

# Communicating with Patients Who Have Limited Literacy Skills

## Report of the National Work Group on Literacy and Health

*The National Work Group on Literacy and Health\**

Between 40 and 44 million persons in the United States have rudimentary literacy skills, and are unable to understand written materials that require only basic reading proficiency. The purpose of this report is to characterize the current status of illiteracy in the United States, describe the relationship between poor literacy and poor health, and make recommendations on how to deal with patients who have poor reading skills.

Data collected by the National Work Group on Literacy and Health indicate that one quarter of the US population has rudimentary reading skills, and another 25% has limited reading skills. This makes it difficult to have written communication with much of the US population. Poor reading skills are associated with poor health and greater use of health services, but the basis for this association is unclear. Instruments are available to measure patients' reading skills in clinical settings, and information can be

transmitted to patients in ways that make it understandable to poor readers. However, it is not known if using special low-literacy education materials with these patients improves health outcomes.

When written communication with low-literacy patients is essential, materials should be at the 5th-grade level or lower, supplemented by nonwritten communication. Simple and nonwritten materials are appropriate for persons with limited literacy, and also for those with well-developed literacy. Research is needed to clarify the mechanisms through which illiteracy influences health status and health services utilization, and to determine if using low-literacy health education materials improves health outcomes.

**Key Words.** Literacy; illiteracy; health status; patient education; communication. (*J Fam Pract* 1998; 46:168-176)

In 1992, the National Cancer Institute (NCI), in partnership with the AMC Cancer Research Center in Denver, established the National Work Group on Cancer and Literacy (NWG). The NWG was created to focus national attention on the need for more effective communication with individuals who have limited literacy skills, and to provide the NCI with recommendations about the best ways to communicate with such individuals. The NWG consisted of 30 individuals from the fields of education, cancer control, health communications, medicine, nursing, epidemiology, public policy,

and international health.

The findings of the group, presented in this document, indicate that limited literacy has implications not just for cancer, but for all areas of health. Accordingly, in 1996, the group was renamed the National Work Group on Literacy and Health.<sup>1</sup> This report summarizes research reviewed and information collected by NWG members, and reports the NWG's recommendations for dealing with issues related to literacy and health.

### CURRENT STATUS OF LITERACY IN THE UNITED STATES

In recent years, it has become apparent that poor literacy is a widespread problem in the United States. Overall, the average reading skills of adult Americans is between the skills levels of grade 8 and grade 9,<sup>2</sup> and the reading skills of Medicaid participants are at about the 5th-grade level.<sup>3</sup>

The most definitive study of the prevalence of illiteracy was the 1993 National Adult Literacy Survey (NALS), conducted by the US Department of

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Education.<sup>4</sup> NALS investigators tested 26,000 US adults, and categorized their English-language literacy skills into five functional levels by assessing abilities to read and understand prose, informational documents, and quantitative materials.

NALS data indicate that between 40 and 44 million people (approximately one quarter of the US adult population) are at the lowest level of literacy. These individuals have only rudimentary literacy skills, and are often unable to understand written materials that require very basic reading proficiency. For example, persons in this lowest level of literacy would likely be unable to read and understand dosage instructions on medication bottles, poison warnings or directions for use on a bottle of household cleaning chemicals, notes from their child's teacher, a newspaper, or a city bus schedule.

Individuals in the lowest literacy group are heterogeneous. Sixty-two percent did not complete high school, 66% are age 65 or older, and 25% are immigrants who may have only just begun to learn English. Persons of lower socioeconomic status are overrepresented. While a disproportionate number are members of minority groups, the largest number are white and US-born.<sup>3</sup>

## THE RELATIONSHIP BETWEEN LITERACY AND HEALTH

Studies over several decades have demonstrated that in nonindustrialized nations, improved literacy skills of a population are associated with better health status and higher levels of participation in preventive health behaviors, including participation in cancer screening.<sup>5-13</sup> Most of these studies have found that improved population literacy is independently correlated with improved health status, even when confounding variables such as income, education level, employment, and nutritional status are taken into account.

