalence of inadequate literacy translates to many difficult, frustrating, and disturbing experiences for patients in the health care environment.<sup>2, 45, 46</sup> In a study designed to explore these encounters, 60 patients with very low REALM scores were interviewed about their experiences functioning in the health care environment.<sup>46</sup> The dominant, prevailing theme was the sense of shame regarding reading difficulties. Six important problems were identified as barriers commonly faced by patients in their interactions within the health care system: navigation, or finding the hospital and locating departments within the hospital; completion of forms or registration to receive medical care; interpretation and application of dosing instructions; communication between providers and patients; interpretation of appointment slips, which often requires assistance from family members to decipher the

date and time; and coping strategies of patients who have received negative treatment by health care workers in the past when they admitted they had difficulty reading and needed assistance. The following are quotes from patients enrolled in this study:

*I had some papers, but I didn't know they were prescriptions, and I walked around for a week without my medication. I was ashamed to go back to the doctor, but a woman saw the papers I had and told me they were prescriptions. It's bad to not know how to read.*

*All these problems, not knowing how to read, it feels like being blind, ignorant, not able to understand, to explain or ask people. If there are many people around, I feel embarrassed to tell the doctor I cannot understand. I feel really bad, that I am not worth anything, that there is no reason for me to be in this world, that I came into this world only to suffer.*

*What I feel, in my case, if there could be a person that could talk like us, and be kinder, and to ask us if we can read, or offer to fill it out, and with a smile, so we feel the person supports us. But if we see their hard faces, how could we ask for help to fill out the form?*

Several studies have explored the perspectives of patients with low literacy on their inability to read.<sup>47</sup> In one study, participants described exposure of their inadequate reading abilities as a risky situation but identified an opposing force of perceived risk if they did not disclose their inadequate literacy during a hospitalization. Reports of feeling embarrassed or stupid were common, but past experiences reinforced that a lack of knowledge could negatively affect the ability to function in a health care setting. These participants expressed an expectation that the hospital environment should be a safe and caring place, where health care providers are knowledgeable, approachable, compassionate, and respectful of patient confidentiality. Participants agreed that health care professionals should be aware of a patient's literacy status but admitted that some emotional discomfort might result if screening tools such as the REALM are used.

Patients with inadequate health literacy often harbor a deep sense of shame and may not admit that they have difficulty reading, which may result in a delay in seeking medical care. A study, which recruited 202 patients from the emergency department and walk-in clinics at a public hospital, was conducted to explore the relationship

between low health literacy and shame.<sup>48</sup> The survey included administration of the TOFHLA and questions regarding reading difficulty and shame. The TOFHLA scores revealed that 42.6% of patients had inadequate or marginal functional health literacy, but only 67.4% of this group of patients admitted they had trouble reading or understanding what they read. Of those who admitted they had difficulty with these skills, 39.7% admitted shame. Patients in both the adequate and low literacy groups suggested similar coping mechanisms for patients who have difficulty reading, such as bringing along someone who can read, making excuses, watching others, or asking staff for help. When patients who admitted having difficulty reading were asked, "Who knows you have difficulty reading?", 67.2% had never told their spouses and 19% stated they had never disclosed their reading difficulties to anyone. More than three-fourths of patients said they never brought anyone who could read to the hospital with them. This sense of shame and the stigma associated with illiteracy may significantly limit the effectiveness of the health care experience of these patients.

### Consequences of Inadequate Health Literacy

The relationship between literacy and health status in nonindustrialized nations is well known. Studies in these countries indicate a direct relationship between education level attained and key health status indicators such as life expectancy and infant survival.<sup>35</sup> Several studies conducted in the United States have confirmed that low literacy is directly correlated to poorer health and disease state outcomes. Consequences of inadequate health literacy are poorer health status, lack of knowledge about medical care and medical conditions, decreased comprehension of medical information, lack of understanding and use of preventive services, poorer self-reported health, poorer compliance rates, increased hospitalizations, and increased health care costs.<sup>3, 10, 49-63</sup>

### Poorer Health Status

The relationship between literacy and health status among adults with poor literacy skills was examined with the Sickness Impact Profile (SIP).<sup>49</sup> Subjects were recruited from a publicly funded program that offers adult basic education, including literacy training. The SIP is a behavioral measure of sickness-related dysfunction,

which includes 136 items covering 12 categories of daily living. Responses are scored to yield rates for physical and psychosocial dimensions of health, and a composite score, with a lower score indicative of better health. The mean reading level of the participants was grade  $7.2 \pm 2.77$ . Physical, psychosocial, and total SIP scores were significantly related to reading level. The strongest relation was between reading level and SIP physical score. Those who read at or below the 4th grade level had a mean physical SIP score of 6.54 compared with a mean score of 2.48 in those whose reading level was above the 4th grade level ( $p < 0.0008$ ). This relationship remained significant after adjusting for potential confounding variables ( $p < 0.002$ ).

