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The evolving concept of health literacy[☆]

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ABSTRACT

The relationship between poor literacy skills and health status is now well recognized and better understood. Interest in this relationship has led to the emergence of the concept of health literacy. The concept has emerged from two different roots – in clinical care and in public health. This paper describes the two distinctive concepts that reflect health literacy, respectively, as a clinical “risk”, or a personal “asset”. In the former case a strong science is developing to support screening for poor literacy skills in clinical care and this is leading to a range of changes to clinical practice and organization. The conceptualization of health literacy as an asset has its roots in educational research into literacy, concepts of adult learning, and health promotion. The science to support this conceptualization is less well developed and is focused on the development of skills and capacities intended to enable people to exert greater control over their health and the factors that shape health. The paper concludes that both conceptualizations are important and are helping to stimulate a more sophisticated understanding of the process of health communication in both clinical and community settings, as well as highlighting factors impacting on its effectiveness. These include more personal forms of communication and community based educational outreach. It recommends improved interaction between researchers working within the two health literacy perspectives, and further research on the measurement of health literacy. The paper also emphasizes the importance of more general strategies to promote literacy, numeracy and language skills in populations.

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Literacy and health

Poor literacy skills among adults are surprisingly common in developed countries. Estimates of the proportion of the population in individual Organisation for Economic Co-operation and Development (OECD) countries lacking functional literacy skills range from 7% to 47% (UN Development Program, 2007). In developing countries these figures are far higher. Though there is a range of definitions of functional literacy, most focus on the ability to read basic text and write a simple statement on everyday

life. Functional literacy is important. It is through these skills of reading and writing that those who are literate are able to participate more fully in society, both economically and socially, and are able to understand and exert a higher degree of control over everyday events.

Not surprisingly, low literacy in a population is associated both directly and indirectly with a range of poor health outcomes (Parker, 2000). Data from many developed nations show a relationship between low literacy levels and declining use of available health information and services. This is observable in relation to responsiveness to health education, the use of disease prevention services, and in poor self-management of disease (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004).

Indirectly, low literacy is often linked to poor socio-economic circumstances, and this in turn is associated with adverse effects on health that are independent of other risk

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factors. A recently published statement from the WHO Commission on the Social Determinants of Health identified literacy as having a “central role” in determining inequities in health in both rich and poor countries (WHO Commission on the Social Determinants of Health, 2007).

Public discourse on the relationship between literacy and health is poor, and generally disappointing on the full range social determinants of health (Hayes et al., 2007). As such, the corrosive impact of poor literacy on health remains largely hidden, and the opportunity for public debate on the social determinants of health is significantly constrained.

Responding to low levels of literacy in a population involves improving access to effective school education, and providing adult education for those who missed out. The WHO Commission Report concludes that “removing the numerous barriers to achievement of primary education will be a crucial part of action on the social determinants of health”. Thus, achieving high levels of literacy in a population is not only a vital development goal, but will also produce substantial public health benefits (WHO Commission on the Social Determinants of Health, 2007).

From the more narrow perspective of the health system, the effects of poor literacy can be mitigated by improving both the quality of health communications, and greater sensitivity among health professionals to the potential impact of low literacy on individuals and in populations. Such responses can be observed in a range of adaptations to traditional patient and population health education methods in print, broadcast and electronic communication, as well as improved interpersonal communication between the public and health care providers (Coulter & Ellins, 2007; Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005).

Different approaches to health literacy

Health literacy as a risk factor

The growing awareness of the relationship between literacy and health has led to a range of responses to mitigate the negative effects. This interest is observable in research into the measurement of health-related literacy, examination of the relationship between low literacy and a range of health conditions, and progressive testing of interventions designed to mitigate the effects of low literacy through modified communications, and improved service organization (Coulter & Ellins, 2007; Pignone et al., 2005; Rootman & Ronson, 2005). More recently, a small number of studies have also considered the costs of low literacy and a failure to manage the consequences to the health care system (Baker et al., 2002, 2004; Cho, Lee, Arozullah, & Crittenden, 2008; Howard, Gazmararian, & Parker, 2005). In combination this work on the costs and effects on health of low literacy has begun to attract the attention of policy-makers and health service providers.