It is conceptually and methodologically difficult, however, to disentangle the contributions of literacy, as compared with the contributions of other associated sociodemographic variables, to the health status of individuals or populations.<sup>14</sup> Only three studies designed specifically to examine the relationship of literacy level to health status have been performed in the United States. Each of these studies yielded similar results.

The first study of low-level readers enrolled in

adult basic education classes in Arizona<sup>15</sup> found that subjects with the poorest reading skills had poorer physical and psychological health, as measured with the Sickness Impact Profile,<sup>16</sup> than subjects with better reading skills. These relationships persisted, even after statistical adjustments were made for confounding covariables such as age, income, education level, ethnic background, and others. Sickness Impact Profile scores of the lowest-level readers (those who read at the skills levels of grade 0 to grade 3) were in the range found in persons with serious chronic illnesses.

Another study in Arizona evaluated more than 400 randomly selected Medicaid participants,<sup>2</sup> including those who read in either Spanish or English. Unpublished data from this study reveal that among the subgroup of Medicaid enrollees classified as medically needy or medically indigent, those with very low literacy skills had markedly higher health care costs than subjects with more well-developed literacy skills. For those who read at the lowest grade levels (grade equivalent reading level 0 to 2), the average annual health care cost was \$12,974, compared with \$2,969 for the overall population studied. The findings were notable because by including only Medicaid enrollees, the research design provided inherent control for income and employment status.

A more recent study by Baker et al<sup>17</sup> involved subjects at an urban, public hospital in Atlanta. The researchers measured health care utilization of 958 subjects over a 2-year period. Individuals with the lowest level of reading skills (grade levels 0 to 3) had an average of 2.3 more outpatient visits per year, and a 52% greater likelihood of hospitalization, than did those with adequate literacy skills. Increasing use of services among those with low literacy skills occurred even among individuals who reported having a regular source of health care. Those with poor literacy skills were more likely to report their health status as poor. The findings persisted after adjustment for potentially confounding sociodemographic variables.

Despite these limited but remarkably consistent results linking low literacy to poor health and higher health services use, the mechanisms by which poor literacy is associated with poorer health status are not clear. The relationship is not likely to be directly causal, in that the inability to read does not automatically make the person ill. Rather, low literacy is



probably a marker for some other unmeasured, but co-varying, factor or behavior. However, as the relationship between low literacy and health status persists even when study designs control or make adjustments for sociodemographic characteristics, it is not simply a matter of illiteracy serving as a marker for some other sociodemographic factor.

Instead, a variety of other mechanisms have been proposed to explain the linkage between illiteracy and health. For example, it has been suggested that persons with poor literacy skills may lack a sense of self-empowerment or self-efficacy, and be unable to master the assertiveness necessary to successfully negotiate their way through our increasingly complex and bureaucratic health care system.<sup>18,19</sup> Poor readers have less knowledge about their chronic illnesses than do those who read at higher levels,<sup>20</sup> and this lower knowledge may somehow contribute to poorer outcomes. It also possible that low literacy is a marker for behaviors that predispose to illness, or that individuals with low literacy may fail to understand written information they receive from health care providers, thereby contributing to noncompliance, errors in treatment, and poor outcomes.<sup>21</sup> More research is needed to clarify the mechanisms by which poor literacy skills are associated with poor health status.

