

**T**he concept of health literacy means more than being able to read and write. It also includes the broader skills needed to function in a health care environment. Health literacy is the “degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”<sup>1</sup> Individuals with low health literacy have more difficulty understanding the written and oral instructions given by health care professionals, following directions such as prescriptions or appointment schedules, and understanding the health care system well enough to obtain needed services.<sup>2</sup>

As noted in Chapter 1, there are no validated measures to assess a person’s overall health literacy. As a proxy, researchers have measured general literacy skills, including the ability to read and perform basic calculations in a health context. These measures do not fully capture all the people who have problems obtaining, processing, or understanding basic health information and services.

### Measuring Literacy in a Health Context

There are generally two different ways to analyze literacy skills: on a population basis or with specific people. Measuring literacy on a population basis provides an estimate of the number of people with certain literacy skills. Measuring literacy of specific people helps identify individuals with low literacy so as to design interventions or specific communication strategies tailored to their skill levels.

#### *National Population Estimates*

The most comprehensive national assessment of health literacy was recently completed as part of the 2003 National Assessment of Adult Literacy (NAAL).<sup>3</sup> The NAAL measures the English language literacy of adults age 16 and older in the United States.<sup>4</sup> The NAAL has three literacy scales:

- *Prose literacy* involves the skills necessary to search, comprehend, and use information included in continuous text. This skill set includes the ability to read and understand news stories, brochures, or instructional materials.
- *Document literacy* involves the skills needed to search, comprehend, and use information in noncontinuous text. This skill set includes the ability to fill out a job application, understand a map or bus schedule, or read and understand drug and food labels.
- *Quantitative literacy* involves the skills needed to perform quantitative tasks, including computations or use of numbers included in printed materials. Examples include balancing a checkbook or completing an order form.

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a The assessment was administered to more than 19,000 adults. The 2003 NAAL updated the 1992 National Assessment of Literacy Survey (NALS). Participants were asked to read certain information and then respond to questions based on the information they read. The assessment included 152 tasks drawn from actual documents. Of these, 65 were taken from the 1992 survey (in order to compare results between the two surveys), and 87 were new.

More than two out of every five adults (43%) have basic or below basic literacy skills.<sup>4</sup> In addition to overall literacy scores, a subset of the NAAL's tool measured a person's ability to use reading and basic computation skills in a health-related context. Specifically, the NAAL tool included questions that tested a person's literacy skills using written information the person might encounter in a clinical setting, with preventive services, or in trying to navigate the health care system. Most of the NAAL's health-related literacy questions were taken from health experiences that are relatively common in a health care setting and thus do not accurately gauge how well people would do in understanding or processing new health information or in understanding or processing health information or terminology that is more complex.

*Approximately 34% of the population perform at the basic or below basic health literacy skill levels and would have difficulty understanding basic health information.*

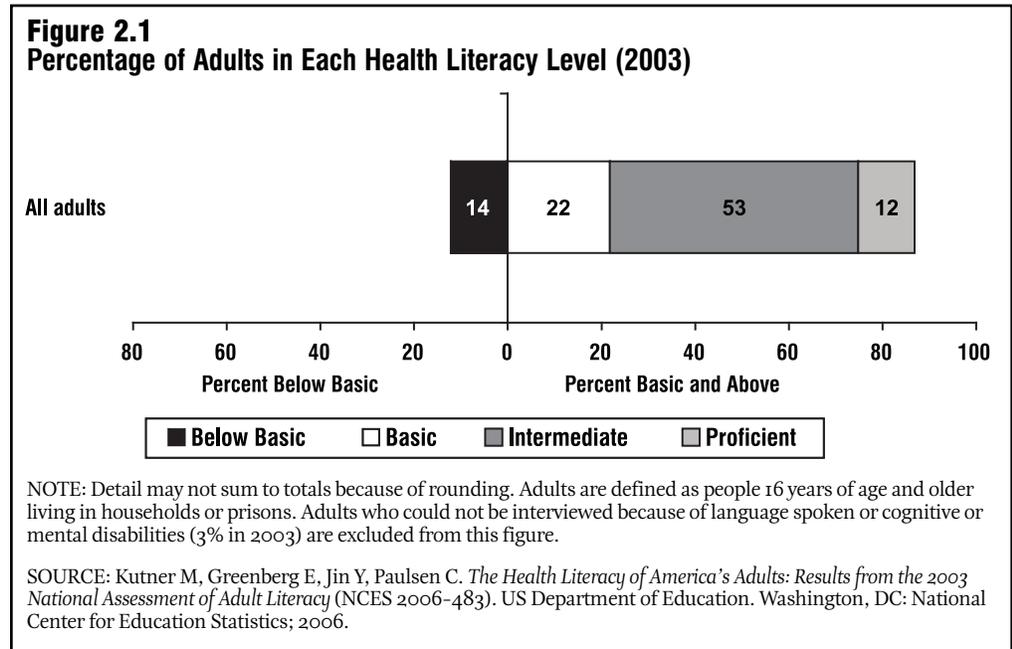
- The *clinical domain* includes activities that are common in a clinical setting, including filling out a patient information form during an office visit, understanding how to take medication appropriately, or understanding recommended treatment or diagnostic procedures.
- The *prevention domain* includes activities associated with maintaining and improving health. This domain includes the ability to understand basic health information included in informational brochures, identify symptoms that require a physician's care, or follow a schedule of age-appropriate preventive screenings.
- The *navigation of the health care system domain* includes activities that relate to how the health care system works, including the ability to read and understand an insurance summary of benefits (describing covered and non-covered services), determine potential eligibility for public assistance, or provide the information needed to give informed consent.