Much of the original research that has exposed the relationship between low literacy, patient decision-making, compliance with prescribed medication use, and capacity to self manage disease has emanated from the United States. In this literature, the term “health literacy” is commonly used to describe the set of individual literacy

capacities that act as a mediating factor in health and clinical decision-making (Baker, 2006). In this context, poor literacy skills are seen as a potential risk factor that needs to be managed in the process of providing clinical care.

A landmark publication in recent years has been the US Institute of Medicine 2004 report *Health Literacy: A Prescription to End Confusion* (Institute of Medicine, 2004). The US Institute of Medicine report 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.

The Institute’s Report records important work done mostly in the US on the development of health literacy measurement tools and “screening aids” for clinicians such as the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) or the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995). It also describes the state of the science of health literacy and its association with a range of health practices and outcomes, especially effective management of chronic disease, compliance with medication and other health advice, and participation in health and screening programs.

The Institute’s definition goes on to recognize the social context of health decision-making:

...based on the interaction of the individual’s skills with health contexts...and broad social and cultural factors at home, at work and in the community.

The Institute of Medicine definition examines health literacy as a set of individual capabilities in the four domains of cultural and conceptual knowledge, speaking and listening skills, writing and reading skills and numeracy. This conceptualization of health literacy as a set of capacities also implies that health literacy is partly knowledge based, and may be developed through educational intervention. It also emphasizes that health literacy is context specific and subject to influence by health care interactions and structures such as the way in which services are organized and delivered.

Baker has offered a thoughtful examination of the definition and highlights some of the continuing confusion and disagreement concerning the use of the term (Baker, 2006). He particularly draws attention to the measurement challenges that emerge from the definition proposed by the Institute stating that if health literacy is the capacity of a person, measures of an individual’s reading ability and vocabulary are appropriate. Baker also argues that if health literacy depends on the relationship between individual communication capacities, the health care system, and broader society, measures at the individual level are clearly inadequate. Finally, he makes the point that if knowledge is a part of the definition of health literacy, then this too must be measured (Baker, 2006). None of the commonly used screening tools offers this breadth of assessment.

Paasche-Orlow and Wolf (2007) have proposed a logic model linking this conceptualization of health literacy to health outcomes. This too emphasizes both an individual

patient and health care system perspective to health literacy. They propose that health literacy influences health outcomes at three critical points, namely, access to health care, the interaction between patients and their health care professionals, and self-care. The authors acknowledge that their model is limited both by the availability of relevant empirical data, and the complexity of the relationships that are summarized in this type of model. Nonetheless, the paper provides clear signals as to three key issues that need to be considered when planning interventions to compensate for poor literacy and language skills.

Fig. 1 offers a summary representation of the Institute of Medicine model for health literacy taking account of the modifications proposed by Baker (2006) and the logic model proposed by Paasche-Orlow and Wolf (2007). The model places health literacy as a risk factor that needs to be identified and appropriately managed in clinical care. It begins with assessment of relevant prior knowledge and/or individual reading literacy using a screening tool such as REALM or TOFHLA (1). It reflects the importance of the context for communication, through health service organization and a clinical environment that is more sensitive to the needs of individuals with low literacy (2). Improved service organization and clinician sensitivity can improve access to health care services, and enhance the quality of interaction between patients and health care providers (3). This leaves a clinician better placed to provide patient education that is tailored to individual needs and capacities (4) that is more likely to result in improved patient capabilities to adhere to recommended clinical care (5). In turn, this leads to improved health outcomes associated with successfully implemented clinical care (6).

Health literacy as asset

A distinctly different conceptual approach has evolved from origins in public health and health promotion. This

conceptualization emanates from an understanding of the role of health education and communication in developing competencies for different forms of health action (personal, social and environmental). Health literacy in this case is seen as a means to enabling individuals to exert greater control over their health and the range of personal, social and environmental determinants of health.

From this public health perspective, health literacy is seen as an asset to be built, as an outcome to health education and communication that supports greater empowerment in health decision-making. This contrasts markedly from the conceptualization of health literacy described in Fig. 1. Actions to improve health literacy are focused on developing age and context specific health knowledge, and the self-efficacy necessary to put that knowledge into practice in ways that enable people to exert greater control over their health and health-related decisions (Nutbeam, 2000). This conceptualization of health literacy has its roots in educational research into literacy, and concepts of adult learning and health promotion (Freebody & Luke, 1990; Imel, 1998). Research to support these ideas is at a more developmental stage and has emanated mainly from the UK, Australia, and Canada (Coulter & Ellins, 2007; Renkert & Nutbeam, 2001; Rootman & Ronson, 2005).

