

HEALTH LITERACY

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This chapter presents an overview of literacy and functional health literacy and their impacts on health and healthcare.

What is Literacy?

The meaning of **literacy** is constantly evolving. It is best understood and studied, not as a fixed individual capacity, but as a reflection of social, religious, economic and cultural context. It is about negotiating society in all its contexts as the need arises. In 19th Century America the definition of literacy evolved from the ability to make your mark, usually with an 'X', to ability to recite prose, usually scripture. Just one hundred years ago, although books were readily available, ability to sign one's name was the commonly accepted measure of literacy. With the rise in compulsory public education in the 20th century, literacy became equated with educational achievement. The army required soldiers to have a fifth grade education while the Census Bureau established a sixth grade education as the standard for literacy in civilian life. Mid-century the Department of Education recognized that years of education does not necessarily reflect literacy skills and changed the standard to an eighth grade *reading* level. However, experts argued (and still do today) that equating adult literacy to a school grade level is uninformative and misleading. For example, in accordance with the Bell Curve of Normalcy, in any given seventh grade class there will be students reading at the second grade level and others reading at the high school graduate level. Nevertheless, the current medical literature continues to report literacy as a school grade level reading equivalent.

**LITERACY IN AMERICA
TODAY MEANS ABILITY
TO:**

- Read, write and speak in English
- Compute and solve problems
- Function on the job and in society
- Achieve one's goals
- Develop one's knowledge and potential

US Congress 1991
National Literacy Act

The 1991 National Literacy Act ¹ established the concept of *functional literacy*. In this broader view, adult literacy level is determined not by skill level but by what those skills enable a person to *do*. An individual's functional literacy level varies with circumstances and social contexts. For example, a man may function at a high level in familiar surroundings at home and on the job. He does not need to read a map or a bus schedule because he boards the bus at the same place and time each day. He does not need to read street signs because he knows what they say; they serve as landmarks. Since he learned his job through demonstration and practice he did not need to read an operators' manual. This man is functionally literate in his usual environment. However, in unfamiliar contexts, such as the healthcare environment, the same man's functional literacy plummets. He encounters difficulty at every level of the healthcare system from finding the institution and the clinic to filling out forms, to understanding and adhering to treatment. In this context, he is said to have *low functional health literacy*. In the same way, a person with strong literacy skills and high functional health literacy may have low computer literacy.

Note that the definition of literacy in America today specifies proficiency in *English*. This reflects the fact that regardless of a person's intelligence and literacy skills in other languages, with limited English proficiency they have low functional literacy, that is, they do not have full access to the opportunities and benefits of the information economy.

How is Literacy Measured?

The 1992 National Adult Literacy Survey (NALS) ² was designed to assess American adults' functional literacy. In a continuing effort to move away from reporting literacy as a school grade level equivalent, NALS used a continuous scale of Levels 1 to 5 for prose literacy (comprehension of text), document literacy (capacity to use forms, maps, charts) and quantitative literacy (using numbers) in a nationally representative population of 26,000 adults over age 16. The results of this research shocked the nation by demonstrating that nearly half (48%) of the US population scored at a Literacy Level of 1 or 2. That is, they could read short

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simple text to locate a single piece of information, enter personal information on a form and perform simple calculations with numbers provided. Most professionals scored at Level 3; they could make low level inferences, integrate information from lengthy text and generate a response based on easily identifiable information. Less than five percent of adults scored in Level 5 indicating ability to search for information in dense text, make high level inferences, use specialized knowledge, and use background knowledge to determine quantities and appropriate numerical operations. In the medical literature these findings have been extrapolated to estimate that 90 million Americans lack sufficient literacy skills to use the healthcare system.

Skills needed to use the US Healthcare System

- Conceptual knowledge
- Speaking
- Listening
- Writing
- Reading
- Numeracy

Institute of Medicine 2004 ³

| NAAL Level | Capacity | % US Adults |
|--------------|------------------------------|------------------------------|
| Below Basic | Very simple, concrete tasks | 14% |
| Basic | Simple everyday tasks | 29% |
| Intermediate | Moderately challenging tasks | 44% |
| Proficient | Complex tasks | 13%* |
| | | * Significant drop from 1992 |