## COMMUNICATING WITH PATIENTS WHO HAVE LIMITED LITERACY SKILLS

### CURRENT WRITTEN PATIENT EDUCATION MATERIALS

Given the limited reading skills of many adult Americans, it is perhaps surprising that professional health organizations distribute materials to patients that require advanced reading skills for comprehension. The reading level of consent forms for research projects, cancer trials, and invasive procedures are typically written at the college or graduate school level.<sup>22-27</sup> This suggests that true informed consent is difficult to achieve among persons with low literacy skills when currently available written materials are used. While efforts are underway to develop methods for enhancing the readability of informed consent documents through use of simplified language and formats,<sup>28-30</sup> recent legal opinions indicate that health providers could be held liable for failure of informed consent if pertinent information is not presented in a way that patients can understand.<sup>31</sup>

Similarly, investigators have found that highly developed reading skills are required for comprehension of most patient information brochures, pamphlets, and handouts, regardless of the topic or clinical content. Studies of widely available patient education materials indicate that they are written at the 10th grade level or higher,<sup>32-45</sup> though some more recent materials are being written at lower reading levels (Appendix A). Thus, much printed health education material, as well as consent forms, might be unusable by individuals who have low reading skills. In fact, because the average American's reading skill is at the 8th to 9th grade level, much written health information might not be understood even by those with average reading ability. This issue is of particular concern for at-risk populations such as the poor and the elderly, for whom research indicates that substantial proportions of patients do not understand written materials given to them by clinicians.<sup>46</sup>

Several national accrediting agencies now require that health care providers ensure that patients understand the medical information they are given. For example, the 1995 National Committee for Quality Assurance (NCQA) guidelines include provisions that focus on the reading level of written materials provided to clientele of managed care organizations.<sup>47</sup> The Joint Commission on Accreditation of Health Care Organizations (JCAHO), in its *Accreditation Manual for Hospitals*,<sup>48</sup> now requires that hospitals establish a mechanism to determine if their informed consent procedures, medication and discharge instructions, and other communications can be understood by patients. Legal experts interpret these requirements to mean that ignoring patients' literacy levels may cause an institution to fall below the level of required care.<sup>31</sup> Implicit in the new JCAHO directives is the importance of assessing patients' learning needs to ensure a good match between health care providers' educational message and patients' reading skills. This may require that health care providers quantify the literacy skills of their clientele.

### PRACTICAL ASSESSMENT OF LITERACY IN CLINICAL SETTINGS

Health professionals often do not realize that their patients cannot understand written material. Little or no information about this issue is included in medical school curricula, and the possibility that patients cannot read is frequently not considered in



routine clinician-patient interactions.<sup>49</sup>

It is important for health care providers not to assume that they can recognize patients with poor literacy skills, because most individuals with limited literacy try to hide the fact that they cannot read. Clinicians have reported numerous strategies used by their patients to hide a lack of reading ability, including use of statements such as "I forgot my reading glasses," "I don't need to read this through now; I'll read it when I get home," or "I'd like to discuss this with my family first. May I take the instructions home?"<sup>50</sup>

Therefore, some experts recommend direct assessment of the literacy skills of either individual patients or of the patient populations of health care facilities. Either approach is reasonable, depending on the needs of the practice. Others recommend not testing patients' reading skills, but instead using simple low-literacy materials for all patients in the practice, regardless of their reading skills. Still others advocate using nonwritten materials. Each of these approaches has merit, and there is no current consensus about which is preferable.

**Testing All Patients.** In some practices, all adult patients undergo testing with a rapid literacy-screening instrument. As described later in this paper, these tests take only a few moments to administer. To avoid embarrassment to patients, a common routine is for a member of the nursing staff to administer the screening test in the examination room after recording vital signs and collecting other information. The patient can be told that the doctor has heard that some patients are having trouble understanding medical forms and brochures and, therefore, the doctor wants to know the patients' reading skills so that appropriate patient education materials can be used.

**Testing a Sample of Patients.** Others recommend testing a random sample of patients in a practice to determine the general reading skills of the practice population. This approach provides clinicians with information about the average level and range of reading levels among their patients, so that educational materials can be targeted to the practice's patient population as a whole. This kind of testing can be performed by nurses at check-in, accompanied by the same explanation described above.