#### Lack of Knowledge and Decreased Comprehension

A study in general medicine clinics at two urban public hospitals evaluated 402 patients with hypertension and 114 with diabetes mellitus to examine the relationship between functional health literacy and knowledge of chronic disease.<sup>50</sup> The TOFHLA was used to measure functional health literacy. Knowledge of hypertension and diabetes was assessed by using two validated questionnaires developed from written patient education materials. The questionnaire on hypertension consisted of 21 questions that assessed patients' knowledge of normal and high blood pressure readings, duration of disease, lifestyle modifications, symptoms, and complications. The questionnaire on diabetes consisted of 10 questions that assessed patients' knowledge of normal blood glucose levels, symptoms, drugs, lifestyle modifications, and complications. Functional health literacy scores strongly correlated with patients' knowledge of their illness. Forty-nine percent of patients with hypertension and 44% of patients with diabetes had inadequate functional health literacy. Those with poor literacy skills were less likely to answer questions about their disease state correctly than those with adequate functional health literacy. For example, only 42% of those with inadequate functional health literacy knew that a blood pressure of 130/80 mm Hg was normal ( $p < 0.001$ ). Only 40% of the same group of patients knew that exercise lowers blood pressure, whereas 68% of those with adequate functional health literacy responded appropriately to this question ( $p < 0.01$ ). Eighty-eight percent of those with hypertension and

inadequate health literacy answered at least half of the questions incorrectly. Of the patients with diabetes, 73% had attended diabetes education classes, but there was no relationship between the number of classes attended and functional health literacy. Of those with inadequate functional health literacy, only 58% could identify a normal blood glucose level compared with 88.2% of those with adequate health literacy ( $p = 0.003$ ), and only 50% knew that feeling shaky, sweaty, and hungry were indicative of a low blood glucose level compared with 94% of those with adequate health literacy ( $p = 0.001$ ).

In a second study conducted in an urban public hospital, 483 patients with asthma were enrolled to determine the relationship of literacy to asthma knowledge and the ability to use a metered-dose inhaler (MDI).<sup>51</sup> The REALM was used to assess literacy, and knowledge was measured with a verbally administered, 20-item questionnaire adapted from a previously validated questionnaire. Proficiency in the use of an MDI was measured on a six-step scale adapted from the literature. Poor literacy skills correlated with poor knowledge of asthma and improper MDI technique. Only 31% of patients reading at a 3rd grade level or below knew that they should see a physician even when not having an asthma attack, compared with 90% of those reading at a high school level ( $p < 0.001$ ). Compared with those with adequate literacy levels, many patients with low literacy did not understand when to take "as needed" asthma drugs ( $p < 0.001$ ) and did not realize the importance of using an MDI properly ( $p < 0.001$ ). Mean knowledge scores directly correlated with reading level. The mean number of correct steps in using an MDI also strongly correlated with reading level. Those who read at a 3rd grade level or less performed a mean of 1.6 steps correctly compared with the 3.3 steps adequately addressed by those with a high school reading level ( $p < 0.01$ ). After adjusting for education and other sociodemographic variables, literacy level was the strongest correlate of health knowledge and disease management skills.

The relationship between functional health literacy and health-related knowledge was studied in 228 patients with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome.<sup>52</sup> Eighteen percent of individuals had inadequate functional health literacy, and those with adequate health literacy were significantly more likely to have undetectable viral loads ( $p = 0.05$ ). Patients with inadequate

functional health literacy were more likely to visit a physician at least once/month ( $p=0.01$ ) and significantly less likely to understand the meaning of their CD4 counts and viral load tests ( $p<0.01$ ). Those with lower literacy were also significantly more likely to have misconceptions that HIV therapy reduces the risk of transmission and, as a result, were more likely to relax safe-sex practices while taking these drugs ( $p<0.01$ ).

#### Lack of Understanding and Use of Preventive Services

The lack of knowledge associated with low levels of literacy often translates to low usage and understanding of preventive health services. In a study of 445 women who had not had a mammogram in the past year, a lack of accurate information about mammography was prevalent among those with low REALM scores.<sup>53</sup> Of those who read at a 3rd grade level or less, 61% did not know why mammograms were recommended, compared with 88% of those who read at a high school level or higher ( $p<0.0001$ ). In a study of 212 men at a prostate cancer clinic, those with low literacy levels measured by the REALM were more likely to have advanced-stage prostate cancer at presentation than those with higher reading abilities ( $p=0.02$ ).<sup>54</sup> This may result from a lack of awareness of the availability and importance of prostate screening. In a study of 646 parents and caregivers, a bivariate comparison showed a significant association between low reading ability and smoking, never breastfeeding, and lack of private health insurance ( $p<0.05$ ).<sup>28</sup> Among female Medicaid enrollees aged 19–45 years, those who scored lowest on an abbreviated version of the TOFHLA were 4.4 times more likely than those with adequate literacy skills to have incorrect knowledge about when they were most likely to get pregnant (95% confidence interval [CI] 2.2–9.0).<sup>55</sup> On a more positive note, in a study of 633 parents accompanying their children to an acute care center, parental REALM scores did not correlate with use of preventive services or parental understanding of or ability to follow medical instructions for their children.<sup>56</sup>

