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*Literature Review*

DANIELA MAAG\*

## HEALTH LITERACY – COMPENDIUM OF PRIOR RESEARCH

This review provides a compendium of prior research on Health Literacy and elaborates on the interdisciplinary foundations of the concept and the variations in its definition and measurement. It is proposed that an innovative approach to Health Literacy is needed if trying to address the challenges of an ever more complex environment for health decisions and choices, of a more complex healthcare system, and of increasing healthcare costs.

*Keywords:* literature health literacy; measurement and identification of health literacy; health literacy intervention.

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## 1. Introduction

Health has become a major theme of modern societies (Kickbusch 2004). People are inundated by health information and whether or not their response to this information translates in *healthy choices* is key to the future of health and health care systems. In this sense Health Literacy has been receiving increased attention as a critical component for managing personal health (Schulman 2004) and navigating the health system. It has been recognized internationally that Health Literacy is an important public policy issue (Dubow 2003) and that limited Health Literacy is an enormous burden to the US healthcare system (DeBuono, 2004). This paper provides a review on prior research about the critical issue of Health Literacy: How has Health Literacy been conceptualized, how is it measured, and what are possibilities for the improvement of Health Literacy?

## 2. Method

The Pub Med (MEDLINE®) Database was used for a systematic search of the period from 1995 to July 2005 with the search term *Health Literacy*. On July 20, 1995, 232 references were found. Of the 232 articles retrieved, 145 presented the term *Health Literacy* in the title. 17 articles presented the term *Mental Health Literacy* and were not included in this analysis. The articles revised for this review present the major contributions to Health Literacy research. References of leading articles and previously conducted literature searches were considered for the present analysis.

## 3. Health Literacy research

At least three major issues have been addressed extensively in research on Health Literacy:

- (a) The genesis, scope, and prevalence of Health Literacy
- (b) The measurement and identification of Health Literacy
- (c) Interventions for the improvement of Health Literacy

### *(a) The genesis, scope, and prevalence of Health Literacy*

The Center for Health Care Strategies Inc. (2003) proposes a basic definition of Health Literacy using a functional approach: "*Health Literacy is the ability to read, understand and act on health care information.*"

Functional Health Literacy focuses on the ability to apply reading and numeracy skills in the health care setting. Skills include the ability to read consent forms, medical labels and insertions, and other written health-care information, the ability to understand written and oral information given by healthcare professionals (e.g. healthcare instructions), and the ability to act upon necessary procedures and directions such as medication and appointment schedules (Andrus & Roth 2002). Inadequacy of these skills stems from both limited literacy skills of consumers and the provision of information to consumers in forms that are inadequate or incomprehensible.

According to the U.S. National Adult Literacy Survey (NALS) (Kirsch et al. 1993), about 21% of American adults lack the necessary literacy skills to function effectively in society, and another 27% present only marginal literacy skills. As such, nearly half of the adult U.S. population has inadequate reading or computation skills to deal effectively with highly literate healthcare information. Understanding and acting upon health information is also difficult for many individuals due to inadequate, user-unfriendly, and incomprehensible consumer information, as well as confusing interactions with healthcare professionals (Hochhauser 2003; Faguy 2004). Health materials such as patient education brochures, discharge and contraception instructions, and consent forms are often written at levels exceeding patients' reading skills (Ad Hoc Committee on Health Literacy for the Council of Scientific Affairs 1999). Complex medical information presented in ever changing formats challenges even audiences with adequate literacy (Merriman et al. 2002). The terminology or "*language*" doctors are using in healthcare encounters is a barrier to effective interaction (Williams et al. 2002). Often doctors, nurses, and other healthcare professionals – who are all well educated – do not understand that what seems obvious to them can cause confusion in patients. Nurses, who are among the most trusted of health professionals, are especially challenged when interacting with low literate patients (Mason 2001). Low functional literacy has serious consequences for individual health (Brown et al. 2003; Scholman 2004). People with limited Health Literacy have difficulties understanding oral and written information provided by health professionals (e.g. doctors (Williams et al. 1995; Parker & Jacobson 2000)) and acting upon this information (e.g. comply to prescriptions). This is compounded by the fact that health care professionals are seldom aware of patients' literacy problems (Montalto & Spiegler 2001). Patients with low literacy may not realize what information doc-

