

Rethinking Health Literacy

Abstract

In the US the term *health literacy* is used to describe and explain the relation between patients' reading skills and their ability to comply with prescribed therapeutic regimens. These fundamental but narrow definitions flow from school-based concepts of literacy and miss much of the deeper meaning and purpose of literacy in adult life. They exclude the concept of *functional literacy* promoted by the 1992 National Adult Literacy Survey (NALS) and the 2003 National Assessment of Adult Literacy (NAAL). The literature from other disciplines and nations presents broader definitions of health literacy, which suggest that social support may determine whether low health literacy actually leads to negative outcomes. This article reviews current concepts of health literacy in the US, explores other views, and discusses implications for practice and future research.

Introduction

Healthy People 2010 Objective 11-2:

To improve the health literacy of persons with inadequate or marginal literacy skills

This current national public health objective reflects widespread concern over the prevalence and consequences of low literacy and low health literacy in the United States. Since health literacy improvements are likely to result in greater adherence to treatment regimens, engagement in appropriate self-care, improved health status, and greater efficiency and cost savings to the health system, health literacy is an element of all the Healthy People 2010 objectives (DHHS 2003b p13). In addition, the Institute of Medicine (IOM 2004) reports that efforts toward another major public health goal – reducing disparities in access and outcomes – cannot succeed without improvements in health literacy. Further, the outcomes of most health education, health promotion and social service programs are determined to some degree by participants' literacy skills and functional health literacy.

To achieve the national objective of measurable improvement in health literacy by 2010 and to overcome health disparities, it will be necessary to re-evaluate the logic and language of our approach to health literacy. This article reviews current concepts and operational definitions of health literacy in the

United States, explores other views, and discusses implications for public health practice and health services delivery.

Limitations in the current literature

Three limitations of the current US literature point to a need to re-evaluate the prevailing concept of health literacy in order to meet Healthy People 2010 objectives and to overcome disparities in access and outcomes:

1) The school-based view of literacy that focuses on testing reading skills and leaves out the functional aspects of adult literacy and health literacy, notably, the possibility of progress over time toward optimal functioning in health contexts.

2) The premise that treats individuals as isolated passive actors and considers health literacy simply as an individual trait independent of social support and resources

3) The narrow view that considers health literacy only in the healthcare system and ignores impacts at home and in the community where most health-related information is applied, or not.

The school-based view of health literacy and how to measure it

In the current US medical literature, the term *health literacy* is used to describe and explain the relation between patients' reading skill and their ability to comply with prescribed therapeutic regimens. These fundamental but narrow definitions miss much of the deeper meaning and purpose of literacy (Nutbeam 2000).

Health literacy is the degree to which individuals have the capacity to obtain and understand basic health information needed to make appropriate health decisions.

National Academy of Science, Institute of Medicine 2004

The term "health literacy" refers to a patient's ability to understand common health care communications, such as prescription instructions, test results and insurance forms.

AMA Foundation

<http://www.ama-assn.org/ama/pub/category/8577.html>

The fundamental but narrow US definitions of health literacy miss much of the deeper meaning of literacy.

Perspectives from other disciplines and nations

The scientific literature on literacy reveals an ongoing debate about different 'types' of literacy (such as computer literacy or health literacy) and their practical application in everyday life. One approach suitable to health literacy discussions identifies 'types' of literacy not as measures of reading or writing ability, but in terms of what it is that literacy enables a person to do (Freebody & Luke 1990). This approach is reflected in US definitions of adult literacy from sources outside healthcare.

The 1991 National Adult Literacy Act and Congress' official definition of literacy in America recognizes the idea that literacy in adult life is more about functioning in society than it is about decoding words and their meaning. The 1992 US National Adult Literacy Survey (NALS) similarly defined *functional literacy: Using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential* (Kirsch, Jungeblut, Jenkins & Kolstad 1993). The NALS made clear that literacy is not something that you have or do not have. Rather, a person's *functional literacy level* varies by context and develops with need, opportunity, support and resources (Purcell–Gates 2003; DHHS p6).

