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Top Down versus Bottom Up: The Social Construction of the Health Literacy Movement

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Reviewed work(s):

Source: *The Library Quarterly*, Vol. 82, No. 4 (October 2012), pp. 429-451

Published by: [The University of Chicago Press](http://www.press.uchicago.edu)

Stable URL: <http://www.jstor.org/stable/10.1086/667438>

Accessed: 11/09/2012 16:00

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# TOP DOWN VERSUS BOTTOM UP: THE SOCIAL CONSTRUCTION OF THE HEALTH LITERACY MOVEMENT

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The health literacy movement has been socially constructed over time. Unlike the consumer health information movement, which developed with broad public support, the health literacy movement has been fashioned primarily from the top down, initiated by policy makers and imposed on targeted populations. Interest in the health literacy movement has waxed and waned, often dependent on political agendas. In an era of increasing health care costs, it is not surprising that health literacy is once again at the forefront, given that economists and policy makers currently estimate the cost of limited health literacy in the United States to be between \$1.6 to \$3.6 trillion annually. Health literacy has been recognized as an issue key to the success of health care reform and to the continued advancement of the nation's status as an international leader where health and well-being are concerned. Yet, the health literacy movement has met with limited success.

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## Introduction

In light of an ongoing debate in the United States regarding health care reform, some leaders in the health care arena have emphasized a focus on health literacy to address issues of cost containment, more effective health care delivery, and improved health outcomes. Currently, it is estimated that the cost of limited health literacy to the US economy is between \$106 and \$236 billion annually. It is further estimated that the real present-day cost may well be in the range of \$1.6–\$3.6 trillion US dollars annually [1], depending on future costs that result from current actions or inactions. In a world of shrinking resources coupled with increased demand, health care leaders are doing everything they can to cut costs yet retain quality

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[*Library Quarterly*, vol. 82, no. 4, pp. 429–451]

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0024-2519/2012/8204-0003\$10.00

care. Academic and governmental leaders have discussed these issues, including the impact of low health literacy on overall health outcomes, for decades. By the 1970s some policy leaders had realized that if individuals could understand more about their bodies and their care, they might become more willing to make lifestyle choices that would keep them out of hospitals and physician offices [2]. There was a barrier, however: a surprising number of Americans were barely literate, let alone health literate. Thus, a campaign was born.

The term *health literacy* was first used in 1974, but the concept that people ought to have the basic skills needed to function in the health care environment has had a long history in the United States. In the 1940s, when US soldiers were coming home from World War II, the military recognized that the health-related material they were providing the soldiers was unreadable by most and that some sort of plain language was needed for the information to be universally understandable. Intelligence began to be seen as capital in the 1960s and, sparked by the consumer movement, patients began demanding health information. The previously passive patient began to take an active role in an increasingly personalized health care environment.

During the last decades of the twentieth century, US leaders from academia, government, and business made note of the progressively more complex health care system, the educational level required to access it in meaningful ways, and a widening disparity in the educational and literacy levels of the citizenry. In 1999 the American Medical Association formally defined health literacy as the “constellation of skills, including the ability to perform basic reading and numerical tasks, required to function in the health care environment” [3, p. 553]. Since then this widely accepted definition of health literacy has undergone several iterations. Although many of the definitions have originated in significant agencies and organizations, as recently as July 2009, scholars were still calling for “the need to refine health literacy definitions and conceptual models” [4] (see table 1).

Implicit in most definitions is the notion that health literacy, much like any other type of literacy, goes well beyond mere numeracy and grade-level reading ability. Rather, it is contextual and includes sociocultural elements. Health literacy transcends provider-patient communication to include peer, family, and community communication channels. Community health education has a long and successful history of using peer educators to address specific health problems in a particular group, such as the soaring rates of type 2 diabetes mellitus in Hispanics [5], weight loss in low-income populations [6, 7], and promotion of breast-feeding [8].

