# Evidence Report

# Chapter 1. Introduction

## Burden of the Problem

The National Literacy Act of 1991 defined literacy as "an individual's ability to read, write, and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and to develop one's knowledge and potential."[1] Low literacy is common in the United States. In 1993, the National Adult Literacy Study (NALS) reported that 40 million adult Americans scored on the lowest of five levels (level 1) and another 50 million scored at level 2.[2] Individuals are categorized in these two lowest levels if they have trouble finding pieces of information or numbers in a lengthy text, integrating multiple pieces of information in a document, or finding two or more numbers in a chart and performing a calculation.[2] Economists and educators have estimated that meeting the requirements of an ever-increasing percentage of jobs and the demands of day-to-day life, such as processing insurance forms and obtaining credit, requires skill above levels 1 and 2 on the NALS.[3]

Low literacy may also impair an individual's ability to function in the health care environment, which has increasingly relied on complex written information to guide medical care and improve health. Historically, the average reading level of patient materials related to health care has been 11th to 14th grade, but the average person's reading level is much lower.[4] Additionally, even patients who read at the college level have been found to prefer medical information written at the 7th grade level.[4]

Substantial research has documented the strong relationship between years of formal education and health outcomes.[5] In the 1990s, evidence emerged about the prevalence of low literacy among patients in the health care setting and its association with adverse health outcomes. For example, at two public hospitals in Atlanta and Los Angeles, 35 percent of English-speaking patients had inadequate literacy skills to function in the health care setting, based on the Test of Functional Health Literacy in Adults (TOFHLA).[6] In addition, 20 percent to 30 percent of patients incorrectly answered how many pills of a prescription should be taken, and similar proportions did not know how to read when their next appointment was scheduled.[6] In a national managed care program for Medicare enrollees, 34 percent of English-speaking patients had inadequate or marginal literacy based on the Short-TOFHLA (S-TOFHLA).[7] As a result of these and other reports, the nation has become more aware of the prevalence of low literacy and its effect on the health of the population.

Although one's literacy level is related to one's educational status, the correlation between years of education and literacy is imperfect. An individual's reading grade level is often found to be several grades below the last year of school completed.[4] Additionally, because of the emphasis in the United States on completing high school, 12 years of education represents a very large distribution of literacy levels. The ability to complete 12 years of education may draw on several factors in addition to the ability to read, including social support, community resources, motivation, and family expectations.

The impact of an individual's literacy level may go beyond his or her ability to understand written or even spoken instructions. It is one of several factors that may insidiously affect patient-physician communication dynamics and inadvertently lead to substandard medical care.

**Note:** Appendixes and Evidence Tables cited in this report are provided electronically at http://www.ahrq.gov/clinic/epcindex.htm

Some studies suggest that patient-physician communication may be part of the pathway from low literacy to worse health.[8] In February 1999, the American Medical Association (AMA) Council on Scientific Affairs published a report on health literacy and recommended the allocation of federal and private funds for research in this area.[9]

## Literacy and Health Literacy

An important step in examining the relationship between literacy and health outcomes is to clarify what literacy means and how it has been measured. In the English language, literacy has taken on several different meanings. In its most common usage, literacy refers to an individual's ability to read and write.[10] It is also sometimes used to describe a person's facility with or knowledge about a particular topic. For example, we often see phrases such as "science literacy," "computer literacy," and "sports literacy." These terms generally refer to a person's ability to function in a particular context that requires some background knowledge.

In this same way, "health literacy" has been defined as a constellation of skills that constitute the ability to perform basic reading and numerical tasks that are required to function in the health care environment.[9] Patients with adequate health literacy can read, understand, and act on health care information.[9] Some authors have used an expanded definition of health literacy that includes a working knowledge of disease processes, self-efficacy, and motivation for political action regarding health issues.[11] These definitions have value, but when evaluating the relationship between health literacy and health outcomes, one must consider what has actually been measured. To date, instruments used to measure literacy in the health care setting have focused on the ability to read and, in some cases, to use numbers.

Instruments commonly used to measure health literacy (Table 1) include the Wide Range Achievement Test (WRAT) reading subtest,[12] the Rapid Estimate of Adult Literacy in Medicine (REALM),[13] and the TOFHLA.[6] The WRAT and REALM are word recognition tests that assess whether a person can correctly pronounce a series of words listed in order of increasing difficulty. Both instruments have been validated as instruments of reading ability; they are highly correlated with one another (Table 2) and other traditional reading assessments in the educational literature.[13] The main difference between the REALM and WRAT is that the REALM uses words commonly seen in the health care setting. Although this choice adds face validity to the instrument for use in health care settings, the reported correlation between REALM and WRAT ($r = 0.88$) suggests that the information provided by the two instruments is not very different.

