Just *What* Did the Doctor Order?

Addressing Low Health Literacy in North Carolina

August 2007

North Carolina Institute of Medicine
In collaboration with the North Carolina Department of Health and Human Services and the North Carolina Area Health Education Centers Program

Funded by the North Carolina Department of Health and Human Services, Division of Public Health, Chronic Disease and Injury Section, Heart Disease and Stroke Prevention Branch and Division of Medical Assistance

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North Carolina Institute of Medicine
Woodcroft Professional Center
5501 Fortunes Ridge Drive, Suite E
Durham, NC 27713
919.401.6599

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Carolina at Chapel Hill; Lisa Dieter, MS, Director, Consumer Strategy and Planning, Pfizer Inc.; Nancy Henley, MD, MPH, FACP, Medical Director, North Carolina State Health Plan; Meera Kelley, MD, Vice President, Quality and Patient Safety, WakeMed Health and Hospitals; Barbara Knopp, Education Consultant, North Carolina Board of Nursing; Michael Lancaster, MD, Chief of Clinical Policy, Division of Mental Health, Developmental Disabilities and Substance Abuse Services; Timothy W. Lane, MD, Moses Cone Health System; Denise Levis, RN, BSN, MSPH, Director of Quality Improvement, Senior Consultant, Community Care of North Carolina; Diana McDuffee, MLS, Network Director, Information and Library Systems, AHEC; Michael D. Murray, PharmD, MPH, Professor and Chair, Pharmaceutical Outcomes and Policy, School of Pharmacy, University of North Carolina at Chapel Hill; Melanie Phelps, North Carolina Medical Society; Marcus Plescia, MD, Chief, Chronic Disease and Injury Section, Division of Public Health; William H. Shrank, MD, MSHS, Instructor in Medicine, Division of Pharmacoepidemiology and Pharmacoeconomics, Harvard Medical School; Christie Silbajoris, MSLS, Director, North Carolina Health Info; Jason M. Spangler, MD, MPH, Consultant, Public Health and Policy, Pfizer Global Pharmaceuticals; Gina Upchurch, RPh, MPH, Executive Director, Senior PHARM*Assist*; Sarah Verbiest, MSW, MPH, Center for Maternal and Infant Health, University of North Carolina.

North Carolina Institute of Medicine Health Literacy Task Force

Co-Chairs

Thomas J. Bacon, DrPH
Executive Associate Dean and Director
NC Area Health Education Centers (AHEC) Program
University of North Carolina at Chapel Hill School of Medicine

L. Allen Dobson, MD, FAAFP
Assistant Secretary for Health Policy and Medical Assistance
NC Department of Health and Human Services

Task Force Members

Susan Auger, MSW
President
Auger Communications, Inc.

Karen M. Brown
Adult Basic Education/English Second Language Coordinator
NC Community College System

Heather Burkhardt, MSW
Planning and Evaluation Coordinator
NC Division of Aging and Adult Services

Patricia C. Casper, MSW, LCSW
SWII-Family Home Visitor
Orange County Health Department

Laura Coffee, MSW
Director of Basic Skills Education
Alamance Community College

Toni Cordell
Patient Advocate

The Honorable William A. Current, Sr., DDS
Representative
NC General Assembly

Dominque Davis
Adult Literacy Coordinator
Durham Literacy Center

Darren DeWalt, MD, MPH
Assistant Professor of Medicine
Division of General Internal Medicine
University of North Carolina School of Medicine

Sandy Diehl, MPH
Doctoral Student
Department of Health Behavior and Health Education
University of North Carolina at Chapel Hill

Carolyn Dunn, PhD
Professor
Department of 4H Youth Development and Family and Consumer Sciences
NC Cooperative Extension
NC State University

Art Eccleston, PsyD
Clinical Policy Specialist
Division of Mental Health, Developmental Disabilities and Substance Abuse Services

Chris Evans, JD, MAEd
Director of Network Operations and Strategic Planning
NC State Health Plan

Olivia Fleming, MA
Clinic Community Affairs Outreach Coordinator
Urban Ministries of Wake County

Jane M. Foy, MD
Professor of Pediatrics
Wake Forest University Baptist Medical Center

Janice A. Freedman, MPH
Executive Director
NC Healthy Start Foundation

The Honorable Rick Glazier
Representative
NC General Assembly

James J. Gooch, DrPH
Director
Institute for Public Health
North Carolina A&T State University

Francis N. Kateh, MD, MHA
Health Director
Anson County Health Department

Meera Kelley, MD
Vice President
Quality and Patient Safety
WakeMed Health and Hospitals

Michael Lancaster, MD
Chief of Clinical Policy
Division of Mental Health, Developmental Disabilities and Substance Abuse Services

Timothy W. Lane, MD
Moses Cone Health System

Denise Levis, RN, BSN, MSPH
Director of Quality Improvement and Senior Consultant
Community Care of North Carolina

H. Nolo Martinez, EdD
Assistant Director for Research and Outreach
UNCG Center for New North Carolinians

Gerri Mattson, MD
Pediatric Medical Consultant
Children and Youth Branch
Women and Children's Health Section
Division of Public Health

Linda Mayne, PhD
Associate Professor
East Carolina University School of Nursing

Meg Molloy, DrPH, MPH, RD
Executive Director
NC Prevention Partners

Ben Money, MPH
Associate Director
NC Community Health Care Association

Merry-K Moos, RN, FNP, MPH, FAAN
Professor
Maternal Fetal Medicine Division
Department of Obstetrics and Gynecology
University of North Carolina at Chapel Hill

Michael D. Murray, PharmD, MPH
Professor and Chair
Pharmaceutical Outcomes and Policy
School of Pharmacy
University of North Carolina at Chapel Hill

Mike Newton-Ward, MSW, MPH
Social Marketing Consultant
NC Division of Public Health/Turning Point
Social Marketing National Excellence Collaborative
Department of Health and Human Services

Lloyd F. Novick, MD, MPH
Director
Division of Community Health and Preventive Medicine
The Brody School of Medicine

April Locklear Oxendine, MAEd
Member of the Lumbee Nation
Enhanced Counseling/HIV Outreach Coordinator
Robeson County Health Department

Marcus Plescia, MD
Chief
Chronic Disease and Injury Section
NC Division of Public Health
Department of Health and Human Services

Ronald Plummer, EdD
Adult Learning Manager and "Ready To Earn" Director
UNC-TV

Elmira J. Powell, MEd, PA-C
Physician Assistant
Piedmont Healthcare for Women
Central Carolina OB-GYN Division

LaHoma Smith Romocki, PhD, MPH
Assistant Professor
Department of Health Education
North Carolina Central University

NC IOM Health Literacy Task Force

J. Carson Rounds, MD
President
NC Academy of Family Physicians
Village Family Care of Wake Forest

Alice J. Schenall, MPH, CHES, RHEd
Director
Allied, Dental, and Public Health Education
Area L AHEC

Jason M. Spangler, MD, MPH
Consultant
Public Health and Policy
Pfizer Global Pharmaceuticals

Brenda Sparks, RN, CPUR
Executive Director
Carolina Collaborative Community Care, Inc.

Karen Stallings, RN, MEd
Associate Director
AHEC

Annamarie Streilein, MHS, PA-C
Instructor
Physician Assistant Program
Department of Community and Family Medicine
Duke University Medical Center

Jeffrey Weinstock
Senior Communications Advisor
Enterprise Project Office
Blue Cross and Blue Shield of North Carolina

Cynthia Wells, EdD
Director for Administration
Wake AHEC

Susan D. Yaggy, MPA
Chief
Division of Community Health
Department of Community and Family Medicine
Duke University Medical Center

Steering Committee

Thomas J. Bacon, DrPH
Executive Associate Dean and Director
AHEC

Darren DeWalt, MD, MPH
Assistant Professor of Medicine
Division of General Internal Medicine
University of North Carolina School of Medicine

Barbara Moeykens, MS
Media Intervention/Social Marketing Specialist
Heart Disease and Stroke Prevention Branch
Chronic Disease and Injury Section
NC Division of Public Health

Marcus Plescia, MD
Chief
Chronic Disease and Injury Section
NC Division of Public Health
Department of Health and Human Services

Sarah Verbiest, MSW, MPH
Executive Director
UNC Center for Maternal and Infant Health

Alexander White, JD, MPH
Heart Disease and Stroke Prevention Branch
Chronic Disease and Injury Section
NC Division of Public Health

North Carolina Institute of Medicine Staff

Pam Silberman, JD, DrPH
President and CEO

Mark Holmes, PhD
Vice President

E. Kiernan McGorty, JD, PhD
Project Director

Kristen Dubay, MPP
Project Director
Managing Editor for the *North Carolina Medical Journal*

Kimberly Alexander-Bratcher, MPH
Project Director

Thalia Fuller
Administrative Assistant

Adrienne Parker
Director of Administrative Operations

Phyllis Blackwell
Editorial Assistant
Assistant Managing Editor for the *North Carolina Medical Journal*

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.

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.

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.

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.

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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.

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The Problem of Low Health Literacy

Chapter 2

The 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."[1] 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.[2]

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.

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.

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).[3] The NAAL measures the English language literacy of adults age 16 and older in the United States.[a] 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.

a The assessment was administered to more than 19,000 adults. The 2003 NAAL updated the 1992 National Assessement 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.[4] 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.

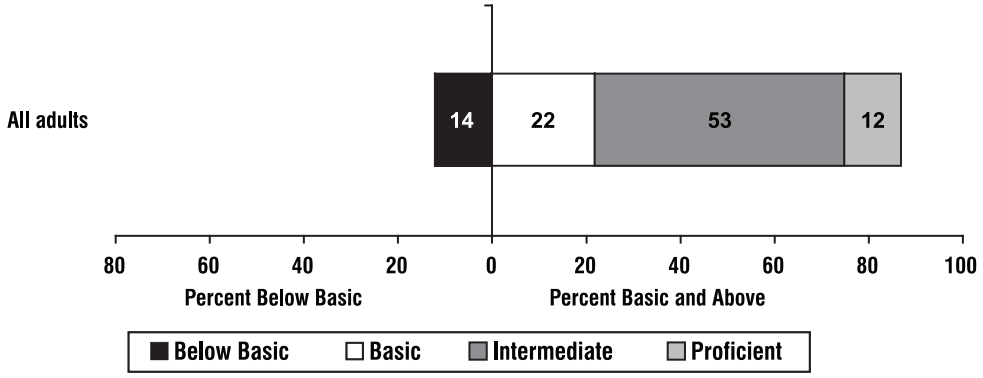
- The *clinical domain* includes activities that are common in a clinical setting, including filling out a patient information form during an office visit, understanding how to take medication appropriately, or understanding recommended treatment or diagnostic procedures.
- The *prevention domain* includes 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.[b] Within the health care context, much of the information presented would require intermediate or proficient literacy skill levels.[5] 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

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.

Figure 2.1
Percentage of Adults in Each Health Literacy Level (2003)



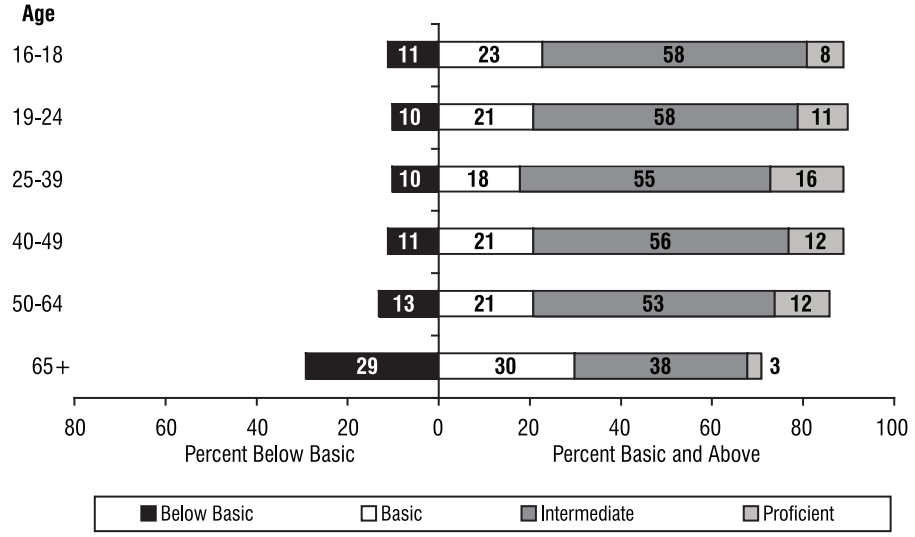
NOTE: Detail may not sum to totals because of rounding. Adults are defined as people 16 years of age and older living in households or prisons. Adults who could not be interviewed because of language spoken or cognitive or mental disabilities (3% in 2003) are excluded from this figure.

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.

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

Figure 2.2
Percentage of Adults in Each Health Literacy Level, by Age (2003)



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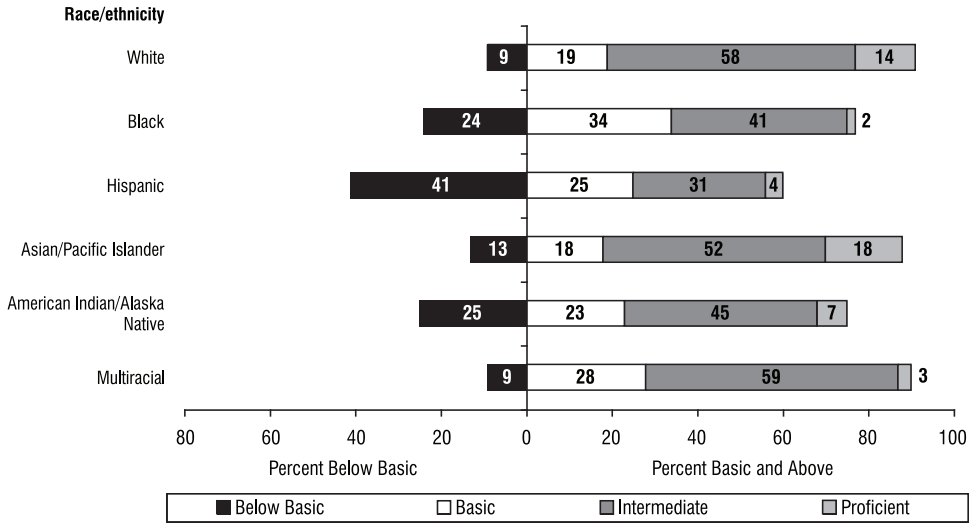
literacy scores (16 to 18-year-olds). Compared to other age groups, older adults are far more likely to have below basic or basic health literacy skills.

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.[c] 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.[d,6]

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.

