

The ABCs of Health Literacy

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A significant portion of the US population has serious problems with both literacy and understanding how to effectively use and understand health-related information. An understanding of the breadth and significance of this problem and its impact on health outcomes is now clear. Interventions and strategies for effectively working with patients with limited literacy must be developed and evaluated. An agenda for medical and public health workers, health educators, and researchers is suggested. **Key words:** *health education, health literacy, patient education*

DESPITE almost one century of compulsory education for children aged 6 to 14, many adults in the United States have significant problems with literacy. The National Adult Literacy Survey (NALS), conducted by the US Department of Education, showed that 45% of the adult population in the United States has limited literacy skills and almost one quarter is functionally illiterate.¹ Illiteracy statistics translate into millions of people challenged in their daily lives, especially when addressing new situations or negotiating the complex institutions necessary to receive even minimal healthcare services. The NALS finding that 75% of respondents with a chronic disease also had limited literacy skills is directly relevant to healthcare providers, health educators, and policy analysts.¹

People with limited literacy skills have problems accessing services and have worse health outcomes than patients with full literacy.² The US healthcare system is intricate, disjointed, and specialized, and patients must be able to access information, get health services, communicate with healthcare professionals about their illness, sign consent forms, understand treatment options, and follow through on treatment plans.³ Patients who have low literacy, do not speak English, or have limited English fluency are challenged as they access health services for themselves and their families.

A public health approach to health literacy involves 4 steps: surveillance (what is the problem?), risk factor identification (what is the cause?), intervention evaluation (what works?), and implementation (how do we do it?). Knowledge about the 2 initial steps is available. We know that poor health literacy exists and the extent that it affects people. We know that there are several reasons for it, such as lack of education and high reading-level expectations in the medical setting. It is important to find more information about the "what" and "how" of addressing health literacy problems to affect current level of people with health disparities in the United States. This article reviews definitions of health literacy, the association between health literacy and health outcomes, and the interventions

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that have been used to improve health literacy, and offers an interdisciplinary model for improving health literacy.

HEALTH LITERACY DEFINITIONS

The dictionary definition of *literacy* is “the ability to read and write” and the “quality of being knowledgeable in a particular subject or field.”⁴ Health literacy is considered a variant of functional literacy. For example, the Center for Health Care Strategies^{5(p1)} definition of health literacy is, “the ability to read, understand and act on health information.” Their inclusion of the concepts of understanding and action significantly extends the definition. *Healthy People 2010*, in its public health goals for the nation, defines health literacy even more comprehensively 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.”^{6(pp11-19)} This definition also includes numeracy, the skill to use basic numerical information, such as “Let’s set a goal of losing 10% of your body weight,” or “Give 1/2 teaspoon 4 times a day.” Because this definition includes the individual ability to acquire both health information *and* services, some critics find it overly broad, suggesting that acquisition of services is more a function of resources than of literacy.⁷

The World Health Organization (WHO) has proposed an even broader definition of health literacy:

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.^{8(p357)}

In addition to information, access to health resources is explicit in this definition. However, this definition emphasizes that it is not enough for people to have information. The

relationship between health literacy and empowerment is explicit: people must also have access to healthcare. They must move from passive subjects to active participants in their healthcare and effectively use the healthcare system. The WHO definition moves health educators beyond providing information to also initiating the process of empowerment. Kickbusch⁹ proposes the WHO’s definition of health literacy as a working goal for all educators because it encompasses the concept of “potential,” thus including capability and motivation into preventive and health promotion behaviors.

The continuum of health literacy skills proposed by Nutbeam¹⁰ can be useful for implementing literacy programs and moving toward the personal empowerment goals of the WHO definition. This continuum of health literacy begins with *functional health literacy*, moves to *communicative/interactive health literacy*, and then to *critical health literacy*. Functional health literacy includes the basic skills needed to navigate the health system. Communicative/interactive health literacy combines functional health literacy with the ability to apply new information to different situations. Critical health literacy combines functional health literacy with both interactive health literacy and personal and community empowerment.

