

Limited English Proficiency and Low Health Literacy¹

Two Barriers to Quality Health Care

“Limited English proficiency” (LEP)² and “low health literacy”(LHL) ”are two barriers to an individual’s ability to obtain, process, and understand basic health information necessary for navigating the health care system, making reasoned health care decisions, and maintaining health. With LEP, the barrier affects individuals whose native language is not English and who do not understand English well enough to navigate an English-speaking health care system. With LHL, the barrier rests in the lack of understanding one’s native language well enough to navigate the health care system in that language.

Many LEP individuals, already at a distinct communication disadvantage in the English language, must also contend with low health literacy and lack of oral communication skills in their native languages. It is at this juncture--the point where LEP and LHL in one’s native language meet in the same individual--that translated materials may be too complex in presentation, writing style, and vocabulary for individuals with low-levels of functional literacy in their native languages. Similarly, in order to assure appropriate oral communication, interpretation must also consider oral skill level.

Health Literacy and the CMS Beneficiary Population

Although health literacy problems affect people from all backgrounds, older people, non-whites, immigrants and those with low incomes are disproportionately more likely to have trouble reading and understanding written information. In significant part, these are the very populations who rely primarily on Medicare, Medicaid, and the State Children’s Health Insurance Program for their health care.

The 1992 National Adult Literacy Survey³ (NALS) found that approximately 65 percent of adults age 60 and over have inadequate or marginal reading skills. Minorities surveyed in the 1992 NALS disproportionately suffered from inadequate or marginal reading skills.⁴ (About 50 percent of Hispanic and 40 percent of African American respondents.) Approximately 75 percent of Americans who reported having a long-term illness (six months or more) also were found to have limited literacy. Although the

¹ CenterPage has previously published articles on limited English proficiency: Spring 2003 and Fall 2003.

² LEP individuals are those who do not speak English as their native language and who have a limited ability to read, write, speak and understand English.

³ Kirsch J, et al. *Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey*. U.S. Department of Education, 1993. The NALS did not include health-related items, and it is unclear how many elderly people in the general population have inadequate health literacy.

⁴ Of the ninety million Americans projected by NALS to have limited literacy, about 15 percent were born outside the country. Although the majority of adults with poor literacy skills are white, native-born Americans, language differences, cultural barriers, and different educational opportunities place the growing populations of minorities at relatively higher risk for low literacy.

NALS did not measure health literacy, the implication from this finding is that low literate individuals know less about their health conditions or how to handle symptoms.⁵ Moreover, the data in the report showed that the likelihood of being on welfare increased as literacy levels went down. About three out of four recipients of public assistance, food stamps, and Aid to Families with Dependent Children were at the lowest levels of literacy.⁶

A Brief Look At Low Health Literacy

*Healthy People 2010*⁷ defines health literacy 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.” In a seminal 1999 article reviewing health literacy peer-reviewed articles and initiating a “call for action,” the American Medical Association’s Council of Scientific Affairs (CSA) defined *functional* health literacy as “a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment.”⁸ The definitions are compatible.

The CSA concluded that there was a disparity between the skills needed for adequate health literacy and the literacy skills of many Americans. The article identified health literacy as a critical health care issue and presaged inclusion of health literacy in *Healthy People 2010* and the formation of an Institute of Medicine panel on health literacy. Notably, the panel’s report is in its final drafting stage.

The article reviewed numerous studies documenting the fact that health materials, such as patient education brochures, discharge instructions, contraception instructions, and consent forms, are often written at levels exceeding patients’ reading skills. As we now know, people with low health literacy are less likely to (1) understand written and oral information given by government agencies, health care organizations, insurers, and physicians and other health care providers; (2) act upon necessary procedures and directions such as medication and appointment schedules; and (3) be able to navigate the health system to obtain needed services.⁹

Two studies deserve separate mention. A study of 979 emergency department patients with inadequate health literacy, 81 percent could not read the rights and responsibilities

⁵ The 2003 NALS survey, which may still be in the field, includes questions related directly to health care, including Medicare. Inclusion was the result of CMS’ staff working directly with Health and Human Services’ staff to influence the Department of Education’s selection of survey questions.

⁶ Barton PE, et al. “Literacy and Dependency: The Literacy Skills of Welfare Recipients in the United States.” 1995: Policy Information Center, Educational Testing Service, Princeton, New Jersey.

⁷ U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion.

⁸ American Medical Association. “Health Literacy Report of the Council on Scientific Affairs,” *Journal of the American Medical Association*, 1999; 281:552-557.