Individuals were classified into four skill levels: below basic, basic, intermediate, and proficient.<sup>b</sup> Within the health care context, much of the information presented would require intermediate or proficient literacy skill levels.<sup>5</sup> However, approximately 34% of the population perform at the basic or below basic health literacy skill levels and would have difficulty understanding basic health information. (See Figure 2.1.) Although these scores indicate our population may have better health-related literacy than general literacy, the problem is still immense. First, 34% of the population is still a very sizable number. Second, so many of the tasks in the health care environment require advanced literacy skills beyond what was measured in the NAAL study. Overall, navigating health care is still much more difficult than most other contexts in our society.

Health literacy skills, like overall literacy skills, vary by demographic characteristics. On average, older adults aged 65 or older, certain minority groups, low-income

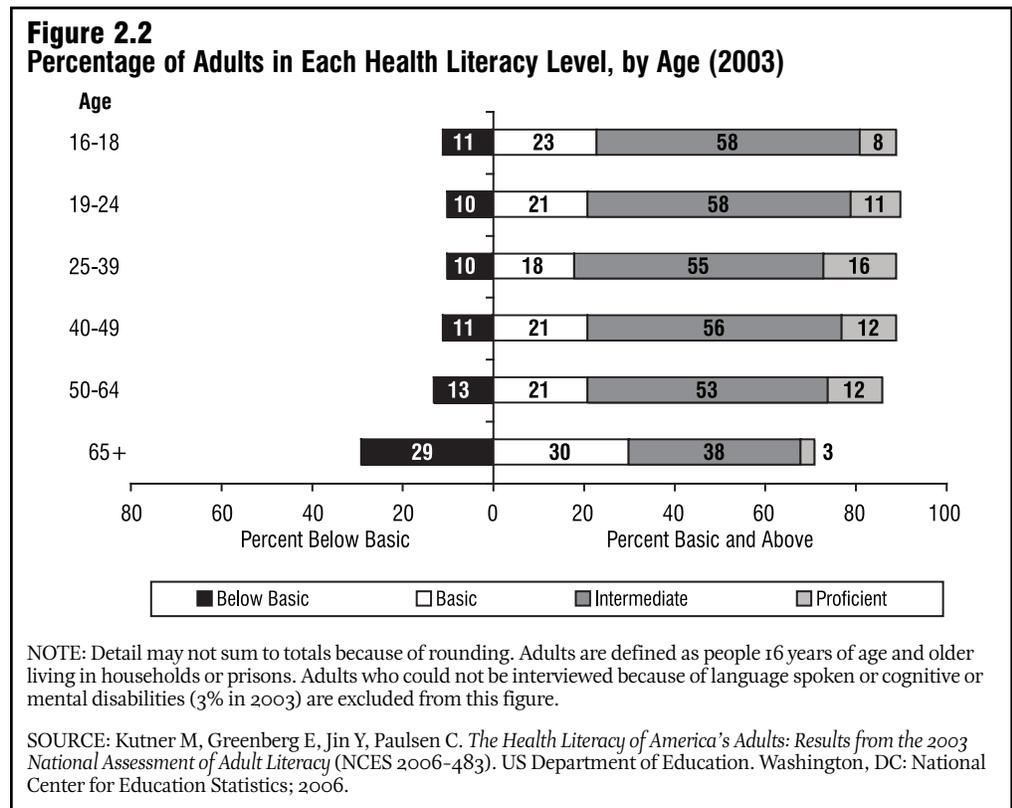
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b People whose literacy was classified as below basic had skills that ranged from being nonliterate in English to having very rudimentary skills. Individuals who scored at this level could perform no more than the most simple and concrete literacy tasks. Individuals who scored at the basic level could understand information in simple documents and could solve one-step arithmetic questions. Performance at the intermediate level indicated that individuals could perform more challenging literacy activities, such as reading and understanding moderately dense prose texts, locating information in complex documents, and using quantitative information to solve problems. Proficient literacy indicated that individuals had the skills needed to perform more complex and challenging literacy activities, including the ability to synthesize abstract information, integrate information from multiple documents, and locate quantitative information and use it to solve multi-step problems.



individuals, and individuals with lower educational achievement have lower health literacy scores.

