Adequate Literacy and Health Literacy: Prerequisites for Informed Health Care Decision Making

Importance of Literacy and Health Literacy in Health Care

To navigate the health care system effectively, an individual must have a battery of skills that enable him or her to read, understand, and act on written and quantitative materials such as enrollment forms, appointment slips, prescriptions, self-care instructions, informed consent forms, and oral and written communications. In addition, decision making requires recall, perception, attention, assessment, synthesis, computation, comparison-making, and other capabilities, some of which decline with age (Stevens 2003).

Increasingly, individuals are expected to actively participate in their health care by making informed decisions and partnering with their clinicians to arrive at treatment decisions and to manage their chronic conditions. They can be confronted with an extraordinary amount of material in written and electronic formats supplied by physicians, employers, and the media that they must read, process, and potentially incorporate into their decision making. Even those who routinely read and assimilate large amounts of information can be overwhelmed by the sheer quantity of health material that is available. However, those who have poor literacy and health literacy skills may be at risk of making decisions that could adversely affect their health and/or financial situation.

Health experts recognize the importance of literacy and health literacy. For example, one goal of Healthy People 2010 is to improve the health literacy of persons with inadequate or marginal literacy skills (Office of Disease Prevention and Health Promotion 2004). The Institute of Medicine identified health literacy as a high-priority area for improvement in health care quality (Committee on Identifying Priority Areas for Quality Improvement 2003) and has published a comprehensive study on the subject (Committee on Health Literacy- Institute of Medicine 2004). Health literacy has also been recognized internationally (e.g., by the World Health Organization and the European Union) as an important public policy issue, although it is not yet widely addressed by policymakers in this country (Parker, Ratzan, and Lurie 2003).

Literacy

The National Literacy Act of 1991 defines literacy as the 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” (1991). To assess literacy levels in the U.S., the National Adult Literacy Survey (NALS) was administered in 1992 to a nationally representative sample of 13,600 adults age 16 and older (Kirsch, Educational Testing Service, and National Center for Education Statistics 1993). This survey considered literacy across a continuum of skills: prose, document, and quantitative.1 Within each of these domains, based on their scores,

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1 Prose literacy represents the knowledge and skills needed to understand information from texts; document literacy is used to understand applications, forms, maps, and tables; quantitative literacy is the knowledge to use arithmetic operations (Kirsch, et al. 1993).
participants were assigned to one of five levels, with the fifth representing the highest level of proficiency.

Although there was a range of performance, across all domains, between 21 and 23 percent (40-44 million adults) had only rudimentary skills (Level I) as demonstrated by being able to find a single piece of information in a short, simple paragraph; adding numbers on a bank slip; or entering personal information (e.g., their name) on a document (Kirsch et al. 1993) (Table 1). About 40 percent of those in the lowest level in each literacy domain were poor, and a disproportionate share of individuals in Level I were black, Hispanic, and Asian/Pacific Islanders. About one-third of those in Prose Level I were age 65 or older.

Table 1
Percent of Adults, by Level of Literacy Proficiency and Domain

<table>
<thead>
<tr>
<th>Proficiency Level</th>
<th>Prose</th>
<th>Document</th>
<th>Quantitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level I</td>
<td>21</td>
<td>23</td>
<td>22</td>
</tr>
<tr>
<td>Level II</td>
<td>27</td>
<td>28</td>
<td>25</td>
</tr>
<tr>
<td>Level III</td>
<td>32</td>
<td>31</td>
<td>31</td>
</tr>
<tr>
<td>Level IV</td>
<td>17</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>Level V</td>
<td>3</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Source: Kirsch, et al. 2003
(Note: Level I is the lowest and Level V, the highest proficiency level.)

Tasks in Level II required the reader to integrate more pieces of information than in Level I and to make low-level inferences (Kirsch et al. 1993). Only 3-4 percent of all respondents performed at the highest level of proficiency across all literacy domains. The characteristics of adults who performed at Prose Level I are presented in Table 2.