Figure 2.3
Percentage of Adults in Each Health Literacy Level, by Race/Ethnicity (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. All adults of Hispanic origin are classified as Hispanic, regardless of race. The Asian/Pacific Islander category includes Native Hawaiians, Black includes African American, and Hispanic includes Latino.

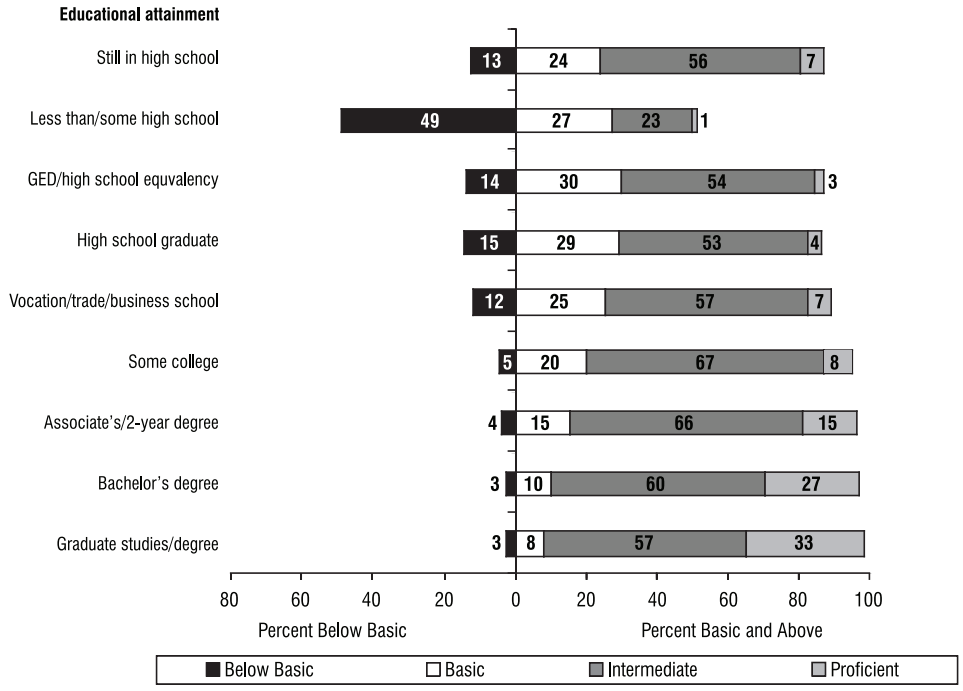
SOURCE: Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy* (NCES 2006-483). US Department of Education. Washington, DC: National Center for Education Statistics; 2006.

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.[6]

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.[e] 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)

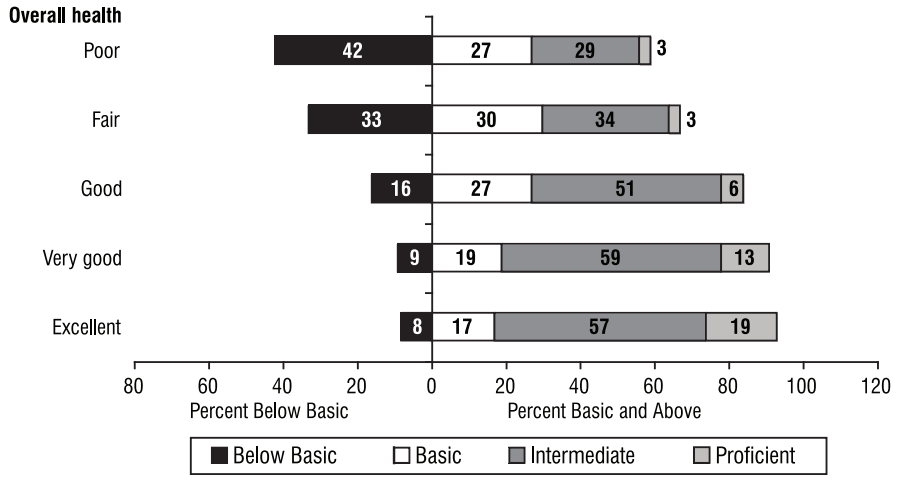


NOTE: Detail may not sum to totals because of rounding. Adults are defined as people 16 years of age and older living in households or prisons. Adults who could not be interviewed because of language spoken or cognitive or mental disabilities (3% in 2003) are excluded from this figure.

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).

Figure 2.5
Percentage of Adults in Each Health Literacy Level, by Self-assessment of Overall Health (2003)



NOTE: Details 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.

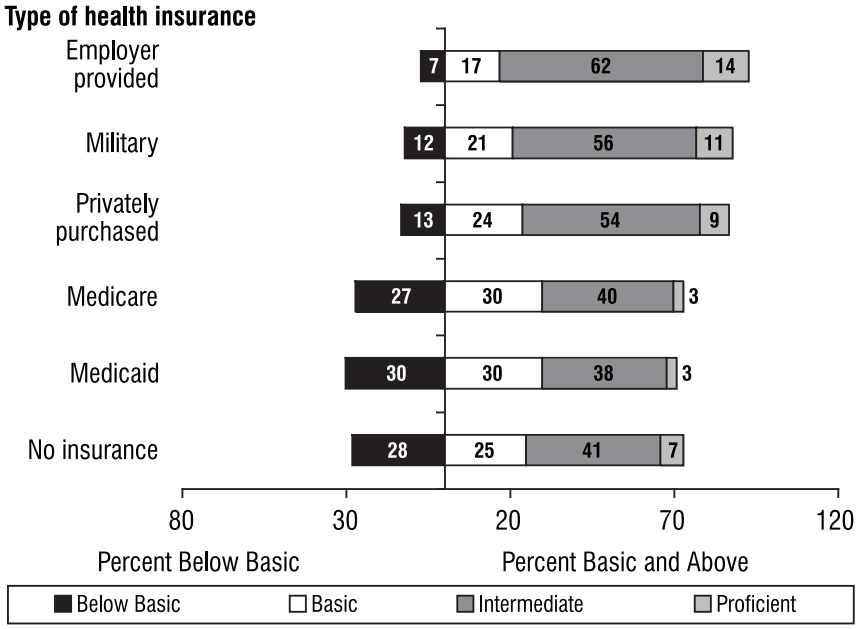
Health literacy also varies by self-reported health and health insurance status. Individuals with lower self-reported health status also are more likely to have lower average health literacy scores. (See Figure 2.5.) A much higher proportion of those who report being in poor or fair health score below 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.[7] Portland State University developed a state level estimate of adult literacy levels based on the 1992 NALS assessment.[8] 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.

strong correlation between the scores that people receive on general adult literacy tasks and on tasks specific to health literacy.[f] 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.[g] The 1992 survey may understate the extent of the problem today, with the recent influx of immigrants and the aging of the population.[h]

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

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.[9,10] 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.[8]

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.[45] Similarly, among the 50 states, North Carolina had the 12th fastest growing population of individuals age 65 or older.[46] 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.[11,12]

There are individual assessment tools available that practitioners can use to assess an individual's literacy skills:[13]

- 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.[14]

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.[15,16] 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.[17] 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.

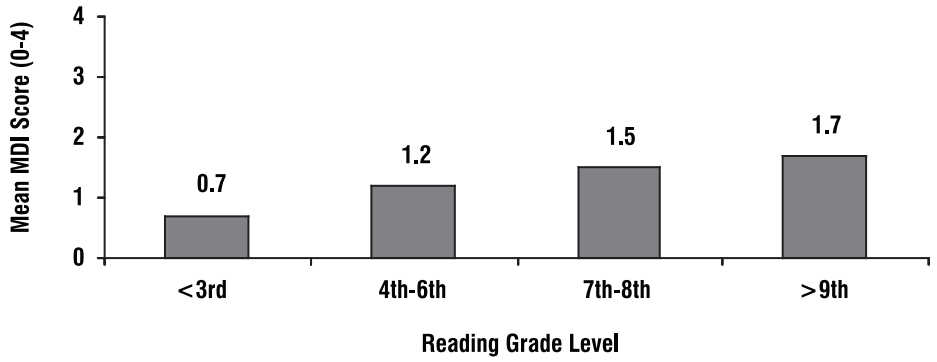
Literacy and Knowledge

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.[13] 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,[18] cervical cancer screening,[12] HIV medication knowledge,[19] emergency department discharge instructions,[20] smoking,[21] asthma,[22] hypertension and diabetes.[23]

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.[22] (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.

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.

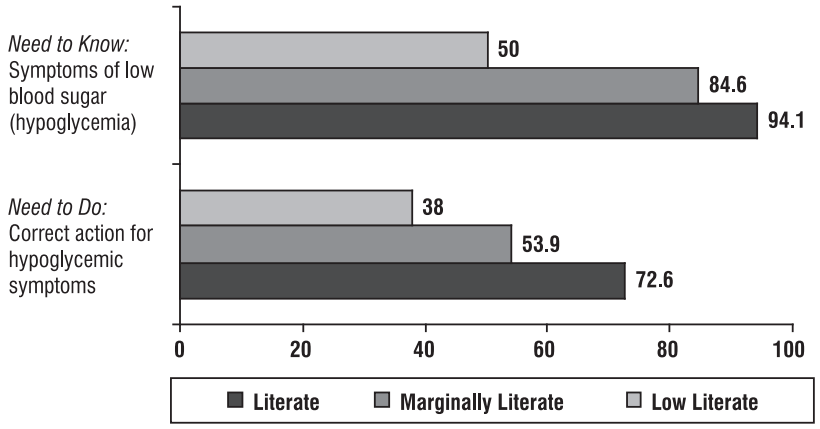
Figure 2.7
Asthma Patients with Low Literacy have Poorer Metered Dose Inhaler (MDI) Skills



SOURCE: Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest*. 1998;114:1008-1015.

Similarly, adults with diabetes who have low literacy skills are less likely to understand diabetes or how to manage their health problems.[23] (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.[24]

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.[25] 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.[26-28]

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.[29] 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,[30] and another showed a 29% increased risk of hospitalization.[31]

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.[32] Similarly, a study by Ross et al. found parents' reading skill levels were positively correlated with their children's glycemic control.[33]

Literacy and Patient Safety

Medication errors are the most common form of medical mistake.[34] 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.[35]

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

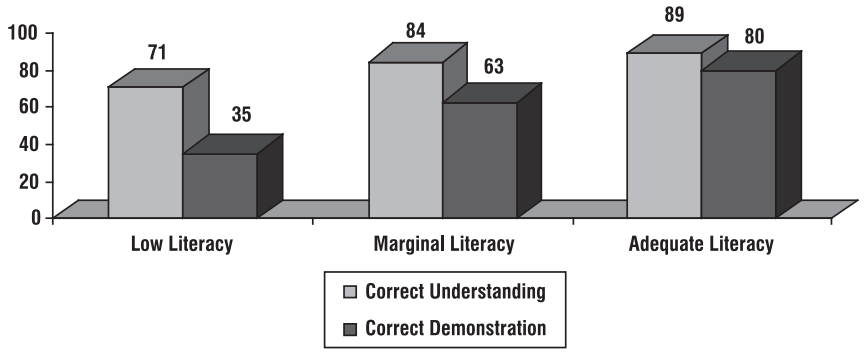
Nationally, pharmacists fill approximately three billion prescriptions each year, and 90 million Americans have trouble understanding and complying with medication instructions.[36] On average, more than 80% of all adults take at least one form of medication each week (including prescriptions, over-the-counter drugs, vitamins, and herbal supplements).[35] 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[37] and see eight different physicians.[38]

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.[39] 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."[40] 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."[41] (See Figure 2.10.)

Figure 2.9
Rates of Correct Understanding vs. Demonstration "Take Two Tablets by Mouth Twice Daily"



SOURCE: Davis TC, Wolf MS, Bass PF, et al. Literacy and misunderstanding prescription drug labels. *Ann Intern Med.* 2006;145:887-894.

Figure 2.10
Comprehension Increased with Patient Literacy Level

Prescription Label	Patient Literacy Level		
	<6	7-8	>9
TAKE WITH FOOD ©1990	79%	86%	88%†
DO NOT CHEW OR CRUSH, SWALLOW WHOLE. ©1976	35%	66%	78%*
FOR EXTERNAL USE ONLY ©1976	8%	64%	82%*
REFRIGERATE-SHAKE WELL DISCARD AFTER_____ ©1976	8%	18%	23%*
DO NOT TAKE DAIRY PRODUCTS, ANTACIDS, OR IRON PREPARATIONS WITHIN ONE HOUR OF THIS MEDICATION.	0%	6%	15%*

* p<.0001, † p<.05

In multivariate analysis only literacy and age predicted comprehension.
Patients with low literacy (< 6th grade) were three times more likely to incorrectly interpret warning labels.

SOURCE: Davis TC, Wolf MS, Bass PF, et al. Low literacy impairs comprehension of prescription drug warning labels. *J Gen Intern Med.* 2006;21:847-851.

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).[42, 43] 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.[44]

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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Effective Communication Practices

Chapter 3

People's health status depends, in large part, on whether they can understand and remember the health information they receive. Current communication strategies are failing in this regard. Most people forget what their providers tell them,[1] and others remember the information incorrectly.[2] It is unrealistic to expect patients will significantly improve their reading, mathematic, or health literacy skills in the context of a medical visit. Therefore, more needs to be done to improve the ability of health care providers, including practitioners, insurers, health educators, health administrators, pharmaceutical manufacturers, and others, to convey complex health information to low health literate populations. It also is important to use different methods for reaching patients. Because there are many different learning styles (eg, visual, auditory, and kinesthetic), it is critical to use both verbal and written communication tools. The Task Force recommended health care providers strive to improve their health communications with all patients, regardless of their literacy level. More effective communication strategies developed to better serve low health literate populations will also benefit more literate populations. This chapter reviews communication strategies that have been designed and/or proven to improve health literacy across a variety of populations.

Most people forget what their providers tell them, and others remember the information incorrectly.

Improving Verbal and Written Communication

People receive health information from a variety of sources, the most frequent of which are verbal and written messages. Thus, health care providers should incorporate more effective communication strategies into both types of communication.