tors need from them and may not have the vocabulary to report symptoms adequately (Williams et al. 2002). These patients often receive subsidized health services, cause higher health costs, are less healthy, have a higher hospitalization rate, and are less responsive to preventive care (Joint Committee on National Health Education Standards 1995; Baker et al. 1997; Baker et al. 1998; Williams et al. 1998a; Williams et al. 1998b; Schillinger et al. 2002; Nielsen-Bohlman et al. 2004; Vastag 2004). Functional Health Literacy is particularly low and problematic among older persons (Gazmararian 1999; Baker et al. 2000; Chew et al. 2003). Inadequate Health Literacy among elderly managed care enrollees was found to be a predictor for hospital admission (Baker et al. 2002a) and lower use of preventive health services (Scott et al. 2002).

Poor Health Literacy skills have been associated with a lack of knowledge about health concepts, disease, and cure (Parker 1996; Williams et al. 1998a; Williams et al. 1998b; Kim 2001; Weiss 2001). Studies on specific Health Literacy problems found that illiteracy and poor health status are independently associated, with a particularly strong association between literacy skills and physical health (Weiss et al. 1992). Health Literacy is significantly related with ever having had a mammogram (Guerra 2005), as well as screening for cervical and colorectal cancer (Davis et al. 2001; Lindau et al. 2002). For the case of cancer, inadequate Health Literacy also hinders discussions about risks and benefits of treatment options, informed consent and routine procedures, and clinical trials (Davis et al. 2002). Health-related knowledge – including sources of information and knowledge (Wolf et al. 2004) – and adherence to treatment for HIV and AIDS is strongly related to levels of education and functional Health Literacy (Kalichman et al. 1999; Kalichman & Rompa 2000; Devereux 2004). Low Health Literacy is also a predictor of poor glycemic control in diabetics and is associated with a lower likelihood of achieving tight adherence (Rothman et al. 2002; Schillinger et al. 2002). Beyond functional literacy, some definitions of Health Literacy address the ability to *apply* general literacy skills to the healthcare setting. On this view, Health Literacy is not only the ability to read and act upon health information (Kickbusch & Ratzan 2001; Cutili 2005), but to use this information effectively. Parker, for example, defines Health Literacy as the “*degree to which people have the capacity to obtain, process and understand basic health information and services and make appropriate health decisions* (2003).” The World Health Organization (WHO) defines Health Literacy as the “*social and cognitive abilities that enable a person to*

*act in a health promoting way* (1998; Nutbeam 2000),” including the access to information, the capability of understanding it, and the ability to deal with it (Duetz 2003). Nutbeam (2000) proposes a definition of Health Literacy conceptualizing it on three different levels (Tones 2002) and argues that Health Literacy involves a complex constellation of skills that are needed to function effectively in the health care setting (Fetter 1999; McCray 2005). In his model, he includes *functional*, *interactive*, and *critical* Health Literacy. Functional Health Literacy is defined by basic reading and writing skills that enable an individual to function effectively in health. Interactive Health Literacy refers to more elaborate literacy and social skills that can be used to actively participate in health. Finally critical Health Literacy encompasses advanced cognitive and social skills needed to critically analyze health information and understand political and economic dimensions of health. In sum, an individual with an adequate level of Health Literacy has basic and elaborated knowledge, competencies, learned skills, and abilities to take the responsibility to act in a health promoting way in everyday life. Health Literacy further includes the knowledge of whether and when to establish contact with the health system, how to navigate it, and how to interact with health professionals.

*(b) The measurement and identification of Health Literacy*

Healthcare professionals cannot assume that all patients know how to read and have adequate literacy skills. However, directly questioning patients about reading and writing levels might also be ineffective, as their illiteracy causes shame and embarrassment (Parikh 1996). Although there is a relationship between education and literacy, reading skills and understanding cannot be accurately deduced from educational attainment (Davis et al. 1998). In the face of these difficulties, most healthcare professionals have developed some informal methods enabling them to determine whether their patients may read and express themselves at adequate levels. These informal assessments include posing informal questions to patients, like asking them to explain prescription labels and medication regimes. Another is the teaching-back method where patients are asked to refer to the physician what was explained just before.