Table 2
Characteristics of Adults at Prose Level I

<table>
<thead>
<tr>
<th>Self-reported characteristic</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Foreign-born</td>
<td>25</td>
</tr>
<tr>
<td>Did not complete high school</td>
<td>62</td>
</tr>
<tr>
<td>Completed 8 years of school or fewer</td>
<td>35</td>
</tr>
<tr>
<td>Age 65+</td>
<td>33</td>
</tr>
<tr>
<td>Physical, mental, or health condition that precludes full participation in work or other activity</td>
<td>26</td>
</tr>
<tr>
<td>Vision problems that make it difficult to read print</td>
<td>19</td>
</tr>
</tbody>
</table>

Source: Kirsch, et al. 2003

The average educational attainment of adults in the U.S. is 12th grade (Selden et al. 2000), yet about 40 million Americans performed at the lowest proficiency level, signifying grave difficulty in reading, comprehension, computation, communication, writing, and problem solving (Kiefer 2001). These individuals read at a fifth-grade level or less. An additional 50 million adults have marginal reading skills and read at a seventh-grade level (Parker 2002).

Experts estimate that literacy levels can lag behind educational attainment by four or five years (Baker et al. 1997; Tooth 2000). The NALS results indicate that, on average, older adults completed fewer years of school than younger persons did. Differences in educational attainment across age groups tracked literacy proficiency, a finding that could be attributable to less schooling among older participants (Kirsch et al. 1993). While the relationship between literacy and attained years of education is not perfect (Berkman et al. 2003), grade-level measures can provide initial indications of text complexity. However, many experts do not consider grade level as a meaningful norm-referenced score (Committee on
Health Literacy- Institute of Medicine 2004).

Reading requires adequate vision, concentration, word recognition, working memory, and ability to process information—competencies that deteriorate with age and that may affect an individual’s ability to read (Baker et al. 2000). Some studies suggest that reading ability may decline with age.

In addition, literacy is situation-specific (Selden et al. 2000). Although an individual may be able to read materials whose content is familiar, he or she may have difficulty understanding materials that address unfamiliar subjects or concepts (Parker 2002). The NALS did not include health-related questions. Nevertheless, experts believe that its findings are relevant to assessing individuals’ ability to understand “essential” health information as they navigate the health care system (Baker et al. 2002). The 2003 National Assessment of Adult Literacy includes two additional components to assess (1) literacy among the least literate adults and (2) basic reading processes. It also includes a health literacy report (Kirsch et al. 1993; National Center for Education Statistics - Institute of Education Sciences - US Department of Education).

Health Literacy

Health literacy is “the degree to which people have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Parker et al. 2003). Several instruments are used to measure or to serve as a proxy for health literacy, including the Wide Range Achievement Test (WRAT), the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Test of Functional Health Literacy in Adults (TOFHLA) (Berkman et al. 2003). The WRAT and the REALM test word recognition and correct pronunciation. The TOFHLA is a health-specific instrument that tests reading comprehension and numeric ability by asking participants to fill in the correct word in a passage where every fifth to seventh word is omitted; it can reliably indicate an individual’s ability to read health-related materials (Parker et al. 1995). A short version, the S-TOFHLA, is also available. Both the WRAT and the REALM are also considered useful when rapid screening is required (Baker et al. 1996); the former takes about 10 minutes to administer, the latter, one to two minutes (Berkman et al. 2003). However, experts recognize that current instruments do not capture the full range of health literacy skills, such as listening and communicating (Committee on Health Literacy- Institute of Medicine 2004).

Prevalence of Inadequate or Marginal Health Literacy Is Higher Among Older Persons

There is no estimate of health literacy among the population as a whole. As noted, the 2003 National Assessment of Adult Literacy will include a health literacy score based on responses to questions embedded in the literacy assessment as well as 10 additional health-related questions in an enhanced background questionnaire (National Center for Education Statistics - Institute of Education Sciences - US Department of Education).