The NALS concept of numbered literacy levels did not catch on. Most reports, including those in medical journals, translated the NALS Literacy Levels back to grade level equivalents. The 2003 National Assessment of Adult Literacy (NAAL) introduced the current method of reporting literacy in four levels from Below Basic to Proficient.⁴ *Below Basic* indicates the lowest levels of performance such as signing a form or adding the amounts on a bank deposit slip. *Basic* means a person can perform simple everyday tasks such as comparing the ticket price of two sporting events or understanding a pamphlet that describes how a person is selected for jury duty. *Intermediate* means that a person can do moderately challenging tasks such as calculating the cost of an order from an office supply catalog or identifying a specific location on a map. A person *Proficient* in English can perform complex activities such as comparing viewpoints in two editorials or interpreting a table about blood pressure and physical activity. NAAL found Americans’ literacy essentially unchanged in 10 years since the NALS except for a

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statistically significant drop in the percentage of adults proficient enough to complete complex literacy tasks. Healthcare providers must be prepared to engage and treat patients with limited literacy skills, limited English proficiency and limited contact with healthcare environments.

How are health and literacy linked?

Any way health and literacy are defined or measured, they are inextricably linked. Research in several countries has repeatedly documented the negative effect of limited literacy on virtually all aspects of health including overall levels of morbidity and mortality, accidents and a wide range of diseases including diabetes, cardiovascular disease, and rheumatoid arthritis. Disease and violent death are more prevalent in areas with low levels of literacy. Hospital utilization by children is highest in communities with limited literacy levels.

The impacts of literacy on health are both direct and indirect. Persons with low literacy find it difficult to access, understand and use health information and services. Those with less than proficient literacy encounter difficulties at every level of the health care system, especially completing forms, informed consents and interacting with health care providers. They may have trouble seeking timely appropriate intervention, administering medication, following treatment regimens, and engaging in self-care.

Not only is literacy a major determinant of health; it also is closely associated with other socio-economic conditions that indirectly influence health, such as income, social status, employment opportunities, social support, and early childhood development. People with limited literacy are relegated to low-paying jobs and so are likely to live in poverty with limited food supplies, poor quality housing in unsafe neighborhoods, low quality schools, high stress, low self-esteem, and isolation. Thus, they are likely to have poorer health, higher rates of injury, chronic disease and earlier death. . Parents with low literacy skills and low functional literacy face significant barriers to fostering healthy development and school readiness in their children.

What is health literacy?

Health literacy is a 'type' of functional literacy. Like computer literacy, it develops with need, opportunity and experience. While much attention has been given to "patients who can't read", the difficulties of working with them, and the extra costs they incur, such patients are the exception. Very few Americans cannot read at all. Still, nearly everyone has low functional health literacy; that is, they have below basic to proficient literacy skills, but lack background knowledge, medical vocabulary, and experience in the healthcare system. For example, few people have need or opportunity to learn and talk about diabetes until they experience it. Upon initial diagnosis, their health literacy - or more specifically in this example - their "diabetes literacy" begins to develop. Similarly, until a person has need of medical services and opportunity to utilize the healthcare system, they will lack the background knowledge and vocabulary to navigate the system efficiently. With experience, their health literacy, or specifically in this example, their "healthcare literacy" improves – they progress toward higher levels of functioning in the context of that system. In this manner of thinking, everyone has low functional health literacy; screening is not necessary; and universal precautions are in order.

Health literacy is:

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

~ Ratzan & Parker
Institute of Medicine
American Medical Association⁵

"...the ability to function in the health arena"

~ Ian Bennett, MD⁶

How is health literacy measured?

The term *health literacy* also refers to an emerging field of research still evolving toward a standard conceptualization of health literacy and definition of terms. Studies in the last decade have focused on the individual patient's ability to read in a healthcare setting. Researchers have adapted reading and comprehension tests from the field of Education to identify patients

| HALS Health Activity Literacy Scale 2004 | |
|---|-----|
| Below Basic Health Literacy | 19% |
| Basic | 27% |
| Intermediate | 36% |
| Proficient | 18% |

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with low health literacy so that providers can tailor communications to increase understanding and compliance. Most commonly used are the REALM – Rapid Estimate of Adult Literacy in Medicine, a word recognition test, and TOFHLA – Test of Functional Health Literacy in Adults. The latter has been administered in English and in Spanish. The two tests are closely correlated. While these tests have established a necessary foundation for understanding health literacy, they have been demonstrated useful only for research purposes since they are stressful and embarrassing for patients, and time consuming for providers. It is now recognized that these tests measure reading ability; they are not measures of functional health literacy. ⁷

In an effort to assess the Nation’s functional health literacy, researchers derived the Health Activity Literacy Scale (HALS) using results on 191 health-related literacy tasks from NALS ⁸. HALS findings indicate that large percentages of vulnerable populations in the US do not have adequate skills to meet many of the healthcare-related demands they are likely to encounter. Only 18% of adults scored in the Proficient range and would be expected to function well in the healthcare system. Adults with low functional health literacy are generally those who have not completed high school or obtained a GED, have health-related restrictions on their ability to attend school or work, are members of minority population groups or have immigrated to the United States. They are likely to live in poverty, less like to read for fun, use a library or vote. Television is their primary information source. Thus low health literacy may exacerbate existing disparities in healthcare access and outcomes.