#### Poorer Self-Reported Health

Inadequate functional health literacy can result in poorer self-reported health. In a study of 2659 patients at two urban public hospitals, poorer self-reported health was strongly related to lower TOFHLA scores ( $p<0.001$ ).<sup>58</sup> Those with inadequate functional health literacy were more

likely than those with adequate functional health literacy to report their health as poor. This relationship did not appear to be explained by differences in health care access or self-reported use of ambulatory care services.

#### Poorer Compliance Rates

Noncompliance with drug therapies can be a significant consequence of inadequate health literacy.<sup>59, 60</sup> Poor compliance may result not only from willful disregard for instructions, but because of failure to understand directions.<sup>6</sup> In patients with HIV, lower TOFHLA scores were found to be a predictor of noncompliance with antiretroviral drugs during the previous 2 days.<sup>60</sup> Those with inadequate functional health literacy were 4 times more likely to be noncompliant than those with higher levels of literacy (odds ratio 3.9, 95% CI 1.1–13.4,  $p<0.05$ ). Patients with lower health literacy were more likely to have missed a dose of antiretrovirals because they were confused about their treatment regimen, were depressed, or desired to cleanse their body of drugs.

#### Increased Hospitalizations

Inadequate health literacy may increase the risk of hospital admission. A study was conducted in 958 low-income patients who were interviewed and administered the TOFHLA on presentation to an emergency care center or walk-in clinic.<sup>62</sup> The hospital information system was used to retrospectively determine the number of hospitalizations/patient during a 2-year period. Patients with inadequate health literacy were twice as likely to be hospitalized compared with those with marginal or adequate health literacy (31.5%, 16.4%, and 14.9%, respectively,  $p<0.001$ ), even after adjustment for health status and various socioeconomic indicators.

#### Increased Health Care Costs

Increased health care costs may be partially explained by inadequate health literacy. In a study of English- and Spanish-speaking Medicaid participants classified as medically needy or indigent, those who read at the lowest grade levels (grade equivalent reading level 0–2) had average annual health care costs of \$12,974 compared with \$2969 for the overall population studied.<sup>3, 10</sup> These findings included only Medicaid enrollees, which inherently controls for

income and employment status. In contrast, a second study of 402 Medicaid recipients did not demonstrate a significant relationship between reading levels measured with the IDL and cost of medical care over 1 year ( $p=0.43$ ).<sup>63</sup> Although the impact of inadequate health literacy on health care costs requires additional study, the consequences of inadequate health literacy appear to have an effect on various aspects of health care, which ultimately affect overall cost.

### Summary

It is not clear exactly what mechanisms are responsible for the association between inadequate health literacy and poorer health. Low literacy and inadequate health literacy are likely predictors of behaviors that influence care. A lack of self-empowerment and a sense of shame can cause difficulties navigating the health care system.<sup>10</sup> Likewise, poor knowledge about disease states, limited understanding of medical instructions, noncompliance, lack of involvement in care, and a lack of understanding of the need for preventive services may all contribute to poor health outcomes.

### Addressing the Problem and Creating Solutions

#### Improve Patient Education Materials

Health literature often is written for skilled readers, contains complex words and sentence structures, and attempts to explain difficult scientific concepts. Most patients, regardless of literacy level, prefer simple, easy-to-read materials.<sup>3, 6, 45-46, 64-66</sup> Patients with limited reading skills take words literally rather than in context, quickly tire of long passages, and often skip over unfamiliar words.<sup>10</sup> Those with low literacy often guess their way through instructions and read so slowly that they miss the context of the information and draw incorrect conclusions.<sup>64</sup> Patients with inadequate literacy usually have adequate intelligence and are capable of learning new information if it is presented in a way that links it to information they already know or is personally relevant.<sup>64</sup> Table 2 lists strategies for improving patient education.<sup>2-3, 6-8, 31, 45-46, 49, 56, 64, 67-68</sup>

The Maine Area Health Education Center (AHEC) Literacy Center has been training health professionals to create easy-to-read health materials since 1990. They have produced a checklist for easy-to-read materials to ensure that patient education pamphlets are appropriate for