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2 Although the REALM incorporates words commonly used in a health care setting and could be considered to have more face validity for measuring health literacy than the WRAT, the results of both instruments are highly correlated (0.88 [P<0.001]) (Berkman et al. 2003.)
Education Sciences-US Department of Education. However, health literacy has been studied among certain population groups. For example, using the S-TOFHLA, Medicare beneficiaries over age 65 who were enrolled in four managed care health plans located in four different states were assessed to determine their health literacy levels. At these sites, the prevalence of inadequate or marginal functional health literacy ranged from 26.8 to 44.0 percent for English-speaking participants and from 40.4 to 76.0 for Spanish speakers. There was considerably higher prevalence of inadequate and marginal health literacy among persons 85 years of age and older (Gazmararian et al. 1999).

Another study, conducted at two public hospitals, found a high prevalence (22.0 to 61.7 percent) of inadequate or marginal functional health literacy among English- and Spanish-speaking patients age 18 years and older who were predominantly indigent and African American. Among participants who were 60 years of age and older, 47.9 to 80.5 percent had inadequate functional health literacy (Williams et al. 1996). Patients with inadequate health literacy did not read medication dosing instructions, appointment slips, and directions for an X-ray procedure accurately. Those who had marginal proficiency scored better on these items than those deemed to have inadequate health literacy, but they misread instructions for taking all the pills prescribed and directions for taking medication on an empty stomach; they also had difficulty understanding information about Medicaid rights and responsibilities (Williams et al. 1996).

Functional health literacy has been found to be “markedly lower” among older persons, even after adjusting for higher prevalence of dementia or cognitive impairment; chronic diseases that could impair cognitive or sensory function; worse physical and mental health; and lower frequency of reading behaviors (Baker et al. 2000). Some experts recommend longitudinal research to better understand the relationship between increasing age and functional health literacy and to confirm that an individual’s reading ability declines with age, even in the absence of dementing impairments (Baker et al. 1997).

Effects of Inadequate Health Literacy on Health Outcomes

Numerous studies demonstrate a relationship between low literacy and poor health or poor health outcomes. A study of mostly young adults with similar demographic characteristics suggested that illiteracy and poor health status are independently associated, with a particularly strong association between literacy skills and physical health (Weiss et al. 1992). Another study found that patients with inadequate functional health literacy were more likely to report poor health than were patients with adequate reading skills (Baker et al. 1997).

A study among patients with type-2 diabetes found that those with inadequate functional health literacy were less likely to have good glycemic control and more likely to have poor control than those with adequate health literacy (Schillinger et al. 2002). Another study found that after adjusting for sociodemographic characteristics, chronic condition(s), and having had a recent physician visit, individuals with inadequate health literacy

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3 The Agency for Healthcare Research and Quality recently published an evidence report on literacy and health outcomes (Berkman et al. 2003).
reported lower use of preventive health services (flu and pneumococcal vaccinations, pap smears, mammograms) than did those with adequate functional health literacy (Scott et al. 2002).

Focus groups and individual interviews with patients who have inadequate or marginal health literacy have identified problem areas: navigation, completing forms, following medication instructions, provider-patient interactions, appointment slips, and coping strategies (Baker et al. 1996). These areas, which bear on the quality of an individual’s interaction with the health care system, could present impediments to timely access to care and cause inappropriate use of services, including medical mistakes.

Experts estimate that the ability to conduct the functions of everyday life requires skill greater than Level II on the NALS (Berkman et al. 2003). This has profound implications for consumers seeking to navigate the health care system. For example, patient involvement through self-management, behavior change, psychosocial support, and patient participation are key components of effective chronic care management (Wagner, Austin, and Von Korff 1996). The evidence that health literacy may interfere with efforts to educate patients about their chronic conditions (Williams et al. 1998) suggests that health literacy issues must be addressed if initiatives designed to improve chronic care for older persons are to succeed.

Several confounding variables can influence both reading ability and health outcomes, such as lack of health insurance and low income (Berkman et al. 2003), as well as failing eyesight, reduced memory, and hearing loss (Murphy et al. 1993). Patients’ inability to understand providers’ directions may mean that those with marginal functional health literacy skills receive ineffective care (Baker et al. 1997).

