Issue Brief

Just *What* Did the Doctor Order?

Addressing Low Health Literacy in North Carolina

August 2007

Health information can be very technical and hard to understand. Most of us have had trouble understanding our doctor's instructions at one time or another. Sometimes providers use medical or scientific terms that are confusing. Patients with different health problems may have trouble keeping track of everything their providers tell them.

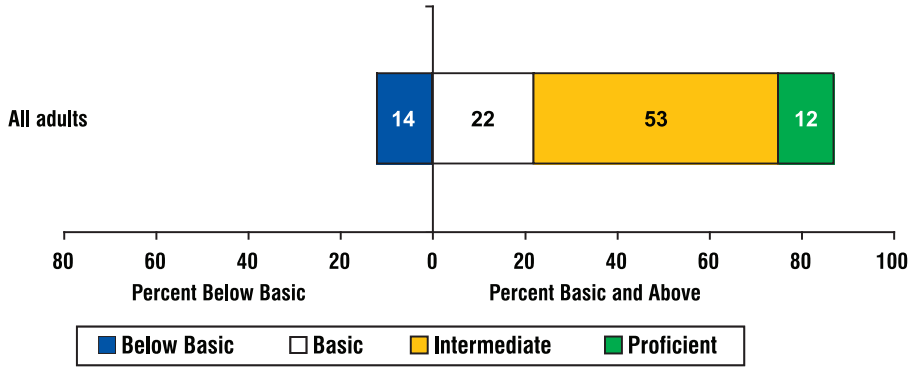
Most of our current efforts to improve health depend on having informed health care consumers. However, people cannot make informed health care decisions if they do not understand the health information they receive. Studies have shown 40-80% of the medical information patients receive is forgotten immediately.[1] Nearly half of the information they do remember is incorrect.[2]

Low Health Literacy Leads to Worse Health Outcomes and Higher Health Care Costs

Health literacy is the degree to which individuals have the capacity to obtain and understand the basic health information and services needed to make appropriate health decisions. Health literacy means more than the ability to read and write. It requires reading skills as well as the ability to explain health problems to health care providers and staff. Health literacy includes the ability to understand what health professionals say, to use numbers and math skills, and to understand how to obtain needed health services. Health literacy is needed to comprehend prescriptions and warning labels. In addition, patients need adequate health literacy skills to fill out or understand health insurance forms or public assistance applications. Low health literacy can have a negative impact both on an individual's health and on overall health care costs. One of the reasons for rising health care costs is the increase in the number of people with chronic illnesses. People who do not understand their doctors' orders have a harder time controlling their chronic illnesses than those who can understand what they have been told.[3]

Literacy is an essential part of health literacy. People who have low literacy skills are less likely to comply with treatment protocols because they do not understand their diagnosis or treatment instructions. They also are more likely to have poor health outcomes. People with low literacy skills have more problems controlling their asthma or diabetes than people with higher literacy skills.[4,5] They also are more likely to experience depression, be admitted to a hospital, or die prematurely.[6,7] In addition, people with low literacy skills are less likely to understand warning labels on drug bottles.[8] Children of parents with low literacy are more likely to miss school, visit the emergency department, and be hospitalized compared to children of parents with higher literacy.[9] Older adults, people with less education or with

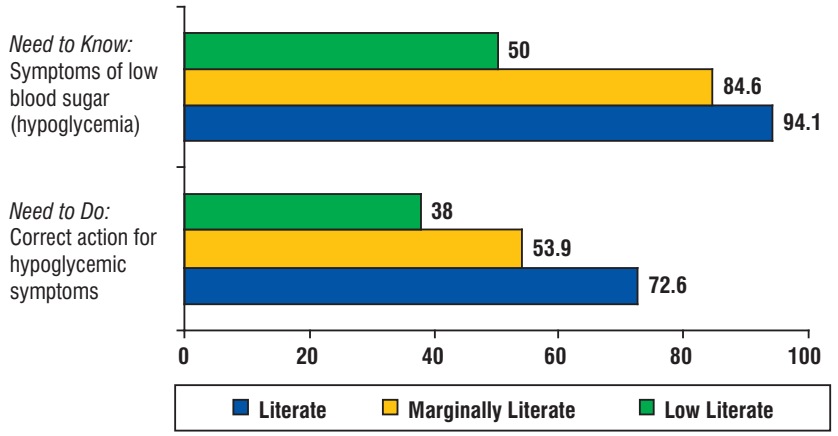
Figure 1
Percentage of Adults in Each Health Literacy Level (2003)



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.

Figure 2
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.

cognitive impairments, racial and ethnic minorities, and low income individuals are more likely to have literacy problems than other people.[10]

According to the most recent National Assessment of Adult Literacy, 93 million American adults (43% of the adult population) have basic or below basic literacy skills.[11] State-level estimates indicate more North Carolinians function at these lower literacy levels compared to people nationally.[12] State-level estimates place North Carolina 41st of all states in basic or below basic adult literacy levels. Estimates of the number of people with low literacy skills probably underestimate the number of people with low health literacy skills. People of all literacy and educational levels can have difficulty understanding complex health information.