Cancer screening provides an example of the continuum. People must have knowledge about what screening tests are important, why and when in their lives the tests should be performed, and where they are available. However, they also need access to the services, the ability and the means to make an appointment, arrive at the appointment, and follow through on any instructions. If the services are not available, people ideally should be able to voice the need for more screening services. Health literacy classes might begin with interactive materials that provide information that teaches functional health literacy, and then work with that knowledge through a visit to a clinic and a walk-through of the appointment, testing, and follow-up process. Finally, the class might provide specific strategies for increasing or improving services, such

as a visit to the city council, discussion with the local cancer society, or letter writing campaign to the newspaper, that is, empowerment!

MEASURING HEALTH LITERACY

To date, 3 instruments are available to measure health literacy, the Test of Functional Health Literacy in Adults (TOFHLA), the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Wide Range of Achievement Test Reading subtest (WRAT). No instruments are available to assess broader definitions of health literacy.

Researchers at Georgia State University and Emory University developed the TOFHLA to measure adult literacy in a healthcare setting. It has been validated in both English and Spanish and measures subjects' abilities in reading comprehension and numeracy. To assess reading comprehension, subjects are asked to read sections of an informed consent document and sections of a medical procedure instruction sheet. Using a modified Cloze procedure, every fifth to seventh word is deleted in the passage and subjects select from a list of words the one that best fits in the blank. To assess numeracy skills, subjects are asked to read prescription medication instructions and an appointment reminder card, and are then asked questions about what they read. Scores are translated into categories of inadequate, marginal, and adequate functional health literacy. The short version of the test takes about 7 minutes to administer while the full version takes about 22 minutes.¹¹

The REALM was developed to provide a quick estimate of reading level in a medical setting and takes approximately 2 to 3 minutes to administer. Assessing word recognition and pronunciation, it uses 66 words commonly found in the English language. The words are divided into 3 columns, with 1 and 2 syllable words first and more complex words later. The WRAT contains a reading subtest that is highly correlated with the REALM; both correlate well with the TOFHLA.¹² However, word recognition tests have only been validated in English-speaking populations and

cannot be used with patients whose primary language is Spanish.¹³ Neither test has been validated with adolescent populations.

The results of the most recent NALS are eagerly awaited because the 2003 version contains a section on health literacy. Twenty-six health-related questions were embedded in the primary literacy assessment and 10 health-related questions were added to the background section. This will be the first national survey data available on health literacy and results are expected in mid-2005 (<http://nces.ed.gov/naal/>).

THE EPIDEMIOLOGY OF LOW HEALTH LITERACY IN THE UNITED STATES

A detailed portrait of the literacy of adults in the United States was provided by the NALS in 1992, which found that 90 million adults, 47% of the population, have limited literacy skills.¹ Some specific findings include the following:

- 42 million adults had skills at NALS Level 1, which means they can perform simple, routine tasks with uncomplicated materials. However, they would not be able to determine the correct dose of pediatric cold medicine from information on the back of the package.
- 50 million adults had skills at NALS Level 2, which means they can locate information in moderately complicated text. Individuals at this level may or may not be able to locate the correct dose of children's medicine, but it will be a difficult task. They will probably not be able to understand information on standard informed consent forms.

While the largest ethnic group with below-average NALS scores were native-born Caucasian English-speakers, other characteristics of groups with below-average scores on the NALS include those who

- are poor
- are members of ethnic and cultural minorities
- live in southern and western areas of the United States
- have less than a high school degree or GED

- are older than 65
- have physical or mental disabilities (ie, vision, speech, hearing problems)
- are prisoners
- are homeless
- are military recruits

These epidemiologic data are important in identifying groups with below-average scores to target them and to design appropriate interventions. In all of these groups, shame and stigma are associated with limited literacy—even spouses and children may not be aware of the limitation.¹¹ The hidden nature of limited literacy is an important barrier to overcome as interventions are developed.