According to broader US and international definitions, literacy in adult life is more about functioning in society than it is about decoding words and their meaning

Literacy is:

An individual's ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and develop one's knowledge and potential 1991 National Literacy Act

Using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential
1992 National Adult Literacy Survey

Cognitive and social skills that determine motivation and ability to gain access to understand and use information in ways that promote and maintain health
1996 World Health Organization

Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions
2000 World Health Organization

The capacity to function in the health arena
2004 Bennett et al

Few US health literacy studies have considered this broader view of adult literacy as the capacity to use information to function in everyday and new situations, to learn, gain confidence, and make progress in different contexts of daily life.

The World Health Organization (WHO) promotes the idea that a patient/client does not function as an isolated individual who has or does not have health literacy. WHO (1998) defined health literacy as *the cognitive and social skills that determine motivation and ability to gain access to, understand and use information in ways that promote and maintain health*. WHO later expanded its definition adding that *health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions*. WHO also reports that improved health literacy is necessary for people to increase control over their health. Thus health literacy is critical to empowerment. Health literacy research will be more informative when it differentiates literacy skills (reading) from functional health literacy – the capacity to function in the health care system and in health contexts at home and in the community.

Health Literacy Testing: Are we measuring the right thing?

School-age literacy skills center on decoding words and comprehending their meaning. Working from this school-based view of literacy, researchers have adapted school-based methods for measuring individual's health literacy by performance on reading and comprehension tests designed for use in healthcare settings. Commonly used are the Wide Range Achievement Test (WRAT) reading subtest, the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). The WRAT and REALM are word recognition tests validated as instruments of reading ability. The TOFHLA and a short version (S-TOFHLA) assess literacy by a modified cloze method, which involves filling in words deleted from text. Cloze testing is frequently used to assess foreign language acquisition (Gonzales & Smith 1999). All these instruments are highly correlated with one another (Berkman et al 2004). They all measure reading ability – not functional health literacy. Accordingly, these tests express health literacy in terms of school-grade-equivalent reading ability. This practice is prevalent but highly misleading since literacy skills vary widely within grades and test subjects are long out of school.

In addition, reporting literacy or health literacy as a grade level equivalent implies that health literacy is simple and easy to measure. It does not acknowledge the functional aspects of health literacy or the possibility for progress toward optimal functioning (Barton 1994). Rather, current practice erroneously equates reading skill with capacity to function in the health arena.

The 2003 National Assessment of Adult Literacy (NAAL) Health Literacy Component (HLC) was an effort to assess the functional health literacy of the national population and to move away from school-based tests and grade-level-equivalent scoring. Still, the HLC was a paper and pencil test of adults on literacy tasks thought to represent typical health care encounters. Some experts object that the HLC tested adults with known low literacy skills on commonly used health information materials although three decades of research, over 300 studies (IOM), show that these materials exceed the literacy skills of most Americans. HLC findings correlate very closely with results for general prose literacy and likely reflect the known complexity of materials and systems rather than individuals' or the public's ability to function in health contexts (DHHS 2003).

Current school-based health literacy assessment tools, including the HLC, focus on failure, bring up feelings of shame and produce anxiety (Gonzales & Smith 1998), which interferes with cognition (Newcomer, Selke & Melson 1999). These tests address only reading skills, they do not address health-related functioning or consider health literacy impacts at home or in the community. They do not constitute measures of functional health literacy (DHHS b p42).

A useful literacy screen for clinical practice

Bennett et al (2004) developed a literacy screening test for use with disadvantaged parents of children to age six in primary care settings. While the test is derived from and correlated with the REALM and reports a school-grade-equivalent score, it makes significant improvements over earlier tests of health literacy. Notably, Bennett's screen, modeled on the CAGE questionnaire for alcohol use, uses three innocuous questions to identify persons likely to have reading ability less than a sixth grade equivalent as measured by the REALM. Two follow-up questions facilitate referral to literacy enhancing programs (Adult Basic Education, Family Literacy, ESL). Bennett's screen takes less than one minute, requires no testing, and is not intrusive. It intends to link the patient/client to literacy-enhancing resources in the community. This is beneficial to patients and appropriate for routine use in primary care and home

visitation with parents of young children. The screening tool should be further validated for use in other healthcare settings. Still, screening for low literacy skills is not informative about a patient's functional health literacy level or how to prevent or mitigate negative outcomes.