Perhaps some of the confusion around how to define health literacy is due to the diverse disciplines studying and participating in the field. Nearly

TABLE 1  
SELECT DEFINITIONS OF HEALTH LITERACY

Author	Year	Definition
Nutbeam [37] and the World Health Organization	1998	“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”
American Medical Association [3]	1999	“Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment”
Selden, Zorn, Ratzen, Parker, and Ruth [9]	2000	“The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”
US Department of Health and Human Services [21]	2000	<i>Healthy People 2010</i> adopts definition from Selden et al. [9]
Pfizer, Inc. [24]	2003	“Health literacy can be defined simply as the ability to <i>read, understand,</i> and act on health information”
Institute of Medicine [23]	2004	Adopts definition from Selden et al. [9]
Medical Library Association	2003	“Health Information Literacy is the set of abilities needed to: recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyze, understand, and use the information to make good health decisions”
National Health Literacy Act of 2007 [26]	2007	Adopts definition from Selden et al. [9]
Freedman, Bess, Tucker, Boyd, Tuchman, and Wallston [35]	2009	“Public health literacy is defined here as the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community”
Patient Protection and Affordable Care Act	2010	Adopts definition from Selden et al. [9]
<i>National Action Plan to Improve Health Literacy</i> [1]	2010	Adopts definition from Selden et al. [9] but cites it as a definition provided by the US Department of Health and Human Services in <i>Healthy People 2010</i> [21]

every aspect of the health care system, the education system, and the communications field takes ownership in the health literacy field in one way or another. One of the most commonly used definitions, and the operative one in this essay, comes from the Institute of Medicine, which 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” [9]. This definition, with minor variation, appears in the Patient Protection and Affordable Care Act (PPACA) signed into law by President Barack Obama on March 23, 2010.

### History of the Definition of Health Literacy and Its Conceptualization

The term *health literacy* was first used in 1974 by S. K. Simonds in a paper titled “Health Education as Social Policy” [2] as a goal to be established for grades K–12. Yet, the concept was not developed in a vacuum. Indeed, it was the confluence of several concepts that led to Simonds’s use of the term. As early as World War II, the federal government recognized the importance of literacy and the need for universally understandable language [10]. Additionally, intelligence was emerging as capital, in and of itself, and it was becoming increasingly more important to have a literate citizenry [11]. The federal Adult Education Act of 1966 [12] recognized the need for a literate population and set adult literacy as a priority for the country. During this time, in a parallel effort, nurses were engaged in patient education as a method for health improvement [13].

In 1990 National Literacy Day was declared, and the second iteration of the US Department of Health and Human Services’ *Healthy People* was established. (In 1979 the Surgeon General issued a report titled *Healthy People: The Surgeon General’s Report on Health Promotion and Disease Prevention*. From this document came subsequent iterations of *Healthy People*, the first of which was *Healthy People 1990*, succeeded by *Healthy People 2000*, *Healthy People 2010*, and *Healthy People 2020*.) *Healthy People 1990* did not include any direct reference to health literacy, but it was the precursor to later versions of *Healthy People*, which did. *Healthy People 2000* advanced the agenda that allowed for significant governmental, private, and academic interest in the field and challenged the nation to become a healthy population through actively practicing prevention and making healthy lifestyle choices rather than relying on innovative medical treatments [14].

In 1991 the National Literacy Act [15] and the Neighborhood Schools Improvement Act [16] were passed. Among other things, the National Literacy Act instructed the National Center for Education Statistics to carry out a national literacy assessment, and in 1992 the National Adult Literacy

Survey (NALS) [17] was conducted. In the following years, several assessments of reading and literacy were developed.