**Table 2. Strategies for Improving Patient Education**<sup>2,3, 6-8, 31, 45, 46, 49, 56, 64, 67, 68</sup>

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General concepts	
	Create a shame-free environment and offer assistance when needed.
	Use simple and clear language.
	Link information to previous knowledge.
	Personalize the message.
	Establish an open relationship with the patient.
	Tailor information to the individual by giving examples and explaining relevance.
	Reinforce and repeat information often.
	Invite family members or friends to participate in patient visits.
	Ensure understanding through open-ended questioning, demonstration techniques, and other strategies.
Written materials	
	Anticipate reading ability at least two grade levels below last grade completed.
	Prepare at a 5th grade reading level.
	Use simple words with one or two syllables.
	Use short sentences with 8-10 words/sentence.
	Use simple large-font print with a mixture of upper- and lowercase letters.
	Use ample "white space" to avoid a cluttered look.
	Use bullets for lists.
	Reduce content to what patients really need to know.
	Avoid large amounts of background information, statistical information, and technical jargon.
	Give priority to patient action and motivation.
	Tailor information to the individual by writing his or her name on the materials.
	Highlight or underline important concepts.
	Reinforce with verbal instructions.
	Use illustrations to attract attention and reemphasize text.
	Use simple illustrations appropriate for the intended audience.

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those with low levels of literacy.<sup>2, 65</sup> Several other sources also have guidelines for creating appropriate educational materials and are listed in Appendix 2. Numerous low-literacy patient education materials have been developed, but many of them are locally created by health care organizations and are not widely available.<sup>10</sup> Also, several national organizations have developed low-literacy education materials that are available to the public, some of which are listed in Appendix 3.<sup>10</sup> The readability of printed materials can be measured with a variety of formulas and computer programs to ensure that patient education materials reasonably match the patient reading skills of a particular population. The program Readability Calculations contains nine formulas for assessing the reading level of written materials: Dale-Chall, Flesch Reading Ease, Flesch Grade Level, Fry Graph, FOG, Powers-Sumner-Kearl, SMOG, FORCAST, and Spache. Each formula has a slightly different use,

but the package enables multiple formulas to be applied to a text. A second program, Vocabulary Assessor, may be purchased for use with Readability Calculations. This program identifies exactly which words in the text are likely to be troublesome for the intended readers. Information on ordering these programs is provided in Appendix 2.<sup>69</sup> Microsoft Word also enables the writer to check the readability of a document, using the Flesch Reading Ease score and the Flesch-Kincaid Grade Level score.

The provision of easy-to-read patient materials is a legal responsibility. The Joint Commission on Accreditation of Health Care Organizations mandated that hospitals ensure that informed consent documents, drug dosing and discharge instructions, and other communication be understood by patients. This requires that an assessment be made of how well patients understand their instructions, so that education can be provided "specific to the patient's assessed needs, ability and readiness."<sup>2, 10, 45, 70</sup>

Several investigations by the same authors have examined comprehension of a simplified version of a Center for Disease Control and Prevention (CDC) polio vaccine pamphlet.<sup>71-73</sup> Each study evaluated the reading time and comprehension of the standard CDC pamphlet versus a simple low-literacy pamphlet developed by the authors. In the first study, the CDC pamphlet had 16 pages, over 18,000 words, no graphics, and required a 10th grade reading level, whereas the authors' pamphlet had 4 pages, 211 words, 7 graphics, and a 6th grade reading level.<sup>71</sup> The authors' pamphlet produced higher levels of comprehension among all subjects, regardless of reading ability ( $p < 0.001$ ) and was preferred over the CDC pamphlet. In the second very similar study, mean comprehension and reading time did not differ for the two pamphlets among those reading at a 3rd grade level or less.<sup>72</sup> Mean comprehension was greater for the authors' pamphlet in those with reading abilities above the 3rd grade level. In the third study, the CDC pamphlet had been updated and shortened.<sup>73</sup> It consisted of a double-sided sheet with black and white print, 2 illustrations, and 736 words written at a 6th grade level. The authors' pamphlet also was updated to include full-color graphics on the front, 7 instructional graphics, 391 words in question and answer format, and a readability level of 6th grade. Parents preferred the authors' pamphlet, and it achieved slightly higher levels of comprehension in one area (65% vs 60%,  $p < 0.05$ ). This difference may not be

clinically significant, as the only information that achieved statistically significant higher comprehension rates was that which included instructional graphics. These recent findings suggest that simplification of materials, while increasing appeal, may not necessarily increase comprehension, unless instructional graphics are used.