Verbal Communication

Research indicates low health literate patients face difficulties understanding information communicated orally during the provider-patient encounter, in addition to problems they may have understanding written communications.[3] In fact, studies indicate patients only understand and retain about half of what a provider tells them.[4] Patients often do not feel comfortable asking providers to clarify or repeat information. Research has shown personal interactions between providers and patients impact patient satisfaction, patient self-care, and health outcomes.[3] Therefore, verbal communication during a provider-patient encounter is extremely important, particularly for low health literate patients who may lack the resources and skills necessary to obtain needed health information on their own.[4]

Low health literate populations, along with many individuals with higher literacy skills, often have difficulty understanding complex medical or technical terminology. For example, one study of low health literate patients being screened for colorectal cancer found patients were unfamiliar with the words polyp, tumor, growth, lesion, and blood in the stool, which were commonly used during provider-patient encounters.[5] Providers should avoid using jargon and complicated medical terminology. When it is necessary to use a clinical word in practice, providers should make an effort to use plain language to explain that word. Low health

literate patients also are more likely to struggle when technical information is conveyed at a rapid pace.[3] Providers should be conscientious of the speed at which they talk and should emphasize the key messages they want their patients to remember. Providers should use visual materials to reinforce their messages and should limit the amount of advice given to patients.[6]

Improved provider-patient communication will benefit all patients, but particularly low health literate patients. One of the most effective methods to improve information retention and understanding is the "teach-back" technique. Providers using the teach-back method ask their patients to repeat information they just heard in their own words. One study found retention of information among patients asked to restate information was 83.5% compared to 60.8% for patients not asked to restate information.[7] In addition to improving information retention for a patient, the teach-back technique also lets the provider know whether the patient understood the information. This technique gives the provider an opportunity to correct any misunderstandings and reiterate critical information that was forgotten.

Retention of information among patients asked to restate information was 83.5% compared to 60.8% for patients not asked to restate information.

Teach-back can play a particularly important role when a patient is faced with a complex procedure. In such cases, the teach-back technique can complement written information. For example, patients who are undergoing complex procedures are required to sign an informed consent form. Informed consent forms are meant to ensure patients understand and accept the potential risks and consequences of their treatment. These forms are legal documents and are often written at the college reading level. As such, they are not understandable to a large portion of the population. At the University of Virginia Medical Center, it became clear many patients were canceling or delaying surgeries because they did not understand the information they were being told prior to their operations.[8] The Medical Center introduced the use of the teach-back technique in conjunction with informed consent forms to address this problem. This new informed consent "process" evaluates patients' understanding of their upcoming procedures at three points: in the surgical clinic, in the Preanesthesia Evaluation and Testing Center, and on the day of surgery. At each of those points, patients are asked what procedure they are expecting to have. In addition, patients are asked to explain their food restrictions prior to surgery and the risks that may occur during the surgery. Furthermore, patients are sent home with simplified versions of informed consent documents, which include a phone number to call if patients have any questions about their procedures.

The methods mentioned above focus on improving provider communication with patients. However, there also are initiatives that encourage consumers to take a more active role in learning about their health problems. One example is AskMe,[3] a campaign developed by the Partnership for Clear Health Communication.[9] The campaign encourages patients to ask their provider three questions during a health visit:

- What is my main problem?
- What should I do about this problem?
- Why is this important to me?

The campaign strives to inform consumers of the importance of being able to answer those three questions before they leave their providers' offices. Consumers need to understand their main health problem and what they can do about it. It also is important for consumers to understand why they need to address their health care problem. It is not always self-evident why an individual with hypertension needs to control his or her salt intake or why a diabetic has to monitor his or her glucose level. Explaining why the action steps are necessary is critical to enhancing patient motivation and compliance. If consumers know they need to understand certain health information before they leave their providers' offices, they can reduce the confusion and miscommunication that currently exists. The best time to clarify any concerns is when patients are still in providers' offices, when there are health care professionals available to answer outstanding questions.

Another relatively new communication strategy is the group medical visit. Group medical visits were developed to respond to a number of growing concerns, including the time constraints of managed care, the increasing number of individuals with chronic diseases, the increasing number of elderly individuals, and the need to include family members in disease management.[10,11] Group medical visits also may be helpful to low literacy populations. Group medical visits allow providers to communicate with a greater number of patients with similar health concerns at one time and in a more comprehensive way. The visits are generally conducted by a team of medical professionals, including a nurse, physician, and other health care professionals. Group medical visits foster group discussion and information sharing. In a group setting, patients may get answers to questions they did not think of themselves or were too embarrassed to ask. Group visits have been found to reduce emergency department visits among older adults with chronic illnesses.[12] Furthermore, initial results of a project to improve the self-management skills of low health literate patients with diabetes found group medical visits increased patient engagement in care and clinical activity.[13] These studies suggest group medical visits may be a promising practice for serving low literacy patients with complex health concerns.

Group medical visits foster group discussion and information sharing. In a group setting, patients may get answers to questions they did not think of themselves or were too embarrassed to ask.

Communication of health information also can be improved through the use of community health workers (also known as lay health advisors, promotora de salud, or community outreach workers) or trained health educators. Community health workers are able to reach underserved populations,[14-17] and they attempt to make health information meaningful and culturally relevant to their patients.[18-20] Community health workers use their social networks to engage and empower patients to get involved in their own health care.[21] Studies indicate community health workers are a cost effective way[21] to improve patients' access to care, health knowledge, and health-related behaviors.[15,16,22-25] Trained health educators are paraprofessionals specifically trained to work with patients to increase their knowledge about health promotion or specific chronic diseases and to improve overall health or manage chronic conditions.

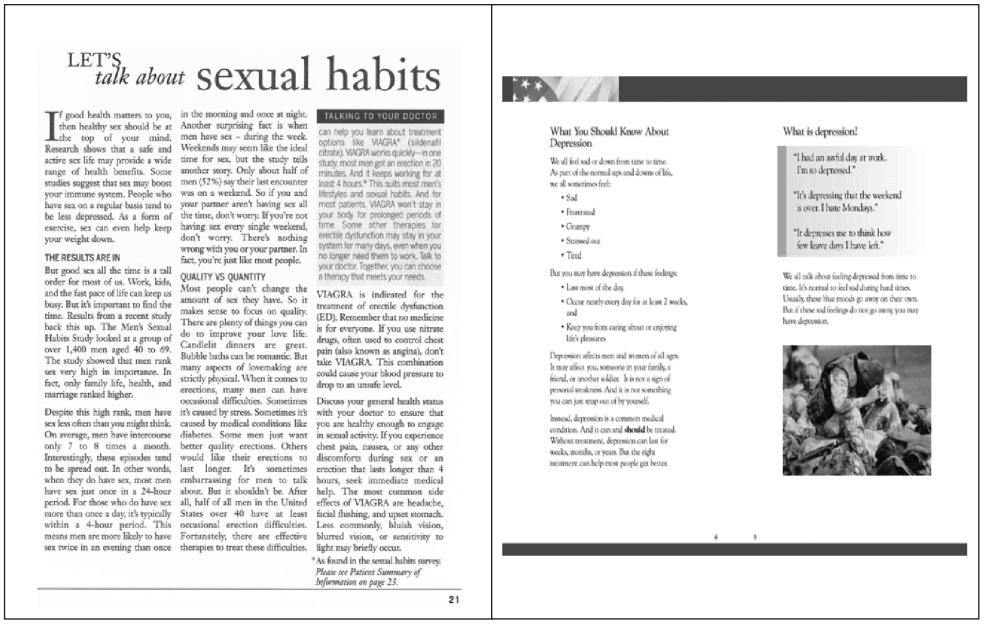
Written Information

There are thousands of different consumer health education documents aimed at providing information about health promotion, specific health conditions, self-management techniques, treatment guidelines, the health care system, and

insurance coverage. Too often, these materials are difficult to understand. They are often written at the college level, in small print, with a lot of complex medical terminology. The images below provide an example of a consumer education document that is difficult for many people to understand, versus one that is more inviting and understandable to the reader.[26] (See Figure 3.1.)

Figure 3.1
Examples of Difficult Versus Easy to Read Health Information Documents

Difficult to Read | Easy to Read



LET'S *talk about* sexual habits

If good health matters to you, then healthy sex should be at the top of your mind. Research shows that a safe and active sex life may provide a wide range of health benefits. Some studies suggest that sex may boost your immune system. People who have sex on a regular basis tend to be less depressed. As a form of exercise, sex can even help keep your weight down.

THE RESULTS ARE IN

But good sex all the time is a tall order for most of us. Work, kids, and the fast pace of life can keep us busy. But it's important to find the time. Results from a recent study back this up. The Men's Sexual Habits Study looked at a group of over 1,400 men aged 40 to 69. The study showed that men rank sex very high in importance. In fact, only family life, health, and marriage ranked higher.

Despite this high rank, men have sex less often than you might think. On average, men have intercourse only 7 to 8 times a month. Interestingly, these episodes tend to be spread out. In other words, when they do have sex, most men have sex just once in a 24-hour period. For those who do have sex more than once a day, it's typically within a 4-hour period. This means men are more likely to have sex twice in an evening than once in the morning and once at night. Another surprising fact is when men have sex – during the week. Weekends may seem like the ideal time for sex, but the study tells another story. Only about half of men (52%) say their last encounter was on a weekend. So if you and your partner aren't having sex all the time, don't worry. If you're not having sex every single weekend, don't worry. There's nothing wrong with you or your partner. In fact, you're just like most people.

QUALITY VS QUANTITY

Most people can't change the amount of sex they have. So it makes sense to focus on quality. There are plenty of things you can do to improve your love life. Candlelit dinners are great. Bubble baths can be romantic. But many aspects of lovemaking are strictly physical. When it comes to erections, many men can have occasional difficulties. Sometimes it's caused by stress. Sometimes it's caused by medical conditions like diabetes. Some men just want better quality erections. Others would like their erections to last longer. It's sometimes embarrassing for men to talk about. But it shouldn't be. After all, half of all men in the United States over 40 have at least occasional erection difficulties. Fortunately, there are effective therapies to treat these difficulties.

TALKING TO YOUR DOCTOR

can help you learn about treatment options like VIAGRA* (sildenafil citrate). VIAGRA works quickly—in one study most men got an erection in 20 minutes. And it keeps working for at least 4 hours.* This suits most men's lifestyles and sexual habits. And for most patients, VIAGRA won't stay in your body for prolonged periods of time. Some other therapies for erectile dysfunction may stay in your system for many days, even when you no longer need them to work. Talk to your doctor. Together, you can choose a therapy that meets your needs.

VIAGRA is indicated for the treatment of erectile dysfunction (ED). Remember that no medicine is for everyone. If you use nitrate drugs, often used to control chest pain (also known as angina), don't take VIAGRA. This combination could cause your blood pressure to drop to an unsafe level.

Discuss your general health status with your doctor to ensure that you are healthy enough to engage in sexual activity. If you experience chest pain, nausea, or any other discomforts during sex or an erection that lasts longer than 4 hours, seek immediate medical help. The most common side effects of VIAGRA are headache, facial flushing, and upset stomach. Less commonly, bluish vision, blurred vision, or sensitivity to light may briefly occur.

*As found in the sexual habits survey.

Please see Patient Summary of Information on page 23.

21

What You Should Know About Depression

We all feel sad or down from time to time. As part of the normal ups and downs of life, we all sometimes feel:

- Sad
- Frustrated
- Grumpy
- Stressed out
- Tired

But you may have depression if these feelings:

- Last most of the day,
- Occur nearly every day for at least 2 weeks, and
- Keep you from caring about or enjoying life's pleasures

Depression affects men and women of all ages. It may affect you, someone in your family, a friend, or another soldier. It is not a sign of personal weakness. And it is not something you can just snap out of by yourself.

Instead, depression is a common medical condition. And it can and **should** be treated. Without treatment, depression can last for weeks, months, or years. But the right treatment can help most people get better.

What is depression?

"I had an awful day at work. I'm so depressed."

"It's depressing that the weekend is over. I hate Mondays."

"It depresses me to think how few leave days I have left."

We all talk about feeling depressed from time to time. It's normal to feel sad during hard times. Usually, these blue moods go away on their own. But if these sad feelings do not go away, you may have depression.

4 5

SOURCE: Dieter L. Putting clear health communication into action. Aug. 15, 2006; Presentation to NC IOM Health Literacy Task Force. Available from: http://www.nciom.org/projects/health_literacy/08-15-06_Dieter.pdf.

Documents that effectively communicate information must be understandable to the populations they are meant to reach.

Adult literacy experts have created guidelines to ensure health information is understandable to a wide audience. Documents that effectively communicate information must first and foremost be understandable to the populations they are meant to reach. Therefore, they must be written at an appropriate reading level. Across the country, almost half of the population reads at or below an eighth grade reading level.[27] People with low health literacy often have lower reading abilities. 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 at an appropriate level for the targeted audience.

Besides using less complex syntax, it also is important to use plain language in written documents. Plain language means using common words and the active voice. It is written like a conversation and has short sentences. Plain language documents often include a glossary that explains more complicated words that must be included in medical or health information. Another important component of effective written communication is ensuring a document has sufficient white space and margins. Less dense language on a page is more inviting to the eye and less intimidating to the reader. Documents also should use clear and descriptive headings and include pictures and diagrams that help illustrate or explain the written text.

Studies have shown the use of pictures in health information improves consumer comprehension, recall, and adherence.[28] Pictures should be concrete rather than complex. Unnecessary details should be removed from pictures to avoid distraction. Also, pictures should be closely linked to the text or captions that explain them. Both health professionals and consumers should be involved in the design of materials. For example, health professionals should be involved in selecting pictures to ensure accuracy, whereas consumers are needed to ensure materials are understandable.[28]

Adult literacy experts have created guidelines to ensure health information is understandable to a wide audience. These guidelines, adapted from the Center for Health Studies Readability Toolkit,[29] include:

1) write information at an appropriate reading level
2) replace complicated medical or technical words with plain language (when appropriate)[a]
3) use short sentences and short paragraphs
4) write using the active voice
5) use clear and descriptive headings
6) use adequate white space and margins
7) use pictures and diagrams that clarify written concepts
8) focus materials on desired behaviors rather than on medical facts
9) make information culturally sensitive and motivate consumers to take action

Basic strategies such as using plain language, targeting written materials to an appropriate reading level, and using pictures in health information improves consumer understanding.

Pfizer Global Pharmaceuticals, one of the forerunners in the development of plain language medical and health documents, uses similar guidelines in the development of their health education materials. Pfizer developed the Principles for Clear Communication, which serves as a guideline for developing documents that communicate motivating, useful, and understandable information about medical conditions and treatment options.[b] Pfizer also developed an internal review

a It is sometimes necessary to include certain medical terminology in documents, even if the words are above the targeted reading level. For example, it is important the consumer know the word for their underlying medical condition (such as "diabetes"). However, the document also should include definitions of medical or technical words that are used.

b The Principles for Clear Communication include five elements:

1 *Explain the purpose of the document* – Consider the purpose and benefits from the patient's viewpoint, limit content to only what is necessary to know, plan the sequence of topics, and review key points.

2 *Involve the reader* – Create interaction with the reader, emphasize desired patient actions and behaviors, spell out realistic action steps, make it culturally/age/gender appropriate.