### Governmental and Organizational Support for Health Literacy

On the heels of the publication of the National Adult Literacy Survey in 1993, which found that the average reading level of Americans was between the eighth- and ninth-grade levels [17], members of the medical profession began turning their attention to the ability of patients to understand the medical system and terminology. Not until 1999 did an ad hoc committee of the Council of Scientific Affairs of the American Medical Association (AMA) officially recognize and define functional health literacy as “the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient” [2, p. 552]. The Agency for Healthcare Research and Quality (AHRQ) later broadened the AMA’s definition, calling it “a constellation of skills that constitute the ability to perform basic reading and numerical tasks for functioning in the health care environment and acting on health care information” [18, p. 1]. International organizations evinced interest in health literacy. In 1997 the Plain Language Service was established in Canada [19], and in 1998 the Canadian Public Health Association began its National Literacy and Health Program [20]. After the first National Library of Medicine Current Bibliography of Medicine (CBM) regarding health literacy appeared, the US Department of Health and Human Services (HHS) embraced the concept and included an objective in their *Healthy People 2010* document: “Improve the health literacy of persons with inadequate or marginal literacy skills.” The inclusion of this objective clearly demonstrates the intent to address limited health literacy [21]. In 2003 the US Department of Education (DOE), with the support of the Institute of Educational Sciences’ National Center for Education Statistics, administered the National Assessment of Adult Literacy (NAAL)—the renamed NALS—and included a health literacy component to collect data for the *Healthy People 2010* objective.

The NAAL was the first large-scale measurement of health literacy. Three domains of health were assessed: clinical, preventive, and navigational [22]. These are reflected in the definition utilized by the DOE, which was at that point also being used by HHS in their *Healthy People 2010* document and the Institute of Medicine in their *Health Literacy: A Prescription to End Confusion* report. This definition stated that health literacy was “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” [23, p. 32]. A closer investigation reveals that this definition was

actually first stated in Catherine R. Selden, Marcia Zorn, Scott C. Ratzan, and Ruth M. Parker [9], by Ratzan and Parker, who wrote the introduction to the CBM. Ratzan and Parker adopted the above definition for the purposes of the bibliography, the purpose of which they state is “to help define and describe the evidence base for advancing health literacy programs by examining theories, strategies, and tactics in the published literature” [9] to further the study of health literacy. This definition clearly broadened the scope of health literacy. It removed specific examples—for instance, language about prescription bottles and appointment slips were discarded—and placed less emphasis on the “patient.”

Private and for-profit companies were also recognizing the importance of having a health-literate population. The most notable has been Pfizer, Inc., who, through programs such as their Clear Health Communication Initiative, actively engaged the research and practice communities. In a white paper published in 2003, Pfizer defined health literacy “simply as the ability to *read*, *understand*, and *act* on health information” [24, p. 2]. This was the first conception of health literacy that emphasized the individual’s role in and responsibility for acting on health information, rather than being a consequence of simply being health literate.

Concurrent with the publication of the Pfizer white paper, AHRQ was conducting an assessment of literacy and health outcomes. As a result, seventy-three articles were found to be relevant to the two questions being asked:

1. Are literacy skills related to (a) use of health care services? (b) health outcomes? (c) costs of health care? and (d) disparities in health outcomes or health care service use according to race, ethnicity, culture, or age?
2. For individuals with low literacy skills, what are effective interventions to (a) improve use of health care services? (b) improve health outcomes? (c) affect the costs of health care? (d) improve health outcomes and/or health care service use among different racial, ethnic, cultural, or age groups? [18]

In general, the AHRQ report reached similar conclusions to previous analyses of health literacy and health outcomes—specifically, that the literature revealed a clear correlation between “low reading skill and poor health” [18, p. 6].

The National Institutes of Health (NIH) held a Surgeon General’s workshop on improving health literacy in September 2006. Individuals from across the health care spectrum participated in a joint effort to describe the state of health literacy. The workshop was divided into three panels: health literacy, literacy, and health outcomes; meeting the health literacy

needs of special populations; and toward an informed and engaged public. As a result of the workshop, four basic conclusions were reached. First, the role of public health officials in health communication was defined, and it was concluded that the public cannot be expected to adopt health behaviors without clear communication, the implicit assumption being that communication begins with public health professionals. Second, without attending to health literacy, advances in medicine, health information technology, and the delivery of health care will not be realized. Third, health literacy must be viewed within the context of complex systems such as social, cultural, educational, and public health systems. And fourth, that although there is sufficient information to make improvements in health literacy, more research is needed [25]. The same year the Health Literacy Act of 2007 [26] was proposed in the US Senate, the Medical Library Association (MLA) adjusted their definition of health literacy to “health information literacy,” as indicated on MLA’s website, emphasizing the connection between health literacy and information literacy. This shift also required a person to recognize an information need as well as have the ability to find, evaluate, and actually use that information.