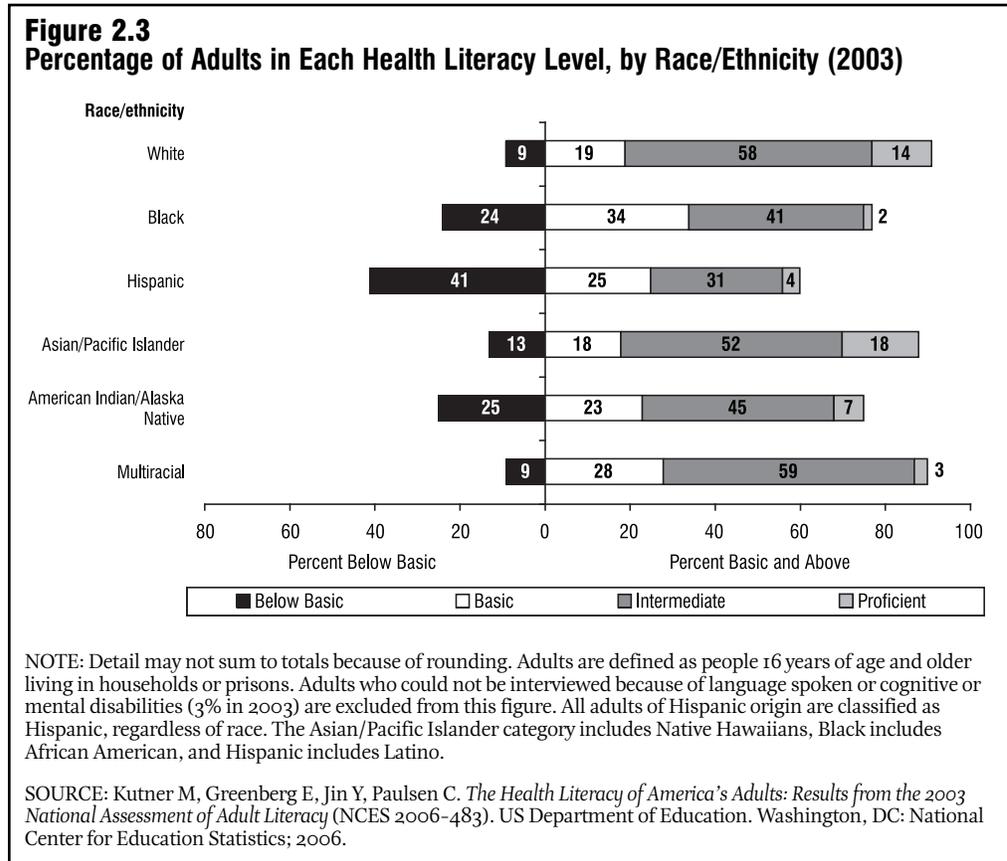
The average health literacy score is relatively consistent among all age groups until reaching age 65. (See Figure 2.2.) Older adults have average scores that are approximately 12% lower than the age group with the next lowest average health



literacy scores (16 to 18-year-olds). Compared to other age groups, older adults are far more likely to have below basic or basic health literacy skills.

African Americans, American Indian/Alaska Natives, and Hispanics have lower health literacy levels than Whites and Asian/Pacific Islanders. (See Figure 2.3.) A disproportionate number of Hispanics have below basic health literacy skills. Presumably this discrepancy is due to the large number of Hispanics who have recently immigrated to America and do not speak English as their primary language. The NAAL written assessment materials were presented in English only, although questions were in both English and Spanish. In part, this test measures English proficiency. Thus, individuals needed to have a basic ability to read and understand English in order to answer the test questions.<sup>c</sup> Survey results showed people who spoke English in the home before entering school generally had higher health literacy scores than those who spoke only Spanish prior to starting school. Native Spanish speakers may have scored more highly on a health literacy test if the written assessment materials were presented in Spanish. However, native Spanish speakers still generally score lower than English speakers on other health literacy tests that are administered totally in Spanish.<sup>d,6</sup>

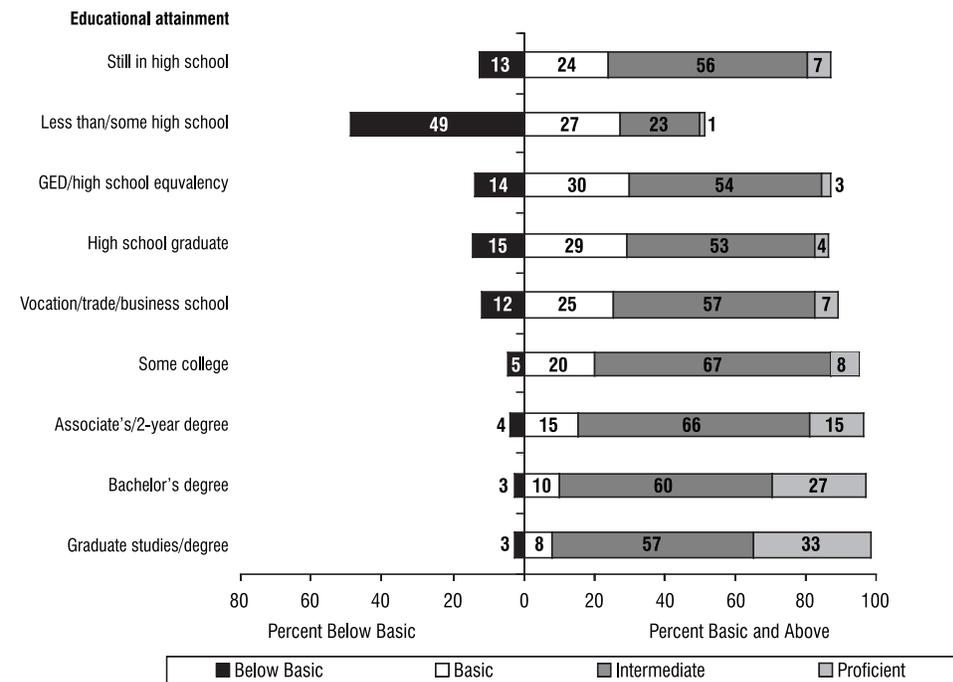
*On average, older adults aged 65 or older, certain minority groups, low-income individuals, and individuals with lower educational achievement have lower health literacy scores.*



- c Approximately 5% of all respondents were considered nonliterate in English, either because they were unable to communicate in English or Spanish (2%) or, while they could communicate orally in English or Spanish, they were unable to read or understand materials written in English (other than very simple words and phrases, letters, or numbers).
- d The Test of Functional Health Literacy in Adults (TOFHLA), another literacy test that has been validated for use with both Spanish and English speakers, found that 62% of native Spanish speakers had low health literacy, compared to 35% of native English speakers.<sup>6</sup>

Individuals living below poverty also have lower health literacy scores compared to those with higher incomes. On average, people with incomes below 125% of the federal poverty guidelines have health literacy scores that would place them in the basic range.<sup>e</sup> Those individuals with higher incomes (175% of the federal poverty guidelines or higher) have higher average health literacy scores, placing them in the intermediate level. Similar effects are found among individuals with different educational achievements. People with less than or some high school had much lower health literacy levels than high school graduates, those with a GED, or those with further educational training. (See Figure 2.4.) Aside from those who spoke only Spanish prior to school, individuals who failed to complete high school (or an equivalent) had the lowest average health literacy.