⁹ See, for example: Gazmarian JA, et al. “Health Literacy Among Medicare Enrollees in a Managed Care Organization.” *Journal of the American Medical Association*, 1999; 281:545-551; Hopper KD, et al. “The Readability of Currently Used Surgical/Procedure Consent Forms in the United States.” *Surgery*, 1998; 123(5); Davis TC, et al. “Knowledge and Attitude on Screening Mammography among Low-Literate, Low-Income Women.” *Cancer*, 1996; 78(9); and Baker DW, et al. “The Health Care Experience of Patients with Low Literacy.” *Archives of Family Medicine*, 1996; 5:329-334.

section of a Medicaid application and 74 percent did not know if they were eligible for free care.¹⁰ A second study, measuring functional health literacy at a public hospital, found that 81 percent of English-speaking patients aged 60 years or older had inadequate health literacy; e.g., they could not correctly read such basic items as prescription drug bottles and appointment slips.¹¹

On the other hand, people with low health literacy are more likely to (1) receive health care services through publicly financed programs, even after controlling for such factors as age, education or socioeconomic status; and (2) incur higher health care costs.¹² (A study of Medicaid patients found those reading below the third grade level had average annual health care costs four times (\$12,974 compared with \$2,969) those of the overall Medicaid population!¹³)

Low Health Literacy Is Bad For Your Health

Poor health status is disproportionately high among patients with low functional health literacy even after adjusting for socio-economic and other demographic factors. For example, a study in general medical clinics at two public hospitals evaluated 402 patients with hypertension and 114 with diabetes mellitus and found patients' functional health literacy (measured in English or Spanish) strongly correlated with knowledge of their illness. Among patients with diabetes, only half of those with inadequate literacy knew the symptoms of hypoglycemia compared with 94 percent of patients with adequate literacy. Similarly, fewer patients with hypertension and inadequate literacy knew that blood pressure could be lowered with weight loss and exercise.¹⁴

A study of 212 low-income men found that low literacy was a better predictor than race or age for patients with advanced prostate cancer.¹⁵ The study concluded that low literacy presented a significant barrier to the diagnosis of early-stage prostate cancer among low-income white and black men.

In another study in which the test was administered in both English and Spanish, among primary care patients with Type 2 diabetes, inadequate health literacy was found to be independently associated with worse blood glucose control and higher rates of retinopathy. Inadequate health literacy was noted as contributing to the disproportionate

¹⁰ Baker DW, et al. "The Relationship of Patient Reading Ability to Self-Reported Health and Use of Health Services." *American Journal of Public Health*, 1997; 87:1027-1030.

¹¹ Williams MV, et al. "Inadequate Functional Health Literacy among Patients at Two Public Hospitals." *Journal of the American Medical Association*, 1995; 274: 1677-1682.

¹² Weiss BD, et al. "Communicating with Patients Who Cannot Read." *New England Journal of Medicine*, 1997; 337:272-274.

¹³ Weiss BD, et al. "Illiteracy among Medicaid Recipients and its Relationship to Health Care Costs." *Journal of Healthcare for the Poor and Underserved*, 1994; 5:99-111.

¹⁴ Williams MV, et al. "Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease: A Study of Patients with Hypertension or Diabetes." *Archives of Internal Medicine*, 1998; 158:166-172 and "Inadequate Functional Health Literacy Among Patients at Two Public Hospitals." *Journal of the American Medical Association*, 1995; 274:1677-1682.

¹⁵ Bennett CL, et al. "Relationship Between Literacy, Race and Stage of Presentation Among Low-Income Patients with Prostate Cancer." *Journal of Clinical Oncology*, 1998; 16:3101-3104.

burden of diabetes-related problems among disadvantaged populations.¹⁶ Patients with inadequate health literacy were more likely than patients with adequate health literacy (1) to be older, female, non-white, and Spanish-speaking, (2) to have Medicare coverage, (3) to have received only some high school education or less, and (4) to have had diabetes longer.

Low health literacy was also seen as an independent risk factor for hospital admissions among elderly Medicare managed care enrollees.¹⁷ More generally, emergency room patients with inadequate literacy were twice as likely to be hospitalized as those with adequate literacy, even after adjusting for self-reported health, health insurance and socioeconomic characteristics.¹⁸

Medicare Beneficiary Health Literacy: The Prudential Study

In a groundbreaking study among community-dwelling Medicare managed care patients, 34 percent of English-speaking and 54 percent of Spanish-speaking seniors enrolled in four geographically separate Prudential managed care plans had inadequate or marginal health literacy in their native languages.¹⁹ Respondents with inadequate functional health literacy (23.5% English-speaking; 34.2% in Spanish-speaking) often misread simple prescription instructions, information regarding the results of blood sugar tests, and the simplest reading comprehension passage with instructions for preparation for a medical procedure.