### The Concept of Health Literacy

As the discussion above describes, the definition of health literacy, and subsequently the conceptualization of the term, has undergone substantial changes through its brief history. Josephine M. Mancuso provides an excellent summation of the history. She states: “Health literacy has originated from the necessary skills of reading and numeracy to one of critical thinking, problem-solving, decision-making, information-seeking, and communication, along with a multitude of social, personal, and cognitive skills that are imperative in order to function in the health care system. In addition, health literacy has expanded into the realm of culture, context, and language” [27].

Two formal concept analyses have been conducted regarding health literacy, both from the nursing literature; however, the two authors used different methods. In 2005 Carolyn Speros performed an analysis of the concept of health literacy in order to clarify its meaning, reduce ambiguities, and promote consistency using an eight-step process of concept analysis first described by Lorraine Olszewski Walker and Kay Coalson Avant [28, 29]. Mancuso’s aims were similar in that she sought to develop a clearer understanding of the term; however, she used a methodology defined by Beth L. Rodgers [30, 31].

Speros and Mancuso arrive at similar conclusions. Regarding the antecedents of health literacy, Speros cites reading skills, numeracy skills, com-

prehension, capacity to use health information in decision making, and successful functioning in the patient role. Mancuso defines six dimensions of competence from the literature: operational, interactive, autonomous, informational, contextual, and cultural. Mancuso's attributes—capacity, comprehension, and communication—fall into Speros's literacy attribute, yet she includes having health-related experiences as well. Mancuso provides further analysis of the concept by Chantal D. Caron and Barbara J. Bowers's [32] methods of dimensional analysis. She presents the philosophical foundation, perspective, and context for the term from five disciplines: education, library and information science, health care, public health, and mental health.

In 2005 the National Health Education Standards defined health literacy as "the capacity of individuals to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which enhance health" [33, p. 5]. Drawing from this definition, Mancuso argues that from an educator's perspective, health literacy is a "complex relationship between both knowledge and skills that individuals (referred to as learners) need to attain as a result of instruction to obtain the goal of health literacy" [30, p. 250].

The health care setting, Mancuso argues, uses the American Medical Association definition adopted in 1999 as well as the National Library of Medicine's definition [30]. Yet, Mancuso claims that the library and information science (LIS) profession has a different understanding of health literacy and extends their definition to include a moral aspect, stating that one has a "right to access and understand health information" [30, p. 251]. Citing Erica Burnham and Eileen Beany Peterson [34], she indicates that LIS also considers the individual as an active agent in what can be considered as the health literacy process; that is, the individual must act upon information.

### Public Health Literacy

The public health profession is also a field that has seen an increase in interest in health literacy. Although the literature dates back only to 2000, Mancuso claims that "within the domain of health care, public health is a dominant force in the literature of health literacy" [30, p. 252]. The public health conception of health literacy includes notions of empowerment and civic engagement; moreover, it takes a population-based approach to what had previously been an individual approach. Darcy A. Freedman, Kimberly D. Bess, Holly A. Tucker, David L. Boyd, Arleen M. Tuchman, and Kenneth A. Wallston define public health literacy as "the degree to which individuals and groups can obtain, process, understand,

evaluate, and act upon information needed to make public health decisions that benefit the community" [35, p. 448]. Although the authors claim this is a conceptualization that is both distinct and related to individual health literacy, it proposes a dramatic shift from the approach. They argue that health literacy, as conceived outside the public health realm, is limited in two senses: (1) that it approaches health literacy as an individual problem and (2) that it addresses "secondary and tertiary [aspects] rather than the primary prevention of the disease" [35, p. 447].