Nearly 50 studies support an association between people’s ability to read printed health information and a variety of health outcomes and have set an initial foundation for future research. Still, the impact of the mismatch between the average skills of U.S. adults and the sophisticated demands of the U.S. health system has not been fully assessed. Additional research is needed to expand understanding of health literacy beyond the current focus on reading skill, to explore the role of social support and

See from the patient’s view

- What do you call the problem?
- What do you think caused it?
- What does it do? How does it work?
- How severe is it?
- How long does it last?
- What do you fear about it?
- What do you think treatment should be?
- What important results should come from the treatment?

Arthur Kleinman, MD Harvard

channels for promoting health literacy outside the healthcare system, and to develop instruments for measuring the function in functional health literacy, particularly longitudinal studies to document individual's progress over time toward higher level functioning.

What promotes health literacy?

To date most work to improve health literacy has focused on healthcare providers enhancing information delivery. The source of most healthcare communication problems is a mismatch between providers' and patients' logic, language and experience.⁹ Due to special training and vocabulary, physicians and other healthcare professionals think and talk about health, illness and treatment like no one else. While physicians may interact daily with institutions and technology, for many patients, major illness or injury marks their first encounter with an institution of any kind. Even with native-born patients proficient in English, culture and language can be barriers to efficient effective care. Federal and state law, Medicare and Medicaid regulations, and accreditation standards place responsibility for patient understanding squarely with the physician. Kleinman developed a set of interview questions to elicit a patient's experience of a condition and treatment.¹⁰ Practitioners can use these questions to close gaps between a patient's logic, language and experience and their own. Another promising practice is a "teach back" method in which the provider asks the patient to "show me what you are going to do."

Over 300 studies make clear that most written health information exceeds patients' literacy skills. Numerous guidelines have been published to increase the readability of health education materials, including the FONBAYS method developed by the authors of this chapter for simplifying the readability of text and survey questions.

"...give it to them briefly so they will read it, clearly to they will appreciate it, picturesquely so they will remember it, and above all accurately so they will be guided by its light."

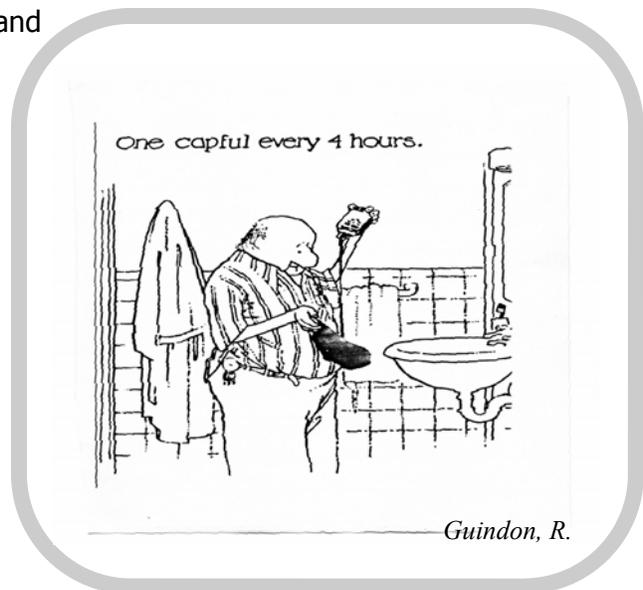
~ Joseph Pulitzer

However, improved information delivery alone is not likely to mitigate the relationship between low literacy and poor outcomes. Investigating whether and how literacy skills and functional

health literacy affect self-efficacy, self-care, trust and satisfaction may lead to effective strategies. Theoretically, social support from family, friends or social services providers may buffer the negative impacts of low literacy and low health literacy by enabling a person to understand information, enter and navigate the health system and adhere to treatment regimens.¹¹ Collaboration between healthcare organizations and literacy enhancing community services, such as adult basic education and English language learning classes, may also prove beneficial.