3 *Make the document easy to read* – Use active voice and common words, provide examples for difficult words and concepts, put context first, break up complex topics, present each topic in an uninterrupted layout, do not use vertical text, use road signs and chunking, keep paragraphs short and focused on a single topic, avoid long and complex sentences.

4 *Make the document look easy to read* – Avoid reverse type/all caps/italics, use sharp contrast and large font type, include a lot of white space and no dense text, use cueing to direct attention to key points.

5 *Select visuals that clarify the document or motivate the reader* – Select realistic visuals, omit distracting details, use graphics that contribute to the message, use action captions, and explain lists and charts with examples.

process to ensure documents meet the Principles prior to being distributed to consumers. This accountability is integral to the implementation of effective communication principles in all Pfizer documents. Chapter 4 discusses how this same process can be used to guide the development of documents in North Carolina.

Websites

Websites are one of the newest and most popular mediums for distributing health information to consumers. Over time, more consumers have started to use the Internet to access health information. Searching for medical information is the eleventh most popular activity done on the Internet.[30] Websites offer several advantages over traditional written materials. For example, information on websites can be updated by the producer at any time. Additionally, if consumers do not find the information they are seeking from one website, they can access other websites to gather the information. However, this dynamic nature also can be problematic. In many cases, the accuracy and comprehensive nature of the information can vary dramatically across websites. Furthermore, there is no systematic program for evaluating websites.

Websites are one of the newest and most popular mediums for distributing health information to consumers. As such, websites need to employ clear communication techniques, such as plain language, large white space, and few distractions.

A study of health information on websites found websites with health information generally provided about half the information experts felt was critical to specific health topics.[31] Furthermore, locating information using search engines is not very reliable. The study found only 34% of the links found on the first page of search results were relevant to the health topic researched. Problems continue even when a consumer finds a relevant website with useful information. Berland et al. found the average reading level of English-language websites to be at the college reading level. None were found to be lower than the tenth grade reading level. Therefore, it is critical health-related websites follow similar guidelines to the ones recommended for printed written materials. Websites should use plain language, large white space, and bulleted lists. In addition, websites should be written at appropriate reading levels.

However, websites should follow slightly different guidelines with respect to visuals, such as pictures and graphics. Website consumers use computers, browsers, and Internet connections with varying capabilities. Therefore, some consumers cannot view graphics or video as clearly as others. As a result, a small amount of text should be used to describe visuals on a website in case some users cannot or have chosen not to load images.[32]

Information on websites should be presented in a well-organized way, and the number of distractions, such as background patterns and links on the page, should be limited. Furthermore, information telling the consumer who, what, where, when, why, and how should be visible without scrolling down the page.[32] Websites should undergo usability testing that demonstrates the consumer can find needed information without difficulty.

Other Media

Health information also can be shared using other media, such as videotapes, DVDs, audiotapes, and CDs. These forms of communication are generally more easily

understood by people of varying literacy levels. They can be used to communicate health information at many different points in the health care delivery system. An added benefit of using these media is the opportunity to include emotional as well as educational content, which can be beneficial when dealing with sensitive or embarrassing health topics.[32]

Osborne makes several recommendations for improving the understandability of health information delivered through videotapes, DVDs, audiotapes, and CDs.[32] Personal stories are more effective in these media than presentations of complex data and information. Also, the key messages should be limited (generally to no more than five key points), which should each be emphasized at the beginning, middle, and end of the presentation. The tone of the message should engage the audience without being too emotional and the content of the messages should be culturally appropriate for the expected audience(s). The sound and visual quality of the media is also important. Because Osborne's recommendations have not been studied to determine their effectiveness, it is unclear which techniques will produce the greatest improvement in understanding.

Successful interventions should improve outcomes in both low and high literacy individuals and narrow the disparities between low and high literacy groups.

Evidence-Based Models and Promising Practices

Health care practitioners and health services researchers have tested many different types of interventions to improve consumer understanding of health information, change health behaviors, and improve health outcomes. However, only a limited number of these interventions have been studied to determine their efficacy, especially among people with low health literacy. Ideally studies would compare a group of people who receive the intervention (intervention group) to another group who does not receive the intervention (control group). In addition, studies should include individuals of all literacy levels and stratify the interventions by literacy level. This methodology would help identify successful interventions for people with different literacy levels. Successful interventions should improve outcomes in both low and high literacy individuals and narrow the disparities between low and high literacy groups.[6] A review by DeWalt and Pignone found only 20 systematic studies of health and literacy used previously validated instruments to measure the literacy of study participants.[33] Of those studies, few examined whether the intervention was specifically effective in the low literacy population or whether the intervention reduced the disparities in outcomes from literacy differences.

In DeWalt and Pignone's review, more than half (12) of the studies evaluated the impact of interventions on knowledge and comprehension of health materials. The studies had mixed results regarding the impact of interventions on low literate populations. For example, one study found no difference in knowledge from a brochure written at the twelfth grade level compared to a videotape education tool with language at a similar grade level.[34] In contrast, a study found reading materials and a video presented at fifth to sixth grade reading levels increased knowledge compared to a control intervention.[35] Written materials using illustrations can be more effective in imparting knowledge among lower literate individuals than materials with only text.[33]

Some of the studies in the review evaluated the impact of interventions on health behaviors. For example, one study demonstrated improvements in self-care

among patients with educational materials that used photographs, as compared to illustrations. In another study, the introduction of verbal teaching improved medication compliance among older adults, but the use of a color-coded medication schedule did not. An interactive video was found to improve self-care among populations of varying literacy levels.[33,36] In contrast, interventions with low health literate patients focused on dietary behaviors produced small changes, if any, in health behaviors.[33]

Overall, most of the studies on health and literacy indicate interventions aimed at making health care materials easier to understand improve knowledge in populations with low literacy. However, most of these studies did not focus on the impact of these interventions on health outcomes.

Health care interventions aimed at people with low health literacy can have a positive effect on health outcomes.

More recent studies have demonstrated health care interventions aimed at people with low health literacy can have a positive effect on health outcomes. Some of the leading national studies have been conducted at the University of North Carolina at Chapel Hill (UNC-CH). These studies have found disease management programs coupled with educational materials and interventions aimed at people with low health literacy can be very helpful for low literate populations. DeWalt et al. found teaching self-management for heart failure can be effective if the intervention is limited in scope, making it more manageable for the patient.[37] This study used an intervention that included a one-hour individualized education session, an education booklet written below the sixth grade reading level, a digital bathroom scale, scheduled follow-up phone calls, and facilitated access. The intervention reduced the guideline list of information for heart failure patients from 21 topics to six. This program increased patient knowledge about heart failure, self-efficacy, and self-care behavior. Furthermore, it reduced hospital admission rates and the overall death incidence rate among the population receiving the intervention. Notably, the intervention had a greater impact on decreasing hospitalization or death among patients with lower literacy skills.

Another example of an effective intervention is the planned diabetes care program at the University of North Carolina general internal medicine practice.[38] This pharmacist-led program was integrated into the primary care setting. It incorporated the use of a database, patient education, care coordination, phone follow-up, and treatment and monitoring algorithms. The goal was to improve the glucose control of the patient population. A study of the program found improved glucose levels among both the control and intervention groups, but the intervention group's improvement was greater. Notably, within the intervention group, lower health literate patients demonstrated greater improvement in their glucose levels than higher health literate patients. The study found easy-to-read materials were necessary but not sufficient for improving glucose control. It was necessary to involve the patient actively in self-care. Frequent reinforcement and encouragement also was necessary to improve health outcomes.[6]

Health care providers are beginning to understand the connection between health literacy and health outcomes. As noted above, several studies have demonstrated a correlation between health literacy and appropriate use of health services, knowledge of health issues, understanding of health care advice and treatment regimens, and

better health outcomes. We have a growing but limited understanding of how to intervene effectively to address these problems.[36] More research is needed to identify effective communication and support strategies to address the problems faced by individuals with low health literacy.

North Carolina is well poised to assume a national leadership role in this area. Interdisciplinary researchers in the School of Medicine, School of Public Health, School of Nursing, and School of Pharmacy at UNC-CH are involved in some of the leading research in this area, including the congestive heart failure and diabetes studies mentioned previously. Two North Carolina researchers have received prestigious Pfizer National Fellowships or Grants in Clear Health Communications. Several researchers at UNC-CH as well as one at Duke University have received National Institutes of Medicine or Agency for Healthcare Research and Quality funding for work examining the role of health literacy in health outcomes and to develop and test interventions to mitigate the effects of low health literacy.[c] North Carolina adult literacy educators also have developed innovative curricula incorporating health literacy training into their literacy courses. (See Chapter 5.)

North Carolina should develop a Health Literacy Center of Excellence that will assume a leadership role in coordinating and disseminating health literacy information across the state.

North Carolina should develop a Health Literacy Center of Excellence that will assume a leadership role in coordinating and disseminating health literacy information 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 the academic health centers, health professions training schools, North Carolina Area Health Education Centers (AHEC) Program, and health professional associations to educate health professionals about strategies to improve communication skills with individuals of all literacy levels. The Center also would help identify health education materials that have been tested for use with individuals who have low literacy skills. Health education materials that are effective with patients of different literacy skill levels should be available to practitioners throughout the state. The Center would be guided by an Advisory Committee that includes adult literacy experts, publicly funded agencies, collaborating institutions, health professions training schools and associations, private insurers, and consumers. Not only will this group help steer the work of the Center, but it also can be a vehicle for more broad-based dissemination of successful strategies.

Recommendation 3.1

Foundations at state and national levels should develop a competitive process to create a North Carolina Health Literacy Center of Excellence. The Center would work collaboratively with other organizations to

c In addition, Duke University was selected to participate in the National Institute of Health's Clinical and Translational Science Award (CTSA) consortium, and UNC-CH and Wake Forest University Health Sciences received planning awards to help them prepare their CTSA applications. The CTSA consortium is a new consortium of academic health centers charged with translating interdisciplinary health science research into information and treatments that can be used by practitioners and patients in the community.[39] Although the consortium is not focused on health literacy, these universities can apply the skills they use in translating bench science or health services research into more readily accessible information to other areas of health information.

educate health professionals, identify evidence-based guidelines or best practices of health communication, collect and disseminate appropriate health education materials, and otherwise work to address problems of low health literacy throughout the state.

a) The Center should help increase the capacity of health care professionals to communicate more effectively and otherwise address the problems faced by people with low health literacy. Specifically, the Center should work in conjunction with other appropriate organizations to:

   i) review existing and emerging research to identify evidence-based methods of communicating health information and serving people with low health literacy;

   ii) disseminate evidence-based models of health care communication and services for people with low health literacy;

   iii) develop undergraduate, graduate, and continuing education curricula that teach health professionals about the problems of health literacy and evidence-based guidelines or best practices for people with low health literacy; and

   iv) develop expertise in designing health education materials appropriate for people with low health literacy and work with other organizations on "train the trainer" events to help disseminate these skills to state and local agencies, health care providers, and other organizations.

b) The Center should help increase the capacity of adult literacy professionals to address problems of low health literacy. Specifically, the Center should work with adult literacy experts to:

   i) identify best practices in improving health literacy skills and

   ii) develop a health literacy toolkit designed to build literacy and self advocacy skills for use in adult education settings.

c) The Center should identify, collect, and disseminate examples of effective written and nonwritten health information designed to educate consumers with low health literacy about different health conditions and about how to manage health problems. The Center should identify, collect, and disseminate practical tools for providers to evaluate current materials and should provide links to examples of effective health information. These materials and tools should be made available throughout the state to public and private agencies, organizations, and providers through the Area Health Education Centers (AHEC) Program Digital Library and NC Health Info. The Center should develop a process to evaluate or obtain feedback on the usefulness of the materials and tools in providing and evaluating health information.

d) **The Center should evaluate the effectiveness of its dissemination and educational efforts to ensure the Center's collaborative activities are helping improve communication and health services provided to people with low health literacy.**

(e) **The Center shall have an Advisory Committee that includes, but is not limited to, representatives of adult literacy programs and local literacy councils, academic medical schools and other health professions schools, AHEC, North Carolina Department of Health and Human Services divisions and agencies, North Carolina Community College System, health professional associations, health care providers, safety net providers, Community Care of North Carolina, North Carolina State Health Plan, private insurers, and consumers with low health literacy.**

The Health Literacy Center of Excellence can help identify evidence-based and promising practices to better serve patient populations, particularly those with low literacy. These practices have the potential to improve health care quality and outcomes. However, a system is needed to teach providers new communication skills, disseminate best practices, and ensure they are incorporated into practice. Chapter 4 provides guidelines for integrating health literacy into practices and institutions.

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Improving Communication in Current Systems of Care

Chapter 4

Effective provider-patient communication is critical to the overall functioning of our health care system. Yet, few providers are taught how to communicate effectively with their patients. The previous chapter outlined successful strategies to make it easier for people to understand oral, written, and visual health information. Health care providers who employ these strategies will be more successful in communicating complex health information to their patients. These clear communication strategies are important for all health care practitioners, including physicians, nurses, physician assistants, pharmacists, allied health professionals, and health educators. Using clear communication strategies is important whether the health care professional is working with individual patients or involved in population-based health education efforts. Furthermore, everyone —not just those with low health literacy—benefits from the use of these evidence-based clear communication strategies.

Many practitioners are unfamiliar with the concept of low health literacy.

Despite the emerging evidence about effective provider-patient communication strategies, health care providers do not universally use these methods. Many health care providers have little, if any, familiarity with the issue of low health literacy or communication strategies that have been shown to increase comprehension of health information. More outreach and education is needed to ensure health care professionals understand this issue and learn the skills needed to successfully communicate health information to their patients.

Office-Based Practitioners

Most Americans use office-based providers as their usual source of care. More than four-fifths (84%) of people with a usual source of care use an office-based provider as their usual source.[1] However, many practitioners are unfamiliar with the concept of low health literacy.[2] For example, when internal medicine residents were provided case studies suggesting low literacy, less than one quarter of the residents identified low literacy as a potential contributing cause of admission, even when provided clinical clues.[3]

Our understanding of the relationship between low health literacy and health outcomes is relatively new. Thus, providers who completed their training years ago will have had very limited exposure, if any, to this issue. In addition, many recent graduates are limited in their understanding of health literacy and its effect on health. For example, one study that assessed the health literacy knowledge of graduating nursing students found less than half correctly identified the age group with the highest risk of low health literacy, and only 15% correctly identified health literacy—not socioeconomic status—as the more important predictor of health status.[4] Although they may be aware of the issue, recent graduates may lack the skills to assess literacy levels. In another study, approximately 30% of family medicine residents expressed reluctance in assessing literacy in adults out of fear of offending patients, which lends support to advocating a universal approach. Residents actually were more comfortable discussing illicit drug use than literacy

levels.[5] Although there have been numerous calls for increased training and awareness of health literacy among health professionals,[6,7] few examples of health literacy curricula have been developed.[8]

Even those health care professionals who have some understanding of the problem are unable to accurately identify their own patients with low health literacy skills. One study found residents overestimated the literacy skills of patients; more than one third of the patients who the residents perceived to have no literacy problem had low scores on a literacy assessment.[9] Underestimating the prevalence of low health literacy in a patient population may lead some health care practitioners to believe they do not need to worry about the problem or learn new communication skills. Thus, it is important to educate *all* health care providers about this problem. Health care providers need to understand how many people in North Carolina have low health literacy and how low health literacy affects patient knowledge, adherence to treatment recommendations, and overall health status.