Those with marginal health literacy performed better on all these tasks, but showed poor comprehension of blood glucose tests, instructions for taking medication on an empty stomach, and the Medicaid rights and responsibilities reading comprehension passage. Individuals with adequate health literacy did well on most tasks, although some had difficulty interpreting more complex numerical tasks. For example, 23.5 percent did not understand a blood glucose reading and 17.3 percent had poor comprehension of a passage describing Medicaid rights.

Characteristics associated with higher rates of inadequate health literacy included race (African American), ethnicity (Hispanic/Latino), older age, fewer years of school completed, and “blue collar” occupations. For example, 18.9 percent of white/non-Hispanics had inadequate health literacy as compared with 29.5 percent of English-speaking Hispanics, 34.3 percent of Spanish-speaking Hispanics, and 52.1 percent of African Americans.

Moreover, the relationship between age and health literacy showed a strong trend, with the prevalence of inadequate health literacy steadily increasing from 15.6 percent of

¹⁶ Schillinger D, et al. “Association of Health Literacy with Diabetes Outcomes.” *Journal of the American Medical Association*, 2002; 288:475-482.

¹⁷ Baker DW, et al. “Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees.” *American Journal of Public Health*, 2002; 92:1278-1283.

¹⁸ Baker DW, et al. “Health Literacy and the Risk of Hospital Admission.” *Journal of General Internal Medicine*, 1998; 13:791-798.

¹⁹ Gazmarian, op.cit. at ftnt. 8.

individuals aged 65 to 69 years to 58 percent of those aged 85 years and over. Age was also strongly related to health literacy skills, when adjusting for education and cognitive impairment, the odds ratio for having inadequate or marginal health literacy was more than eight times as great for enrollees 85 years or older.

What CMS Is Currently Doing

Meaningful health communications must be conducted in culturally and linguistically appropriate formats that take literacy into account. Culture and language may affect health, healing, and wellness belief systems; how illness, disease and their causes are perceived; the behaviors of individuals seeking health care; and the delivery of health care services and provider behavior. In addition, literacy confounds how well the message is received, understood and acted upon.

Three efforts underway at CMS impact language and literacy. In September 1999, the Centers for Medicare and Medicaid Services published “Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies.”²⁰ The purpose of the Guide was to provide technical assistance to states in preparing written materials about Medicaid managed care. In the context of “easy to read and understand” written communication, the author dedicated separate chapters to culture and language. CMS is preparing a second guide that will address the Medicaid, Medicare and SCHIP population, and will include the latest research on reporting comparative health information, designing forms, writing for the web, and producing materials in plain Spanish.

CMS’ Regional Education About Choices in Health (REACH) is a national educational and promotion campaign that provides a local “face” for the National Medicare Education Program (NMEP). It supports NMEP’s main information channels (1-800 MEDICARE²¹ and medicare.gov). REACH is dedicated to building bridges to community-based organizations where effective systems exist to reach out to low income and hard-to-reach beneficiaries in order to overcome communication barriers, including literacy, language, and cultural barriers faced by vulnerable beneficiaries.

The HORIZONS Project works toward improving CMS' communication of Medicare and related information to beneficiaries and their caregivers from diverse populations (African American, Hispanic, Asian American/Pacific Islander, and American Indian/Alaska Native). Activities include adapting or “transcreating” Medicare program information for cultural and linguistic appropriateness, and identifying effective outreach

²⁰ In September 1999, the Centers for Medicare and Medicaid Services published “Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies.” The purpose fo the Guide was to provide technical assistance to CMS’ partners in preparing written materials about Medicaid managed care. Chapter 10 addresses translating materials in the context of preparing information that is readily understandable. However, more generally, the Guide applied to CMS’ staff as well. CMS is currently preparing a second guide that will address the Medicaid, Medicare and SCHIP population, and will include the latest research on reporting comparative health information, designing forms, writing for the web, and producing materials in plain Spanish.

²¹ It is noteworthy that the 1-800 number provides interpretation services through a telephone language line.

opportunities. Materials, including print and audiovisual public service announcements, are tested to assure understandability and usability.

Conclusion

LEP and LHL are both part of Bush Administration initiatives to make federal programs and activities more accessible to vulnerable populations. Health literacy is one of the five areas Secretary Thompson has identified as critical to the Department's health care quality effort.²² The White House is fully engaged on the LEP issue and supports federal agency initiatives to ensure that LEP beneficiaries receive equal access to federal programs and activities.²³ Continued CMS efforts on LEP and LHL remain critical.

²² Health literacy is one of the five areas Secretary Thompson has identified as critical to the Department's health care quality effort. Also, see, for example, "Communicating Health: Priorities and Strategies for Progress—Action Plans To Achieve the Health Communication Objectives in *Healthy People 2010*."

²³ See, for example, www.lep.gov.