Introduction

Chapter 1

The American health care system is focusing increasingly on the role patients play as the central agents in managing their own health. Federal and state initiatives aimed at increasing the transparency of cost and quality in health care, the inclusion of "patient-centeredness" as one of the seven domains of quality health care by the Institute of Medicine of the National Academies of Science, and a nationwide focus on "lifestyle diseases" and prevention are all examples of this paradigm shift. "Patient activation" and "patient empowerment" are phrases commonly used to underscore this new model. These concepts place the patient as the locus of control, rather than the provider. Ultimately, the consumer-directed health care movement depends critically on the patient being an informed participant in his or her health care decisions. If the patient is ill-informed, does not fully understand the issues, or has self-doubt that inhibits decision making, the central goal of patient activation will not be met. Even with more traditional models of provider-patient interaction, patients need to understand what they are being told.

Unfortunately, many patients do not fully understand health care information they receive. Studies have shown 40-80% of the medical information patients receive is forgotten immediately,[1] and nearly half of the information retained is incorrect.[2] Lack of patient adherence to medical recommendations is often cited as a primary reason chronic illnesses are so poorly controlled.[3] Practitioners may decry the lack of patient adherence, without understanding why patients fail to follow their instructions. If patients do not understand or retain the health information they receive, they will not be able to manage their own health.

The degree to which people understand health information and can successfully navigate the health care system is described as their *health literacy*. Patients must communicate health problems to their providers and understand health information conveyed by practitioners. People need basic literacy skills to be able to read prescription bottles and understand how often and under what circumstances to take medications. They also must be able to read and understand warnings to recognize potentially life-threatening complications from medications. People with chronic conditions need literacy skills to be able to manage their health at home and to determine appropriate treatment responses. People need basic reading skills to be able to fill out or understand health insurance forms or public assistance applications.

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions.

The concept of *health literacy* differs from that of *literacy*. Health literacy entails a broader set of skills and abilities than reading and writing. Health literacy requires some reading skills but also the ability to understand oral communication, use numbers and math skills, and understand the health system on a basic level. Health literacy also encompasses the ability to communicate with health care providers and their staff.

Many people are literate but have trouble understanding health care information and making health care decisions. Health literacy is defined as:

> "The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions."[4]

This broader concept of health literacy has not been measured in its entirety. Rather, the research literature has focused on the more narrow relationship between literacy and health. Because literacy is such an essential component of health literacy, the body of research around low literacy can inform how we address and mitigate the effects of low health literacy. Understanding the basic skills of the population and how those skills relate to health care services and outcomes is the starting point for addressing the broader issue of health literacy.

Low literacy is associated with poor understanding of written and spoken medical advice and adverse health outcomes.

Low literacy is associated with poor understanding of written and spoken medical advice and adverse health outcomes. People with low literacy are less able to understand health care information, including their own diagnosis and treatment recommendations. They are less likely to comply with treatment protocols, because they do not understand the instructions. Low literacy is an independent risk factor for difficulty with asthma self-management, poor glycemic control, depression, more hospital admissions, and earlier mortality.[5,6] Literacy problems are particularly prevalent among racial and ethnic minorities, older adults, people with less education or with cognitive impairments, and low income individuals.[7]

According to the most recent National Assessment of Adult Literacy (NAAL), 93 million American adults—43% of the adult population—have basic or below basic literacy as compared to intermediate or proficient levels.[8] Generally, people in these groups cannot perform tasks such as reading a bus schedule or bar graph or writing a simple letter explaining an error on a bill. Adult literacy levels did not change significantly between the 1992 National Assessment of Literacy Survey (NALS) and 2003 NAAL. State-level estimates, based on the 1992 survey, indicate more North Carolinians function at the lowest literacy levels compared to people nationally.[9] The state level estimate placed North Carolina 41st of all states in basic or below basic adult literacy levels. These estimates of the numbers of people with low literacy levels probably underestimate the numbers of people who struggle to understand and process complex health information.

