Why Literacy Matters

Links Between Reading Ability and Health

Paul P. Lee, MD, JD

The ability to understand verbal and written materials is central to modern life. Yet, the US Department of Education estimated that 47% of all adult Americans in 1993 had poor reading and comprehension skills. Analyses of the readability of patient education materials, discharge instructions, and consent forms throughout many specialties within medicine have found almost uniformly that these materials are written at too complex a level for many or most patients. For example, a study of the patient ophthalmic education materials of the American Academy of Ophthalmology by Ebrahimzadeh et al found large amounts of the material exceeded the reading abilities of much of the American adult population. Yet, this is only one small part of understanding the effects of literacy and reading abilities on our patient’s health and their use of our increasingly complex health care system.

DEFINING LITERACY AND READING ABILITY

The United Nations’ definition of literacy requires that an individual be able to “both read and write a short simple statement about everyday life.” Others in the United States have defined literacy as the number of grade levels or of educational attainment. However, studies that directly compare reading ability levels to the grade levels completed in school find that there is an average deficiency of 3- to 5-grade levels in reading ability relative to the number of years of schooling completed. In other words, use of educational levels or number of grade levels completed will overestimate the reading ability on average by 3- to 5-grade levels. Furthermore, even having adequate reading and writing skills does not mean that someone can understand, interpret, or use the content of the materials.

As a result, the fundamental concept of reading ability today is based on “functional literacy.” Individuals need to be able not only to read and write but also to understand and to act on that understanding. It is unrelated to intelligence or IQ scores. Instead, patients with low literacy have difficulty with both reading and organizing the data acquired. Further, such individuals often think in very concrete terms. Thus, reading skills and the larger concept of functional literacy need to be explicitly examined and assessed.

HOW DO WE MEASURE LITERACY AND READING ABILITIES?

Various instruments have been used to measure reading skills or functional literacy in patients. One of the most widely used instruments is the Wide Range Achievement Test-Revised, originally developed in 1936. It has 3 subscales—arithmetic, reading, and spelling—and the reading subscale measures the patient’s ability to recognize words by reading aloud from a list of 74 words. Another widely used, nationally standardized test is the Slosson Oral Reading Test-Revised, which is also based on a person’s ability to pronounce words in ascending order of difficulty. Both of these are thus general literacy tests. The Peabody Individual Achievement Test, a third, standardized, wide-range screening measure, in contrast, asks the patient to read whole sen-
tences and then to select 1 of 4 possible pictures of the sentences' meaning. The Peabody Individual Achievement Test thus explicitly tests for understanding and reading ability. All 3 of these tests, however, share the drawback that they are obvious tests of literacy skills. For this reason, many patients with lower literacy skills may refuse to participate in such assessments.

In the last few years, 3 specific tests geared for medical literacy have been developed. One is the Rapid Estimate of Adult Literacy in Medicine (REALM), which was designed to be used in public health and primary care settings to identify patients with low reading levels. It has good correlation scores with the 3 general reading tests described earlier. In addition, it is purposefully designed to be nonthreatening to patients with low literacy. It does so by asking patients to read aloud a list of words that are commonly used in medical care and interactions, both for relevancy and because individuals perceive medical words as being difficult for everyone so that missing words may not have as much stigma. Most importantly, it has been found to be usable and useful in assessing literacy in public clinics and with other disadvantaged or at-risk populations. However, it is invalid as an indicator in Spanish.

A second instrument is the Test of Functional Health Literacy in Adults. This is a 50-item reading comprehension and 17-item numerical ability test, which takes up to 22 minutes to administer. As such, it takes substantially longer than the REALM test. However, it more fully assesses functional literacy as well as reading ability because it’s development was based on the CLOZE technique, which measures comprehension of written passages through the systematic deletion of every fifth word. The reader is expected to determine the missing words and complete the blanks. Scores of 60% or above indicate complete understanding, while those below 40% indicate difficulty in comprehension. Analyses indicate that results correlate well with scores on the more generalized reading tests noted above (Wide Range Achievement Test-Revised score at 0.74) and the REALM (r=0.84).

Finally, the Medical Terminology Achievement Reading Test is designed to resemble a prescription label. Thus, it explicitly designs the assessment to mimic meaningful clinical scenarios while being nonthreatening to patients. Like the REALM, this is a reading level test as opposed to an explicit functional literacy test. Cronbach α with the Wide Range Achievement Test-Revised score is 0.98.