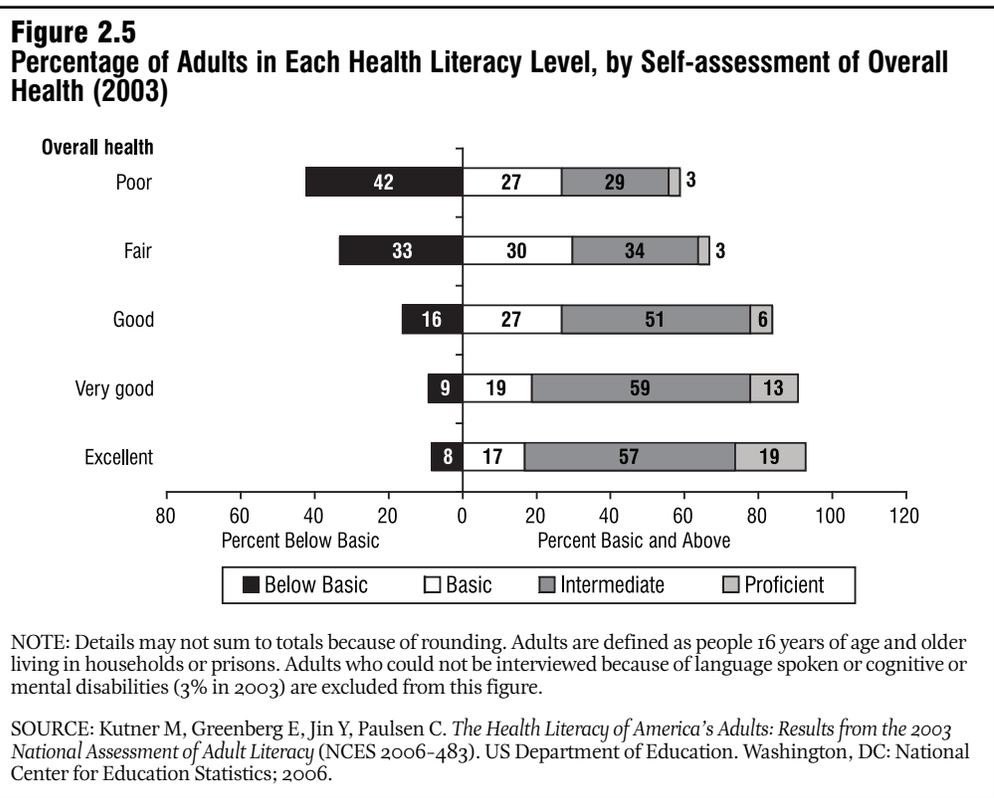
**Figure 2.4**  
**Percentage of Adults in Each Health Literacy Level, by Highest Educational Attainment (2003)**



NOTE: Detail may not sum to totals because of rounding. Adults are defined as people 16 years of age and older living in households or prisons. Adults who could not be interviewed because of language spoken or cognitive or mental disabilities (3% in 2003) are excluded from this figure.

SOURCE: Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy* (NCES 2006-483). US Department of Education. Washington, DC: National Center for Education Statistics; 2006.

e The US Department of Health and Human Services produces the federal poverty guidelines. They are based on the federal poverty threshold, which is updated every year by the US Census Bureau and is used to estimate the number of people in poverty. The federal poverty guidelines vary by size of family. In 2007, 125% of the federal poverty guidelines is \$12,250/year for an individual and \$25,000/year for a family of four. An individual living at 175% of the federal poverty guidelines would make \$17,150/year or \$35,000/year for a family of four. 72 Fed. Reg. 3147-3148 (Jan. 24, 2007).



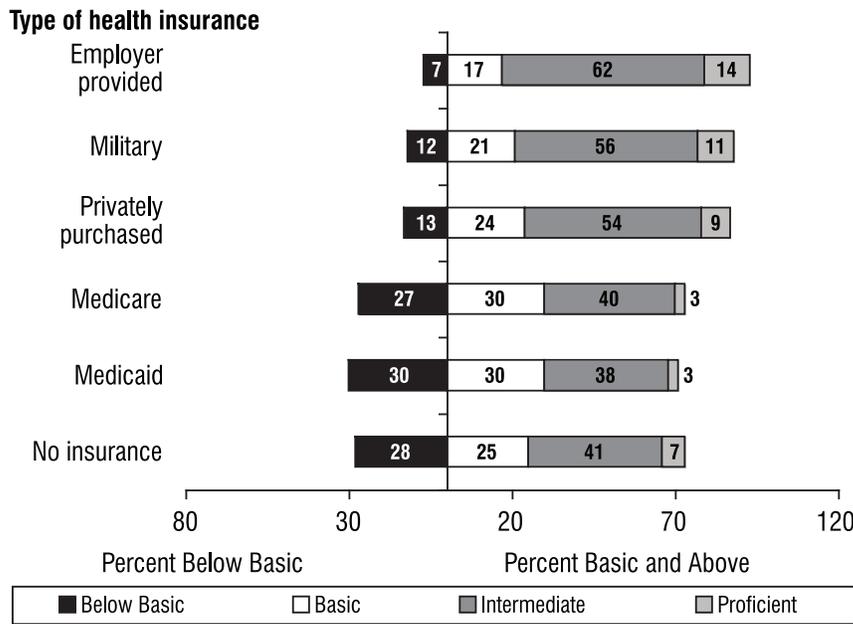
Health literacy also varies by self-reported health and health insurance status. Individuals with lower self-reported health status also are more likely to have lower average health literacy scores. (See Figure 2.5.) A much higher proportion of those who report being in poor or fair health score below basic health literacy levels compared to those self-reporting very good or excellent health status.