**Bennett's Health Literacy Screen
for Disadvantaged Parents of Children to Age Six**

How many years of education have you completed? (<12)
Is the child's other parent living with your now? (No)
Do you ever read for fun? (No)

Less than 12 years education and one No answer indicate less than sixth grade level health literacy as measured by the REALM

Follow-up Referral Questions

Do you think your reading could be better?
Would you be interested in getting help with your reading?

Yes answers to the follow-up questions further indicate low literacy. (Bennett, personal communication August 2004)

Observed functioning as a measure of functional health literacy

To measure a person's *functional* health literacy, it makes sense to observe and document their *functioning* in health contexts. This review located only one validated instrument for documenting change in a person's level of functioning in the health arena over time. The Life Skills Progression instrument (LSP) (Wollesen 2005) produces a "snapshot" of a parent's current observed level of functioning in health contexts at home and in the health care system on a scale of 1 (inadequate – a need) to 5 (optimal- a strength). Repeated observations at six-month intervals show progress toward optional functioning in areas such as use of preventive services (prenatal care, well-child check-ups, immunizations), presence or absence of a medical home and a dental home, self-care practices, health behaviors, sick-care seeking and follow-through, information seeking and application, and use of resources. The instrument also summarizes assessments of child development. Wollesen developed the LSP to document functioning of disadvantaged parents of infants and toddlers in maternal child health home visitation programs such as Early Head Start, Healthy Families America, and National Healthy Start. It is currently in use in over 50 sites in 7 states. Inter-rater reliability is established at 90%. Independent evaluators

reported the LSP detects changes in study periods as short as 6 months and found the instrument more than adequate for research purposes. Preliminary data indicates it is feasible to collect common data across program models and compare results to identify best practices for supporting literacy skills development and promoting health literacy.

The LSP may overcome several problems in the way that health literacy is measured and discussed. It focuses attention on the *function* in *functional* health literacy, rather than on reading skill. It considers social support and other factors beyond reading ability that affect health literacy. It documents parent's progress toward optimal functioning rather than documenting failure. It identifies persons with low general literacy skills without reading tests. It relies not on questionnaires that persons with low literacy may not be able to complete accurately, but rather on frequent observation and formal assessments by trained home visitors.

The LSP instrument is completed and scored in less than five minutes; and the data is immediately useful to the home visitors and programs that collect it. Users report it is efficiently useful in practice. In addition to measuring effects of home visitation, the LSP has been used to evaluate telephone case management services for new mothers. Its application in other settings warrants investigation. Instruments such as the LSP, which monitor parent's functioning in health contexts and document progress over time toward higher functioning, warrant further validation as tools for measuring functional health literacy and identifying best practices for promoting health literacy and supporting development of literacy skills.

The role of social support in health literacy outcomes

Health status is significantly determined by an individual's social, economic and environmental circumstances. The relationships between these social factors and health are easy to observe, but not well understood (Nutbeam 2000). Lee et al (2004) proposed a conceptual framework of social support and health literacy that suggests positive supports can improve ability to acquire and understand health and medical information and to negotiate the healthcare system. Such social supports and resources would be particularly important for those with low functional health literacy in facilitating establishment of healthful attitudes and behaviors, increasing use of preventive and routine physician visits, improving

compliance and medication use, improving health and reducing the amount of emergency and hospital care. Conversely, lack of support may amplify adverse health situations for those made vulnerable by low health literacy.