The TOFHLA takes a different approach and assesses literacy by using a modified Cloze method. In this approach, subjects read passages in which every fifth to seventh word has been deleted and insert the correct word from a choice of four words.[6] The TOFHLA also has subjects respond to prompts, such as pill bottle instructions and appointment slips, thus measuring patients' ability to use basic numerical information (numeracy) in a health context. The structure of this instrument, therefore, facilitates assessment of both reading comprehension and numerical comprehension (rather than just word recognition). During the development and validation of the TOFHLA, the authors found that the quantitative or "numeracy" subtest was highly correlated with the reading comprehension subtest ($r = 0.79$). The TOFHLA is also highly correlated with the REALM ($r = 0.84$) and the WRAT ($r = 0.74$).

Because the TOFHLA takes more than 20 minutes to administer, the developers created a short version (S-TOFHLA). This shortened version originally used two reading comprehension passages and four quantitative questions. The S-TOFHLA strongly correlates with the TOFHLA ($r = 0.96$). Perhaps more important, the reading comprehension section of the S-TOFHLA, without the quantitative questions, correlates almost as strongly ($r = 0.92$), leading the investigators to drop the quantitative questions and use only the two reading passages.

Although the TOFHLA is labeled as an instrument to measure health literacy, its style and structure, together with validation data, suggest that it is a measure of reading ability similar to the REALM and WRAT. As an example, individuals who read at the high school level but know nothing about diabetes are much more likely to score higher on the TOFHLA, REALM, and WRAT than people who read at the grade school level but know a good deal about their own diabetes and how to perform effective self-care. To date, no current instrument adequately assesses the more global concept of health literacy.

Although basic numeracy skills are commonly required to function in the health care setting, whether measuring them provides additional information beyond the reading assessment is not clear. As previously discussed, the TOFHLA includes several quantitative questions to measure how patients use basic numerical information. However, although the scores on the quantitative section are highly correlated with the reading comprehension section, they have not been independently validated.

A less common approach to measuring numeracy evaluated how people deal with information about probability, as would be needed to evaluate the risks and benefits of different treatment options.[14] Although the results of these studies have demonstrated that people have trouble with probability concepts, the scores on such assessments have not been studied in relation to health outcomes and are therefore excluded from this analysis.

Because of the ambiguity in the meaning of health literacy and the fact that instruments used in outcomes studies focus on ability to read, we use the term "reading ability" to describe the variable measured as the exposure in this body of literature. Most researchers and educators would agree that reading ability is a critical component of literacy and health literacy, even though it may not reflect other important factors such as speaking, writing, or problem solving, as discussed in the National Literacy Act, or ability to act on health information, as discussed in the AMA definition of health literacy. Researchers and advocates will continue to ponder and debate what "health literacy" should mean, but as yet, its measurement as a single variable eludes us. Therefore, this report focuses on the relationship between reading ability and health-related outcomes, including interventions that may strengthen that relationship.

## Literacy and Vulnerable Populations

Although a significant proportion of the general population has low literacy, certain groups have an even higher prevalence. The NALS demonstrated a higher prevalence of poor literacy skills among the elderly.[2] This association has proven consistent with other studies of literacy in health care settings. However, because all the studies have been cross-sectional, we cannot differentiate between a cohort effect and a decline in individual literacy as a person ages. Both factors likely play a role. Educational opportunity has increased over the years in this country, and part of the association between age and literacy may reflect this trend (i.e., cohort effect). Studies have also shown that lower literacy is associated with lower cognitive ability.[15] Because

cognitive decline occurs more commonly in older age groups, literacy may also decline (i.e., an age effect).

The NALS also reported strong relationships between literacy and race or ethnicity. Self-reported scores from white adults are about 25 to 80 points higher on a scale of 0 to 500 than scores for any of the other racial or ethnic groups evaluated. Differential access to education by disadvantaged members of nonwhite populations may, at least partially, explain this result. This finding raises the question of whether literacy acts as a mediator in racial or ethnic disparities in health. If literacy is related to health outcomes, different literacy levels among different groups could contribute to differential health outcomes.

Additionally, one could consider whether an interaction exists between literacy and race or ethnicity with respect to health outcomes. For instance, a person with low literacy from a minority racial or ethnic background may experience more of an effect of low literacy than an individual from a majority race because of cross-cultural differences in communication or racism.

The NALS reported disparities in literacy level according to other markers of vulnerability. For example, years of education had the strongest relationship to literacy skill. Those who completed fewer years of education were much more likely to score at a lower level on the NALS. Similarly, the number of years of education achieved by one's parents was correlated with one's score on the NALS, but this association was not found to be as strong as the subject's own education.

Other factors associated with differences in literacy skill include geographic location, sex, incarceration, and income. Subjects living in the West and Midwest scored slightly higher than those in the Northeast and South. Males scored slightly higher than females on the document and quantitative scales but similarly on the prose scale. Incarcerated individuals scored significantly lower than the general population, largely explained by education and other demographic factors. Lower literacy skill was also much more common among those classified as poor or near poor. An important and as yet unanswered question is whether literacy is a mediator of adverse outcomes or whether it is merely a marker for other associated factors, such as poverty, lack of access to care, or lack of health insurance, that actually lead to poorer health outcomes.