LITERACY AND HEALTH OUTCOMES

Low literacy is associated with poor health outcomes and increased resource utilization in a variety of studies. New Medicare managed care enrollees with inadequate health literacy had a 2-fold greater chance of hospitalization than those with adequate literacy.¹⁴ Among diabetic patients at 2 primary care clinics at a San Francisco public hospital, those with low health literacy were more likely to have poor glycemic control and retinopathy.¹⁵ Men presenting with early prostate cancer at 2 Veterans Administration hospitals had higher literacy skills than men presenting with late disease.¹⁶ Low literacy is cited as a potential contributor to depression and a barrier to the treatment of sexually transmitted diseases.^{17,18}

These outcomes may be partially explained by inadequate disease knowledge. Only half of diabetic patients with low health literacy at a Los Angeles clinic knew the symptoms of hypoglycemia, compared to 94% of those with adequate literacy levels.¹⁵ Similar low knowledge levels about hypertension treatment guidelines were found among Atlanta patients with low-literacy levels.¹⁹ Looking at the association between health literacy and reproductive issues, 40% of women at a Chicago women's clinic had literacy below the ninth grade level; women in this group were more likely to have incorrect knowledge about the

purpose of a pap smear and to report that they would use emergency departments to seek care for an illness.²⁰ Pregnant women in Louisiana with low-literacy levels had less knowledge and concern about smoking.²¹

Parental literacy levels can be hypothesized to affect the health of children but only limited data are available to support this hypothesis. Parents from more than 600 families were asked to recall their child's diagnosis and medication prescribed (including purpose and instructions for use) 48 to 96 hours after their doctor visit. No relationship was found between parental literacy and understanding of medical information. However, the parents' perception of illness was correlated with literacy, with low-literacy parents being more likely to rank their child's present level of illness as more severe than parents with higher literacy. Interestingly, the presence of low literacy was found among all socioeconomic groups and lack of knowledge about children's health among all literacy levels, suggesting that healthcare providers should not assume that only low-literacy parents need more education about their child's health.²²

HEALTH LITERACY INTERVENTIONS

A recent review by the Agency for Healthcare Research and Quality found a paucity of research-based interventions with low-literacy populations that demonstrated significant results in terms of health outcomes, costs, or service utilization. Studies either had limited strength of evidence, methodological flaws, or limited or no change in outcomes.²³

The national Reach Out and Read (ROR) program supplies books to children at primary care visits and has volunteers reading to children in waiting rooms. Families having more contact with ROR had greater reading activities, book sharing, literacy orientation, and book ownership than those with less contact.²⁴ In both English and non-English speaking populations, ROR contact was correlated with improvements in young children's language.²⁵ This program shows a concrete way the healthcare system/providers can

impact literacy itself, and build on modeling and the power implicit in a physician's professional role. ROR is an excellent example of an interaction of the healthcare system with literacy activities; however, it is not a health literacy intervention per se.

A PROGRESSIVE AGENDA FOR HEALTH LITERACY

Public health workers

Improving literacy for its own sake is a worthwhile social goal that may be more appropriately located in the domain of education. However, people drop out of the education system at all points and the healthcare system directly feels the impact of low literacy. Viewing health literacy as both a health and a social issue makes explicit the responsibility for interventions between health educators and adult literacy educators. Adult literacy educators can develop materials that provide current, innovative information on health topics in adult education classes, and give students opportunities to learn more about health issues for themselves and their families. This shift can be part of a move toward recognizing adults as responsible partners who care about their health and the health of their families and want to see change in their lives.²⁶

Health educators can learn teaching strategies, and ways to make materials linguistically appropriate and culturally relevant from literacy education professionals.²⁷ Health education materials are needed that are linguistically appropriate and culturally relevant. On many occasions, materials that are written in English and then translated to another language lose their original meaning. Careful work, including field-testing, is necessary to ensure that materials are appropriate for the target audience.