Task Force Work

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 was a collaborative effort between the NC IOM, NC DHHS, and North Carolina Area Health Education Centers (AHEC) Program. The Task Force was chaired by Thomas J. Bacon, DrPH, Executive Associate Dean and Director, AHEC, University of North Carolina at Chapel Hill School of Medicine, and L. Allen Dobson, MD, FAAFP, Assistant Secretary for Health Policy and Medical Assistance, NC DHHS. It included 49 other Task Force and Steering Committee members (See the Acknowledgements section for a complete listing of Task Force and Steering

Committee members). The Task Force met a total of seven times over nine months. The Task Force was charged with:

1. Identifying evidence-based models, or best practices, of communicating health-related information and skills to people with low health literacy.
2. Improving health literacy awareness, knowledge, and skills among health care professionals in clinical settings in order to improve patient understanding and help patients make appropriate health decisions.
3. Improving health literacy awareness, knowledge, and skills among literacy professionals in order to increase health literacy education in targeted low literacy populations.
4. Developing systems to improve health care communications to people with low health literacy skills in publicly-funded programs, including public health, mental health, Medicaid, and aging.
5. Identifying strategies to more effectively communicate population-based health education messages to people with low health literacy.

Ultimately, North Carolina's goal should be to improve the literacy and health literacy status of everyone in the state. However, until that time, we need to improve the communication strategies of health care providers so that they can more effectively communicate with individuals who have low health literacy. Throughout this report, we refer to health care providers. We use that term to include health care professionals, insurers, health educators, health administrators, pharmaceutical manufacturers, and others who provide health information to patients and their families. This report is a call to action. We will have little ability to improve health outcomes unless we ensure individuals with low health literacy have the ability to understand basic health information, make informed health decisions, and carry out those decisions appropriately.

This report is a call to action. We will have little ability to improve health outcomes unless we ensure individuals with low health literacy have the ability to understand basic health information, make informed health decisions, and carry out those decisions appropriately.

People with low literacy skills are not always easily recognizable. Over time, individuals develop coping mechanisms that mask their literacy skills. Many people with low literacy abilities are ashamed to admit they do not understand.[10,11] In addition, people of all literacy and educational levels can have difficulty understanding health information. Most people prefer materials written in or verbally explained in clear, plain language without complicated concepts or wording.[12,13] Additionally, retention of information is a huge challenge in improving health literacy. As such, the Task Force advocates improving health communications that will benefit all audiences.

The report includes six chapters, the first being a brief introduction. Chapter 2 includes an overview of the problem and examines the relationship between literacy and health. Chapter 3 includes a description of clear communication strategies for people with low health literacy. Chapter 4 describes strategies to improve communication in our current systems of care. Chapter 5 includes a discussion of how to use existing adult literacy and basic education systems to improve health literacy. Chapter 6 includes the conclusion and summary of recommendations.

References

1. Kessels RP. Patients' memory for medical information. *J R Soc Med*. 2003;96:219-222.
2. Anderson JL, Dodman S, Kopelman M, Fleming A. Patient information recall in a rheumatology clinic. *Rheumatol Rehabil*. 1979;18:18-22.
3. Murphy J, Coster G. Issues in patient compliance. *Drugs*. 1997;54:797-800.
4. Office of Disease Prevention and Health Promotion. Health communication. In: U.S. Department of Health and Human Services, ed. *Healthy People 2010: Understanding and Improving Health*. 2nd ed. Washington, DC: U.S. Government Printing Office; 2000.
5. DeWalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP. Literacy and health outcomes: A systematic review of the literature. *J Gen Intern Med*. 2004;19:1228-1239.
6. Sudore RL, Yaffe K, Satterfield S, et al. Limited literacy and mortality in the elderly: The health, aging, and body composition study. *J Gen Intern Med*. 2006;21:806-812.
7. 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). U.S. Department of Education. Washington, DC: National Center for Education; 2006.
8. National Center for Education Statistics. National Assessment of Adult Literacy: Key Findings. Available at: http://nces.ed.gov.libproxy.lib.unc.edu/NAAL/index.asp?file=KeyFindings/Demographics/Overall.asp&PageId=16. Accessed Mar. 13, 2007.
9. Comprehensive Adult Student Assessment System. Adult Literacy Estimate. Available at: https://www.casas.org/lit/litcode/Search.cfm. Accessed Mar. 13, 2007.
10. Baker DW, Parker RM, Williams MV, et al. The health care experience of patients with low literacy. *Arch Fam Med*. 1996;5:329-334.
11. Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. Shame and health literacy: The unspoken connection. *Patient Educ Couns*. 1996;27:33-39.
12. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. Health literacy: Report of the Council on Scientific Affairs. *JAMA*. 1999;281:552-557.
13. Davis TC, Crouch MA, Wills G, Miller S, Abdehou DM. The gap between patient reading comprehension and the readability of patient education materials. *J Fam Pract*. 1990;31:533-538.