Recent changes in professional certification standards, as well as the increased emphasis on measures of quality and outcomes, may help provide incentives for practitioners and health care organizations to implement more effective communication strategies.

Recent changes in professional certification standards, as well as the increased emphasis on measures of quality and outcomes, may help provide incentives for practitioners and health care organizations to implement more effective communication strategies. Some specialty boards, including family medicine, internal medicine, and pediatrics, require that physicians periodically demonstrate continued competence in order to maintain their board certification. Physicians must demonstrate competence in provider-patient communication as part of the maintenance of certification (MOC) requirements.[a] In addition, the Accreditation Council for Graduate Medical Education has made interpersonal and communication skills one of the six competencies for residents.[b,10]

The Joint Commission, which is the predominant standards-setting and accrediting body for health care organizations, recently issued a call to action to improve health communication, especially for people with low health literacy.[11] The Joint Commission recognized providers put patients at risk when they communicate using medical jargon and unclear language. According to the Joint Commission:

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a Internists can complete their MOC requirements by completing the Patient and Physician Peer Assessment Module, which provides performance data obtained from surveys of patients and physician peers regarding humanism, communication, interpersonal skills, and clinical practice.[44] After reflecting on the data, internists have to submit a quality improvement plan. The American Board of Internal Medicine also offers communication modules that use revised physician-level Consumer Assessment of Health Plans Study surveys, which collect patient experiences about practice systems and physician and staff communications. Family physicians must complete a Performance in Practice Module to fulfill their MOC.[45] Beginning in 2007, physicians can satisfy this requirement by completing a Methods in Medicine Module. This module focuses on fundamental skills such as information management and patient communication and includes quality improvement concepts and activities. As part of the program for MOC in pediatrics, physicians must show evidence of satisfactory performance in practice.[46] Beginning in 2008 or 2009, patients will complete surveys that solicit information about their pediatricians' interpersonal and communications skills and professionalism. The surveys are meant to provide meaningful feedback to pediatricians and to give them an opportunity to reflect on their patients' perceptions of their skills.

b To demonstrate competency in this area, residents must be able to demonstrate interpersonal and communication skills that result in effective information exchange and teaming with patients, patients' families, and professional associates. Residents are expected to (1) create and sustain a therapeutic and ethically sound relationship with patients, (2) use effective listening skills and elicit and provide information using effective nonverbal, explanatory, questioning, and writing skills, and (3) work effectively with others as a member or leader of a health care team or other professional group.

> Health literacy issues which go unrecognized and unaddressed undermine the ability of health care organizations to comply with accreditation standards and safety goals meant to protect the safety of patients. The safety of patients cannot be assured without mitigating the negative effects of low health literacy.[11]

The panel of experts appointed by the Joint Commission to examine the problem of health literacy made the following recommendations: make effective communications a priority in protecting the safety of patients; address patient communications needs across the spectrum of care; and pursue public policy changes that promote better communications between health care practitioners and patients. In addition, several of the Joint Commission's National Patient Safety Goals, which are requirements for accreditation, specifically address provider-patient communication issues. The Joint Commission also has launched the Speak Up initiative, a national campaign to urge patients to take a role in preventing health care errors by becoming active, involved, and informed participants on the health care team.

Health literacy training should be incorporated into undergraduate, graduate, and continuing education curricula for all health professionals.

Many payers also are moving towards reimbursement systems that reward quality. The goal of many of these "pay-for-performance" systems is to focus on health outcomes, not merely process measures. If a provider has poor communication skills, his or her patients may have worse quality outcomes, which may reflect poorly on the provider. To the extent quality measures are sensitive to the effectiveness of provider-patient communication, providers have an incentive to use more effective communication strategies.

There are several opportunities to educate providers about these issues. The Task Force recommended a multi-faceted approach that exposes providers to the issue at several points throughout their training and careers. This long-term educational approach will serve to reinforce the key elements of low health literacy, motivate providers to increase their focus on the issue, and expose health care professionals to best practices that can increase their communication with all North Carolinians, regardless of health literacy status.

Recommendation 4.1

a) **Institutions and organizations that train health professionals should incorporate health literacy training into their undergraduate, graduate, and continuing education curricula. Health literacy training should be integrated into existing provider-patient communication classes, condition-specific educational curricula, interpreter or cultural sensitivity courses, clinical rotations, and ongoing continuing education courses. The curricula should provide information about the number of people with low health literacy and how low health literacy affects patient understanding, adherence to medical instructions, and health outcomes. Trainings should emphasize communication skills that enhance consumer understanding of health care information. In addition, training should give providers an opportunity to test and model new communication skills.**

i) **Medical and other health professions schools should incorporate health literacy information into their undergraduate and graduate curricula, clinical rotations, and residency programs.**

ii) **North Carolina community colleges should incorporate health literacy information into their allied health, interpreter training, practice management, and other health-related curricula.**

iii) **The North Carolina Area Health Education Centers (AHEC) program should incorporate health literacy information into their continuing education courses, residency programs, and clinical training in community settings.**

iv) **Professional associations should include information on health literacy in their annual meetings and continuing education curricula.**

b) **AHEC, Carolinas Center for Medical Excellence, Community Care of North Carolina, Division of Public Health, North Carolina Center for Hospital Quality and Patient Safety, North Carolina Community Practitioner Program, safety net organizations, and health professional associations should work collaboratively to help practices and health care professionals effectively implement successful health literacy strategies into their practices.**

Although there is a growing body of literature about effective communication and disease management strategies for people with low health literacy, there are many barriers to integrating these strategies into practice. One of the greatest barriers is the considerable time cost of researching best practices and translating them into daily behaviors. Efforts are needed to make it easier for providers to incorporate effective communication strategies and self-care models into their practices. The Health Literacy Center of Excellence outlined in Chapter 3 would help disseminate best practices to North Carolina providers. A Center specifically charged with evaluating and disseminating best practices in health literacy will enhance the ability of North Carolina providers to increase their portfolio of skills and will give providers materials to increase the quality of provider-patient communication.

Pharmacies

As noted in Chapter 2, medication errors are among the most common medical mistakes that occur in America.[12] The health care delivery system has moved toward increased use of pharmaceuticals. On an average week, roughly 80% of adults take at least one medication and about a third take at least five.[13] With such prevalent use of medications, it is not surprising that high rates of medication errors occur. Medication errors take many different forms, including prescription, dispensing, and patient errors. Research has found patients with lower literacy have poorer understanding of drug labels. Furthermore, even patients who can correctly explain dosage often struggle to demonstrate how to take medication correctly.[14,15]

Drug labels are a primary source of drug information for consumers. However, the content on many of these labels is prone to misinterpretation. For example, "Take two tablets twice a day" is an ambiguous directive. While the provider is trying to

get the patient to take two tablets in the morning and another two in the evening, some people could misinterpret the instructions to mean take one pill at two different times during the day.

Patients with low literacy are three times more likely to incorrectly interpret warning labels on prescription drug packages.[14] Only 8% of patients with low literacy understood the label "for external use only," compared to 82% of people with higher literacy levels. Similarly, only 35% of patients with low literacy levels understood a warning label that stated to swallow whole, compared to 78% of those with higher literacy levels. Consumers also may get consumer medication information (CMI) in the form of package inserts or medication guides, but this information is typically more dense and hard to read. One study found CMI for asthma inhalers was typically not written at a level that would be understandable to a broad audience. For example, the average grade level was 8.2 and the average text size was 9.2. This format is problematic because half of adults read at or below the eighth grade reading level[16] and consumers prefer reading information in a large font size.[17] Instructions for use did not always follow the generally accepted step-by-step directions. In some inserts, the instructions were out-of-order or incomplete (such as failure to direct the patient to hold her breath after operating the inhaler).[18]

Patients with low literacy are three times more likely to incorrectly interpret warning labels on prescription drug packages.

The content of drug container labels is regulated by the North Carolina Board of Pharmacy.[19] The content of other prescription drug information (package insert and medication guides) is regulated by the Food and Drug Administration, and data management companies develop CMI without regulation. Thus, the state has the most direct influence over the content of drug container labels. The North Carolina Board of Pharmacy has a great opportunity to improve the content of drug labels to increase patient understanding.

Currently, research is being conducted to identify key elements of a drug label that will enhance patient understanding. Shrank and his colleagues have conducted a literature review to identify label formats that improve readability and understanding. Research shows patients prefer:[20,21]

- specific directions that avoid vague terminology;
- a list of the benefits of the medication (ie, what the medication is for);
- a list of warnings and possible side effects;
- suggested responses to side effects (eg, when to call a doctor or stop taking the medication);
- how long to take the medication; and
- large font size.

Although there are a few examples of improved drug labels,[c] the common labeling practice often does not coincide with patient preferences or best practices. Using

c Target's ClearRx product places a different color band for each member of the family on pill bottles, prints the instructions in larger and clearer font, and includes a slot for placing consumer medication information so the patient can easily refer to more documentation. The radical redesign of the prescription bottle has received attention in popular media.[47]

data from 85 container labels collected at community pharmacies across the country, researchers found the most visible elements on labels were typically related to the pharmacy, not the medication itself. For example, the average font size of the pharmacy name was 13.2, whereas the average font size on warning stickers was less than half that size at 6.5. Instead of highlighting specific directions or warnings, labels often highlight the pharmacy logo or prescription number. The pharmacy logo was the most common element displayed in color; the prescription number was the most common element displayed in boldface or highlighted. Less than 30% of labels contained a description of the pill. In short, medication labels are generally not patient-centered.

Prescription bottle labeling should be improved to ensure understanding and medication compliance.

To improve understanding and compliance, prescription information must be accurate and the amount of information must be limited. Consumers will be able to understand prescription information materials more readily if the information is standardized and tested to ensure comprehension.

Recommendation 4.2

The North Carolina Board of Pharmacy should develop requirements for oral and written consumer medication information and standard prescription bottle labeling that incorporate evidence-based guidelines or best practices for effective communication of prescription information to consumers. The North Carolina Board of Pharmacy should consult with stakeholders, consumers, and content experts in developing these materials.

Another strategy to increase patient understanding and compliance is to increase the time patients receive in face-to-face consultations. Written materials should be complemented by verbal instruction from practitioners and time for patients' questions. Although patients often receive some counseling when prescriptions are written, instructions on how to take medications or possible adverse side effects may be forgotten once the patient leaves the health care professional's office. Thus, it is important for the pharmacist to offer counseling when the patient is picking up his or her medications. Furthermore, pharmacists may have a better understanding of other drugs a patient is taking. In contrast, an individual physician or practitioner may only know what medications he or she prescribed. As a result, pharmacists may have more complete information to identify potential drug-drug interactions or counter indications.

Pharmacists in every state are required by law to offer patients counseling about their medications.[22] In North Carolina, the pharmacy regulations require pharmacists to offer patient counseling:[d]

> "Patient counseling" shall mean the effective communication of information... to the patient or representative...to improve therapeutic outcomes by maximizing proper use of prescription medications, devices, and medical equipment....
>
> An offer to counsel shall be made on new or transfer prescriptions at the time the prescription is dispensed or delivered to the patient or representative. The

d 21 NCAC §46.2504(a)(b).

> offer shall be made orally and in person when delivery occurs at the pharmacy. When delivery occurs outside of the pharmacy, whether by mail, vehicular delivery or other means, the offer shall be made either orally and in person, or by telephone from the pharmacist to the patient. If delivery occurs outside of the pharmacy, the pharmacist shall provide the patient with access to a telephone service that is toll-free for long-distance calls....An offer to counsel shall be communicated in a positive manner to encourage acceptance.

Despite state regulations that require pharmacists to offer counseling to patients, there are many barriers which reduce the likelihood counseling will occur. Pharmacists are overwhelmed with the increased numbers of prescriptions that need to be filled. From 1991 to 2000, dispensed prescriptions per North Carolina pharmacist increased 56%.[23] In addition, pharmacists have had poor training in counseling techniques.[22] Pharmacists may be further discouraged because they generally are not reimbursed for the time they spend providing counseling.

Despite these barriers to effective pharmacy counseling, there have been some model pharmacy counseling programs that have been shown to increase patient understanding and adherence to prescription drug therapy. For example, the Asheville Project has demonstrated the cost-savings of effective medication therapy management.[24,25] The primary component of the Asheville Project was an enhanced clinical role for community pharmacists. Pharmacists increased their clinical contacts with patients to help them set goals and monitor their health. The project demonstrated both short and long term cost savings for patients with diabetes. Similarly, a study conducted at the University of North Carolina at Chapel Hill found a pharmacist intervention improved adherence to cardiovascular medications of patients with low literacy who had heart failure.[26] The intervention involved pharmacists providing medication management for nine months. Ensuring patients with chronic disease remain compliant with their medication regimens is a challenge, especially among patients with low health literacy. One study found weak evidence that among patients with cardiovascular disease, those with low literacy were less likely to adhere to their medication regimens.[27] Another found lower adherence for patients with low literacy among patients with HIV/AIDS.[28]

With the increased prevalence of chronic conditions in the population and the growing reliance on medications to manage chronic conditions, it is imperative that the state develop new strategies to ensure patients understand how to appropriately take their medicines.

With the increased prevalence of chronic conditions in the population and the growing reliance on medications to manage chronic conditions, it is imperative that the state develop new strategies to ensure patients understand how to appropriately take their medicines.

In order to enhance the ability of pharmacists to provide effective communication to patients, the Task Force recommends:

Recommendation 4.3

a) **North Carolina foundations should fund demonstration projects to test new models of care that enhance the role of pharmacists as medication counselors to ensure patients understand how to appropriately take their medicine. New models should be evaluated to determine whether they enhance patient understanding of medication, improve medication adherence, and improve health outcomes.**

b) **If successful, public and private insurers and payers should modify reimbursement policies to support the long-term viability of these successful models of care.**

Public Programs that Work with Individual Patients

North Carolina, like many states, offers a variety of public programs that address the health care needs of individual patients. Most of these programs are administered through the North Carolina Department of Health and Human Services (NC DHHS) and local public agencies. Although the Task Force did not have enough time to study the literacy efforts of every public program, the Task Force did consider the programs offered by four of the NC DHHS divisions, including Community Care of North Carolina, Division of Public Health, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, and Division of Aging and Adult Services.