Providers

Providers can be in the forefront of promoting a progressive agenda for health literacy by increasing awareness among all staff about the high levels of low health literacy in patient populations and the need for sensitivity

in assessing and addressing these problems. During the health visit, teaching strategies can help patients compensate for limited literacy. These strategies include the following:

- Teaching in a step-by-step process; present the most important information first.
- Asking patients to restate their understanding of the material presented.
- Identifying and using visual aids.
- Using simple words, and being consistent in the use of terms and avoiding jargon.²⁸ Remember that concepts often taken for granted by health professionals may be completely new to your patient.
- Changing the unidirectional nature of standard health education and considering instead the regular use of an interactive communication loop with patients.²⁹ Health providers should explain each concept of a treatment plan and assess patient recall and understanding. This understanding should then be expanded upon or modified and patient understanding assessed again.
- Encouraging patients to share their difficulties in understanding.

Another important aspect of improving care to patients with low health literacy is creating a shame-free environment. A shame-free environment is a requirement if patients are going to be able to admit to their healthcare providers that they need help or do not understand. Healthcare providers must be sensitized and trained on the best ways to assist and approach those with limited literacy so that the patient does not feel patronized. Further, the patient must be made to feel comfortable enough so that they trust their healthcare provider with such a powerful emotion. If patients are so embarrassed that they do not share this information with even those that are closest to them like family members, it will take a great deal of effort to overcome this barrier.

Researchers

The knowledge base about the high level of health illiteracy is now available. This enables

researchers to move beyond documenting the prevalence of health literacy in any population. The association between low health literacy and increased levels of morbidity and mortality is also clear and well documented. The 21st century research agenda is to demonstrate the relationships between efforts to increase health literacy and improve health outcomes, that is, intervention research. For example:

- What works to improve literacy so that health can be improved?
- Do brief interventions have any impact?
- What type of impact or outcomes can be expected?
- Which theoretical approaches are effective?
- Develop shorter screening instruments appropriate for non-English speakers, young adults, and others.
- What specific effect does low parental literacy have on the health of children?
- How does learning differ in populations of young parents and senior citizens?
- Which settings are most effective?
- What is the relationship of literacy to health literacy?
- What is the calibration of the levels of complexity of materials used in health?
- How is health literacy related to domains

of speaking and listening comprehension?

- What role does previous cultural knowledge play in intervention efforts?

A critical step in implementing this research agenda is to bring the target population to the table. To date, the voices of people with low-literacy levels have been notably absent in the professional literature. Reports using quantitative methods or a model of participatory action research will provide the healthcare community with insight about this population and direction toward meaningful interventions.

CONCLUSION

Health literacy is a well-documented problem in the United States. Public health researchers need to develop meaningful interventions that can tackle the problem and improve health outcomes. Health workers must also work to assist patients to reach critical health literacy so that personal and community empowerment can be reached and unfavorable health outcomes can be changed. Directing efforts to health literacy problems will provide an imperative contribution to the resolution of health disparities in the United States today.

REFERENCES

1. Kirsch IS, Jungeblut A, Jenkins L, Kolstad A. *Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey*. Washington, DC: National Center for Education Statistics, US Department of Education; 1993.
2. Baker DW, Schillinger D, Gazmararian JA. The health care experience of patients with low literacy. *Archives of Family Medicine*. 1996;5(6):329-334.
3. Parker RM. Health literacy: a challenge for American patients and their health care providers. *Health Promotion International*. 2000;15(4):537-542.
4. *The American Heritage Dictionary of the English Language*. 4th ed. Boston, MA: Houghton Mifflin; 2000.
5. Center for Health Strategies Inc. *Fact Sheet. What is Health Literacy?* Princeton, NJ: CHCS; 2000.
6. US Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Healthy People 2010. Available at: <http://www.health.gov/healthypeople>. Accessed August 2, 2005.
7. Hurowitz J. Toward a social policy for health. *The New England Journal of Medicine*. 1993;329(2):130-133.
8. Nutbeam D. Health promotion glossary. *Health Promotion International*. 1998;13(4):349-364.
9. Kickbusch IS. Health literacy: addressing the health and education divide. *Health Promotion International*. 2001;18(3):289-297.
10. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st Century. *Health Promotion International*. 2000;15(3):259-267.
11. Parker RM, Baker DW, Williams MV, Nurss JR. The Test of Functional Health Literacy in Adults (TOFHLA): a new instrument in measuring patient's