## Analyzing the Relationship Between Reading Ability and Health Outcomes

Etiologic research focuses on understanding the relationship between exposures and outcomes of interest. In this report, we want to determine whether poor reading ability (the exposure) leads to worse health outcomes. However, confounders (other variables that are related to both reading ability and health outcomes) can influence (i.e., bias or hide) the relationship between reading ability and health outcomes.

For instance, poor reading ability is often associated with lack of health insurance, lower income levels, and age. Each of these variables is also associated with worse health outcomes. Therefore, upon finding a relationship between literacy and a health outcome, exploring whether that relationship is causal or is a result of confounding is important. To do this, many researchers use analytic methods to try to "adjust" or account for confounders when trying to observe the true relationship between reading ability and health outcomes. Because adjusting for

confounders is an imperfect science, clear reporting of the methods and measurements is important to understand the study result.

# Readability

For written educational materials to be effective, the target audience must be able to read and understand them. In evaluating interventions, researchers must consider the readability of written materials. Several approaches have been developed to measure "readability." Readability assessments often use formulas such as the Fry,[16] the Flesch-Kincaid formula (Microsoft Word®), or others that take into account length of sentences and the number of syllables in the words.

Some authors have recently suggested more comprehensive methods for assessing suitability of educational materials that take into account an expanded view of readability, including use of common words, graphics, and cultural appropriateness.[17] All these methods offer some objective means for determining the suitability of health education materials.

Several authors have published analyses of health education materials in which they assessed readability. Almost universally, the readability level of the materials exceeded the reading level of the average user. One could assume that because the readability level of the materials exceeds the users' measured reading level, the materials will not be understood. However, because both assessment of readability and reading ability are imperfect, such studies are not adequate on their own and cannot inform the key questions of this report. Therefore, we limited this report to studies with health outcomes and did not include literature evaluating readability unless the effect on health outcomes was reported.

# Production of This Evidence Report

## Organization

Given that low literacy is presumed to affect health and well-being negatively, the Agency for Healthcare Research and Quality (AHRQ) commissioned an evidence report through its Evidence-Based Practice Program and assigned it to the RTI International–University of North Carolina Evidence-Based Practice Center (RTI-UNC EPC). This issue is of particular concern to AMA, which originally nominated the topic. Our systematic review consolidates and analyzes the body of literature that has been produced to date regarding the relationship between literacy and health outcomes and the evidence about interventions intended to improve the health of people with low literacy.

Chapter 2 describes our methodological approach, including the development of key questions and their analytic framework, our search strategies, and inclusion/exclusion criteria. In Chapter 3, we present the results of our literature search and synthesis. Chapter 4 further discusses the findings and offers our recommendations for future research. This is followed by references, a listing of excluded studies, and a copy of our quality rating form. Appendixes are provided electronically at http://www.ahrq.gov/clinic/epcindex.htm and provide a detailed description of our search strings (Appendix A), our quality rating form (Appendix B), detailed evidence tables (Appendix C), and acknowledgments (Appendix D).

## Technical Expert Advisory Group

We identified technical experts in the field of health literacy to provide assistance throughout the project. The Technical Expert Advisory Group (TEAG) (see Appendix D) was expected to contribute to AHRQ's broader goals of (1) creating and maintaining science partnerships as well as public-private partnerships and (2) meeting the needs of an array of potential customers and users of its products. Thus, the TEAG was both an additional resource and a sounding board during the project. The TEAG included eight members: five technical/clinical experts; two members whose expertise and mission concern the interests and perspectives of patients and consumers; and one potential user of the final evidence report, an AMA representative.

To ensure robust, scientifically relevant work, the TEAG was called on to provide reactions to work in progress and advice on substantive issues or possibly overlooked areas of research. TEAG members participated in conference calls and discussions through e-mail to

- refine the analytic framework and key questions at the beginning of the project;
- discuss the preliminary assessment of the literature, including inclusion/exclusion criteria; and
- provide input on the information and categories included in evidence tables.

Because of their extensive knowledge of the literature on health literacy, including numerous articles authored by TEAG members themselves, and their active involvement in professional societies and as practitioners in the field, we also asked TEAG members to participate in the external peer review of the draft report.

## Uses of This Report

This evidence report addresses the key questions outlined in Chapter 2 through systematic review of published literature. Our preliminary data already were made available to the Institute of Medicine (IOM) for its study on health literacy. We anticipate that the report will be of value to AMA for its various efforts to inform and educate physicians, including the *Roadmap for Clinical Practice* initiative. This report can inform practitioners about the current state of evidence and provide an assessment of the quality of studies that aim to improve health for people with low literacy. Researchers can obtain a concise analysis of the current state of knowledge in this field and will be poised to pursue further investigations that are needed to improve health for low-literacy populations. Health educators can also use this report to guide future interventions to improve health communication. Finally, policymakers can use this report to inform new strategies and the allocation of resources toward future research and initiatives that are likely to be successful.