People who are uninsured or who are enrolled in publicly-sponsored health insurance (Medicare or Medicaid) have lower average health literacy levels than those with military coverage, employer-sponsored insurance, or privately-purchased health insurance coverage. (See Figure 2.6.) This result is not surprising, given the demographics of individuals who enroll in these public insurance programs. Medicare is a health insurance program that targets older adults (age 65 or older) or individuals with disabilities. Medicaid is limited to certain individuals and families with low incomes. As previously discussed, both the elderly and those with lower incomes have lower health literacy scores. Therefore, programs targeted at those populations also are more likely to enroll individuals with lower health literacy. More than one quarter of the uninsured, Medicare, and Medicaid populations have below basic health literacy skills, which is more than twice the rate of those with privately-purchased health insurance coverage.

### North Carolina Estimates

There are no direct estimates of the number of North Carolinians with low health literacy. However, the National Center for Education Statistics is in the process of developing small area estimates (including state level estimates) from the 2003 NAAL.<sup>7</sup> Portland State University developed a state level estimate of adult literacy levels based on the 1992 NALS assessment.<sup>8</sup> While not exactly congruent, there is a

**Figure 2.6**  
**Percentage of Adults in Each Health Literacy Level, by Type of Health Insurance (2003)**



NOTE: Detail may not sum to totals because of rounding. Adults are defined as people 16 years of age and older living in households. Adults who could not be interviewed because of language spoken or cognitive or mental disabilities (3% in 2003) are excluded from this figure. Adults who reported they had more than one type of health insurance are included in each applicable category in this figure.

SOURCE: Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy* (NCES 2006-483). US Department of Education. Washington, DC: National Center for Education Statistics; 2006.

*Many people with low literacy skills are ashamed to admit their problem and often describe themselves as reading and writing English well.*

strong correlation between the scores that people receive on general adult literacy tasks and on tasks specific to health literacy.<sup>f</sup> The state level estimates developed from the 1992 NALS assessment suggest North Carolina had a higher than average percentage of adults with low literacy levels.<sup>g</sup> The 1992 survey may understate the extent of the problem today, with the recent influx of immigrants and the aging of the population.<sup>h</sup>

### *Assessing Literacy of an Individual*

Although national assessments suggest more than one third of the adult population has low literacy skills, recognizing the problem on an individual basis is difficult. Many people with low literacy skills are ashamed to admit their problem and often describe themselves as reading and writing English well.<sup>9,10</sup> Studies suggest

f In the 2003 survey, 14% of respondents had a below basic skills level for prose and 29% had a basic skills level for prose, compared to 14% with below basic health literacy and 22% with basic health literacy.

g The 1992 survey categorized people into five skill levels (as opposed to the four levels used in the 2003 assessment). Nationally, 50% of the respondents scored in the two lowest skill levels (Levels 1 and 2), whereas 52% of North Carolinians were estimated to fall into these levels.<sup>8</sup>

h Since 1992 North Carolina has seen a rapid increase in Latino immigrants and older adults. Between 1990 and 2000, North Carolina had the fastest growing Latino population of any state in the country.<sup>45</sup> Similarly, among the 50 states, North Carolina had the 12th fastest growing population of individuals age 65 or older.<sup>46</sup> Thus, it is likely that North Carolina has an even higher proportion of adults with low literacy skills in 2003 than it did in 1992, which is likely reflective of the health literacy of the population, as well.

physicians and other practitioners often cannot recognize individuals with low literacy skills because many individuals with low reading skills have learned different strategies to mask their difficulties.<sup>11,12</sup>

There are individual assessment tools available that practitioners can use to assess an individual's literacy skills:<sup>13</sup>

- The Wide Range Achievement Test (WRAT) measures word recognition and pronunciation. It is a short test that only takes about 5 minutes to administer, but it does not test comprehension and does not include health-related words.
- The Rapid Estimate of Adult Literacy in Medicine (REALM) measures word recognition and pronunciation. It is designed to be used in public health and primary care settings to identify individuals with low literacy skills. The words are taken from patient education materials. It is quick to administer, but it does not test comprehension.
- The Test of Functional Health Literacy in Adults (TOFHLA) is used to measure functional health literacy, including both numeracy and reading skills. It takes longer than the other tools to administer (generally 20-25 minutes, although there is a shorter version that tests reading comprehension alone and only takes 5-10 minutes).
- The Newest Vital Sign is a new tool that measures functional literacy by asking people questions about a nutrition label. This measure is fast to administer (less than 5 minutes) and is available in English and Spanish.<sup>14</sup>

These assessment tools may be used by health care professionals in order to tailor their communication or health education materials. However, they are not often used by physicians or other health care providers. Many practitioners are unaware of the extent of the literacy problem and thus would not consider an assessment tool to be valuable.<sup>15,16</sup> Even practitioners who recognize this issue are reluctant to use assessment tools. Some practitioners are concerned their patients may feel stigmatized if they are singled out for a literacy assessment. Other practitioners are concerned with the additional time it would take to administer a test. Thus, these tests are most often used by researchers trying to measure the effects of interventions upon people with different literacy or health literacy levels.