The Chronic Disease and Injury Section of the Division of Public Health, North Carolina Department of Health and Human Services (NC DHHS) asked the North Carolina Institute of Medicine (NC IOM) to convene a task force to study the problem of low health literacy. The NC IOM Health Literacy Task Force made 14 recommendations to improve health care communications so that all people have the ability to understand basic health information, make informed decisions, and carry out these decisions appropriately. The Task Force set out to identify the most effective strategies to communicate health-related information for all populations. The Task Force also identified strategies to improve health literacy awareness among health care professionals and literacy professionals. In addition, the Task Force developed recommendations to incorporate health literacy strategies into adult literacy, Adult Basic Education, and English as a Second Language courses.

North Carolina Health Care Professionals and Other Health Care Leaders Should Work Together to Address the Problems of Low Health Literacy

Across the country, almost half of the population reads at or below an eighth grade reading level.[13] People with lower reading abilities often have lower health literacy. The Task Force recognized the importance of using clear, plain language without complicated concepts or wording to improve health communications. To effectively communicate information, documents or other materials must be understandable to the populations they are meant to reach. **Therefore, the NC IOM Health Literacy Task Force suggested all documents developed by North Carolina state and local agencies, health care providers, and insurers be written or produced at an appropriate level for the targeted audience.**

The "teach-back" technique is one of the most effective methods to improve understanding and retention of health information. Providers using the teach-back method ask their patients to repeat information they just heard in their own words. Another relatively new communication strategy is the group medical visit. Group medical visits encourage group discussion and information sharing among a number of patients with similar health problems. Communication of health information also can be improved through the use of community health workers or trained health educators.

The Task Force recommended North Carolina develop a Health Literacy Center of Excellence that will assume a leadership role in coordinating and disseminating effective health literacy strategies across the state. The Center would review existing and emerging research to identify evidence-based methods of communicating health information to individuals with low health literacy. The Center would disseminate this information to North Carolina health care systems, health care practitioners, publicly-funded programs, and private insurers and payers. Furthermore, the Center would work collaboratively with academic health centers,

health professions training schools, North Carolina Area Health Education Centers Program, and health professional associations to educate health professionals about strategies to improve communication skills with individuals of all literacy levels.

Unfortunately, many providers and other health care professionals do not understand the relationship between low health literacy and health outcomes. Even those professionals who know about the problem may not know the most effective communication strategies. More education is needed so that health care professionals understand this problem and have the skills needed to effectively communicate with their patients. **Therefore, the Task Force recommended:**

- **Educational institutions and other organizations that help train health professionals should include health literacy training in their education curricula.**
- **The North Carolina Department of Health and Human Services should ensure there are trained and competent staff in each division who can disseminate health literacy skills and strategies.**
- **The North Carolina Board of Pharmacy should develop requirements for effective communication of prescription information to consumers.**
- **Malpractice carriers should incorporate health literacy education and effective provider-patient communication skills into their risk management training.**

New models of care also are needed to ensure people with low health literacy skills obtain the information they need to appropriately manage their health problems. This information is particularly important for people with chronic health problems. A recent study found disease management programs coupled with easy to understand educational materials can help improve health outcomes for people with heart failure.[14] Another study found a pharmacy-led program with patient education, care coordination, and follow-up phone calls led to improved patient outcomes.[15] Both studies showed improved outcomes for all populations but bigger improvements for people with lower literacy skills. Individual and group education sessions that teach patient-self management skills also can be effective. **The Task Force recommended public and private agencies, insurers, and organizations include health literacy strategies in their disease management and case management programs.** In addition, the Task Force realized more work is needed to test new models of care. **Thus, the Task Force recommended the state and North Carolina foundations help pilot new models of care or communication strategies to improve health outcomes for people with low health literacy skills. If these models are successful, public and private insurers and payers should pay for the services to encourage the use of these models.**

Education and Outreach Efforts are Needed to Help People with Low Health Literacy Gain Skills Needed to Understand and Manage Their Health

The Task Force also wanted to help people with low health literacy gain the skills they need to understand and manage their health. For example, the North Carolina Division of Public Health developed an award-winning public service announcement ("Lost in Translation") that depicted a patient who was overwhelmed by the health care information he was being given. One of the goals of this public service announcement was to encourage patients to ask questions when they do not understand what providers are telling them. **Thus, the Task Force recommended the North Carolina Division of Public Health expand its public education and outreach campaign to encourage consumers to ask questions and more actively participate in their own care.** Other strategies are more targeted to people with low overall literacy skills. **The Task Force recommended programs that provide literacy education, such as Adult Basic Education and English as a Second Language programs within the North Carolina Community College System, local literacy councils, and other community-based organizations, should disseminate and incorporate health literacy curricula.**

North Carolinians with low health literacy face a variety of challenges in maintaining and improving their health. The statewide problem is considerable, given that nearly half of adults in North Carolina have low health literacy. While the problem of health literacy disproportionately impacts certain people, almost all North Carolinians face challenges understanding health concepts and the increasingly complex health system. It is therefore critical that all members of the health care system adopt new strategies to effectively communicate with health care consumers. Ultimately, this will help people better manage their own care and reduce health care costs. Although such strategies can lead to cost-savings, the real payoff is in the increased quality of life and improved outcomes due to better patient understanding.

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A complete copy of the Task Force Report, *Just* What *Did the Doctor Order? Addressing Low Health Literacy in North Carolina* is available at http://www.nciom.org/projects/health_literacy/health_literacy.html. For more information about the Task Force's work, contact Pam Silberman, JD, DrPH, President & CEO, North Carolina Institute of Medicine. 5501 Fortunes Ridge Drive, Suite E, Durham, NC 27713. 919-401-6599 ext 23. pam_silberman@nciom.org.

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