- *Community Care of North Carolina (CCNC)* is a statewide Medicaid program that provides services to Medicaid beneficiaries through community-based networks of practices.[e] The goal of CCNC is to improve care and reduce variability across practices through better management of beneficiaries with chronic or high cost medical conditions. Each of the Medicaid beneficiaries enrolled in CCNC has a "medical home" in a primary care practice. Primary care providers, along with case managers, help Medicaid beneficiaries manage their health problems. Currently, CCNC provides disease management education and self-management skills to people with asthma, diabetes, and congestive heart failure. In addition, several of the individual networks have launched other disease management initiatives, including management of chronic obstructive pulmonary disease, mental health problems, obesity, and sickle cell. The activities of each of the 14 networks are directed by local physicians in the community, increasing local provider "buy-in" into the activities and priorities of the network. Since CCNC is a statewide program, it is an effective vehicle for reaching most of the 1.3 million North Carolinians on Medicaid.

  Patient education materials are produced at both state and regional levels. The CCNC program office has produced specialized tools that are available throughout the state. For example, CCNC program office staff have worked with other organizations to produce heart failure management notebooks, educational materials on appropriate use of the emergency department, and asthma self-assessment tools. These materials have been tested for appropriate literacy levels and reviewed by CCNC participants prior to use. Most of the other patient education materials are designed and distributed at the network level. Local network staff design these materials with the goal of being understandable to people with lower health literacy. However, the materials do not always meet the criteria

e CCNC currently provides services to Medicaid recipients through 14 different regional networks. Each network is comprised of primary care providers, hospitals, health departments, social services agencies, and other safety net organizations.

listed in Recommendation 4.4 and are not always reviewed by consumers and families prior to use. All CCNC materials are produced in English and Spanish; some materials exist in other languages (such as Vietnamese or Hmong) depending on local populations. Furthermore, there is no central "clearinghouse" of regionally produced CCNC materials, so multiple networks may develop materials without knowing other networks are working on something similar.

- *The Division of Public Health (DPH)* is charged with ensuring the health of *populations*, rather than the health of *individuals*. In addition to broad-based health promotion and disease prevention efforts, DPH and local health departments provide certain clinical services, including but not limited to oral health screenings for children, family planning and maternity care, well-child services and adolescent health, nutrition services (including Women, Infants, and Children), communicable diseases and sexually transmitted disease control, and screening and referrals for certain chronic health conditions. State and local health departments often employ trained health educators to provide population-based health education, although these health educators may not have been trained in effective ways to communicate with people with lower health literacy. DPH makes a concerted effort to ensure the materials produced are written at between a sixth and eighth grade reading level. Some, but not all, of DPH materials are reviewed by community and consumer representatives. Currently, however the Division does not have uniform guidelines to ensure the materials produced are appropriate for people with lower health literacy. (See Recommendation 4.4.)

  In addition to written community education materials, DPH is increasing its use of social marketing to help the general public understand important health information and engage more actively in their own care. The promotional piece of one such campaign included an award-winning[29] public service announcement ("Lost in Translation"), which depicted a patient who was overwhelmed by the information provided by the health care provider. The message had two aims: to increase patient awareness of cardiac risk factors and to improve provider-patient communication. Specifically, the campaign underscored the need for patients to ask questions when they do not understand what the provider is telling them.

- *The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MHDDSAS)* is responsible for providing or arranging for services for North Carolinians with, or at risk of, mental illness, developmental disabilities, and/or substance abuse problems and their families.[30] MHDDSAS provides written materials, targeted at sixth to eighth grade reading levels. Materials are designed to improve the exchange of information between the service provider and consumer and to more actively engage the consumer in his or her own care.

  The Division does not directly assess literacy levels of consumers. However, MHDDSAS has consumer and family advisory groups review information, provide feedback, and help develop documents. With some services, the Division uses trained peers to convey health care information to consumers.

Trained peers may help make the information more understandable because they are less likely to use professional or medical jargon.

Many consumers in the MHDDSAS system have a difficult time understanding the importance of their medications or other health care needs. Thus, MHDDSAS uses written materials as a mechanism to engage consumers in further discussion, rather than as the primary means of information delivery. As with CCNC and public health programs, MHDDSAS tries to engage consumers so they become more actively involved in their own care.

- *The Division of Aging and Adult Services (DAAS)* and local agencies provide a wide range of health, social services, educational, housing, nutrition, transportation, recreational, and other services to older adults and adults with disabilities. DAAS typically works through local organizations, such as Area Agencies on Aging, Senior Centers, or Departments of Social Services to provide services. Most of the materials DAAS disseminates are produced by other organizations, including but not limited to Alzheimer's Association, American Diabetes Association, and the Centers for Medicare and Medicaid Services. Materials are available on the DAAS website and are distributed through health fairs, senior centers, and other venues. Despite the high percentage of older adults with lower health literacy skills, program specialists at DAAS have not been trained in communication strategies or how to produce materials that are appropriate for people with lower health literacy.

The public organizations outlined here face different challenges in developing materials that are accessible to persons of all literacy levels. Although most of the Divisions conduct some evaluation of the grade level of the written material they provide to the public, communication would be improved by developing a formal, Department-wide standard process for ensuring material is accessible to all North Carolinians. Chapter 3 included the best practices to use in developing written and visual information to ensure health information is understandable to a wide audience. Information should be targeted to the appropriate reading level of the audience, with lots of white space and visuals. The information conveyed should be linguistically and culturally appropriate and involve the reader in their own health care. Ideally, information should be reviewed by consumers and families prior to use, although this review process should not be used to inappropriately delay the development of new consumer education materials.

Barriers to care exist beyond just readability. In addition to addressing patients' clinical needs, understandable consumer education materials also are needed to empower consumers to access needed services. NC DHHS agencies should review other forms and consumer information materials, such as applications, handbooks, and appeal forms, to ensure these materials are understandable.

Based on these guidelines for communicating more effectively through written documents, the NC IOM Health Literacy Task Force made the following recommendations:

Recommendation 4.4

a) The North Carolina Department of Health and Human Services (NC DHHS) should develop standardized criteria to guide the development of all written consumer information materials used by state and locally funded programs. The criteria should be based on adult education principles aimed at ensuring the readability of written materials for people with lower literacy levels. To the extent possible, written materials should:

   i) be written at an appropriate level for the targeted audience;

   ii) be easy to read with a lot of white space;

   iii) include visual materials that motivate the reader or explain the text;

   iv) be linguistically and culturally appropriate;

   v) engage and inspire the reader towards targeted health behaviors; and

   vi) be reviewed by consumers and families prior to use.

b) NC DHHS also should incorporate best practices for website development that include, but are not limited to, the factors listed above.

c) NC DHHS should review other visual or audio patient or community education materials to ensure the materials are linguistically and culturally appropriate and should incorporate best practices for communication in these media. To the extent possible, materials should be reviewed by consumers and families prior to use.

d) NC DHHS should refine the existing review process in each division to ensure materials are understandable for the targeted audience prior to use.

e) NC DHHS and all appropriate divisions and agencies should review their paperwork and procedures to ensure materials and signage do not discourage individuals with low health literacy from obtaining needed assistance.

The North Carolina Department of Health and Human Services should ensure all their materials are understandable for the targeted audience.

Generally, written materials aimed for the general public should be targeted at no greater than a sixth grade reading level. However, a sixth grade reading level may be too high for some target populations (eg, low literate populations or non-native speakers). Thus, materials should be appropriate for the intended audience.

Trained health educators or other staff who understand effective communication strategies for people with low health literacy are needed in state agencies, as well as in local agencies or regional networks. These staff can help educate health care professionals (both public and private), as well as other staff, about effective communication strategies and can help agencies design written and other materials that are understandable to the target audience.

Recommendation 4.5

The North Carolina Department of Health and Human Services (NC DHHS) should ensure there are trained and competent staff in each division who can disseminate health literacy skills and strategies more broadly to health care professionals and others who work with people with low health literacy:

a) Community Care of North Carolina (CCNC) should ensure there is at least one case manager (eg, nurse, social worker, or health educator) in each CCNC network that is competent to teach health literacy skills and strategies and is responsible for disseminating this information to other health professionals and care coordinators in his or her network.

b) The Division of Public Health should ensure there is at least one health educator in each health department who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to other health department staff and local providers of care.

c) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MHDDSAS) and local management entities should ensure there is at least one health educator at the state and local management entities who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to providers of MHDDSAS services.

d) The Division of Aging should ensure there is at least one health educator at the state level who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to Area Agencies on Aging, senior centers, and other organizations serving older adults.

e) Other NC DHHS divisions and agencies that work with health care professionals should ensure there is at least one trained and competent staff person who can disseminate health literacy skills and strategies to other staff and to providers of care at the state and local communities.

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 more broadly to health care professionals and others who work with people with low health literacy.

Written Materials by Private Providers and Health Insurers

In general, health care documents tend to be difficult to read due to their length, complexity, and technical nature.[31] Several studies have examined the readability of medical consent forms. A study of 60 medical consent forms found the average readability of the forms was only slightly lower than readability scores for scientific medical journals and 61% of the forms required college-level reading ability.[32] Another study found the mean reading level of 88 medical consent forms was 13.4 years of schooling.[33] Other types of health information prepared by insurers and health systems, such as insurance forms and explanation of benefits, may be even more difficult to read due to their content and length. The North Carolina insurance laws require materials be produced at no higher than a twelfth grade reading level. N.C. Gen. Stat. §§ 58-38-1, -25, 58-66-1, -25, (1979). However, the state allows

insurers to exclude medical terminology in their assessment of reading levels. N.C. Gen. Stat. §§ 58-38-30 (1979), 58-66-30 (1995). Because of this exclusion, insurance materials are often difficult to understand.

Patients receive health information from other sources as well. Consumer medication information typically is included in a pharmacy's computer system, and therefore the pharmacy has no ability to control its content and format. Likewise, office-based providers may have the capacity to generate consumer information from their electronic health record system. In most cases, these information sheets are included as part of the software and cannot be easily edited by the provider. Thus, providers are limited in their ability to modify materials to make them more understandable, even if they are aware of and concerned about the ability of their patients with low health literacy to understand these materials. Thus, all providers of health-related information, including health-related businesses and electronic health record and software vendors, need to ensure their health-related information is understandable to a broad-group of health care consumers and the information meets the standards for effective communications described in Chapter 3.

All providers of health-related information need to ensure their health-related information is understandable to a broad-group of health care consumers.

Recommendation 4.6

In order to ensure written health care materials are understandable to people with low literacy levels:

a) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other health-related businesses should develop criteria to guide the development of all written consumer information materials. The criteria should be based on adult education principles aimed at ensuring the readability of written materials for people with low literacy levels. To the extent possible, materials should:

i) be written at an appropriate level for the targeted audience;

ii) be easy to read with a lot of white space;

iii) include visual materials that motivate the reader or explain the text;

iv) be linguistically and culturally appropriate;

v) engage and inspire the reader towards targeted health behaviors; and

vi) be reviewed by consumers, families, and other members of the target population prior to use.

b) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other health-related businesses should incorporate best practices for website development that include, but are not limited to, the factors listed above.

c) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other

health-related businesses should establish a review process to ensure all materials are reviewed for understandability prior to use.

c) Public and private insurers and payers, health care systems, and health care providers should review other visual or audio patient or community education materials to ensure the materials are linguistically and culturally appropriate and should incorporate best practices for communication in these media. Materials should be reviewed by consumers and families prior to use.

d) The Department of Insurance should seek changes in existing insurance laws, N.C. Gen. Stat. §§ 58-38-1 *et seq.*, 58-66-1 et seq., to ensure the readability of written insurance materials for people with low literacy levels using the criteria listed in (a) above.

e) North Carolina foundations and other health care funders should give priority to organizational grantees that produce health materials for use by consumers that meet the criteria listed in (a) above.

Disease management programs help people manage their chronic health conditions. These programs have great potential as a way to improve health and reduce health care costs.

Health education materials that meet the criteria for clear communication should be made available to providers throughout the state. As noted in Recommendation 3.1, the Health Literacy Center for Excellence should collect and disseminate these materials and make the materials available through the AHEC digital library and NC Health Info.

Disease Management Programs Offered by Public and Private Insurers

Nationally, 56% of workers covered by employer-sponsored health insurance are enrolled in a plan that offers one or more disease management programs (typically diabetes, asthma, hypertension, high cholesterol).[34] One of the reasons for rising health care costs is the increasing number of people with chronic health conditions.[35] Disease management programs aim to increase a person's ability to manage his or her own chronic illness through better knowledge and awareness of his or her condition and strategies to keep the disease "under control." These strategies may focus on overall health (such as exercise and diet) or be prescriptive (such as how many diuretics a patient with heart failure should take to manage fluid retention). Helping individuals successfully manage their chronic health conditions has great potential as a mechanism for improving health and reducing health care costs.

Many of the state's insurers and payers offer disease management programs. As noted previously, CCNC has built a statewide system of care that focuses on care of Medicaid recipients with chronic illnesses. Yet studies show people with chronic illnesses who have low literacy have less knowledge about their disease[36] and are less likely to comply with their treatment protocols.[7] However, as noted in Chapter 3, disease management programs combined with education materials targeted at people with low health literacy have been shown to improve patient outcomes. These combined strategies improve patient outcomes for all patients but appear to have greater benefits for those with lower literacy.

Some health care institutions or community groups have developed other models to enhance health promotion, disease prevention, and chronic care management among populations with low health literacy. Some models involve lay health educators who

are trusted members of the community who can translate complex medical information into information that is understandable to the target audience. Other models include group training sessions so that individuals can learn from the questions other people with similar health problems ask. (See Chapter 3 for a list of best practices and promising models.) While several models have been identified as "promising," there has not been sufficient research to determine whether these models help improve health outcomes. More research is needed to identify the best practices in improving health knowledge and health outcomes of people with low health literacy.

Recommendation 4.7

The North Carolina Department of Health and Human Services, Community Care of North Carolina, Division of Public Health, public and private insurers and payers should:

a) **incorporate health literacy strategies in their disease management and case management initiatives so that people with all levels of health literacy can benefit and become active managers of their own health conditions;**

b) **use and reimburse case managers, health educators, community health workers, and lay health workers who have been trained in health literacy strategies to help educate people about their health problems and how to manage their conditions; and**

c) **explore the appropriate use of CDs, videos, and other non-print information as a means of better educating people with low health literacy.**

Public and private insurers and payers should incorporate health literacy strategies in their disease management and case management initiatives so that people with all levels of health literacy can benefit and become active managers of their own health conditions.