Subtly different to the IOM definition, WHO has adopted a definition of health literacy that reflects a health promotion orientation, as follows:

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.

The WHO definition goes on to say:

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. Thus, health

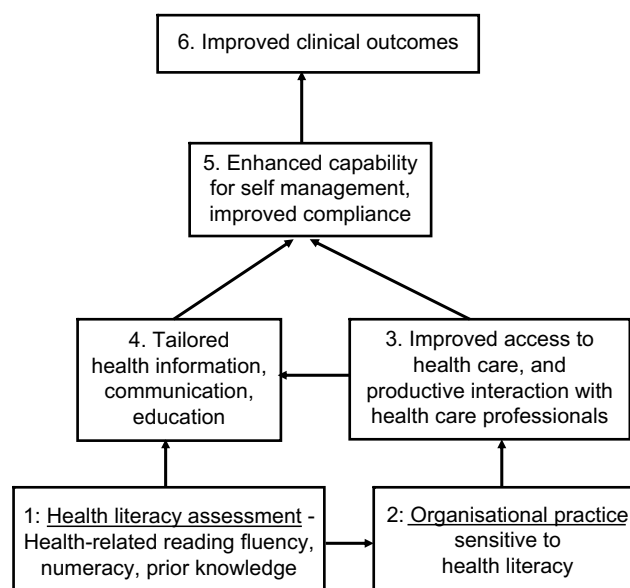


Fig. 1. Conceptual model of health literacy as a risk.

literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment (Nutbeam, 1998).

The definition adopted by WHO aligns health literacy more closely with an understanding that literacy is not simply a set of functional capabilities, it comprises a set of skills that enable people to participate more fully in society, and to exert a higher degree of control over everyday events. The ability to read and write (functional literacy) is a foundation for health literacy on which a range of complementary skills can be built.

The field of literacy studies is alive with debate about different "types" of literacy and their practical application in everyday life, distinguishing for example between functional, interactive and critical literacy (Freebody & Luke, 1990). These different "types" of literacy characterise the practical application of literacy skills ranging from those needed to be able to function effectively in everyday situations (functional), to more advanced cognitive and literacy skills which can be used to actively participate in everyday activities and to apply new information to changing circumstances (interactive), through to the most advanced cognitive skills which can be applied to critically analyse information, and to use this information to exert greater control over life events and situations (critical literacy). These skills can be developed through formal education and through informal personal experiences.

Using such insights from the broader study of literacy, a previous paper proposed that health literacy can be categorized into different levels that progressively reflect greater autonomy and personal empowerment in decision-making, as well as engagement in a wider range of health actions that extend from personal behaviours to social action to address the determinants of health (Nutbeam, 2000). Progression between types is not only dependent upon cognitive development, but also exposure to different forms of communication and message content. Personal responses to such communications are mediated by personal and social skills, and self-efficacy in relation to defined issues that are often context specific. For example, as signaled in the introduction, the capacity of individuals to respond effectively to the social determinants of health will be significantly influenced by the nature of public discourse on the subject.

Conceptualizing health literacy in this way, by recognizing the goal of empowerment through the development of interactive and critical health literacy skills, has important implications for the scope of the content of health education and communication. It follows that health education to improve people's knowledge, understanding and capacity to act, should not only be directed at changing personal lifestyle or improving compliance with prescribed disease management strategies. Health education could also raise awareness of the social determinants of health, and be directed towards the promotion of actions which may lead to modification of these determinants. Even in relation to patient education, educational content may be broadened to include genuine options for the self-management of disease, the development of skills that enable confident interactions with health care providers,

and the ability to navigate or negotiate effectively in the health care system.

This has obvious implications for the methods of education and communication, challenging health educators to communicate in ways that draw upon personal experience, invite interaction, participation and critical analysis. Such an approach to education and communication draws on established principles in adult education that can be applied to people with low and high levels of literacy (Imel, 1998).