Taking the view that everyone has low health literacy, practitioners can apply promising practices as universal precautions:

- Become aware of the culture of Medicine and of your institution.
- Become aware of your patients' culture.
- Use the patient's language. Say 'walk' instead of 'ambulate'.
- Be aware of the pictures your words create in the patient's mind. Be especially aware of common words used as medical terms, for example (stool, screen, cap).
- Ask the patient to 'teach back' to confirm s/he understands the same way you do.
- Focus on behavior. Talk about the patient needs to do now, not facts about the condition.
- Limit discussion to the 'critical minimum' information the patient needs now to cope and recover.
- Adults learn by repetition. Say the most important thing three times.
- Select or prepare written information that is easy to read and understand.
- Reading aloud takes learning deeper faster. Ask patients to read aloud the most important part of treatment instructions.
- Refer patients with less than high school education who do not read for fun to literacy enhancing services.
- Encourage formal education
- Encourage reading for fun, especially reading aloud (including reading to children)



Resources

National Library of Medicine Archive of Health Literacy Literature (1990 -1999)

National Institute for Literacy at www.nifl.gov

National Institute for Literacy Health & Literacy Online Discussion List at www.nifl.gov/mailman/listinfo/Healthliteracy

The Health Literacy Style Manual (Maximus, Robert Wood Johnson Foundation, Covering Kids and Families) at <http://coveringkidsandfamilies.org/resources/index.php?InfoCenterID=194>

Association of Clinicians for the Underserved at acu@clinicians.org

Ask Me Three www.askmethree.org

Reach Out and Read at www.reachoutandread.org

World Education at www.healthliteracy@worlded.org

Recommended Reading

Zakaluk, B.L. and Samuels, S.J. (Eds.) (1988). *Readability, its past, present and future*. Newark, Delaware. International Reading Association

Smith, S.A. Patient Education and Literacy in Labus, J.B and Lauber, A. (Eds.) (2001). *Patient Education and Preventive Medicine*. Philadelphia. WB Saunders. 266-290.

(coming soon to the Further Reading on Health Literacy section of the Beginnings Guides Website:

http://www.beginningguides.net/content/index.php?option=com_content&task=view&id=88&Itemid=169)

References

1. National Literacy Act Public Law 102-73 Stat 333: 1991 online at www.nifl.gov/public-law.html
2. Kirsh I, Jungeblut A, Jenkins L, Kolsad A. (1993) *Adult Literacy in America; a first look at the results of the National Adult Literacy Survey*, Washington: Dept of Education, National Center for Educational Statistic
3. Nielson-Bohlman L, Panzer AM, Hamlin B, Kindig DA (2004) Editors, *Health Literacy: A Prescription to End Confusion* Institute of Medicine. Washington. National Academies Press Prepublication Copy. Online at www.nap.edu
4. National Assessment of Adult Literacy (NAAL) A First Look at the Literacy of America's Adults in the 21st Century. Washington Dept of Education National Center for Education Statistics online @nces.ed.gov/NAAL/PDF/2006470.pdf
5. American Medical Association Report of the Council on Scientific Affairs: Ad Hoc Committee on Health Literacy. *JAMA*, 1999;281(6):552-557
6. Bennett IM, Robbins S, Haecker T. (Sept 2003) Screening for Low Literacy Among Adult Caregivers of Pediatric Patients. *Family Medicine*, Vol 35, No 8:585-90
7. Berkman ND, DeWalt DA, Pignone MP, Sheridan SL, Lohr KN, Lux L, Sutton SF, Swinson T, Bonito AJ Literacy and Health Outcomes. Summary, Evidence Report Technology Assessment No. 87 AHRQ Publication No. 04-E007-1 Rockville, MD: Agency for Healthcare Research and Quality Jan 2004 online @www.ahrq.gov
8. Rudd R, Kirsch I, Yamamoto K (2004) *Literacy and Health in America* Princeton, NJ, Educational Testing Service. Online at www.ets.org/Media/Research/pdf/PICHEALTH.pdf
9. Doak C, Doak L, and Root J 2nd Edition (1996) *Teaching Patients with Low Literacy Skills*, Philadelphia, JB Lippincott
10. Kleinman, A (1989)*The Illness Narratives: Suffering, Healing and the Human Condition*, Basic Books (Perseus) Jackson TN
11. Lee, S-YD, Arozullah AM, Young IC (2004) Health Literacy, Social Support and Health: a research agenda. *Social Science & Medicine* 58:1309-1321
12. Cartoon: Guindon R (1983) *The World According to Karp: A guindon Collection*. New York: Andrews & McMeel
13. Chall JS. The beginning years. In: Zakaluk BL, Samuels SJ eds. *Readability, its past, present and future*. Newark, Delaware: International Reading Association, 1988; pp 2-13