Nutbeam (2000), an Australian researcher, describes three levels of health literacy: *Basic or functional literacy* refers to sufficient skills to function in a person's everyday situations. This is broadly comparable to the prevailing concept of health literacy in the US medical system, if healthcare encounters can be considered "everyday situations". *Interactive literacy* implies more advanced literacy skills, which, together with social skills, can be used to apply new information in changing circumstances (such as pregnancy or diagnosis of a chronic condition). *Critical literacy* combines more advanced literacy skills and social skills to use information to exert greater control over life events and situations (such as choosing a health plan or advocating for child health services). Nutbeam's conceptualization indicates the progressive nature of health literacy. It illustrates that progress is dependent not only on cognitive skills, but is mediated by social support. These broader concepts of the deeper meaning of literacy in adult life need to be taken into consideration to advance understanding of health literacy beyond the current narrow focus on reading.

Implications for Research & Practice

What is the most effective time to promote health literacy?

Pregnancy and early parenting present a unique opportunity to promote health literacy. Pregnancy is a life transition that triggers independent learning (Orr 1990). It also triggers use of significant health services, often for the first time — notably prenatal, obstetric, pediatric and preventive services. Lacey (1988) found that pregnant women and new mothers exhibit readiness to learn well above national norms.

The literature on the quality of prenatal care offers evidence that health literacy during pregnancy can have lifelong effects on maternal child health, school readiness, and healthcare expenditures. Kogan and associates (1994) found that women who recalled learning something about certain health behavior topics during pregnancy had a significantly reduced chance of delivering a low-birth-weight baby. This finding held for all demographic categories after controlling for other variables in a nationally

representative sample of over 9000 women. Those who had the greatest socio-economic risks showed the greatest differentials. In other words, something enabled some women with low income, low education, unmarried and minority status – all risks for low health literacy – to obtain and use information to maintain and promote their health during pregnancy. Those who could not obtain or use health behavior information had worse outcomes despite lower risk. Low-birth-weight is the leading cause of poor development outcomes and infant death. Preventable low birth weight is one example of how the negative impacts of parents' low health literacy extend to their children. Further research is necessary to identify effective interventions to improve health literacy during pregnancy and early parenting.

The child development literature reports on a wealth of recent research from neurobiology and the behavioral and social sciences. Among the core themes of this literature is that all children are born wired for feelings and ready to learn. What happens in the first months and years of life matters because it sets either a sturdy foundation or a fragile foundation for all that follows. (National Academy of Science 2000) Supporting and enhancing parents' functional health literacy can be expected to enhance child health and socio-emotional development -- the foundations for early literacy and school readiness (Wilensky 2003, Halfon 2004). Trials are warranted to determine whether and how social supports provided through maternal-child health home visitation programs buffer the effects of low literacy skills and promote functional health literacy.

What is the most effective channel to promote health literacy?

To date, health literacy has been addressed through the healthcare system with reported studies focused on deficient literacy skills among patients and efforts to improve disease knowledge and information delivery. When presenting to the healthcare system, patients' cognitive abilities are compromised by physical, mental, spiritual, emotional and financial stresses. Providers' efforts to address health literacy are limited by the patient's medical condition and associated cognitive dysfunction, their own low awareness of literacy and health literacy issues, language and cultural gaps, short infrequent visits, and necessary focus on medical needs. It is unlikely that progress to measurable improvement in health literacy can be made through healthcare providers viewing health literacy as lack of reading skill

among medically compromised patients. Maternal-child health home visitation programs present a potentially effective, efficient alternative channel and timing for promoting health literacy.

MCH home visitors may be an effective, efficient channel for health literacy promotion

Established home visitation programs across the country serve an estimated 580,000 disadvantaged families who function at a low level in the healthcare system. Mothers may lack the capacity to access or benefit fully from the prenatal, obstetric, pediatric and preventive services. They probably do not know about – and may not see their need for public health services and community resources. They have difficulty navigating institutions and systems. In another aspect of low health literacy, most families served by home visitation function at low levels in health contexts at home. They may not have developed the knowledge and skills needed to engage in healthy behaviors and appropriate self-care, promote their children's health and development, and provide basic essentials for health (housing, nutrition, income).