This understanding of health literacy identifies it as a distinct concept, rather than a derivative concept from literacy and numeracy skills. Fig. 2 builds upon the foundations of the model described in Fig. 1. As with Fig. 1 it commences with recognition of prior knowledge and capability (1), leading to tailored health education and communication (2). At this point the model varies significantly indicating the purpose of the health education as being directed towards the development of relevant personal knowledge and capability (3), and interpersonal and social skills (4,5). In Fig. 2 health literacy is *the outcome* of education and communication rather than a factor that may influence the outcome (6). People who have better-developed health literacy will thus have skills and capabilities that enable them to engage in a range of health enhancing actions including personal behaviours (7), as well as social actions for health and the capability of influencing others towards healthy decisions such as quitting smoking, or participating in preventative screening programs (8,9). The results are not only improved health outcomes but also a wider range of options and opportunities for health (10).

The measurement of health literacy

The different definitions of health literacy imply that different measurement tools are developed. In the US the TOFLA and REALM measures have been tested, refined and validated over time to provide short screening tools for clinicians to use in everyday practice with a broad range of populations, including, for example, with adolescents (Chisolm & Buchanan, 2007). As indicated above, Baker expresses concern that neither is comprehensive, measuring only selective domains that are thought to be markers of an individual's overall capacity (Baker, 2006). He argues that it is essential that we learn more about how well people can read and comprehend health-related materials ranging from nutrition labels on food through to patient information on specific conditions. These existing measures are also limited in the extent to which they focus on reading literacy, and are not necessarily a good guide to confidence in oral communication.

In the US, the Health Activity Literacy Scale (HALS) gets much closer to this form of more comprehensive test by including different health-related competencies in five domains – health promotion, health protection, disease prevention, health care and maintenance, and systems navigation (Educational Testing Service, 2006; Rudd, 2007). Baker (2006) points out that this test is new, its properties are unknown, and that the full-length test takes up to 1 h to administer. If it is to be more widely used, it will need to be

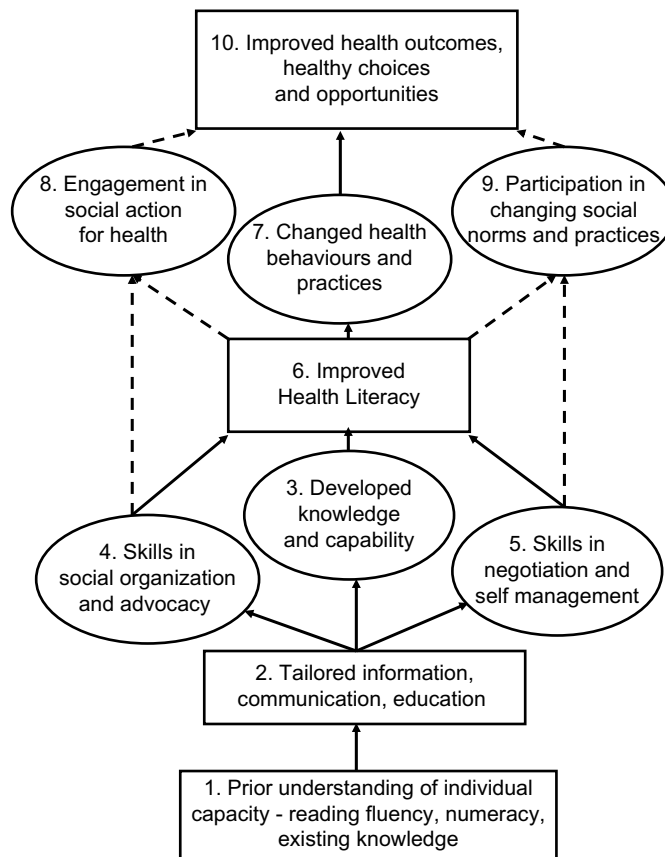


Fig. 2. Conceptual model of health literacy as an asset.

made more accessible to researchers, and an abbreviated version will need to be developed in parallel with its continued use as a benchmark measure.

Even the HALS test still reflects a view of the measurement of health literacy as a derivative of the measurement of literacy, rather than as a distinctive, independent concept. If we accept the idea that health literacy is an independent concept that reflects the skills and capacities that enable people to exert greater control over their health, this has important implications for measurement. In this conceptualization of health literacy, much work remains to be done to develop more comprehensive measures that will assess individual health literacy in terms of a person's ability *to access, understand and use health information* in ways that promote and maintain good health.

It is highly likely that different measurement tools will be required for different ages and stages in life – even if the structure of the concept remains constant. This will take into account the different social contexts in which health literacy is relevant, recognized explicitly in the Institute of Medicine definition, and implicitly in the WHO definition. For example, assessing the health literacy of students in school will require different questions compared to assessing the health literacy of older people with chronic disease. Different measures will be required to distinguish between functional, interactive and critical health literacy.