Formal assessment tools today are mostly used in research to explore relationships between Health Literacy levels and health outcomes. They can be categorized as word recognition tests and instruments for the assessment of functional Health Literacy. Word recognition tests are



employed for the prediction of general reading ability. The assumption behind this is that if patients have difficulties with words, they are most likely to have difficulties with written information.

A number of authors have employed the Rapid Estimate of Adult Literacy in Medicine (REALM) test in either its original or revised version (REALM-R). This measure, based on medical word recognition, provides an assessment of Health Literacy. Shea et al. (2004) evaluated the validity and reliability of REALM scores among various patient subgroups. They found that the REALM is a robust assessment of Health Literacy. Bass et al. (2003) revisited the REALM and developed a shortened version as a rapid screening instrument to assess how well primary care patients read words that they commonly experience and are expected to understand during interactions with their physicians. The REALM has been used to assess the relationship between Health Literacy and agreeing to a screening test for gonorrhoea (Fortenberry et al. 2001). Low Health Literacy is posing major problems and barriers to care for sexually transmitted diseases. This relationship seems to be stable after controlling for selection biases due to missing data, demographic variables such as health status, suspicion of gonorrhoea, and self inspection (Fortenberry et al. 2001). Other studies using REALM describe the relationships between Health Literacy, ethnicity, socioeconomic status, and cervical cancer and prostate cancer screening knowledge and practices (Kim 2001). The REALM was also used by Kaufman et al. (2001) to investigate the effect of functional Health Literacy on the initiation and continuance of breast-feeding in women at a public health clinic. They found that Health Literacy is related to breastfeeding.

Tests for functional Health Literacy move beyond word recognition tests. Functional Health Literacy tests like the Test of Functional Health Literacy in Adults (TOFHLA) assess how well patients not only comprehend but also understand examples out of the healthcare reality. The psychometric properties of the TOFHLA are discussed in Aguirre et al. (2005). The test, also available in Spanish and in a short version (S-TOFHLA) (Baker et al. 1999), provides the physician with indications on how well her or his patients might function in the healthcare environment (Parker 1995). The TOFHLA has been employed in clinical settings investigating relationships between patients' functional Health Literacy and their understanding of health information (Gausman Benson % Forman 2002; Georges et al. 2004), as well as status related to various health problems such as diabetes type 2 (one study for the case of

prenatal diabetes (Endres 2004)), HIV/ AIDS, and other chronic diseases (Williams et al. 1998a; Kalichman et al. 1999; Kalichman et al. 2000; Schillinger et al. 2002; Schillinger et al. 2004).

An innovative study looking at the best questions to identify parents' Health Literacy found that the best indicator is asking them an open-ended question about the number of children's books in their home (Sanders et al. 2004).

Functional Health Literacy is undoubtedly reliant on general literacy and cognitive development (Gottesman 1996). Poor literacy not only hinders Health Literacy but can also limit an individual's personal, social, and cultural development (WHO 1998). Baker et al. (2002b) found this evidence looking at the relationship between a measure of cognitive impairment (Mini Mental State Examination (MMSE)) and performance on the S-TOFHLA.

Health Literacy is also assessed with other instruments than the *standard* measures discussed above. Especially when short screening procedures for the assessment of Health Literacy are needed, existing methods are not always adapted. Chew et al. (2004) developed a series of brief questions to identify patients with inadequate Health Literacy. Their screening questions need to be confirmed for diverse populations. However, they might be an important advance towards developing a real practical method for identifying patients with low Health Literacy.