**Strategies to Address Low Literacy**

Adults with low literacy skills are not necessarily easy to identify (Murphy and Davis 1997). Patients may be reluctant to reveal their difficulties to providers because they may be embarrassed or ashamed. When they are in situations that require literacy skills, such as completing medical histories and other forms, patients with poor literacy may make excuses (e.g., “I forgot my glasses”), delay using recommended materials (e.g., “I’ll think about it later”), or say they understand instructions when they actually do not. However, the coping mechanisms used by some patients with inadequate or marginal literacy, such as persistence in asking for help; reliance on oral explanations and demonstrations of tasks; and having intermediaries serve as surrogate readers, may provide insights to developing strategies to assist them (Baker et al. 1996).

Knowledge of patients’ literacy levels can help to inform program design, improve health outcomes, and avoid unnecessary hospitalizations (Gazmararian et al. 1999). As a starting point, clinicians and health care organizations can assess the extent of low literacy among their patients (Gazmararian et al. 1999; Murphy and Davis 1997; Murphy et al. 1993). One expert has recommended that health care organizations should administer the REALM or the S-TOFHLA to 100 patients to raise general awareness of literacy as an issue among plan personnel (Baker 1998). He also suggests that rapid
screening instruments can be useful in helping providers to gain a better understanding of their patients with chronic conditions and for whom self-management activities may be difficult because of poor literacy skills (Baker et al. 1996). However, some patients may not want their medical records to indicate their health literacy level, so patient involvement in the decision to do so is important.

Structured but less formal assessments may be less threatening to individuals who may be embarrassed by their low literacy skills (Kiefer 2001). Clinicians could determine the ways patients are most comfortable receiving information (e.g., receiving written materials or forms in advance of a visit, verbal counseling). Or clinicians could use education as a proxy for literacy level by asking their patients about the number of years in school they have completed (Gazmararian et al. 1999).

Many techniques are available to simplify information conveyed to patients during interactions with clinicians. Repeating instructions, putting the most important information first, using examples of personal experience to illustrate, and narratives (i.e., stories rather than abstract data) are effective. As a rule, individuals with poor literacy skills rely on their listening skills to learn (Murphy and Davis 1997). However, it is not always feasible to provide one-on-one teaching or counseling.

Experts have identified processes to help individuals use written information to inform choices, including lowering the amount of cognitive effort required to use information (e.g., reducing the amount of information individuals must process); giving consumers a way of relating the implications of a choice to their own experience; and highlighting the meaning and significance of information through specific presentation strategies (Hibbard, Dubow, and Peters 2003). Written materials should use short sentences, the active voice, and large print. Instructions should be provided by grouping segments of information and limiting directions. Visual aids can help to reduce the amount of reading required and clarify written materials (Murphy et al. 1993). The use of narratives and evaluative formatting helps those with moderate skill, but not those in the lowest quartile of skills (Hibbard et al. 2003). For those with low literacy skills, other interventions include offering medical instructions on audio or video tape and providing visual rather than written cues (Gazmararian et al. 1999), and suggesting behaviors and actions that the patient should take. Web-based materials are often very complex and require a unique set of navigation and graphic-reading skills. For Internet-based materials, specific techniques such as graphics, multimedia, and interactive elements may make content more accessible, but they ultimately cannot remove the barriers for individuals with poor health literacy skills (Risk and Peterson 2002).

Finally, it is worth noting that even individuals who read at the college level have been found to prefer medical information that is written at a seventh-grade level (Berkman et al. 2003).

**Public Policy Implications and Conclusions**

Knowledge about the literacy and health literacy of the population has implications for multiple stakeholders in the health care system, including patients, clinicians,
health plans, and health care institutions. Although there is a considerable body of literature on literacy and health literacy, the challenge of addressing the consequences of poor health literacy remains (Parker 2000). Highly educated medical professionals do not realize that their patients may lack adequate health literacy skills (American Medical Association Ad Hoc Committee on Health Literacy 1999; Murphy et al. 1993). The American Medical Association reports that only 33 percent of physicians acknowledge knowing about health literacy (American Medical Association 2003).