Most literacy advocates do not recommend testing literacy in the clinical setting unless it leads to a specific intervention that will improve outcome. Putting a "test" in front of a person with low literacy when they enter the exam room may interfere with the patient-physician interaction. Although many literacy advocates are concerned these tests would create barriers to care, one study found patients with low literacy thought it was helpful to measure their skills and to give that information back to the doctor.<sup>17</sup> Ultimately, the Task Force did not make a recommendation on whether health care professionals should use literacy tests in their practices. To the extent that providers do use literacy tests in clinical settings, tests should be administered in an environment that makes patients feel comfortable and should be used to improve health communications. Rather than focus on testing individual patients, the Task Force advocated for a universal approach, to improve communications for *all* populations.

## Relationship between Literacy and Health

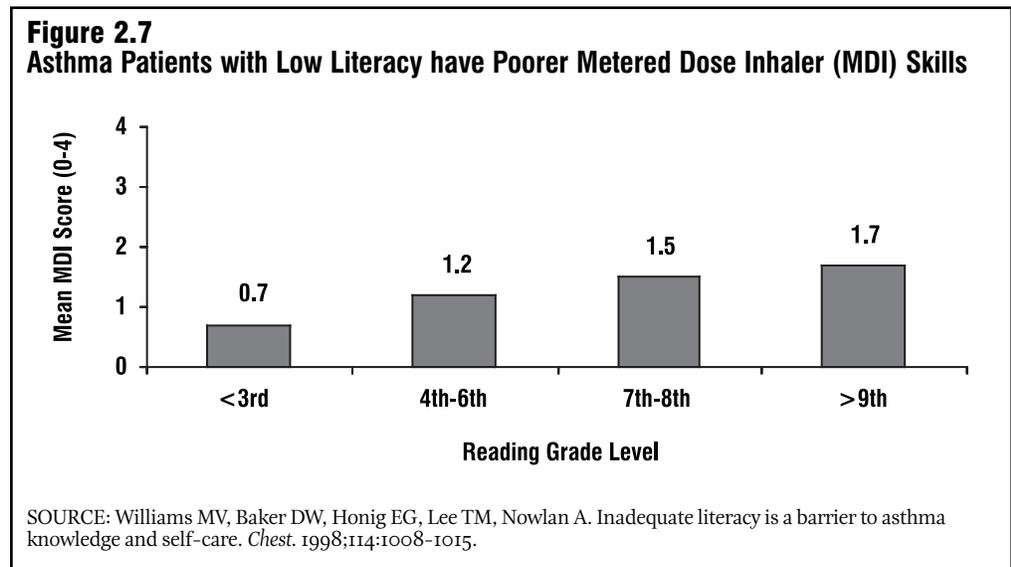
Many studies have found a connection between literacy (ie, reading abilities) and health knowledge, use of services, and outcomes. Some of the studies measure literacy using health-related words and concepts. However, the measures used in these studies reflect a narrow definition of health literacy—one closely related to reading skills and comprehension. These tests do not capture the broader definition of health literacy, including the ability to communicate and understand health care providers or the ability to successfully navigate the health care system.

### Literacy and Knowledge

DeWalt and his colleagues conducted a systemic literature review of health-related literacy research at the request of the US Agency for Healthcare Research and Quality.<sup>13</sup> Numerous studies found a positive relationship between reading ability and a person’s understanding of health services or conditions. For example, studies showed a relationship between literacy levels and knowledge of mammography,<sup>18</sup> cervical cancer screening,<sup>12</sup> HIV medication knowledge,<sup>19</sup> emergency department discharge instructions,<sup>20</sup> smoking,<sup>21</sup> asthma,<sup>22</sup> hypertension and diabetes.<sup>23</sup>

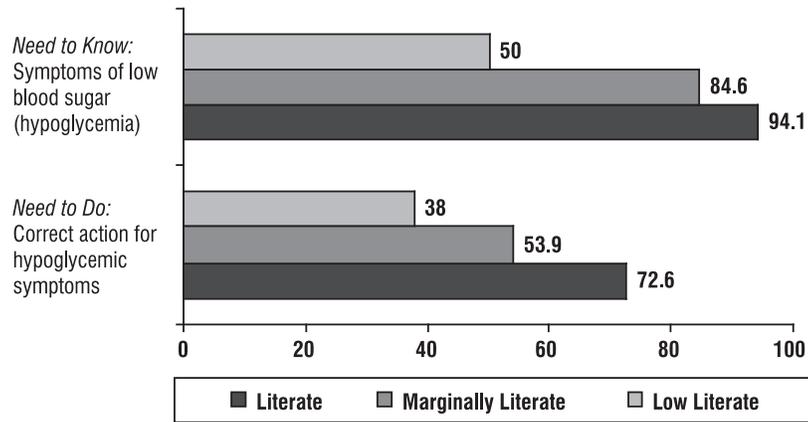
Inadequate knowledge is a barrier to appropriate self-care. For example, people with asthma with low health literacy were less likely to understand how to use their metered dose inhaler properly.<sup>22</sup> (See Figure 2.7.) Out of the four steps necessary to properly use an inhaler, the group with the best health literacy performed less than two of the steps correctly. Individuals with the lowest literacy skills, on average, performed less than one of the four steps correctly. Thus, while people with lower reading skills had more difficulty using their inhaler correctly, all people had some difficulties. This finding underscores the need to improve health communications for all populations.