Through the progression of definitions of health literacy, one can discern a trend from focusing on functional literacy, to communicative and interactive literacy, to critical literacy. This trend is exemplified by the conceptualizations made by the Institute of Medicine (IOM) [23], the Medical Library Association, and, finally, the World Health Organization (WHO) [36, 37]. Don Nutbeam cites the WHO's definition of health literacy as "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," and further, "health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment." This conceptualization, argues Nutbeam, has three implications: it broadens the scope of health literacy, it indicates the personal and social benefits of a health-literate population, and it has direct and profound implications for approaches to health literacy. He concludes by stating that if we are to achieve the ultimate goal for health literacy—which he argues is to promote autonomy and empowerment in both individuals and communities—then what is needed is a recognition of the political aspects of education and a focus on overcoming the "structural barriers," often called "social determinants," of health. In addition, this attempt to build health literacy on a foundation of empowerment and collective good enabled public health professionals to argue that health literacy is an ethical imperative [38]. Two points are warranted here: first, that it is in the conceptualization of public health literacy that the transformation of health literacy from an individual "good" to a "good" individual is most apparent and, second, that again with public health literacy (as with the LIS conception of health literacy) one can see an inclusion of the ethical imperative. The ethical imperative states that the individual ought to act since it is for the greater good, not because that individual has the right to actively participate in his or her health care, as is the case with the consumer health information movement.

There have been fragmented attempts to advocate for public health literacy. Christina Zarcadoolas, Andrew Pleasant, and David S. Greer expand the concept of public health literacy and describe in detail what each

“constituent domain,” that is, fundamental literacy, scientific literacy, civic literacy, and cultural literacy, would encompass in such a conceptualization. They advocate for a clearer understanding of the various domains, explaining “that understanding will help to create successful health communication efforts, provide an analytical framework from which to analyze health communication as it is encountered, and ultimately lead to development of a fuller measure of health literacy” [39, p. 201]. Following Zarcadoolas, Pleasant, and Greer, Pleasant and Shyama Kuruvilla suggest a two-tiered approach to health literacy, one from a clinical perspective and one from a public health approach. They advocate for collaborative and complementary approaches rather than the “unproductive relationship between those perspectives to date” [40, p. 158]. Most recently, Freedman et al. furthered the definition and scope of public health literacy by describing it as “the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community” [35, p. 448]. Moreover, they stated its target population (the public), its purpose (to “improve health of the public”), and its primary aims (to “engage more stakeholders in public health efforts; address social and environmental determinants of health”) [35, p. 448]. Health literacy, it would seem, has turned full circle: from Simonds’s 1974 article about health education as a means of social change; to a medical interpretation of fundamental literacy skills needed to operate in the health care system; to a multidimensional concept; and back to a primary focus on the social, environmental, and systemic issues affecting one’s health and the health of one’s community.

#### Relationship between Health Literacy and the Consumer Health Information Movement

Directly related to health literacy, the consumer health information (CHI) movement seeks to provide individuals with appropriate resources so that they may make better-informed health care decisions. Although health literacy and the CHI movement are interdependent, they are not synonymous. Health literacy focuses more on one’s ability to comprehend and use information, while the CHI movement is concerned more with providing access to relevant information resources. The ultimate goal of the CHI movement, however, demands an informed citizenry and requires that individuals be health literate.

The 2003 National Assessment of Adult Literacy still stands as one of the most significant collections of data regarding health literacy. As a result of the over 19,000 responses collected, researchers from the American

Institutes for Research and the National Center for Education Statistics were able to determine demographic characteristics for health literacy. Broadly, the majority of adults, 53 percent, had “intermediate health literacy,” and 12 percent were “proficient.” Of the remaining respondents, 22 percent were found to be “basic,” and 14 percent “below basic” [22]. More recently, the US Department of Health and Human Services stated in the *National Action Plan to Improve Health Literacy* that nine out of ten individuals have “difficulty using everyday health information that is available from health care facilities, retail outlets, media and communities” [1, p. 3]. Women tended to have higher average health literacy, as did adults who spoke English before starting school. White and Asian/Pacific Islanders had higher averages than black, Hispanic, American Indian, Alaskan Native, and multiracial adults. On average, older adults (aged sixty-five and older) had lower health literacy rates than their younger counterparts. Adults with lower educational attainment and those living below the poverty line also showed lower average health literacy.

