



Health literacy and the elderly

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Summary In 2007, approximately 11 million of the 38 million U.S. seniors aged 65 and older lacked the skills required to manage their health. This number will grow as the “baby boomers” age, causing the senior population to reach 71 million by 2030. Studies have shown that individuals with low levels of health literacy are more likely to be hospitalized and have worse disease outcomes than their health-literate counterparts. A patient’s inability to effectively communicate with a healthcare provider decreases health care access, increases cost and compromises quality of care. Health literacy needs to be addressed by physicians and other healthcare providers in health literacy pilot programs, as well as by legislation at the federal level.

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Introduction

A 2004 Institute of Medicine report, “Health Literacy: A Prescription to End Confusion,” reported that 90 million people lack the “capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,” even though a majority are native-born English-speaking adults.^{1,2} These patients may not be able to read appointment information, understand how to take their medications, or be able to complete medical forms.³ Patients’ lack of ability to effectively communicate with health care providers decreases health care access, increases cost, and compromises quality of care.

Adults with limited health literacy report having a poorer health status.⁴ They are less likely to use preventive services and have less knowledge about disease management.^{1,5} They are more likely to be hospitalized and have worse disease outcomes and higher mortality rates.⁶ Because of inadequate health literacy, adults may not be aware of health

services available to them or be able to complete the paperwork required to have access to services.⁷

There is a strong inverse relationship between health literacy and increasing age.² Lack of health literacy makes the elderly particularly vulnerable because older adults are more likely to have chronic health conditions.⁸ According to the 2003 National Assessment of Adult Literacy (NAAL) report, 29% of adults age 65 and older had below-average basic health literacy.⁹ Based on this ratio, of the estimated 38 million seniors in the United States in 2007, approximately 11 million currently lack the skills they need to manage their health, and that number will grow as the “baby boomers” age and the senior population reaches 71 million by 2030.¹⁰ Health literacy needs to be addressed by physicians and other health care providers in health literacy pilot programs, as well as by legislation at the federal level.

Background

Impact of lack of health literacy

Health literacy is affected by an individual’s age and education.¹ The results of the 2003 NAAL report showed

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that a great proportion of adults over age 65 had lower-than-average health literacy skills than younger adults.⁹ The same assessment showed that fewer seniors had intermediate and proficient health literacy skills compared with younger adults.⁹ A 1997 study of managed care Medicare enrollees indicated that 15.6% of individuals aged 65 to 69 had inadequate health literacy, and more than half (58%) of individuals age 85 and older have trouble understanding health information.¹¹ Adults aged 85 and older are a fast-growing group in Medicare; between the years 1990 and 1996, the growth in population for those aged 85 and older averaged 3.4% per year, whereas the growth for ages 65 to 84 was 1.1% per year.¹²

There is a disparity between the need for high health literacy demands of the health care system and the limited skills of older patients.¹³ Many of the elderly have failing eyesight, decreased hearing, declining mental alertness, a decrease in reading ability because of declines in cognitive function, decreases in sensory ability, and a longer time interval since their formal education.^{3,14} Many patients may not be aware of their inadequate health literacy. Others are aware but are ashamed to admit to it and so they hide it;³ this shame may be a barrier to improving health literacy.¹ Patients might not seek health care for fear of rude or disrespectful treatment by staff because of problems with reading and completing forms or the inability to navigate health care facilities.¹⁵ Signs of problems with health literacy may include postponement of decision-making, noncompliance with medications, not being accompanied by someone who can read, not adhering to recommended interventions, and making excuses such as “I forgot my glasses.”³

There is a strong association between literacy and education; nevertheless, research shows there is a three- to five-grade difference between the number of years of education and reading level.^{11,16} Many high school graduates are illiterate.³ A study showed that participants stated they had a high school education or higher but were found to have inadequate health literacy.¹¹

Chronic medical conditions require more health literacy demands.² About 80% of American seniors have one chronic health problem, and half have at least two health problems.⁸ Senior citizens use two to three times more medications than the general public, but seniors have been found to be less likely to interpret prescription warning labels correctly.¹⁷ A study by Davis et al. found that “low literacy is related to limited understanding and misinterpretation of warning labels and therefore may be a factor in unintentional non-adherence and therapeutic failure.”¹⁸ The study also mentioned that incomplete understanding of warning labels could be a contributor to hospital admissions secondary to medication misuse.¹⁸

Patients who are better informed about their options have better outcomes than those who are not informed. A study involving diabetic patients showed that lack of health literacy was independently associated with worse blood sugar levels and higher rates of complications, including retinopathy.¹⁹ Another study of diabetic patients showed that health outcomes

improved significantly (lower HbA1c levels) when health literacy was addressed.²⁰