WHY READING ABILITY AND LITERACY MATTER

Functional health literacy as measured by the Test of Functional Health Literacy in Adults has been demonstrated to have significant and unique relationships to decreased health status and increased health care utilization. In an assessment of self-reported status, Baker et al demonstrated that those with low literacy had roughly a 2 times greater rate of self-reported poor health than those with adequate literacy. In a subsequent article published in JAMA, David W. Baker, MD, clearly demonstrated a significantly increased rate of utilization of hospital services compared with those with adequate literacy. After age, sex, socioeconomic status, health status, the patient's regular source of medical care, insurance status, and other confounding factors were included in the analysis, there was still a 52% increase in the risk of hospitalization among patients within adequate literacy compared with those with adequate literacy. While this report from a single hospital system requires replication and additional work, the potential magnitude of these findings for the American health care system are profound.

Such implications can be more easily appreciated in trying to understand how low literacy may relate to poor health and increased utilization of more intensive services. First, several prior articles have demonstrated that poorer patient understanding and knowledge of chronic conditions such as diabetes mellitus and hypertension exist among those with poor literacy. For example, while 94% of patients with diabetes mellitus and adequate functional health literacy knew the symptoms of hypoglycemia, only 50% of those with inadequate literacy were able to recognize such symptoms. Thus, patients who do not understand or appreciate the symptoms of early disease or the complications of treatment may not seek timely treatment. Furthermore, failure to understand their conditions severely limits their ability to participate in medical care decision making and the growing emphasis on patient-centered care. In such cases, more paternalistic styles of decision-making by the physician or the failure to recognize that more paternalistic styles may be needed might result in less patient satisfaction with care.

Second, patients may be unable to participate effectively in undergoing vital preventive care. For example, in a study of low-income women in Louisiana, 39% of women reading at or below a third-grade level on the REALM did not know why women were given mammograms, compared with only 12% of those reading at or above at ninth grade level.

Third, researchers and clinicians need to be aware of how the limitations of low literacy may affect our other assessments of our patients. For example, in analyzing the results of Mini-Mental State Examination scores, Mayeaux et al demonstrated that nondemented patients may score in the demented range of the Mini-Mental State Examination because they may not read well enough to complete a self-administered test accurately.

The potential effects of low literacy extend far beyond those areas that are being investigated today. Qualitative data obtained through focus groups have demonstrated that patients with low literacy harbor a deep sense of shame. This sense of shame is reinforced by medical care personnel who become frustrated or angry when individuals cannot complete a form or read instructions. As such, individuals with low literacy related a hesitancy to use health care services to reinforcing the tendency to delay care and perhaps helping to account for the higher hospitalization rate and potentially greater se-
verity of illness on presentation. In addition, many patients recounted serious medication errors resulting from their inability to read labels.

In addition, these patients say that they rely heavily on oral explanations, visual cues, and demonstrations of task. Individuals with low literacy also note that they rely on others such as a friend or family member to assist them with their behaviors and health care. Indeed, there are anecdotes about individuals who swallowed suppositories because of a lack of understanding of how they were to be used.

WHAT DO WE NEED TO DO?

With the rapid changes under way in our health care delivery system, it has become even more important that patients understand their care and the options for treatment. The growing consolidation and bureaucratization of care make it more important for individuals to understand their options and rights to receive care services and to negotiate the increasingly bureaucratic structure of health care delivery systems. Yet, it is clear that many of our patients are unable to read the materials that are essential to selecting a health care plan, navigating the bureaucratic structure of such plans, and then participating in their care, let alone understand all of the nuances involved. As such, this poses a significant challenge for physicians and providers of care to ensure that such patients are not left behind.

The Table provides a synopsis of the challenges that face all health care providers, including optometrists and ophthalmologists, and what steps we may take to identify and to address literacy problems in our patients. Clearly, the first step is to recognize that the problem exists for many of our patients and to understand that we need to be aware of the possibility in our patients. Indeed, some may wish to screen higher-risk individuals, such as those who have not graduated from high school, to identify those that may benefit from literacy education in general and more directed education in the provider’s office in particular.

One step that should be taken today is to simplify the reading materials that are provided to patients. In many practices, the standard handout materials should include a range of materials, based on a patient’s comfort levels in reading materials. Thus, having materials available at the fourth-grade reading level as well as the eighth- and 12th-grade reading levels may make sense for busy practitioners. It would be worthwhile for our professional societies, such as the American Academy of Ophthalmology, and private foundations, such as Research to Prevent Blindness Inc or Prevent Blindness America, to provide assistance with such information.

Such simplification of reading materials, however, is only a first step. Even at the fourth-grade reading level, substantial portions of our population, especially the poor and minority remain at risk in our inner cities. Estimates run as high as 35% to 70% of individuals being served by large public hospitals in cities such as Los Angeles, Atlanta, and New Orleans as being unable to read at even a fourth-grade reading level.2,12,15,25 Thus, it is clear that we need to do more than just simplify our reading materials.