- literacy skills. *Journal of General Internal Medicine*. 1995;10(10):537-542.
12. Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Family Medicine*. 1993;25(6):391-395.
 13. Nurss JR, Baker DW, Davis TC, Parker RM, Williams MV. Difficulties in functional health literacy screening in Spanish-speaking adults. *Journal of Reading*. 1995;38(8):632-637.
 14. Baker DW, Gazmararian JA, Williams MV, et al. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*. 2002;92(8):1278-1283.
 15. Schillinger D, Grumbach K, Piette J, et al. Association of health literacy with diabetes outcomes. *JAMA*. 2002;288(4):475-482.
 16. Bennett CL, Ferreria MR, Davis TC, Kaplan J, Weinberger M, Kuzel T. Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *Journal of Clinical Oncology*. 1998;16(9):3101-3104.
 17. Fortenberry JD, McFarlane MM, Hennessy M, et al. Relation of health literacy to gonorrhea related care. *Sexually Transmitted Infections*. 2001;77(3):206-211.
 18. Gazmararian JA, Baker DW, Parker RM, Blazer D. A multivariate analysis of factors associated with depression evaluating the role of health literacy as a potential contributor. *Archives of Internal Medicine*. 2000;160(21):3307-3314.
 19. Williams DV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. *Archives of Internal Medicine*. 1998;158(2):166-172.
 20. Lindau ST, Tomori C, Lyons T, Langseth L, Bennett CL, Garcia P. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. *American Journal of Obstetrics and Gynecology*. 2002;186(5):938-943.
 21. Arnold CL, Davis TC, Berkel HJ, Jackson RH, Nandy I, London S. Smoking status, reading level, and knowledge of tobacco effects among low-income pregnant women. *Preventive Medicine*. 2001;32(4):313-320.
 22. Moon RY, Cheng TL, Patel KM, Baumhaft K, Scheidt PC. Parental literacy level and understanding of medical information. *Pediatrics*. 1998;102(2):e25.
 23. Berkman ND. Literacy and health outcomes. *Evidence report/technology assessment; no. 87; AHRQ publication; no. 04-E 007-2*. Available at: <http://publ.access.gpo.gov/GPO/LPS47971>. Accessed August 2, 2005.
 24. Klass P. Pediatrics by the book: pediatricians and literacy promotion. *Pediatrics*. 2002;110(5):989-995.
 25. Golova N, Alario AJ, Vivier PM, Rodriguez M, High PC. Literacy promotion for Hispanic families in a primary care setting: a randomized, controlled trial. *Pediatrics*. 1999;103(5):993-997.
 26. Knowles M. *The Modern Practice of Adult Education: From Pedagogy to Andragogy*. Chicago, IL: Association Press/Follet; 1980.
 27. Foulke D, Carroll P, Wood SN. Addressing health literacy: a description of the intersection of functional literacy and health care. *American Journal of Health Studies*. 2001;17(1):7-14.
 28. Dreger V, Tremback T. Optimize patient health by treating literacy and language barriers. *The Association of Perioperative Registered Nurses*. 2002;75(2):280-293.
 29. Schillinger D, Piette J, Grumbach K, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*. 2003;163(1):83-90.