The current design of our health care reimbursement system is a considerable barrier to the successful development and widespread adoption of new models of care for patients with low health literacy. Payers are reluctant to reimburse services that have not been proven to increase health care quality and reduce costs, and providers are reluctant to incur costs of new delivery models unless they receive revenue sufficient to cover those costs. Thus, new models of care will not be developed and adopted without an identifiable effort and financial commitment on the part of payers to reimburse these health care services that increase patient understanding.

Recommendation 4.8

a) **The Division of Medical Assistance should pilot new reimbursement systems to encourage individual and group education sessions that teach patient self-management using appropriate health literacy techniques. In developing this pilot project, the Division should explore tying reimbursement to health care professionals, case managers, health educators, lay health advisors, or other trained health communicators who have received health literacy training.**

b) **Public and private insurers and payers should consider reimbursing for existing CPT codes or other payment methodologies that pay for individual or group education self-management sessions by health**

professionals, care coordinators, health educators, and lay health providers who have received health literacy training.[f]

One way to improve provider-patient communication is to increase providers' revenues based on effective patient communication. Another way to improve provider-patient communication is to focus on reducing providers' costs due to poor communication. For example, there is evidence primary care physicians who were sued for malpractice had poorer communication skills than primary care physicians who were not sued.[37] For example, physicians who were not sued were more likely to verify a patient's understanding during the visit and encourage him or her to talk. Because effective communication is associated with a lower risk of a malpractice claim, malpractice carriers may wish to incentivize providers to improve their communication skills. These incentives could be operationalized in a variety of manners, such as a reduction in premiums for providers who use effective health literacy strategies to ensure consumers understand their health information or integrating health literacy information into risk management education.

Effective communication is associated with a lower risk of a malpractice claim.

Recommendation 4.9

Malpractice carriers should incorporate health literacy education and effective provider-patient communication skills into their risk management training and should develop systems to reward more effective provider-patient communication.

North Carolina foundations can foster new, promising practices that increase patient understanding and health outcomes. These new practices should be evaluated, and if effective, supported financially.

Recommendation 4.10

a) **North Carolina foundations should fund demonstration projects using promising new models of care in both inpatient and outpatient settings that increase the effectiveness of communication provided to patients with low health literacy. New models should be evaluated to determine if they improve health outcomes.**

b) **Public and private insurers and payers should modify reimbursement policies to support the long-term viability of successful models.**

Population-Based Programs

All consumers should be encouraged to take an active interest in their own care. Yet too often patients are intimidated when they interact with health care professionals. They may be afraid or ashamed to admit they do not understand what their provider

f Coding changes made in 2006 are available at http://www.apta.org/AM/Template.cfm?Section=Coding&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=27186. The new codes regarding education and training for patient self-management (98960, 98961, and 98962) may be an appropriate way to pay for individual or group education self-management sessions. These codes were developed to report educational and training services prescribed by a physician and provided by a qualified, nonphysician health care professional using a standardized curriculum to an individual or a group of patients for treatment of established illnesses or to delay comorbidity. These codes are intended to facilitate the reporting of educational and training services designed to teach patients effective self management of their illnesses.

is telling them.[38,39] Other consumers, especially newer immigrants, may not understand how to access health services, and they may experience language and cultural barriers when seeking care.[40] Still others mistrust information provided by traditional health care providers.[41-43] Therefore, it is important to use multiple strategies to educate consumers about their health. Some of these strategies involve using lay health advisors or other community leaders to provide health education materials in a manner that is understandable to the target population. Health information also can be disseminated through group educational settings (when appropriate) or through other community forums (such as churches, health fairs, etc.). One of the goals of these initiatives should be to encourage consumers to more actively engage in dialogue with their health care providers.

Recommendation 4.11

In addition to disease management, the North Carolina Department of Health and Human Services, health care systems and providers, and insurers should explore other ways of educating patients. For example, these organizations and providers should consider:

a) **expanding the use of trained lay health advisors, case managers, and patient navigators to disseminate health information and to prepare patients and their families for provider-patient interactions;**

b) **using group education settings when appropriate;**

c) **disseminating materials through other forums, such as religious institutions, community fairs, senior games, barber shops, or beauty salons; and**

d) **identifying and implementing outreach efforts to encourage consumers to more actively engage in dialogue with their health care providers.**

It is important to use multiple strategies to educate consumers about their health.

The strategies outlined above focus on how providers and health educators can provide more understandable information to consumers. However, effective communication requires both parties be actively engaged. Unfortunately, many patients feel uncomfortable asserting themselves during discussions with health care providers, or they may be too embarrassed to ask their providers to repeat or clarify what they were told. Consumers need to understand the importance of asking their providers to repeat or clarify information if they do not understand what their providers told them. DPH should expand its broad-based social marketing campaign highlighting the need for consumers to ask questions when they do not understand health information. This social marketing campaign should be disseminated through multiple channels, including but not limited to: the media, religious institutions, community fairs, billboards, barber shops, beauty salons, and senior games. In addition to providing broad public education, the social marketing campaign should provide consumers with the skills and strategies needed to more actively engage in the health system and in self-care. The campaign should be continuously evaluated to ensure its effectiveness in reaching target populations and building consumer skills. Increasing consumer engagement can help mitigate the adverse health impact of low health literacy by ensuring consumers obtain the information needed to manage their health needs.

Recommendation 4.12

The North Carolina General Assembly should provide funding for the Division of Public Health to undertake a broad-based social marketing campaign to activate consumers to engage in dialogue with their health care providers to help mitigate the effects of low health literacy. The Division of Public Health should work with the faith community, safety net providers, and other community leaders and organizations to disseminate this information and to engage these groups as partners in other support activities.

Ultimately, we need to address the problems of low health literacy on multiple levels. Providers should learn skills to more effectively communicate health information and consumers need to learn the importance of asking questions if they do not understand what they are being told. However, the supreme goal should be to improve everyone's underlying literacy levels. To do this requires collaboration with adult literacy experts. Chapter 5 discusses how health professionals can work collaboratively with adult literacy experts to improve the health literacy of North Carolinians.

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Incorporating Health Literacy into Adult Education

Chapter 5

To tackle the problem of health literacy, policies need to address both parties involved in provider-patient communication—improving providers' materials and communication skills and improving patients' reading, verbal communication, and listening skills. Chapters 3 and 4 discussed mechanisms for simplifying and clarifying health information. Those techniques are aimed at the producers of health information: providers, pharmacies, insurers, and public and private health programs. This chapter focuses on the consumers of health information and ways to increase their ability to better understand health information. One way to improve health literacy is to improve the literacy of all Americans through the education system.[1] However, improving the overall education system was beyond the scope of the NC IOM Health Literacy Task Force. Instead, the Task Force focused on ways to improve the health literacy of people with low overall literacy skills.

Synthetic estimates project 52% of North Carolinians would score in the lowest two levels of literacy.

There are no direct estimates of the numbers of North Carolinians with low literacy. "Synthetic estimates"[2,3] project 52% of North Carolinians would score in the lowest two levels of literacy.[4] (See Table 5.1.) Persons who score in the lowest level of literacy can perform no more than the most simple and concrete literacy tasks, such as locating a single piece of information stated in short text, locating or entering specific information on a form, and solving one-step arithmetic questions. For example, individuals who score at this level can sign their name and locate the expiration date on a driver's license. Persons who score in the second lowest level of literacy can perform more challenging literacy activities, such as making simple inferences, integrating information from parts of a document, and locating numbers to solve arithmetic questions. Individuals who score at this level can locate an intersection on a map, identify and enter background information on a social security card application, and total the costs of a purchase from an order form.

Table 5.1
Synthetic Estimates of Adult Literacy: North Carolina, 1994 and 1997

	1994 Estimate	1997 Estimate
Mean Proficiency	268	265
Percent in Level 1	18%	22%
Percent in Level 2	32%	30%
Percent in Levels 3-5	50%	48%
Population 16 and Above	4,970,739	5,203,230

SOURCE: Siedow MD. Literacy in North Carolina. 1998. Available at: http://www.ncccs.cc.nc.us/Basic_Skills/publications.htm.

The Task Force believed incorporating health literacy skills into adult education is the most effective and practical way to begin improving consumers' health literacy. Nationwide, adult education programs serve "hard to reach" populations. In 1992, these programs reached 178,000 disabled adults, 1.2 million immigrants, 1.2 million unemployed adults, more than 469,000 welfare recipients, 297,000 incarcerated adults, and 41,500 homeless adults.[5] Many of these individuals suffer from low

health literacy,[6] and low health literacy is associated with less use of preventive screenings or services, less knowledge of health conditions, increased risk of hospitalizations, and worse health outcomes.[7] As a result, the Task Force believed initial efforts aimed at improving consumers' health literacy should be targeted at the most vulnerable populations. Adult education provides an existing system through which to achieve that goal. Although adult education only reaches a small segment of the population (ie, between 2 and 3 million of the 94 million adults with limited literacy skills), these individuals can bring the skills they learn back to their families and communities.[8]

Incorporating health literacy skills into adult education is the most effective and practical way to begin improving consumers' health literacy.

Adult education programs are meant to educate and train individuals and communities.[9] In North Carolina, one out of every six adults enrolls at a local community college each year.[10] The North Carolina Community College System served 627,993 students through its 58 institutions during the 2005-06 academic year.[a,11] Adult education programs serve people in every county of the state.[9]

The Basic Skills Program within the North Carolina Community College System provides educational opportunities for adults who are out of school.[12] (See Table 5.2.) The mission of the program is to address the needs of adults who do not have a high school diploma or who lack sufficient mastery of basic education skills to enable them to function effectively in society. Classes are free of charge and are offered in a variety of settings and at convenient times. The Basic Skills Program enrolled a total of 135,892 students during the 2005-06 academic year.[11] There are four major component areas of the Basics Skills Program:

Table 5.2
Basic Skills Program

Program	Description	2005-06 Enrollment
Adult Basic Education (ABE)	A program of instruction designed for adults who lack competence in reading, writing, speaking, problem solving, or computation at a level necessary to function in society, on a job, or in the family.	75,793
English Literacy/English as a Second Language (ESL)	A program of instruction designed to help adults who have limited English proficiency achieve competence in the English language.	35,258
General Educational Development (GED)	A program of instruction designed to prepare adult students to pass the GED tests that lead to a high school diploma equivalency.	16,258
Adult High School (AHS)	A program of instruction offered cooperatively with local public school systems to help adults earn an Adult High School Diploma.	6,772

SOURCE: North Carolina Community College System. Basic Skills. Available at: http://www.ncccs.cc.nc.us/Basic_Skills/index.html. Accessed March 1, 2007.

a The mission of the North Carolina Community College System is to provide high-quality, accessible educational opportunities that minimize barriers to post-secondary education, maximize student success, develop a globally and multi-culturally competent workforce, and improve the lives and well-being of individuals.[19]

There also are 28 community-based literacy councils that address the literacy needs of North Carolinians. In general, literacy councils teach adults how to read and write better through the use of volunteer, one-on-one tutors or small group programs. For example, the Literacy Council of Wake County helped 350 adults reach their personal literacy goals last year through 21,500 volunteer hours.[13]

Adult education can play an important role in improving consumers' health literacy, especially in low literate populations. One of the advantages of the community college system and community-based organizations is they can be flexible and adapt to the needs of the local population. The instructors and tutors come from a variety of backgrounds and are adept at meeting diverse learner needs, including those of non-native English speakers. Adult education is an appropriate venue for literacy initiatives because it is usually open entry, provides a friendly environment to learn and practice, employs instructors who have expertise in literacy, and is meant to improve functional skills.[14]

Adult education teachers report students' interest, participation, and motivation is greater when health is the vehicle for education, as compared to other topic areas.

Adult education teachers, state directors of adult education, and basic skills programs all see the benefits of using health issues to teach literacy. In a survey of adult basic educators, over 90% of teachers viewed adult education as an appropriate setting to teach and learn about health issues.[15] Teachers who used health to educate their students reported lessons based on health issues enhanced students' dialogue, discussion, vocabulary, reading, language development, and critical thinking. Teachers reported students' interest, participation, and motivation was greater when health was the vehicle for education, as compared to other topic areas. A national survey of state directors of adult education found respondents believed health is an appropriate topic for adult education both as a content area and as a skills area.[8]

State directors did identify several barriers to incorporating health into adult education: lack of curricula, lack of teacher training and confidence, and time constraints. However, basic skills instructors do not have to be health experts. Instructors can use their experience as patients to try to incorporate health issues into literacy lessons. They also can work with health care experts to design stronger health literacy programs for classes with various skill levels. In addition, health literacy curricula are available through several organizations.[b]

Incorporating health issues into adult education also has benefits for the basic skills programs within the community college system. A focus on health literacy allows basic skills programs to teach literacy skills and improve functional skills at the same time. Many adult basic education programs evaluate student progress using the Comprehensive Adult Student Assessment System (CASAS). To measure students' functional reading, math, listening, writing, speaking, and critical thinking skills, CASAS assesses critical competencies and skill areas related to success in the workplace, community, and family.[16] Health is one of the eight areas in which students have to demonstrate competency. Health care provides a good contextual field to teach literacy because health is an important issue to adults and they may

b For example, health literacy curricula can be found at the following websites: http://www.nald.ca/index.htm, http://www.hsph.harvard.edu/healthliteracy/curricula.html, and http://healthliteracy.worlded.org/teacher-1.htm.

be more motivated to learn about this subject matter. In addition to improving health literacy skills, literacy training also may have a positive impact on the health of low literate populations. For example, adult literacy education lowered depression levels of individuals suffering from depression and low literacy.[17,18]

One local example of incorporating health literacy into an adult education program is Expecting the Best, a program developed for use with English as a Second Language students.[c,14] The curriculum is tailored to the expressed learning needs and interests of non-native English speaking adult learners. The curriculum focuses on skills such as where to access health care, how to make an appointment, how to communicate health concerns, how to understand medicine labels and safety instructions, how to call 911, and how to complete or request help to complete written consents and paperwork. Role-play, dialogue, and stories are used to explain health information and practice health skills. A process evaluation of Expecting the Best found it was most useful if incorporated into an existing curriculum, rather than being taught as an entire semester course focused on health literacy. An outcome evaluation with 177 students in 11 counties showed a significant change among the intervention group in health-related knowledge and skills.