There are many similarities between the health literacy movement and the CHI movement, but there are significant differences as well. While not always the case, individuals with limited health literacy may suffer from low literacy in general and often derive from lower socioeconomic status (SES). Individuals actively seeking health information typically are educated and derive from higher socioeconomic status [22], although addressing barriers identified by low SES individuals may make a difference in information-seeking behavior [41]. And whereas individuals who actively seek health information are typically empowered by acquiring knowledge [42, 43], individuals with limited health literacy often choose to operate in the shadows, opting not to ask questions or seek understanding [44, 45].

As with all low-literate populations, people who realize their literacy deficit may feel shame and be unwilling to admit that they do not understand, even when asking questions can lead to improved health. Feelings of shame associated with low or marginal literacy rates “may be externalized to the health care provider, prompting counterproductive actions such as noncompliance and malpractice suits” [44, p. 728]. Shame may also elicit submissive behavior such that patients either do not seek health care or do not follow instructions because of lack of understanding [46]. As noted in the *National Action Plan to Improve Health Literacy*, “Limited health literacy has psychological costs. Adults with limited health literacy skills report feeling a sense of shame about their skill level. They may hide their struggles with reading or vocabulary. As a result of this and other issues, limited health literacy is often invisible to health care providers and other public health professionals” [1, p. 9]. The cost to individuals, families, and society

at large is incalculable, yet the causes and the remedies for low literacy are complex and not easily addressed, especially not in busy health care settings.

While the consumer health information movement has developed from the grassroots across decades, diseases, and locales, the health literacy movement has been fashioned via a top-down construction, based in academic and governmental power centers. The CHI movement built on legislation arising from social movements, popular literature, and organizations, in addition to technological advances that helped enable individuals to acquire the power necessary to take control of their own bodies [47]. Essentially, individuals drive the consumer health information movement in their quest for knowledge that is needed to promote health and well-being. Conversely, the health literacy movement, at least in its current form, operates in a top-down model, where the establishment is primarily prescribing action plans designed to identify individuals with limited or low health literacy and provide interventions that seek to improve one's ability to comprehend and use health information in appropriate ways. The framework associated with "politics of the body versus the body politic" provides a lens through which to examine the relative differences between the health literacy movement and the consumer health information movement.

#### Transformation of Health Literacy from an Attribute of a "Good" Individual into an Individual "Good"

As with literacy itself, health literacy was originally conceived as an attribute of a "good" individual (i.e., an educated individual who can comprehend and use relevant information to promote her/his health and well-being). In this conception, health literacy serves as a potential measure of an individual's value or worth. Over time, however, and especially after World War II, the conception of health literacy was transformed from an attribute of a "good" individual into an individual "good." As Deborah Brandt observed, "Literacy was irrevocably transformed from a nineteenth-century moral imperative into a twentieth-century production imperative—transformed from an attribute of a 'good' individual into an individual 'good,' a resource or raw material vital to national security and global competition. In the process, literacy was turned into something extractable, something measurable, something rentable, and thereby something worthy of rational investment" [10, p. 485]. This transformation reformed the conception and shifted the focus of intent so that it is less on the individual and more on the whole. This conception is manifested in the 2006 Surgeon General's workshop. Participants in the workshop concluded that without a health-

literate individual, the benefits of health information technology will not be realized, and with public health literacy (wherein the individual is a necessary component of a larger movement to recognize and take action on the social determinants of health), many benefits will accrue.

Initially the focus of intent for health literacy was solely at the individual level. In time though, health literacy was conceived as an individual “good,” which allowed it to be treated as a commodity that could enhance the nation’s power to strengthen its economy and augment the status of the United States within the international community, similar in some respects to the evolution of human intellect as capital. The commodification of health literacy helped shape development of the movement itself. Health literacy as an attribute of a “good” individual continues to exist, but the collective value of a health-literate citizenry outweighs its worth to an individual in favor of its overall significance to the nation. This point of view is reflected by the inclusion of health literacy in the Patient Protection and Affordable Care Act, an inclusion that is predicated, in part, on the premise that health reform requires a health literate citizenry. However, people are mistrustful of “movements” that are initiated top-down, an example of which is the Patient Protection and Affordable Care Act. A previous attempt to legislate health care reform, led by Hillary Clinton in 1993–94, was never enacted into law [48]. The Clinton Task Force on National Health Care Reform was even more of a top-down model than PPACA, since its meetings were conducted in secret.