In the design and implementation of programs, policymakers should take into account the prevalence of inadequate and marginal health literacy. Therefore, raising awareness of this issue is essential. A broader constituency needs to be more assertive in addressing literacy and health literacy. The NALS indicated that even a majority of those with Level I proficiency reported they were able to read or write English well (Kirsch et al. 1993).

The current shift in health care to a more competitive, market-oriented environment heightens the importance of being able to read and understand a range of health-related materials. In the Medicare program, beneficiaries will soon be confronted with an array of new decisions that will require the ability to understand differences among health coverage options, prescription drug plans, and the quality of care of physicians, hospitals, and other providers. The decisions they make could have profound implications for their financial and personal health. Vulnerable beneficiaries may have great difficulty understanding changes to Medicare (already a very complicated program), and they will need navigational assistance, decision support, counseling, and education.

Greater awareness of how health literacy affects health outcomes can help policymakers to allocate resources appropriately and focus initiatives on delivery strategies and interventions that are likely to be most effective (Berkman et al. 2003). Within health care programs, knowledge about literacy can also help health plans and practitioners/providers become more responsive to their members by having a more complete understanding of their patients’ capacity to interact with the health care system and to comply with medical regimens.

Health care costs may be significantly increased by poor literacy and health literacy, primarily due to the additional services that may be used if a patients does not understand or misinterprets medical instructions (Murphy et al. 1993). In addition, inadequate functional health literacy is independently associated with the risk of hospitalization (Baker et al. 2002). Existing estimates of the costs of low health literacy range from $30-73 billion annually (Friedland 1998); (Committee on Identifying Priority Areas for Quality Improvement 2003) (Center for Health Care Strategies Inc.). Society as a whole bears the financial burden of low functional health literacy, although costs are not distributed evenly. Estimates of

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how the costs of health literacy are distributed among payers vary depending on the data source and the methodology used. For example, the Center on an Aging Society estimated that in 1998, Medicare and Medicaid bore about 39 percent and 14 percent of the cost, respectively, while employers paid about 17 percent (Friedland 1998). This estimate is based on data from the Survey of Income and Program Participation (SIPP). Another estimate, calculated by the same researcher using data from the Medical Expenditure Panel Survey (MEPS), estimates that the cost of low functional health literacy to Medicare is much lower—19 percent—while the cost to Medicaid is 47 percent. (Center For Health Care Strategies) Additional research is needed to solidify these estimates. Ideally, newer estimates should be based on the results from the 2003 NALS, using MEPS data, since this source most accurately estimates health care use by a nationally representative sample (Friedland 2004).

Some public policy questions cannot be resolved without additional research. In addition to refining estimates of the financial costs of inadequate or marginal health literacy, more study is needed to determine the efficacy of screening for health literacy, and to gain a better understanding of the relationship between health literacy and health outcomes (American Medical Association Ad Hoc Committee on Health Literacy 1999). As noted earlier, longitudinal research needs to clarify the relationship between increasing age and functional health literacy and to confirm that an individual’s reading ability declines with age; this work would bolster efforts to address health literacy in the Medicare program. In addition, a short screening tool to measure a patient’s comprehension skills would be useful to help clinicians and others design more individualized materials and targeted interventions. Although such a screening tool has been developed, further work is needed to validate the index (Hibbard et al. 2000).

Finally, using comparative information to make health care decisions is difficult for many Medicare beneficiaries; those who have the most difficulty are most likely to consider making choices burdensome and prefer to delegate to others (Hibbard et al. 2000). Strategies and interventions must be tailored to individuals’ skill level, not to a homogeneous group (Hibbard et al. 2000). Improving literacy skills could help many older patients to make better use of the health care system, but for those who experience cognitive declines as they age, improving literacy will not be a viable strategy. For this population, redesigning materials so that information is presented in clearly understood formats will be key.

In summary, addressing literacy skills through a combination of improving the literacy level of the population overall (a long-range goal) and, more immediately, devising effective interventions to assist those with inadequate or marginal health literacy could improve the health status of the population overall (Weiss et al. 1992).

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