Studies have shown that individuals with lower levels of health literacy are more likely to be hospitalized and have worse disease outcomes.⁶ The National Academy on an Aging Society reported that in 1994, adults with low health literacy skills who stayed overnight in a hospital averaged 6% more hospital visits and two-day longer hospital stays than adults with higher health literacy skills.²¹ Studies of enrollees in a managed care Medicare program showed increased mortality and increased medical costs for emergency department visits and inpatient care within the low-health-literacy group.²² Limited literacy was found to be independently associated with a nearly two-fold increase in mortality in an elderly population.¹³

Another study of Medicare enrollees found less use of preventive services among a group that lacked health literacy.⁵ Mistrust, fear, or poor communication with health care organizations may be some reasons why older patients with limited health literacy have decreased access to preventive services.⁴ Out-of-pocket costs rise as well. The 2007 National Advisory Committee on Rural Health and Human Services (NACRHHS) found that Medicare beneficiaries who subscribed to Medicare Advantage had unnecessary supplemental insurance premiums because they did not understand their health plan.²³

Patients' lack of understanding—especially about effective management of chronic disease—drives up costs. Treatment of chronic disease cost \$510 billion in 2000 and is projected to cost more than \$1 trillion in 2020.² The nation's health care spending will increase by 25% in 2030 because the cost of health care for older Americans is three to five times greater than for Americans younger than 65.²⁴ A report showed that low functional literacy resulted in an estimated \$32 to \$58 billion in additional health care costs in 2001.²⁵ According to a report released in October 2007 by the University of Connecticut, the cost of low health literacy is between \$106 and \$236 billion annually (based on data from the 2003 NAAL health literacy survey, 2006 US Census Bureau, and Medical Expenditure Panel Survey [MEPS]).^{26,27} Much of the expense is borne by Medicare and Medicaid. The National Academy on an Aging Society reports that Medicare pays 39% and Medicaid pays 14% of the additional expenditures as a result of low health literacy.²¹

Stakeholders

From where should the funding for health literacy programs and studies come? In June 2006, the Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations) and Joint Commission Resources hosted a national symposium on health literacy and patient safety. Information gained from the symposium contributed to the content of the white paper, “What Did the Doctor Say? Improving Health Literacy to Protect Patient Safety.”²⁸ Some of the recommendations in the report included: reimbursement by Centers for Medicare and Medicaid Ser-

vices (CMS) and private insurers for patient education in physician offices be broadened beyond diabetes.²⁸ Pay-for-Performance by CMS and private insurers may provide incentives to encourage patient-centered communication.²⁸ However, pay-for-performance also may encourage health care providers to avoid patients who have decreased health literacy.²⁸

Poor provider-patient communication contributes to rising medical litigiousness.^{29,30} Health care professionals and hospitals have been held liable for poor outcomes when patients did not understand important health care information.³¹ Improvement in health literacy should help decrease errors and miscommunication between patients and health providers and decrease liability. An increase in the number of medical liability insurance companies that offer premium discounts for physicians who attend educational seminars on health literacy and patient-centered communication methods may be beneficial.²⁸

Improving health literacy

Current ways of addressing health literacy include: screening for patients' health literacy, lowering the reading level of educational information, using pictures to help educate patients, decreasing the use of medical jargon by health professionals by using plain(er) language, and using the Partnership for Clear Health Communication Ask Me 3TM and the American Medical Association's (AMA's) *Teach Back* method and *Toolkit*.³²⁻³⁴

Health literacy can be screened using the three-minute Rapid Estimate of Adult Literacy in Medicine, which measures a person's ability to read medical words.³⁵ The 18- to 22-minute Test of Functional Health Literacy in Adults (TOFHLA), or the seven- to ten-minute STOFHLA (shortened version of TOFHLA), tests reading comprehension and numerical skills using hospital materials.³⁵ Both are available in English and Spanish. A new three-minute test marketed as the Newest Vital Sign (NVS) asks six questions based on information on a nutritional label; two or more incorrect answers indicate limited literacy.³⁵ NVS is comparable to TOFHLA in identifying low literacy.³⁵

It appears that most states have recommended reading level guidelines for written Medicaid materials ranging from third grade to eighth grade (Table 1).³⁶ However, the responsibility of health literacy compliance for Medicaid varies from state to state. Currently, the mean grade reading level of patient education materials, informed consent forms, and insurance forms range from grades 9 to 11.^{3,37} The format of patient education information could be changed to be short, clear, simple, include pictures, and be written at a sixth grade or lower level.^{3,38}

Partnership for Clear Health Communication (PCHC) at the National Patient Safety Foundation (NPSF) is a non-profit organization comprised of a coalition of 400 organizations whose mission is "to build awareness and advance solutions to improve health literacy and positively affect health outcomes."³⁹ PCHC introduced the Ask Me 3TM pro-