**Testing Instruments.** For purposes of assessing the literacy skills of patients, clinicians usually want instruments that will quickly provide a general mea-

sure of reading skill. Most instruments used in clinical settings rely on a patient's ability to read and pronounce written words or text. Two of the most commonly used word recognition tests are the Wide Range Achievement Test-Revised (WRAT-R-III) and the Rapid Estimate of Adult Literacy in Medicine (REALM). Information on ordering these word recognition tests is provided in Appendix B. Other, more complex instruments, such as those used in the NALS survey, are also available.

The WRAT-R-III<sup>51</sup> is a nationally standardized word recognition test, used predominantly for children, that categorizes word recognition ability into grade equivalents ranging from less than a 3rd grade level to more than a 12th grade level. It takes 2 minutes to 3 minutes to administer and score the WRAT-R-III, though inexperienced examiners may require more time.

The REALM<sup>52</sup> is a word recognition test that was specifically designed for adults in health care settings; it evaluates the ability to recognize and pronounce medical words. The REALM can be administered with very little training and can categorize an individual's word recognition skills into high, medium, or low levels. The REALM can be administered in less than 2 minutes, though total test time, if one includes explaining the testing procedure to patients, may be somewhat longer. Many members of the NWG are in favor of the REALM because the words used in the test are medical in nature, making it more appropriate for evaluating literacy in a medical setting.

Simple, psychometrically tested literacy tests are not generally available to US clinicians in languages other than English. Several sophisticated Spanish-language literacy assessment instruments exist,<sup>53,54</sup> but they are not practical for day-to-day clinical use.

## USING LOW-LITERACY WRITTEN MATERIALS

Persons at all literacy levels prefer and have a better understanding of simple written materials compared with complex materials.<sup>48</sup> For persons with limited reading skills, however, simplicity is particularly important.<sup>55-57</sup> Individuals with limited reading skills take words literally, rather than in context. They read slowly and either skip over or become confused by unfamiliar words. They tire quickly and often miss the context in which words are presented. So,



written material for such persons must be carefully constructed to assure its comprehensibility. The 5th grade readability level is an appropriate goal for most health care materials intended for the public, but clinicians should keep in mind that even this level will be too difficult for up to one quarter of the population. Even lower readability levels can be achieved by using a narrative or dialogue format to present health information.<sup>48</sup>

A substantial amount of low-literacy patient education material currently exists. Much of it is created by individual physicians, clinics, and health care organizations. In general, these locally created materials are not widely available, and their quality and comprehensibility have not been studied. Several national organizations have also developed low-literacy education materials, some at the 3rd to 6th grade reading levels. These materials are available to health care providers and the public, often at no charge. Unfortunately, there is no national index or database that catalogs low-literacy patient education brochures and handouts. Sources for some of these materials are provided in Appendix A.

Customized, written educational materials can also be designed for populations with limited literacy skills. Excellent practical guides for creating appropriate patient education materials are available from several sources (Appendix C).

### USING NONWRITTEN MATERIALS

Members of the NWG point out that many health professionals rely too heavily on printed materials as a means of communicating health information to patients. Many individuals, even those who can read, frequently depend on nonwritten means of communication to obtain health-related information. For example, 97% of those older than 65 years report that television is a principal source of health information, regardless of their literacy level.<sup>44</sup> Among persons who do not speak English, oral communication may be the primary method of obtaining health information.<sup>58</sup>

A variety of nonwritten health education materials are either available now or are currently being developed. Some are simple: picture books, slide and tape presentations, audiotapes, videotapes, models, and so forth. Others use highly sophisticated computer-based, multimedia technologies.

Multimedia computer-based educational programs designed for adults with limited literacy offer

a variety of choices as to how patients use and interact with the computer. These technologies can be powerful and compelling for patients who are already "television literate."<sup>59,60</sup> With some multimedia programs, patients can choose to see and hear information about one particular facet of a disease or condition that is of interest to them. Text is limited and difficult words, or even every word on the screen, may have a corresponding audio file to which the patient can listen.