In a follow-up to their original study,<sup>30</sup> one group of authors conducted a second study to determine if simplification of emergency department discharge instructions would improve patient comprehension.<sup>74</sup> The sample population of 440 patients was well matched to the original study population. The two sets of standard discharge instructions were simplified in the follow-up study, and new questions were prepared to assess understanding of the new instructions. The mean score of correct responses was significantly improved from the original study ( $p < 0.01$ ). More than 80% of patients, regardless of age, answered at least four of five questions correctly. In another study,<sup>75</sup> a pamphlet designed by the American Academy of Dermatology was simplified, and the reading level difficulty was dropped from 11th grade to 7th grade. Medical students and patients from a private dermatology practice both had a greater understanding of the material in the simplified version compared with the original version. In a third study,<sup>76</sup> subjects who received information on smoking that was written at a 5th grade level demonstrated a 13% improvement in comprehension compared with those who received the same information written at a 10th grade reading level. A study conducted in a Veterans Administration medical center found that drug information regarding warfarin had higher comprehension rates when written at the 5th grade level compared with the 10th grade level.<sup>77</sup> These studies confirm that basic efforts to simplify patient education materials are an important step in improving outcomes in comprehension.

Several studies have examined simplifying informed consent documents to increase comprehension.<sup>78-80</sup> In a study conducted by members of the Procter and Gamble Corporate Institutional Review Board, two versions of an informed consent form describing a test of a new mouthwash product were developed.<sup>78</sup> Both consent forms contained the same core information, but the low-reading-level form was written more concisely at the 6th grade level with fewer syllables, more commonly used words, and

less technical jargon, whereas the high-reading-level form was written at grade level 16. Comprehension scores were higher for the low-reading-level form ( $p < 0.005$ ), which was rated as easier to understand. In a second study, two informed consent documents pertaining to a breast cancer clinical trial were compared.<sup>79</sup> The standard form was written at a 16th grade level with 3438 words, and the simplified form was written at a 5th grade level with 524 words and 11 instructional graphics. The simplified form was preferred over the standard form ( $p < 0.01$ ), and the standard form was rated as more frightening ( $p < 0.01$ ) and more difficult to read ( $p < 0.001$ ). Subjects also reported that the standard form discouraged them from participating in the study ( $p < 0.01$ ). Literacy levels directly correlated with comprehension, which decreased progressively with lower levels of literacy. Although preference for the simplified form was noted and found to be significant, comprehension was not significantly improved with the simplified informed consent form. In a third study, two informed consent documents were developed for a study examining the psychologic correlates of chest pain.<sup>80</sup> The original form contained 283 words in 7 paragraphs requiring college level reading skills. This form was rewritten with simple words and sentences and condensed into 5 paragraphs containing 250 words and written at a 7th grade reading level. Results from the study showed that comprehension increased with educational level ( $p < 0.001$ ) and decreased with age ( $p < 0.001$ ), but the effects of readability level on comprehension were inconsistent.

The objective of a recent study in 433 primary care patients was to determine if the use of a one-page, low-literacy educational tool enhances patient-physician discussion about pneumococcal immunization and increases rates of vaccination.<sup>81</sup> Clinic technicians distributed the tool to patients on check-in and instructed them to read the brochure before seeing their physician that day. The control group received a comparable one-page educational document on nutrition. Patients in the intervention group were 5 times more likely to receive the vaccine that day (relative risk 5.28, 95% CI 2.80–9.93,  $p < 0.001$ ) and nearly 4 times more likely to discuss the vaccine with their physician (relative risk 3.97, 95% CI 2.71–5.83). This study supports the concept that simple, low-literacy educational tools can influence patient-physician communication and preventive care.

Simplifying materials can increase patient preference and acceptability and may increase comprehension, especially when used with other techniques, such as instructional graphics. Whereas simplification may improve the readability of patient education materials, it is but one component of addressing the problem of inadequate health literacy.

#### Increase Use of Nonwritten Information

Nonwritten materials can be an effective means of communicating with those with limited literacy, as many individuals rely on nonwritten forms of communication for obtaining information. In one study, 97% of community-dwelling elderly reported that television is their primary source of health information.<sup>29</sup> Patients with low literacy often seek information from sources other than printed materials, such as television, radio, and friends or family.<sup>64</sup> In a study of patients with sleep apnea, a video and an educational brochure were both designed with the same content at a 12th grade level.<sup>82</sup> Patients either watched the video or read the brochure and then immediately completed a structured questionnaire to evaluate their knowledge of sleep apnea. The video was significantly more effective than the brochure in educating patients, but only in 3 of 11 areas, and low-level readers struggled with both education tools. In a second study examining the use of videotaped materials, patients either read a booklet about colon cancer or watched a video with similar material.<sup>83</sup> Both interventions enhanced patient knowledge about colon cancer compared with the control group, but there was no statistically significant difference in comprehension between those who read the booklet and those who watched the videotape. Other studies have yielded similar results.<sup>84</sup>

As discussed previously, in addition to making patient education materials more attractive to readers, photographs and illustrations can improve comprehension of information by readers with low literacy.<sup>2</sup> In a study designed to examine the effects of illustrations and text style on readability and comprehension, two different pamphlets dealing with cervical cancer and condyloma were developed.<sup>85</sup> The first version presented information in a bullet-style format with no illustrations and had a reading grade level of 7.7, whereas the second version was written in a narrative format, included color illustrations, and had a reading grade level of 8.4.