Table 1 Reading level requirements for Medicaid materials

| | |
|---------------|---|
| No data | Alabama |
| No guidelines | Indiana, Mississippi, North Dakota, South Dakota |
| 3rd grade | Arkansas |
| 4th grade | Florida, Kansas, Nebraska, Ohio, Pennsylvania, South Carolina, Wyoming |
| 5th grade | Washington, D.C., Idaho, New Jersey |
| 6th grade | Alaska, Arizona, Colorado, Delaware, Georgia, Hawaii, Iowa, Illinois, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, Montana, Nevada, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont, Virginia, Washington, West Virginia, Wisconsin |
| 4th-6th grade | California, New York, Texas |
| 7th grade | Connecticut, Minnesota |
| 5th-7th grade | Utah |
| 6th-8th grade | North Carolina |

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gram, which promotes communication between patients and health care providers.¹ Some of the organizations participating in the PCHC include national and state medical associations and societies (AMA, Medical Society of the State of New York); Nursing and Pharmacist Associations (American Nurses Association, American Pharmacists Association); health-related foundations (Robert Wood Johnson Foundation); hospitals and clinics and associated organizations (Mayo Clinic-Rochester, American Hospital Association, the Joint Commission on Accreditation of Healthcare Organizations); associations for geriatric populations (Aging America Resources, National Academy on the Aging Society, American Geriatrics Society Foundation for Health in Aging); pharmaceutical companies (AstraZeneca, Pfizer); health insurers (Aetna, Health Plan of Michigan, various state BlueCross/BlueShield); and health literacy organizations (Health Literacy Foundation, Florida Literacy Coalition, Plain Language and Culture).⁴⁰ The organization's agenda includes increasing the awareness of the "importance of clear health communication (and) to provide training, targeted education, coaching and materials to people who have the most patient interface, and to advocate for clear health communication and increased health literacy resources."⁴¹

The Partnership for Clear Communication program encourages patients to ask their clinician three questions during their visit:

What is my main problem?

What do I need to do?

Why is it important for me to do this?³⁹

The AMA's *Teach Back* method involves asking patients to repeat what they were just told to ensure they understand. Joanne G. Schwartzberg, MD, Director of the Program on Aging and Community Health at the AMA, explains that it is not enough for patients to understand the information—they must act on it. She explains the *Teach Back* method helps providers to determine “whether patients are ready and able to be confident and capable self-managers.”⁴²

The AMA Ethical Force program has also developed a toolkit that “features short, easy-to-understand patient surveys as well as surveys intended for executive leadership and clinical and non-clinical staff.”⁴³ According to the AMA website, the toolkit, funded by a four-year, \$688,000 grant from the California Endowment, is being used by nine hospitals and physician practices around the country to help them assess how well they communicate with patients. “It’s important that the clinic as a whole sees how it communicates with patients,” said Kelly S. Bossenbroek, MD, a family physician at a Meriden, Connecticut health center that is part of the 11-clinic Community Health Center Inc. involved in field-testing the toolkit. “Unless you have actual data, you can’t tell if you’re getting better and you don’t necessarily know where your problem areas are. That makes it difficult to make improvements.”⁴³ Cost of the toolkit ranges from \$250 to \$5,500.⁴³

The Iowa Health System (IHS) Health Literacy Collaborative was started by IHS in 2003 and is comprised of 10 large hospitals in seven cities, 14 rural hospitals, and 430 primary care physicians in more than 30 Iowa communities.⁴⁴ The *Teach Back* and *Ask Me 3™* methods are used.⁴⁵ Patient satisfaction surveys increased during the intervention time.⁴⁶ In 2004 through 2006, Oklahoma’s Medicaid program, Sooner Care, identified patients who were frequently using the emergency department for nonemergency conditions.⁴⁷ Registered nurses used as exceptional needs coordinators contacted and educated this group of patients regarding the use of the emergency department and the need to follow up with primary care providers. As a result of this initiative (SoonerCare Emergency Room Utilization Project), there were fewer emergency department visits, fewer inpatient hospitalizations, and a savings of more than \$1 million.⁴⁸

Health insurers could follow the example of BlueCross/BlueShield of Rhode Island, who started the Rhode Island Health Literacy Project (RIHLP) to address health literacy.⁴⁹ The organization includes Brown University, Quality Partners of Rhode Island, Hospital Association of Rhode Island, Rhode Island Medical Society, Rhode Island Department of Health, Rhode Island Department of Human Services, Rhode Island Health Center Association, Rhode Island State Nurses Association, and others.⁴⁹ The RIHLP provides a free toolkit that includes the *Ask Me 3™* and *Teach Back* methods, as well as information to improve communication about advance directives, health care proxy, and powers of attorney.