The conception of health literacy as an attribute of a “good” individual parallels the struggle for individual rights that have been affiliated with politics of the body. These include such things as the right to be educated; the right to be informed; the right to have access to relevant resources so as to be able to make better informed health care decisions; the right to request or, in some cases, deny certain treatment options; and ultimately, the right to control one’s own body to the greatest extent possible. In contrast, the conception of health literacy as an individual “good” is closely allied with the body politic. In this conception, health literacy becomes something that is needed to advance the status of the nation’s health and well-being. The intent shifts so that it is now more focused on the exertion of institutional and interpersonal power needed to help control the escalating cost of health care and elevate the standard of care in the United States as well as maintain and improve the nation’s status in the world.

The transformation in the conception of health literacy is reflected in the development of the health literacy movement, in general, and public health literacy, in particular. The notion of public health literacy follows the move from an individual approach to a community approach whereby the individual is situated within the community. It is not surprising that public health literacy reflects the most explicit representation of the trans-

formation in health literacy given that public health often has served as the battlefield where wars involving issues associated with politics of the body versus the body politic have been waged. (Examples of such battles, some of them decades long, include the HIV/AIDS epidemic, limitations on tobacco use, and calls for the legalization of marijuana, among many others.)

### Movement Models as They Relate to Politics of the Body versus the Body Politic

Politics of the body have served as triggers for groundswell movements in many instances. Key examples include the women's movement, twentieth-century civil rights movement, modern sexual revolution, contemporary self-help movement, patient empowerment movement, cancer movement, and AIDS movement, as well as the consumer health information movement. With each of these movements, the plight of affected individuals provided them common cause to band together, organize, and present a united front designed to produce change. Whereas politics of the body often are affiliated with groundswell movements, the body politic typically operates in top-down fashion. In this top-down model, the body politic exerts power and influence over the individual, ostensibly for the greater good. Examples of this construct include implementation of Medicare Part D (Medicare Prescription Drug Coverage), promotion of "just say no" campaigns, and establishment of "tobacco-free" zones, as well as development of the health literacy movement. This power structure mandates that individuals take control of their own bodies but within the confines of established customs and norms.

### Success of Health Literacy Movement Relative to the CHI Movement

The consumer health information movement has garnered success on multiple levels. Various patients' bills of rights developed during the twentieth and twenty-first centuries guarantee individuals access to relevant information to assist with informed decision making. Many hospitals and academic medical centers support the provision of CHI resources and services, as do public libraries and a wide variety of community-based organizations. A multitude of government agencies and commercial ventures now produce and distribute consumer health information in print and electronic formats. Never before have individuals had the opportunity to be as informed where their health and well-being are concerned.

The health literacy movement, on the other hand, has been plagued by

a series of starts and stops. Interest in, and support for, the movement have waxed and waned over time, often dependent on political agendas. The shift in recent years toward disease prevention has helped to stabilize support for advancing the health literacy cause, but barriers to program implementation continue to exist. For example, information prescriptions were introduced in the early part of the twenty-first century as a means for a physician to direct a patient to reliable, understandable, up-to-date information about a particular disease or condition. Inconclusive, early research showed promising results regarding the use of information prescription programs [49]. Typically, an information prescription program allows a health care provider to refer a patient to a consumer health information specialist or a consumer health information resource using a customized prescription pad. While this seems like a logical approach to enhancing patient understanding and promoting health literacy, information prescription programs in the United States have met with limited success. Programs that refer patients to a physical consumer health library are limited on several fronts: (1) physician unwillingness to trust a librarian or health educator to provide accurate information; (2) limited patient time; and (3) participation only by patients who are desirous of information, which may eliminate the people who most need the intervention. Other programs ask physicians to refer patients to a quality, noncommercial website like MedlinePlus. In practice, however, even though resources like MedlinePlus can now be incorporated into electronic medical records, the health literacy issue is still often ignored. As Monica R. Leisey and Jean P. Shipman discovered, this approach also has limitations [49]. Even the inclusion of "easy-to-read" resources and multimedia applications does not guarantee that information found on MedlinePlus will be accessible to a patient with low health literacy. Access to this or any other online resource also presupposes that the referred individual has access to a computer and knows how to use it. The challenge of incorporating such a novel program as information prescriptions into the traditional health care environment requires a broad collaboration among librarians, educators, and health care providers if it is to become a standard service in an institution. Lacking such a collaborative effort, one that includes "champions" among all the partners, the top-down, administratively driven approach to implementation is unlikely to succeed.