### *(c) Interventions for the improvement of Health Literacy*

Over the past decade, increased interest in Health Literacy has reinforced movements to empower consumers and patients. The link between literacy and health (Lee et al. 2004) challenges practitioners of health education and health communication (Nutbeam 2000) as well as healthcare providers (McCormick et al. 2003). Kickbusch, for example, has criticized the Health Literacy definition by the World Health Organization, stating that Health Literacy is not only about individual competencies but has to be considered as a concept of public health (2002). She argues that the interplay between the quality of health information and communication that people receive and their level of Health Literacy – determining the ability to understand and use that information – is key to building *healthy nations*. Gazmararian (2005) suggests steps to be put in place for achieving more public health-literate societies by first defining what is meant by public Health Literacy and developing measures. Next, existing health communication efforts have to be critically evaluated in



the light of improving public Health Literacy. Importantly, it has to be recognized that the possession of health related knowledge is necessary but not sufficient for engaging in healthy behaviors. An individual with an adequate level of Health Literacy also has basic and elaborated knowledge, competencies, learned skills, and abilities to take responsibility to act in a health promoting way in everyday life.

This view suggests that, beyond understanding health information, using the health care system, and being knowledgeable about and practicing healthy behaviors, there is a need to support consumers to exercise choice in a highly unregulated health and wellness market. People providing information to the public do have the responsibility to report accurate and easily understandable information (Payne & Schulte 2003). This is, however, rarely translated into reality. Nevertheless, much literature has focused on the improvement of limited Health Literacy. The studies approach the problem from different viewpoints such as (1) systematic intervention studies, (2) patient counseling proposals, (3) recommendations for possible strategies for the improvement of Health Literacy, and (4) studies on educational interventions.

Onishi et al. (2005) report on the implementation of a community based antenatal program for the improvement of maternal Health Literacy among pregnant women who did not complete compulsory education. They found a significant increase in maternal health knowledge after the women's participation in the community-based program. The use of a patient assistant to facilitate medical visits for patients with low Health Literacy improved the healthcare visits of Latin American immigrants who are often burdened by cultural and linguistic barriers and minimal education (Sarfaty 2005).

The role of the pharmacist is a central one in the Health Literacy discourse. Often pharmacists are the first contact for people confronted with health problems and the first ones to recognize inadequate Health Literacy. Pharmacists must recognize each patient's Health Literacy skills and language barriers. Without this clear and thorough recognition, counseling by pharmacists cannot be realized (Hardin 2005). The first interaction between pharmacists and patients can serve as an opportunity for the pharmacist to recognize patients who might have limited or inadequate Health Literacy. The establishment of a caring and trusting relationship between the pharmacist and the patient will help to uncover literacy insufficiencies effectively (Nicholas-English 2000). It is increasingly requested that pharmacists and student pharmacists be edu-

cated about the relationship between literacy and health and are sensitized for the adequate communication with low health literate patients (Youmas & Schillinger 2003).

Health education is another possibility for the improvement of Health Literacy at a school (Leger 2001) or at an adult education level. Numerous studies have investigated the role of health education, counseling, and health education material when it comes to the problem of low Health Literacy. Terry et al. report on the introduction of an HIV prevention counseling program to reduce risk-taking behavior of young adults in Zimbabwe. The program's implementation, consisting of a peer education program, showed positive results reducing risky sexual behavior among program participants (Terry et al. 2005). Health education, especially the role of health educators, is important to promote Health Literacy and enable people, patients, and even whole communities to live healthy lives (Peterson et al. 2001; Tappe & Galer-Unti 2001). Sarang et al. (2004) found that diabetes education material can be effective for the improvement of diabetes self-management, diabetes knowledge, and glycemic control for patients with limited Health Literacy. Expanding educational programs for patients with chronic diseases and low Health Literacy may reduce disparities in health outcomes. Health education was also implemented successfully in antenatal classes for the improvement of maternal Health Literacy. Renkert and Nutbeam (2001) report that women left prenatal classes with the skills and confidence to take a range of actions for a successful pregnancy.