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Similarly, adults with diabetes who have low literacy skills are less likely to understand diabetes or how to manage their health problems.<sup>23</sup> (See Figure 2.8.)

**Figure 2.8**  
**Adults with Diabetes and Low Literacy Skills Less Likely to Understand How to Control Their Diabetes**



SOURCE: Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Arch Intern Med.* 1998;158:166-172.

*People with low literacy are less likely to receive preventive screenings or immunizations, have an increased risk of hospitalizations, and have worse health outcomes.*

**Literacy and Health Outcomes**

Studies on the relationship between literacy and health outcomes are more mixed. However, several studies showed statistically significant relationships between literacy levels and use of preventive screenings or services, increased risk of hospitalizations, and worse health outcomes, even after adjusting for other potential confounding factors, such as age, gender, race, education, and income.

People with low literacy are less likely to receive preventive screenings or immunizations. For example, Medicare enrollees with lower literacy were less likely to have received an influenza or pneumococcal immunization. Female Medicare enrollees with lower literacy were less likely to have received a mammogram in the past two years than enrollees with higher literacy.<sup>24</sup>

One study affirmed adults with diabetes and low literacy levels are less successful in controlling their glucose levels. A study by Schillinger found only 20% of patients with diabetes with lower literacy levels had their blood sugar levels well controlled compared to 33% of those with higher literacy levels.<sup>25</sup> The patients with lower literacy skills also were more likely to suffer adverse health consequences from their failure to control their diabetes, including an increased incidence of retinopathy and cerebrovascular disease. In addition, low health literacy has been associated with depression.<sup>26-28</sup>

Studies have shown an inverse relationship between a man's reading ability and the stage of presentation of prostate cancer: men with lower literacy skills are more likely to present with late-stage cancer.<sup>29</sup> Risk of hospitalization also increases for individuals with low literacy skills. One study found low literacy was associated with a 69% increased risk of hospitalization,<sup>30</sup> and another showed a 29% increased risk of hospitalization.<sup>31</sup>

Not surprisingly, adults with low literacy skills also have difficulty managing the health care needs of their children. A study by DeWalt et al. found asthmatic children of parents with lower literacy levels were 2.5 times more likely to miss school, 1.5 times more likely to receive care in an emergency department to control their asthma, and 3.2 times more likely to be hospitalized than children with parents who had higher literacy levels.<sup>32</sup> Similarly, a study by Ross et al. found parents' reading skill levels were positively correlated with their children's glycemic control.<sup>33</sup>

### *Literacy and Patient Safety*

Medication errors are the most common form of medical mistake.<sup>34</sup> These errors can occur at multiple stages, including procuring, prescribing, dispensing, and administering drugs and monitoring patients' responses. Patients also can cause medication errors through administering the wrong dosages, taking unnecessary medications, failing to adhere to treatment recommendations, or failing to recognize adverse drug interactions.<sup>35</sup>