Although few home visitation programs specifically name promoting functional health literacy as a program objective, the focus of most programs is on providing social support and linking to resources that promote life skills parents need to function in the health arena, achieve their goals, and develop their knowledge and resources for parenting. Particularly, MCH home visitors support and promote parents' capacity to provide for health care and healthy life styles, utilize health information and resources, provide for basic needs and raise children with optimal health and development. Becoming a parent presents the need and motivation to develop functional health literacy; home visitors provide the opportunities, support and resources to make progress.

Home visitors may buffer the negative impact of low health literacy by offering concrete assistance in selecting and negotiating entry into institutional and community-based health resources. In addition to enhancing the likelihood of accessing positive support, home visitors may mitigate the effects of negative support from family and friends.

Home visitors provide reliable information and assist parents to use information to assess and respond to pregnancy complications, medical conditions, and child health and development problems. The parents' literacy skills may or may not be altered by such informational support. However, such support is potentially powerful in buffering the negative impacts of low health literacy skills. Useful

information also helps reduce uncertainty and anxiety, and provides a personal sense of control over individual literacy problems (such as low health literacy) (Antonucci 2001).

The moderating effect of home visitors' support, might take place through altering the perception of low health literacy. Studies have shown that care-seeking behavior is constrained by an individual's socio-psychological circumstances (Alonzo & Reynolds 1998). The stigma and shame associated with low literacy may prevent many disadvantaged parents from communicating their health needs to providers and obtaining timely appropriate care (Nurss 1998; Parikh, Parker, Nurss, Baker & Williams 1996). Tangible support, such as a home visitor urging and helping plan a doctor visit, may overcome such limitations (Gotay 1998). Further, the sense of being supported by a home visitor may enable a parent to face a stressful situation that would otherwise seem overwhelming (Holahan, Moose & Bonin 1997; Pearlin & Aneshensel 1996). Although the parent may or may not become more literate, with home visitor support she may feel less ashamed, more willing to seek help to increase her literacy skills, and more active in seeking advice from the home visitor and healthcare providers. Further, home visitors may compensate for negative effects of low health literacy skills by modeling healthy behaviors and supporting parents in making healthful behavior changes.

Thus the usual activities of home visitation may improve mothers' use of healthcare services and their ability to maintain their health and promote their children's healthy development at home. Improved understanding of how and when this improvement happens can guide design of interventions to actively promote health literacy. Future research should evaluate the effects of home visitation on functional health literacy. This will require new instruments, such as the Life Skills Progression, that document observed functioning in the health contexts at home and in the healthcare system.

Summary

Healthy People 2010 public health objectives for the nation call for measurable improvement in health literacy among persons with low literacy skills. Further, reducing disparities in healthcare access and outcomes requires improved health literacy in all population segments. Current US definitions of health literacy miss the functional nature of health literacy and the possibility of progress over time toward optimal functioning. Broader perspectives suggest that whether low health literacy leads to negative outcomes is determined by the amount of social support and resources present in a person's environment.

The current narrow conceptualization of health literacy as reading ability is inadequate to understand and promote individual's capacity to function in health contexts. Equating health literacy to reading skill is misleading and testing reading ability in healthcare settings is uninformative and demeaning to patients. Efforts to promote health literacy within the healthcare delivery system are unlikely to be effective due to patient and provider limitations.

A more promising alternative may be for healthcare services providers and public health workers to support improved general literacy by facilitating non-intrusive identification of persons with low reading skills and referral to literacy-enhancing services with a screening tool such as the one developed by Bennett et al. To understand health literacy, its factors and implications for practice, functional health literacy may be more informatively measured by periodically observing and documenting a person's functioning in health contexts with instruments such as the Life Skills Progression.

Health literacy may be more effectively promoted through maternal child health home visitation programs that provide social support and build life skills through long term personal relationships and reach a large portion of low-literacy adults at a time when motivation and readiness to learn are high and when both positive and negative outcomes extend to the children, family and community. A trial of home visitation in various existing models as a means to buffer the effects of low health literacy through social support may demonstrate that home visitors improve health literacy through their usual activities and suggest specific interventions.

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