Federal aid would be of immense assistance in addressing health literacy on a national level. In the 110th Congress, The National Health Literacy Act of 2007 was intro-

duced. If the bill had been passed, it would have ensured that all Americans have basic health literacy skills to function effectively as patients and health care consumers.⁵⁰ It would have amended the Public Health Service Act by requiring the Director of the Agency for Health Care Research and Quality to establish a Health Literacy Implementation Center that would improve measurement, research development, and information dissemination to enhance efforts to eliminate low health literacy. The proposed Center would have:

- made health literacy resources available to researchers, health care providers, and the public;
- sponsored demonstration and evaluation projects;
- developed the next generation of health literacy interventions and tools;
- identified and filled research gaps relating to health literacy that have direct applicability to quality improvement;
- assisted federal agencies in establishing specific objectives and strategies for carrying out the Center’s purpose and in monitoring programs;
- entered into implementation partnerships to promote adoption of literacy interventions and tools; and
- entered into an interagency agreement to facilitate coordination of health literacy activities within the Department of Health and Human Services (HHS) and the Department of Education (DOE).

The bill would have required that the Center assemble at least one annual public meeting to promote awareness of the health literacy problem and of federal and state efforts to address the issue. States would have been awarded grants by the Director of the Center to establish health literacy resource centers. There would have been state health literacy resource centers to meet and share best practices models. The Health and Human Services Secretary and Institute of Medicine would have been jointly responsible for identifying opportunities within HHS to improve the public’s health literacy through the Food and Drug Administration (FDA) and Medicare and Medicaid programs.⁵¹

Recommendations

Health literacy can be thought of as “the currency” required to navigate the health care system.⁵² Health care in America is characterized by technological sophistication and increased consumerism that requires a high level of health literacy.² Patients are encouraged to take on more responsibility for their health, but one of three senior citizens do not have the health literacy skills to do so.

The elderly are a particularly vulnerable population because they are more likely to have chronic diseases that require a higher level of health literacy and have age-related diminishment in visual, auditory, and cognitive functions that contribute to the problem. The lack of comprehension of health coverage and/or medical care leads to higher

unnecessary medical costs that are incurred by the patients and health care carriers of the elderly such as Medicare.

How can the health literacy problem be addressed in the elderly population? Both the problem and possible consequences need to be acknowledged by the health care industry, including health care providers and their ancillary staff. Improvement of health literacy is a combination of community-based and patient/health care provider efforts.

Using pictures, enlarged print, and reducing the reading level of medical literature (handouts and signage found in hospitals, medical offices, and clinics) to sixth grade or lower would help patients with limited health literacy. If medical terminology is used, the layman's term should be listed with it, e.g., hypertension (high blood pressure) or ENT (ear, nose, and throat specialty).⁵³ Televisions in waiting rooms could show videos on medical topics or nutrition that would be appropriate for the patient population.

The importance of communicating to patients, especially the elderly, should be taught in medical and health professional school and continue through postgraduate training to practice. A combination of the *Teach Back*, *Ask Me 3*TM, and *Plain Language* methods would be ideal because they complement each other. Professional organizations and hospitals should be encouraged to have continuing education programs on health literacy for their members/employees to improve patient communication.

The burden of improving health literacy must be shared by patients, who should not be afraid to say "I don't understand" and/or ask "please explain this to me" to health care workers and also seek information on their own. Medicare should continue offering funding to programs that advise seniors about Medicare Part D, as done recently.⁵⁴ If possible, Medicare should also offer funding for outreach programs to educate seniors about health care including preventive health at senior citizen centers, hospitals, places of worship, and other interested groups. Tutorials on accessing health information on the Internet would also help because reliable information is available if the person knows how to access it. This could be accomplished through workshops at libraries and senior citizen centers.

Expansion of Medicare reimbursement for patient counseling for diagnoses other than diabetes mellitus may provide incentive for health care providers to spend the extra time with patients. Medical liability carriers could provide courses on health literacy and discounts on insurance premiums for participants enrolled in the courses. Patient surveys such as the AMA Ethical Force Program Toolkit could be used to access patient/health care provider communication.

Radio and television could be used to promote health literacy as public service announcements or programs. Health-related information could be placed in public waiting areas and pharmacies and also given out to people waiting for various things, e.g., for jury duty selection.

Federal funding for health literacy efforts would help ensure that the problem is addressed in all states. It would also provide financial support for pilot programs to establish which tools are most effective; whether it is necessary and

cost effective to screen all, some, or no patients' health literacy with a particular test; and to uncover any other pertinent information relating to improving health literacy. It may also be important to include studies that take into consideration the highest demographic locations of seniors. If a bill similar to the National Health Literacy Act of 2007 would become law, in addition to funding, there would also be a centralization of the information regarding health literacy students to be used nationally.

The problem of inadequate health literacy and the elderly is a health policy problem that should be acknowledged and addressed through the joint efforts of patients and the health care industry.

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