These measures will need to include assessment of a person's ability to

- gain access to age and context specific information from a variety of different sources,
- discriminate between sources of information,
- understand and personalise health information that has been obtained,
- appropriately apply relevant health information for personal benefit.

Assessing interactive and critical literacy will require additional assessment of oral literacy and social skills such as those involved in negotiation and advocacy.

These are not totally new challenges in the social sciences, but will require systematic development and testing in the same way that the existing TOFHLA and REALM measures have been developed.

Where to from here?

The two conceptualizations are similar in some respects but distinctly different in others. Both are dependent on the underlying base of literacy and numeracy, and are context and setting specific. In the asset model, health literacy is a distinct concept, an outcome to health and patient education. In the risk model health literacy is a “prior

status” derived from existing literacy and numeracy. In the asset model, health education is directed towards enabling individuals to exert greater control over a broad range of factors that determine health. In the risk model, health education is more goal-directed, intended to lead to compliance with recommended clinical care. The risk model is mostly restricted to application in clinical settings, whereas the asset model can be applied to a broad range of settings. These fundamental differences have important implications for the measurement of health literacy, and its application as a concept in clinical and community settings.

However, both conceptualizations of health literacy are important. The US “risk” concept reflects recognition of the impact that low literacy can have on the effectiveness of clinical care. As a consequence of this work the actions being taken to improve the sensitivity of clinicians and service managers to the effects of low literacy on health decision-making and compliance will help to minimize the disadvantage suffered by individuals with low literacy. This represents important progress in addressing a source of disadvantage and inequity in the health care system, and suggests that the improvements in patient education and management being achieved in the US should be migrated widely.

However, conceptualizing health literacy as a “risk” does have its limitations. As indicated above, framing health literacy more as an “asset” that can be built through patient education may support more comprehensive options for the self-management of disease, enable the development of skills to foster confident interactions with health care providers, and the ability of patients to navigate or negotiate the health care system. There are welcome signs of recognition of the complexity of health decision-making in current research (Coulter & Ellins, 2007; DeWalt, Boone, & Pignone 2007; Hibbard, Peters, Dixon, & Tusler, 2007). Improved interaction between researchers and advocates of the two health literacy perspectives would undoubtedly enrich both.

The conceptualization of health literacy as an “asset” offers great promise in terms of potential impact on health and the range of actions it may enable. The potential of health education as a tool that enables action on the social determinants of health has been somewhat neglected (Nutbeam, 2000). This conceptualization of health literacy can help to bring it back to life. In addition, the “asset” concept lends itself to a broader application outside of health care settings, for example into schools, adult learning, and community development programs. However, the concept is less well tested through systematic research. In the absence of better-developed measures and quality research and evaluation, the “asset” model remains a powerful idea, but not one that is yet established as practical for widespread implementation. Systematic research is needed to develop the empirical basis for the concept, lest the advocacy for this model exceeds the evidence for its adoption.

Both conceptualizations challenge current health and patient education methods and are helping to stimulate a more sophisticated understanding of the process of health communication in both clinical and community settings, as well as highlighting factors impacting on its effectiveness (Coulter & Ellins, 2007). Both clearly depend

upon levels of literacy, numeracy and language competence in individuals and populations. Individuals with undeveloped skills in reading, oral communication and numeracy will not only have less exposure to traditional health education, but also less developed skills to act upon the information received. For these reasons, strategies to promote health literacy will remain inextricably tied to more general strategies to promote literacy, numeracy and language skills in populations. Innovative initiatives such as the English *Skilled for Health* program illustrate the potential of combining the two goals, by bringing health “content” into an adult literacy program (Department for Education and Skills, 2006).

If achieving health literacy as defined by WHO is to be a goal, some widening of content and methods will need to occur. Improving health literacy in a population involves more than the transmission of health information, although that remains a fundamental task. Helping people to develop confidence to act on that knowledge and the ability to work with and support others will best be achieved through more personal forms of communication, and through community based educational outreach. If the goal of promoting greater independence in health decision-making and empowerment among the individuals and communities is to be achieved, there will need to be more sophisticated understanding of the potential of education to strengthen political action, and efforts to ensure that the content of health communications not only focuses on personal health, but also on the social determinants of health.

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