Doing so, however, opens up wide opportunities for all providers of health care to revolutionize how we educate our patients and involve them in their own care. Studies have clearly demonstrated that use of alternate education strategies, such as videotapes, demonstrations, television, and many others, are helpful in some populations but not others.26-28 The unifying tenet may be that we need to acknowledge that there is not only a literacy problem but also a general educational problem. For example, the general educational literature shows that some people learn best through visual techniques while others learn best through aural methods. Some visual learners prefer to read while others prefer to watch demonstrations or graphical illustrations.

The central tenet should be that we provide the education through whichever means that a given individual patient learns best. No “one-size-fits-all” educational campaign has ever worked, nor should they be expected to work. By understanding how each patient learns, we can be in a better position to meet his or her needs to ensure his or her understanding. Clearly, an inability to communicate and understand the concerns related to one’s own health care can have, as mentioned above, a detrimental affect on one’s health. Even more, such remediable measures may provide an opportunity to

<table>
<thead>
<tr>
<th>Issue</th>
<th>Unfulfilled Opportunities</th>
<th>Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify patients with low literacy</td>
<td>Understanding of eye diseases</td>
<td>Increased patient knowledge and participation in care (eg, symptoms of concern)</td>
</tr>
<tr>
<td></td>
<td>Importance of periodic examinations in diabetes mellitus and chronic diseases</td>
<td>Better compliance and better outcomes</td>
</tr>
<tr>
<td></td>
<td>How to take eye medications</td>
<td>Better compliance and better outcomes</td>
</tr>
<tr>
<td>Eliminate shame of low literacy</td>
<td>Increase use of eye care</td>
<td>More treatment of loss of vision (eg, cataract)</td>
</tr>
<tr>
<td></td>
<td>Earlier visits to eye care provider</td>
<td>Prevent avoidable loss of vision (eg, glaucoma)</td>
</tr>
<tr>
<td>Dependence on others to explain</td>
<td>Less missed appointments/better follow-up</td>
<td>Better compliance and better outcomes</td>
</tr>
<tr>
<td>Appropriate educational materials</td>
<td>Understand reading materials</td>
<td>Increased understanding, increased participation, and better compliance</td>
</tr>
<tr>
<td></td>
<td>Appropriate videotapes or other educational matter</td>
<td>Same benefits</td>
</tr>
<tr>
<td>Understand risks/benefits of treatment</td>
<td>Manage expectations</td>
<td>More satisfied patients, better compliance, and better outcomes</td>
</tr>
<tr>
<td></td>
<td>Involvement in care</td>
<td></td>
</tr>
</tbody>
</table>
reduce health care cost and expenditures while improving and increasing the effectiveness of care and the satisfaction of our patients with their care.

For eye care providers, this is of particular relevance in chronic conditions such as diabetes mellitus or glaucoma. Studies need to be done to understand how literacy skills affect compliance with follow-up or medication compliance. In the meantime, it is abundantly clear that those with lower literacy have less understanding of diabetes processes. For ophthalmologists for care for patients with diabetic retinopathy, knowing the literacy levels of their patients may be critical to identifying those patients at greatest risk and thus greatest need for focused intervention and education. If patients receive the appropriate type of education, they may be better able to participate in their care and to seek follow-up care in an appropriate manner.

In the area of informed consent for refractive surgery or cataract surgery, managing patient expectations may ultimately depend on patient understanding of the eye condition and the treatment effects, both positive and negative. To the extent that lower literacy translates into less understanding, it would clearly be more difficult to address patient expectations in such patients. This is a completely separate issue from the fact that informed consent forms in general are too complex and beyond the reading skills of all but the most educated patients.

Finally, as eye care providers see more and more patients in a shorter period under today’s managed care environment, the risks of patients not understanding and leaving the office confused and upset grow in inverse proportion.

In such a situation, making sure that educational aids, such as written materials or videotapes, are not only available but also appropriate for each patient becomes ever more important. A brochure that is too difficult to read is not only a wasted expense but can contribute to patient dissatisfaction. Thus, from virtually every perspective of the patient and even of practice management, knowing and responding to literacy issues in eye care will become more important in the future.

Accepted for publication September 4, 1998.

This investigation was supported in part by grant NEI RO-I EY 11287 from the National Eye Institute, National Institutes of Health, Bethesda, Md and Research to Prevent Blindness Inc, New York, NY.

Corresponding author: Paul B. Lee, MD, JD, Department of Ophthalmology, Duke Eye Center, Box 3802, Durham, NC 27710.

REFERENCES