Some computer-based educational materials are not simply didactic presentations on a computer screen. They are interactive, in that the computer assesses the patients' responses and creates a customized presentation for each viewer based on those responses. Interactive educational tools have been used to prepare patients for surgical procedures,<sup>61</sup> to communicate informed consent,<sup>62</sup> and to convey practical information about a variety of other health issues.<sup>63-66</sup>

Evaluations of alternatives to printed materials for health education have largely focused on the usefulness of television and video programs. Overall, these evaluations have been positive.<sup>67,68</sup> Television and video programs increase short-term knowledge among all patients, including those with limited literacy skills,<sup>69-71</sup> and they decrease patients' anxiety.<sup>72</sup> However, the effectiveness of videotapes in promoting long-term knowledge retention or changes in behavior varies considerably.<sup>73-76</sup>

### CONCLUSIONS AND RECOMMENDATIONS

- Poor reading skills are associated with poor health status and high use and costs of health care services. The association appears to be independent of other sociodemographic variables. Research is needed to clarify the nature of the correlation between illiteracy, health status, and health services utilization. Research is also needed to determine if using health education materials designed for low-literacy audiences is effective in influencing health outcomes.

- The reading skills of at least one quarter of the adult US population are so limited that written communication with this group may not be effective. Another 25% have limited reading skills that make understanding written communication possible but



difficult. Health professionals are often unaware that a substantial proportion of their patients may be poor readers. Education about the relationship between literacy and health, and about how to effectively communicate with low-literacy patients, should be incorporated into the education of health professionals, both at pre- and post-doctoral levels.

- Rapid reading-skills assessment instruments are suitable for use in clinical settings, if necessary, to measure the reading skills of patients. There is a need to develop a valid and easy-to-use instrument to assess reading skills in languages other than English (especially Spanish).

- When written communication with patients is essential, materials should generally be at the 5th grade level or lower. Thus, materials targeted for low-level readers should change unfamiliar words to common words, explain the meaning of essential unfamiliar words or words used in unusual contexts, use only common uni- or bi-syllabic words in short sentences, and use large fonts and layouts with substantial amounts of blank (white) space to make the text look easy to read.<sup>77,78</sup> Information and illustrations should be culturally relevant, use language(s) spoken by the target population, and be supplemented by other forms of instruction, such as verbal explanation, video, or audio.

- Simple materials, written at the lowest reading level at which the content can be coherently transmitted, are appropriate both for persons with limited literacy and for those with well-developed reading skills.

- Clinicians should verify that patients understand the medical information provided to them.

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## Appendix A

### Sources of Low-Literacy Education Materials

#### National Foundations and Governmental Agencies

- National Cancer Institute, Cancer Information Service. 1-800-4-CANCER.
- American Cancer Society. 1-800-ACS-2345.
- National Heart Lung and Blood Institute. 301-251-1222.
- American Heart Association. 1-800-242-1793.
- National Institute for Literacy. 202-632-1500.
- American Dietetic Association. 312-899-0400.

#### Regional Organizations

- Health Promotion Council of Southeastern Pennsylvania. 215-546-1276.
- AIDS Action Committee. 131 Clarendon Street, Boston, MA 02116.

#### Universities

- Novela Health Education, University of Washington, Campus Box #359932, 1001 Broadway, Suite 100, Seattle, WA 98122.
- Health Literacy Center, University of New England, 11 Hills Beach Road, Biddeford, Maine 04005. 207-283-0171.

#### Commercial Sources

- Channing Bete Co, Inc. 200 State Road, South Deerfield, MA 01373.
- Krames Communication. 1100 Grundy Lane, San Bruno, CA 94066-3030.
- Mosby Consumer Health. 8910 SW Gemini Drive. Beaverton, OR 97008.