Overall, comprehension and reported ease of reading did not differ between the two pamphlets. Differences were seen with low-level readers who had higher comprehension scores for the pamphlet with illustrations and narrative text compared with the original document (60% vs 35% answered at least seven of eight questions correctly). In a second study, the use of cartoon drawings to improve patient comprehension and compliance with discharge instructions for wound care was evaluated.<sup>86</sup> Patients who received wound care instructions with cartoons were more likely to read the instructions, answer wound care questions correctly, and follow the instructions than those who received instructions with text only.

Offering examples through visual illustrations and testimonials from other patients who have successfully followed medical instructions can be helpful.<sup>2</sup> The use of picture labels, such as a sun and a moon, on prescription labels may be helpful.<sup>2</sup> Other approaches that may be helpful in communicating with these patients include picture books, audiotapes, storytelling, drama, puppets, computer-based programs, videotapes, and small discussion groups.<sup>2, 7, 10</sup> In one study of functional literacy in a cardiovascular nutrition education setting, patients with literacy scores at less than an 8th grade level reported greater use of audiotaped educational information than written materials.<sup>87</sup> Pictograms or standardized graphic images that help convey dosing instructions, precautions, and/or warnings to patients and consumers may be beneficial.<sup>8, 60</sup> These can be particularly helpful in patients for whom English is a second language and are being studied as a visual aid for verbal explanations to increase recall rates.<sup>8</sup> With all of these methods, it is important to remember that along with the information, patients need human contact and interaction to learn.<sup>2</sup>

### Ensure Patient Understanding

Pharmacists, physicians, nurses, and all health care professionals must take the time to ensure that patients understand their health conditions, proper administration of their drugs, and general medical instructions.<sup>7</sup> This is best accomplished by making instructions interactive. Practitioners can accomplish this by asking patients to do, write, say, or show something to demonstrate their understanding of a concept. Patient comprehension always should be verified after information is presented, to ensure patient

understanding of the intended message. For example, a patient could be asked to demonstrate how they fill a syringe with insulin or use an inhaler or to explain directions in their own words.<sup>3, 6, 59</sup>

### Advance Research

Studies to date support the findings that lower levels of literacy are associated with poorer health and that lower levels of health literacy have a measurable effect on factors influencing health outcomes. However, the literature provides very few evidence-based strategies for improving health literacy or meeting the needs of those with limited literacy.<sup>13</sup> Written patient education materials can be simplified and improved as one small part of the problem, but data to support that this improves patient comprehension and ultimately health outcomes are inconsistent. Research should continue to focus on the consequences of illiteracy and inadequate functional health literacy, and additional strategies for addressing and improving outcomes in these patients should continue to be explored. Collaborative efforts between the health professions, education, public health, social work, and individual patients are needed to advance the understanding of inadequate health literacy, create solutions, and measure the impact of these solutions. Pooling these resources of expertise and empowering the patient to become more involved in his or her care are important steps in developing effective strategies to address inadequate health literacy.

### Promote Health Literacy

The American Medical Association (AMA) Council on Scientific Affairs recommended five statements on health literacy, which were adopted as AMA policy in June 1998.<sup>3</sup> First was an acknowledgment that low literacy is a barrier to effective medical diagnosis and treatment. Second, a pledge was made to work with other organizations to ensure that the health care community is aware that approximately one-fourth of the adult population has limited literacy and difficulty understanding health care information. Third, the AMA encourages the development of programs to train clinicians in effective communication skills for patients with limited literacy. Fourth, the AMA encourages the U.S. Department of Education to include questions regarding health status, health behaviors, and difficulties communicating with

health care providers in the National Adult Literacy Survey of 2002. Fifth, the AMA encourages the use of federal and private funds for research on health literacy.

The Healthy People 2010 Objectives also recognized the importance of this topic by including an objective to "improve the health literacy of persons with inadequate or marginal literacy skills."<sup>88</sup> Efforts such as these will help to raise the awareness of this important topic so that governmental, social, and medical agencies can work together to address the widespread inadequacies of health literacy in our country.

In addition to these efforts, numerous organizations are promoting health literacy, and a variety of resources are available to health care professionals. A list of organizations and resources can be found in Appendixes 3 and 4.