The NC IOM Health Literacy Task Force made the following recommendation to encourage adult literacy programs to incorporate health literacy strategies into their programs:

Recommendation 5.1

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 that provide literacy education should disseminate and incorporate health literacy curricula. The curricula should incorporate evidence-based guidelines or best practices for enhancing health literacy.

a) The curricula should include, but not be limited to:

i) basic information about the US health system and where to go for care;

ii) information about health insurance programs and billing;

iii) information on nutrition and health-related topics; and

iv) tools designed to encourage consumers to more actively engage in dialogue with their health care providers.

b) Teaching resources should include access to best practices through on-line resources.[d]

c A more complete description of the program can be found at www.expectingthebest.org.

d For example, the ESL Virtual Library contains materials for ESL instructors to use in their classroom teaching.[20]

Incorporating Health Literacy into Adult Education

In addition to having adult education programs incorporate health literacy strategies into their programs, the Task Force recognized the need for health care professionals to learn from the experience and expertise of adult literacy experts. Thus, the Task Force recommended the Health Literacy Center of Excellence work collaboratively with experts in adult literacy in identifying best strategies to improve the health literacy of North Carolinians (Recommendation 3.1). Health professionals and adult literacy experts can learn from each other and together can strengthen the services provided to people with low health literacy.

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Conclusion and Recommendations

Chapter 6

Most of the current efforts to improve health outcomes and reduce health care costs depend on an informed health care consumer. However, people cannot make informed health care decisions if they do not understand the health information they receive. The degree to which people understand health information and can successfully navigate the health care system is described as their health literacy. Patients need adequate health literacy to explain their health problems to their providers and to understand the health information they receive. Health care terminology and treatment instructions can be highly technical and complex. Health literacy is critical for understanding prescriptions and warning labels. In addition, patients need adequate health literacy to navigate our complex health system.

Literacy is an essential component of health literacy. Many studies have examined the relationship between literacy and health. People with low literacy are more likely to have difficulty understanding written or spoken medical advice and to suffer adverse health outcomes. They are less able to understand health care information, including their own diagnosis and treatment recommendations. Consequently, they are less likely to comply with their treatment protocols. Over 40% of American adults have basic or below basic literacy, and North Carolina ranks 41st of all the states in basic adult literacy levels. Whereas people with low reading and/or numeracy skills face challenges on a regular basis, nearly everyone has struggled to understand complex health information at some point in their lives. Thus, health information should be communicated in a way that is understandable to people at all literacy levels.

The NC IOM Health Literacy Task Force examined strategies for improving health communications for the benefit of *all* North Carolinians. Some of the Task Force recommendations are targeted to people with low literacy skills. However, most of the recommendations are universal, in recognition that everyone can experience times of low health literacy if faced with stressful health situations or complex health care information. The Task Force set out to identify best practices of communicating health-related information for all populations and to incorporate these practices into existing systems of care. 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. The Task Force also recommended consumers be more actively engaged in ensuring they understand the health information they receive. Consequently, the Task Force recommended a broad-based social marketing campaign to educate consumers and provide them with skills to address this problem. The following are the Task Force's recommendations along with the groups who have the primary responsibility for implementing these recommendations.

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
Effective Communication Practices						
Rec. 3.1. Foundations at state and national levels should develop a competitive process to create a North Carolina Health Literacy Center of Excellence. The Center would work collaboratively with other organizations to educate health professionals, identify evidence-based guidelines or best practices of health communication, collect and disseminate appropriate health education materials, and otherwise work to address problems of low health literacy throughout the state. a) The Center should help increase the capacity of health care professionals to communicate more effectively and otherwise address the problems faced by people with low health literacy. Specifically, the Center should work in conjunction with other appropriate organizations to: i) review existing and emerging research to identify evidence-based methods of communicating health information and serving people with low health literacy; ii) disseminate evidence-based models of health care communication and services for people with low health literacy; iii) develop undergraduate, graduate, and continuing education curricula that teach health professionals about the problems of health literacy and evidence-based guidelines or best practices for people with low health literacy; and iv) develop expertise in designing health education materials appropriate for people with low health literacy and work with other organizations on "train the trainer" events to help disseminate these skills to state and local agencies, health care providers, and other organizations. b) The Center should help increase the capacity of adult literacy professionals to address problems of low health literacy. Specifically, the Center should work with adult literacy experts to:	✓	✓	✓	✓	✓	✓ (Consumers, Adult Literacy Experts, Academic Health Centers, Community Colleges)

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
i) identify best practices in improving health literacy skills and ii) develop a health literacy toolkit designed to build literacy and self advocacy skills for use in adult education settings. c) The Center should identify, collect, and disseminate examples of effective written and nonwritten health information designed to educate consumers with low health literacy about different health conditions and about how to manage health problems. The Center should identify, collect, and disseminate practical tools for providers to evaluate current materials and should provide links to examples of effective health information. These materials and tools should be made available throughout the state to public and private agencies, organizations, and providers through the Area Health Education Centers (AHEC) Program Digital Library and NC Health Info. The Center should develop a process to evaluate or obtain feedback on the usefulness of the materials and tools in providing and evaluating health information. d) The Center should evaluate the effectiveness of its dissemination and educational efforts to ensure the Center's collaborative activities are helping improve communication and health services provided to people with low health literacy. e) The Center shall have an Advisory Committee that includes, but is not limited to, representatives of adult literacy programs and local literacy councils, academic medical schools and other health professions schools, AHEC, North Carolina Department of Health and Human Services divisions and agencies, North Carolina Community College System, health professional associations, health care providers, safety net providers, Community Care of North Carolina, North Carolina State Health Plan, private insurers, and consumers with low health literacy.						

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
Improving Communication in Current Sytems of Care						
Rec. 4.1. a) Institutions and organizations that train health professionals should incorporate health literacy training into their undergraduate, graduate, and continuing education curricula. Health literacy training should be integrated into existing provider-patient communication classes, condition-specific educational curricula, interpreter or cultural sensitivity courses, clinical rotations, and ongoing continuing education courses. The curricula should provide information about the number of people with low health literacy and how low health literacy affects patient understanding, adherence to medical instructions, and health outcomes. Trainings should emphasize communication skills that enhance consumer understanding of health care information. In addition, training should give providers an opportunity to test and model new communication skills. i) Medical and other health professions schools should incorporate health literacy information into their undergraduate and graduate curricula, clinical rotations, and residency programs. ii) North Carolina community colleges should incorporate health literacy information into their allied health, interpreter training, practice management, and other health-related curricula. iii) The North Carolina Area Health Education Centers (AHEC) program should incorporate health literacy information into their continuing education courses, residency programs, and clinical training in community settings. iv) Professional associations should include information on health literacy in their annual meetings and continuing education curricula. b) AHEC, Carolinas Center for Medical Excellence, Community Care of North Carolina, Division of Public	✓	✓	✓			✓ (Community Colleges, Professional Associations, NC Center for Hospital and Patient Safety, Carolina Center for Medical Excellence, NC Community Practitioner Program)

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
Health, North Carolina Center for Hospital Quality and Patient Safety, North Carolina Community Practitioner Program, safety net organizations, and health professional associations should work collaboratively to help practices and health care professionals effectively implement successful health literacy strategies into their practices.						
Rec. 4.2. The North Carolina Board of Pharmacy should develop requirements for oral and written consumer medication information and standard prescription bottle labeling that incorporate evidence-based guidelines or best practices for effective communication of prescription information to consumers. The North Carolina Board of Pharmacy should consult with stakeholders, consumers, and content experts in developing these materials.						✓ (NC Board of Pharmacy)
Rec. 4.3. a) North Carolina foundations should fund demonstration projects to test new models of care that enhance the role of pharmacists as medication counselors to ensure patients understand how to appropriately take their medicine. New models should be evaluated to determine whether they enhance patient understanding of medication, improve medication adherence, and improve health outcomes. b) If successful, public and private insurers and payers should modify reimbursement policies to support the long-term viability of these successful models of care.					✓	✓ (Pharmacists)
Rec. 4.4. a) The North Carolina Department of Health and Human Services (NC DHHS) should develop standardized criteria to guide the development of all written consumer information materials used by state and locally funded programs. The criteria should be based on adult education principles aimed at ensuring the readability of written materials for people with lower literacy levels. To the extent possible, written materials should:	✓					

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
i) be written at an appropriate level for the targeted audience; ii) be easy to read with a lot of white space; iii) include visual materials that motivate the reader or explain the text; iv) be linguistically and culturally appropriate; v) engage and inspire the reader towards targeted health behaviors; and vi) be reviewed by consumers and families prior to use. b) NC DHHS also should incorporate best practices for website development that include, but are not limited to, the factors listed above. c) NC DHHS should review other visual or audio patient or community education materials to ensure the materials are linguistically and culturally appropriate and should incorporate best practices for communication in these media. To the extent possible, materials should be reviewed by consumers and families prior to use. d) NC DHHS should refine the existing review process in each division to ensure materials are understandable for the targeted audience prior to use. e) NC DHHS and all appropriate divisions and agencies should review their paperwork and procedures to ensure materials and signage do not discourage individuals with low health literacy from obtaining needed assistance.						
Rec. 4.5. The North Carolina Department of Health and Human Services (NC DHHS) should ensure there are trained and competent staff in each division who can disseminate health literacy skills and strategies more broadly to health care professionals and others who work with people with low health literacy: a) Community Care of North Carolina (CCNC) should ensure there is at least one case manager (eg, nurse, social worker, or health educator) in each CCNC network that is competent to teach health literacy skills and strategies and is responsible	✓					

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
for disseminating this information to other health professionals and care coordinators in his or her network. b) The Division of Public Health should ensure there is at least one health educator in each health department who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to other health department staff and local providers of care. c) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MHDDSAS) and local management entities should ensure there is at least one health educator at the state and local management entities who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to providers of MHDDSAS services. d) The Division of Aging should ensure there is at least one health educator at the state level who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to Area Agencies on Aging, senior centers, and other organizations serving older adults. e) Other NC DHHS divisions and agencies that work with health care professionals should ensure there is at least one trained and competent staff person who can disseminate health literacy skills and strategies to other staff and to providers of care at the state and local communities.						
Rec. 4.6. In order to ensure written health care materials are understandable to people with low literacy levels: a) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other health-related businesses should develop criteria to guide the development of all written consumer information materials. The criteria should be based on adult education principles aimed at ensuring the readability of written materials for people with low literacy levels. To the extent possible, materials should:				✓	✓	✓ **(Health Care Systems, Academic Institutions, Researchers, Providers, NC Dept. of Insurance)**

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
i) be written at an appropriate level for the targeted audience; ii) be easy to read with a lot of white space; iii) include visual materials that motivate the reader or explain the text; iv) be linguistically and culturally appropriate; v) engage and inspire the reader towards targeted health behaviors; and vi) be reviewed by consumers, families, and other members of the target population prior to use. b) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other health-related businesses should incorporate best practices for website development that include, but are not limited to, the factors listed above. c) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other health-related businesses should establish a review process to ensure all materials are reviewed for understandability prior to use. d) Public and private insurers and payers, health care systems, and health care providers should review other visual or audio patient or community education materials to ensure the materials are linguistically and culturally appropriate and should incorporate best practices for communication in these media. Materials should be reviewed by consumers and families prior to use. e) The Department of Insurance should seek changes in existing insurance laws, N.C. Gen. Stat. §§ 58-38-1 *et seq.*, 58-66-1 *et seq.*, to ensure the readability of written insurance materials for people with low literacy levels using the criteria listed in (a) above. (f) North Carolina foundations and other health care funders should give priority to organizational grantees that produce health materials for use by consumers that meet the criteria listed in (a) above.						

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
Rec. 4.7. The North Carolina Department of Health and Human Services, Community Care of North Carolina, Division of Public Health, public and private insurers and payers should: a) incorporate health literacy strategies in their disease management and case management initiatives so that people with all levels of health literacy can benefit and become active managers of their own health conditions; b) use and reimburse case managers, health educators, community health workers, and lay health workers who have been trained in health literacy strategies to help educate people about their health problems and how to manage their conditions; and c) explore the appropriate use of CDs, videos, and other non-print information as a means of better educating people with low health literacy.	✓			✓		
Rec. 4.8. a) The Division of Medical Assistance should pilot new reimbursement systems to encourage individual and group education sessions that teach patient self-management using appropriate health literacy techniques. In developing this pilot project, the Division should explore tying reimbursement to health care professionals, case managers, health educators, lay health advisors, or other trained health communicators who have received health literacy training. b) Public and private insurers and payers should consider reimbursing for existing CPT codes or other payment methodologies that pay for individual or group education self-management sessions by health professionals, care coordinators, health educators, and lay health providers who have received health literacy training.	✓			✓		

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
Rec. 4.9. Malpractice carriers should incorporate health literacy education and effective provider-patient communication skills into their risk management training and should develop systems to reward more effective provider-patient communication.						✓ (Malpractice Carriers)
Rec. 4.10. a) North Carolina foundations should fund demonstration projects using promising new models of care in both inpatient and outpatient settings that increase the effectiveness of communication provided to patients with low health literacy. New models should be evaluated to determine if they improve health outcomes. b) Public and private insurers and payers should modify reimbursement policies to support the long-term viability of successful models.				✓	✓	
Rec. 4.11. In addition to disease management, the North Carolina Department of Health and Human Services, health care systems and providers, and insurers should explore other ways of educating patients. For example, these organizations and providers should consider: a) expanding the use of trained lay health advisors, case managers, and patient navigators to disseminate health information and to prepare patients and their families for provider-patient interactions; b) using group education settings when appropriate; c) disseminating materials through other forums, such as religious institutions, community fairs, senior games, barber shops, or beauty salons; and d) identifying and implementing outreach efforts to encourage consumers to more actively engage in dialogue with their health care providers.	✓			✓		✓ (Health Care Systems and Providers)

	NC DHHS	AHEC	Health Professions Schools	Public/Private Payers	Foundations	Other
Rec. 4.12. The North Carolina General Assembly should provide funding for the Division of Public Health to undertake a broad-based social marketing campaign to activate consumers to engage in dialogue with their health care providers to help mitigate the effects of low health literacy. The Division of Public Health should work with the faith community, safety net providers, and other community leaders and organizations to disseminate this information and to engage these groups as partners in other support activities.	✓					
Incorporating Health Literacy into Adult Education						
Rec. 5.1. 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 that provide literacy education should disseminate and incorporate health literacy curricula. The curricula should incorporate evidence-based guidelines or best practices for enhancing health literacy. a) The curricula should include, but not be limited to: i) basic information about the US health system and where to go for care; ii) information about health insurance programs and billing; iii) information on nutrition and health-related topics; and iv) tools designed to encourage consumers to more actively engage in dialogue with their health care providers. b) Teaching resources should include access to best practices through on-line resources.						✓ **(Adult Basic Education, English as a Second Language, NC Community College System, Local Literacy Councils)**