Often, education materials are written and presented at reading levels far above recommended standards or are not tailored to patients' needs (Edmunds 2005). A systematic evaluation of literacy levels of patient education pages in health related journals by Cotunga et al. (2005) confirms this assertion. Besides Ratzan's (2001) strategic approach to aspects of health communication – integrated marketing communication, education, negotiation, and social capital – for the improvement of Health Literacy, many authors are proposing general recommendations on how to interact with patients with low Health Literacy in order to improve knowledge and confidentiality about their disease and lead them to improved Health Literacy. In healthcare, good or poor communication can determine health outcomes (Powell 2004). It is therefore important that physician–patient communication is effective in every healthcare encounter. Recommendations range from very general, such as *“people prefer information that is as easy to understand as possible”*, *“use of plain lan-*

*guage in written materials whenever possible (Merriman et al. 2002)", "[...] it is essential that health care providers promote informed decision making, and facilitate actions designed to improve personal capacity to exert control over factors that determine health and improve health outcomes (Levin-Zamir & Peterburg 2001)", to concrete examples for the improvement of patient-physician communication (no authors listed 2003; Fitzgerald 2004).*

#### 4. Discussion

Various authors cited in this review support the view of Health Literacy being a major issue. The prevalence of limited Health Literacy is causing vital problems in increasingly multifaceted healthcare settings. Patients with inadequate Health Literacy skills are performing poorly in highly complex health markets (they are for example not able to sufficiently interact with healthcare professionals, to read basic health material, and to understand medication instructions) causing enormous costs to the health system and to society in general. The present review shows, that, on the whole, research on Health Literacy has mainly focused on the healthcare system and on the patient's ability to read (write and sometimes express themselves) in this specific setting. In this sense, the concentration of prior research to the healthcare setting and to functional levels of Health Literacy presents two major limitations.

First, prior research does not sufficiently address the *depth* of Health Literacy: While the focus on functional levels is a very useful first step, Health Literacy cannot be limited to the pure ability to read and write health information. Instead, Health Literacy is a critical ability to make sound health decisions in the context of everyday life (Kickbusch & Maag 2005). In this perspective Health Literacy becomes crucial for managing ones own the other's health. Increasingly health skills are a part of the life skills needed in modern societies, and they are subject to rapid and continuous change. In an extended view Health Literacy includes self and family care and first aid, the application of health promoting; health protecting and disease preventing behaviors; health systems knowledge and utilization; as well as market/consumer behavior and political participation. Health Literacy becomes an active process in which people have to continually learn new information and unlearn outdated information in order to maintain good health as well as act and interact as informed citizens and patients.

Secondly, prior research has not sufficiently addressed the *breath* of Health Literacy. Exclusively focusing on the healthcare setting seems to overlook that Health Literacy is expanding beyond the health care setting into the context of everyday life, where ultimately – according the Ottawa Charter of Health Promotion (WHO 1986) – health is created. This view is partly supported by authors of previously published reviews and by major publications on Health Literacy such as the IOM (Institute of Medicine) report: *Health Literacy: A Prescription to End Confusion* as well as the Policy Information Report by Rudd et al.: *Literacy and Health in America*. (Andrus & Roth 2002; Berkman et al. 2004; Nielsen-Bohlman et al. 2004; Rudd et al. 2004; McCray 2005).

## 5. Conclusion

To address the challenges of an ever more complex healthcare system and increasing healthcare costs, it is necessary to have a broad understanding of Health Literacy. Research needs to be expanded from mainly focusing on functional Health Literacy to concentrating on the ability to make sound health decisions for the improvement of personal and other's health. It further has to concentrate on investigating the relationship of Health Literacy to performance in the healthcare setting and in the context of everyday life or to health status. Research has to acknowledge that Health Literacy includes many elements, such as basic health knowledge, knowledge and the application of health promoting, health protecting, and disease preventing behaviors, as well as self and family care and first aid, health systems knowledge and utilization, market/consumer behavior, and voting behavior. Health Literacy research further has to recognize that in modern health societies the concept expands to all aspects of everyday life and includes – besides the health care system – domains of investigation such as the home, the workplace, the marketplace, and the political arena (Kickbusch & Maag 2005; Kickbusch et al. 2005).

Additionally, the provision of pure choices will not suffice to improve health. The real challenge in Health Literacy research will be to make healthy options meaningful to various groups of society. As healthy behavior and the ability to navigate health are strongly related to high levels of Health Literacy, research needs to continue to be committed to find strategies for Health Literacy improvement which translates in sound health decisions in the context of everyday life. As a long term strategy Health Literacy research will need to address issues that are rooted in society, with people, and in the system contemporarily.

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