### Conclusions

The first step toward addressing the consequences of inadequate health literacy is acknowledging that the problem exists.<sup>6, 68</sup> For most health care professionals, reading and comprehending information is so much a part of our daily life that we tend to assume all of our patients can read and understand information adequately.<sup>46</sup> Our health care system places significant reading and comprehension demands on individuals.<sup>46</sup> It is important for all health care professionals to be educated about the prevalence and consequences of inadequate health literacy so that individuals who struggle with this problem can be compassionately identified. Once identified, we can work to assist these patients in overcoming the barriers that may be limiting their ability to function adequately in the health care environment. Additional studies are needed to advance our understanding of inadequate health literacy, and continued research is necessary to determine effective strategies for improving the functional health literacy status of our patients and measuring the impact of such interventions on health care.

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#### **Appendix 1. Ordering Literacy and Health Literacy Tests**

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##### Wide Range Achievement Test, Revised, 3rd ed. (WRAT-R)

Jasktak Associations, Inc., P.O. Box 3410, Wilmington, DE 19804  
Phone: 1-800-221-9728; available at: [www.widerange.com/wrat3.html](http://www.widerange.com/wrat3.html)

##### Rapid Estimate of Adult Literacy in Medicine (REALM)

Prevention and Patient Education Project  
Louisiana State University Medical Center, P.O. Box 33932, Box 598, Shreveport, LA 71130-3932  
Phone: 1-318-675-5856

##### Slosson Oral Reading Test-Revised (SORT-R)

Slosson Educational Publications, Inc., P.O. Box 280, East Aurora, NY 14052-0280  
Phone: 1-800-828-4800

##### Peabody Individual Achievement Test-Revised (PIAT-R)

American Guidance Service, Inc., Box 99, Circle Pines, MN 55014  
Phone: 1-612-786-4343

##### Instrument for Diagnosis of Reading (IDL)

Kendall-Hunt Publications, 4050 Westmark Drive, Dubuque, IA 52002  
Phone: 1-800-228-0810

##### Test of Functional Health Literacy in Adults (TOFHLA), original and shortened versions

Peppercorn Books & Press, P.O. Box 693, Snow Camp, NC 27349  
Phone: 1-877-574-1634

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**Appendix 2. Creating Low-Literacy Education Materials**

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**Training Programs**

Maine AHEC Health Literacy Center: Health Literacy Center, AHEC Program, University of New England, Hills Beach Road, Biddford, ME 04005; phone: (207) 283-0171, ext. 205; available at: [www.une.edu/com/otrdept/hlit/index.htm](http://www.une.edu/com/otrdept/hlit/index.htm).

**Books**

Doak CC, Doak LG, Root J. Teaching patients with low literacy skills, 2nd ed. Philadelphia: Lippincott, 1996.

**Government Publications**

U.S. Department of Health and Human Services. Clear and simple: developing effective print materials for low-literacy readers. NIH publication no. 95-3594. Bethesda, MD: National Cancer Institute, 1995.

National Cancer Institute. Making health communication programs work: a planner's guide. Publication no. 92-1493. Washington, DC: U.S. Government Printing Office, 1992.

Massachusetts Department of Public Health. Guidelines for translating written health education materials. Boston: Massachusetts Department of Public Health, 1994.

AMC Cancer Research Center–Centers for Disease Control and Prevention. Beyond the brochure: alternative approaches to effective health communication. Publication no. 770-488-4751. Washington, DC: U.S. Government Printing Office, 1994.

Shield JE, Mullen MC. Developing health education materials for special audiences: low-literate adults. Publication no. 1312. Chicago: American Dietetic Association, 1992.

Melton RJ. Developing and adapting written materials for the low-literate hypertensive. Salinas, CA: Monterey County Department of Health, 1990.

Redish J. How to write regulations and other legal documents in clear English. Washington, DC: American Institutes for Research, Document Design Center, 1991.

**Journal Articles**

Doak LG, Doak CC, Meade CD. Strategies to improve cancer education materials. *Oncol Nurs Forum* 1996;23:1305–12.

Rice M, Valdivia L. A simple guide for design, use, and evaluation of educational materials. *Health Educ Q* 1991;18:79–85.

Meade CD. Producing videotapes for cancer education: methods and examples. *Oncol Nurs Forum* 1996;23:837–46.