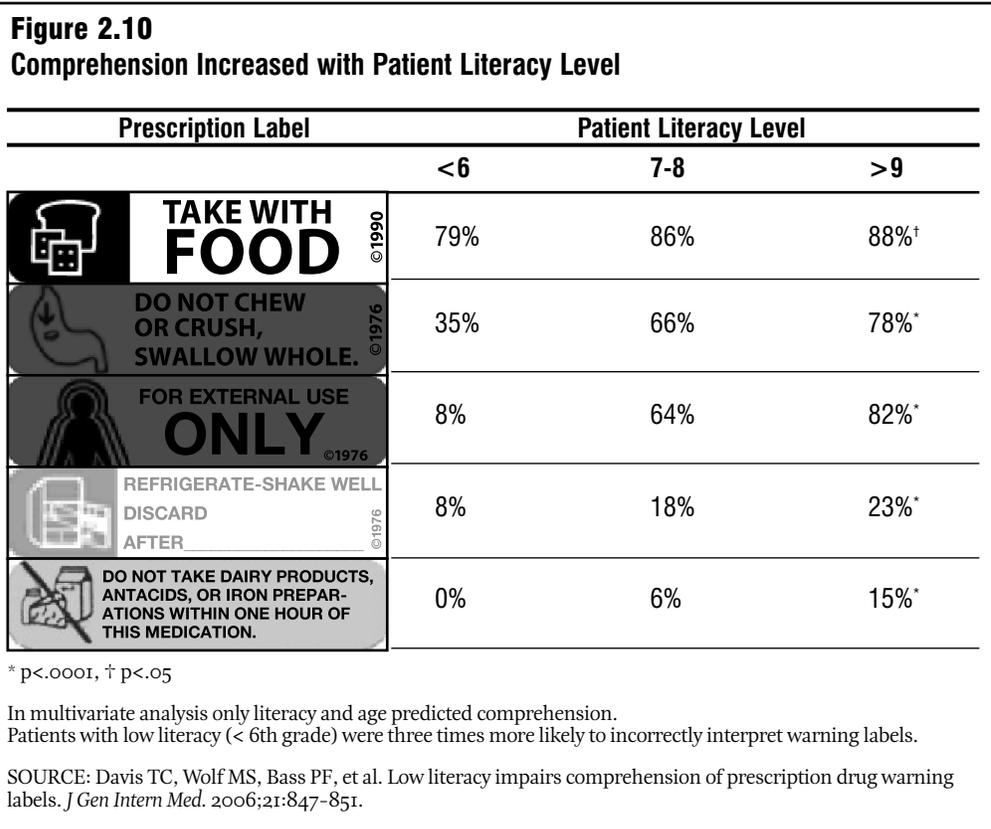
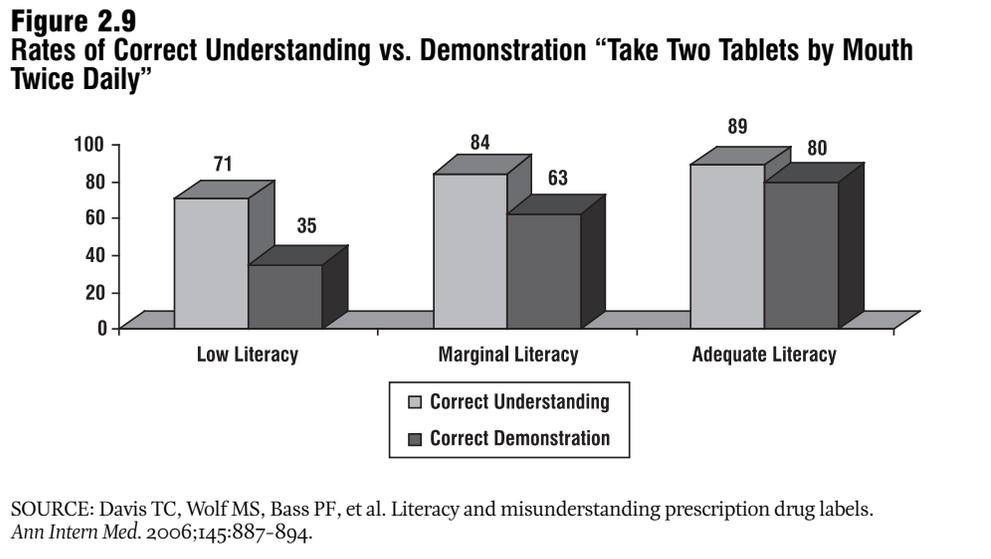
Nationally, pharmacists fill approximately three billion prescriptions each year, and 90 million Americans have trouble understanding and complying with medication instructions.<sup>36</sup> On average, more than 80% of all adults take at least one form of medication each week (including prescriptions, over-the-counter drugs, vitamins, and herbal supplements).<sup>35</sup> The elderly, who are more likely to have literacy problems, also are more likely than other age groups to use prescription medications. On average, Medicare enrollees with chronic conditions fill 23 prescriptions per year<sup>37</sup> and see eight different physicians.<sup>38</sup>

Many medication errors occur because patients do not understand how to take their medications. Patients may not understand how often to take their medications or how much medication they should be taking. For example, one study found only 38% of patients understood the instruction to take medications every six hours. Most patients assumed they were to take their medications only during the hours they were awake and thus took three rather than four doses.<sup>39</sup> This study also found patients often confuse teaspoons with tablespoons. Additionally, patients often are unable to calculate the proper dosage when making individual calculations (eg, calculating the proper dosage for a young child).

One study found people with low literacy have difficulty demonstrating how to take "two tablets by mouth twice daily."<sup>40</sup> In the study, 71% of individuals with low literacy levels correctly reported what the instructions meant, but only 35% could demonstrate how to take the medications. (See Figure 2.9.) Even one-fifth of those with adequate literacy levels could not demonstrate how to take two tablets by mouth twice daily.

Other studies show patients, including those with high literacy levels, often struggle to understand drug warning labels. (See Figure 2.10.) For example, a study by Davis found only 23% of individuals reading above the ninth grade reading level were able to explain the drug warning label "refrigerate, shake well, discard after X date."<sup>41</sup> (See Figure 2.10.)

*Ninety million Americans have trouble understanding and complying with medication instructions.*



**Literacy and Costs**

Studies also have found a correlation between lower literacy levels and higher health care costs. For example, in one study, those with reading levels at or below the third grade level had higher mean Medicaid charges than those with higher reading skills (\$10,688 vs. \$2,891).<sup>42, 43</sup> Similarly, a study of Medicare recipients showed people with low literacy had significantly higher emergency room costs than those with adequate literacy. Inpatient costs were also higher.<sup>44</sup>

As noted earlier, about half of the population (43%) have below basic or basic literacy skills and struggle to understand health information. People with low literacy skills generally have a harder time understanding health information or managing chronic health problems than those with higher literacy skills. However, these problems are not limited to people with low literacy skills. Health care communication often involves the use of complex medical terminology that can be difficult to understand for individuals scoring higher on literacy tests. Studies show a substantial number of people who score at a ninth grade reading level or higher have a hard time understanding certain prescription drug labels or how to appropriately manage chronic health problems. Furthermore, health care and insurance systems can be even more confusing than understanding how to appropriately take medications, making it extremely difficult for even the most literate individuals to navigate the health care system.

Nationally, a lot of attention has been focused on improving the quality of care provided to patients in order to improve health care outcomes and reduce costs. Yet many of these initiatives are doomed to failure, unless the health care system collectively begins to use more effective ways of communicating with people with low literacy. Because many people can encounter difficulties understanding complex health information, the goal of any effort should be to improve health communications for all populations. Chapter 3 describes some of the evidence-based guidelines for effective communication.

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