**Training Videos**

Secret survivors. Training in how to recognize patients with limited literacy skills. Produced by Literacy Volunteers of America, Syracuse, NY; phone: (315) 445-8000

Health education for non-readers. Training in how to conduct effective patient education for persons with limited literacy. Produced by Health Promotion Council of Southeastern Pennsylvania; phone: (215) 546-4276

Counseling the low-literate patient. Training in how to recognize and communicate with low-literacy patients. Produced by North Carolina Pharmaceutical Association; phone: (919) 967-2237

**Readability Software**

Micro Power & Light Co. 8814 Sanshire Avenue, Dallas, TX 75231; phone: (214) 553-0105; available at: [www.readability-software.com](http://www.readability-software.com)

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**Appendix 3. Sources of Low-Literacy Education Materials**

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**National Foundations and Governmental Agencies**

Agency for Healthcare Research and Quality (AHRQ). Available at: [www.ahrq.gov](http://www.ahrq.gov); phone: (301) 594-1364

The Combined Health Information Database (CHID). Available at: [www.chid.nih.gov](http://www.chid.nih.gov)

National Institutes of Health (NIH). Available at: [www.nih.gov](http://www.nih.gov)

The National Heart, Lung, and Blood Institute (NHLBI). Available at: [www.nhlbi.nih.gov](http://www.nhlbi.nih.gov); phone: (301) 251-1222

United States Pharmacopeia (Library of Pictograms). Available at: [www.usp.org](http://www.usp.org); phone: (800) 227-8772

The Indian Health Service. Available at: [www.ihs.gov](http://www.ihs.gov)

National Cancer Institute, Cancer Information Services. Available at: [www.nci.nih.gov](http://www.nci.nih.gov); phone: (800) 4-CANCER

American Cancer Society. Available at: [www.cancer.org](http://www.cancer.org); phone: (800) ACS-2345

American Heart Association. Available at: [www.nationalheart.org](http://www.nationalheart.org); phone: (800) 242-1793

National Institute for Literacy. Available at: [www.nifl.gov](http://www.nifl.gov); phone: (202) 632-1500

American Dietetic Association. Available at: [www.eatright.org](http://www.eatright.org); phone: (312) 899-0400

Office of Minority Health. Available at: [www.omhrc.gov](http://www.omhrc.gov); phone: (800) 444-6472

**Regional Organizations**

Health Promotion Council of Southeastern Pennsylvania. Available at: [www.hpcpa.org](http://www.hpcpa.org); phone: (215) 546-1276

AIDS Action Committee. Available at: [www.aac.org](http://www.aac.org); phone: (617) 437-6200

**Universities**

Novela Health Education, University of Washington, Campus Box #359932, 1001 Broadway, Suite 100, Seattle, WA 98122. Available at: [www.homestead.com/radiokdna/novela.html](http://www.homestead.com/radiokdna/novela.html)

Maine AHEC Health Literacy Center, University of New England. Available at: [www.une.edu/com/otrdept/hlit/index.htm](http://www.une.edu/com/otrdept/hlit/index.htm); phone: (207) 283-0170 ext. 2205

**Commercial Sources**

Channing L. Bete Company, Inc. Available at: [www.channing-bete.com](http://www.channing-bete.com); phone: (800) 477-4776

Krames Communication. Available at: [www.krames.com](http://www.krames.com); phone: (800) 333-3032

Mosby Consumer Health. Available at: [www.mosby.com](http://www.mosby.com); phone: (800) 325-4177

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**Appendix 4. Health Literacy Web Sites**

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The National Center for the Study of Adult Learning and Literacy (NCSALL). [www.gse.harvard.edu/~ncsall](http://www.gse.harvard.edu/~ncsall)  
Harvard School of Public Health, Health Literacy Studies. <http://www.hsph.harvard.edu/healthliteracy>  
The National Library of Medicine, Current Bibliographies in Medicine 2000-2001, Health Literacy.  
<http://www.nlm.nih.gov/pubs/cbm/hliteracy.html>  
American Medical Association, Health Literacy. <http://www.ama-assn.org/ama/pub/category/3125.html>  
National Health Council, Health Literacy Initiatives. [http://www.nhcouncil.org/initiatives/health\\_literacy.htm](http://www.nhcouncil.org/initiatives/health_literacy.htm)  
National Institute For Literacy. [www.nifl.gov](http://www.nifl.gov)  
Maine AHEC Health Literacy Center. [www.une.edu/com/othrdept/hlit/index.htm](http://www.une.edu/com/othrdept/hlit/index.htm)  
World Education. [www.worlded.org](http://www.worlded.org)  
Health Literacy Consulting. [www.healthliteracy.com](http://www.healthliteracy.com)  
Healthy People 2010. <http://www.health.gov/healthypeople/>  
System for Adult Basic Education Support (SABES). <http://sabes.necc.mass.edu>  
Pfizer Journal, Responding to the Challenge of Health Literacy. [www.thepfizerjournal.com/TPJ04.pdf](http://www.thepfizerjournal.com/TPJ04.pdf)  
Pfizer Health Literacy. [www.pfizer.com/hml/literacy/literacyfrm.html](http://www.pfizer.com/hml/literacy/literacyfrm.html)  
Center for Health Care Strategies, Inc. <http://www.chcs.org/resource/hl.html>

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