## Discussion

Addressing health literacy is of paramount importance for economic, public health, and human rights reasons. Both the health literacy movement and consumer health information movement were shaped by social entities

and societal interactions. The framework associated with “politics of the body versus the body politic” provides a useful way to examine what differentiates these two social constructs. While politics of the body are focused more on the individual, the body politic is concerned more with the collective whole. The struggle between these two factions has a long history that continues to play out today [50, 51].

The CHI movement developed as a groundswell movement that originated, in part, from the consumer movement. The health literacy movement—which, to date, has achieved limited success—was fashioned using a top-down model and developed, in part, from the literacy movement. It would seem, then, that a grassroots or bottom-up approach to health literacy would be a more fruitful endeavor, garnering more support from the public, more buy-in from the health care professionals, and, ultimately, better health outcomes. The need for an active health care consumer is still necessary; however, their participation will be required to facilitate the identification of problems, development of solutions, and their subsequent implementation and evaluation. Moreover, consumer participation must be sought in tandem with that of providers and policy makers. Because librarians are significant consumers and disseminators of health information, a place at that table must be reserved for them, which may require new conceptualizations of outreach and engagement.

Health literacy has been recognized as a social determinant of health that can be influenced by relevant interventions. Therefore, addressing health literacy may serve as one vehicle for improving the effectiveness and efficiency of health systems as well as individual health outcomes. Health literacy, however, is difficult to assess and differs from general literacy because of technical vocabulary and the settings in which it is encountered.

To be sure, individuals choose not to participate for many reasons, only one of which may be limited health literacy. (This includes people who speak English as a second language or who speak primarily a language other than English.) People may not feel well enough to ask questions when they visit a doctor, or they may be reluctant to question a person they perceive as an authority figure. Time constraints on the part of both physician and patient play a role in diminished communication as well. Most notable, however, may be two factors: communication between patients and their physicians that may be further complicated by situational anxiety and the feeling of shame regarding literacy levels that often prevent patients from asking questions or seeking information [52–58]. All of these variables present challenges to health literacy programming. Most notable, however, may be the feeling of shame that adults feel when they cannot read or understand health information. In one study, 19 percent of the

cohort evincing “inadequate functional health literacy skills stated they had never disclosed to anyone their problems reading and understanding what they read” [45, p. 37]. A later study conducted by this research team raised the question of measuring literacy level and documenting it in the patient chart, so that providers could be certain to take extra time explaining diagnoses and medication instructions. “Although most patients were willing to allow documentation in their charts concerning their literacy level, a substantial number of patients were not agreeable to this disclosure” [44, p. 728]. In short, patients with limited literacy do not want to admit their deficiency, and providers do not want to make unwarranted assumptions regarding such a sensitive topic. Perhaps the best approach, as concluded by David W. Baker in 2006, is “to assume that all patients experience some degree of difficulty in understanding health information, and we should adopt the perspective of ‘universal precautions’ and use plain language, communication tools, . . . and ‘teach back’” [59, p. 882]. The “teach back” method, also known as “closing the loop” or the “show me” method, is a way to confirm that a health care provider has explained to a patient what he or she needs to know in a manner that is understandable. Patient understanding is verified by having the patient explain the information back to the health care provider.

Progress and future directions related to the health literacy movement are outlined in the *National Action Plan to Improve Health Literacy* [1] and *National Prevention Strategy: America’s Plan for Better Health and Wellness* [60]. While both of these publications document thoughtful strategies designed to improve health literacy, in general they continue to promote operating within a top-down model. Under the current conception, the successful deployment of health literacy requires an active, engaged patient. For the most part, these strategies assume that people want to be informed and educated. This simply is not the case where everyone who interacts with the health care system is concerned. As stated previously, health literacy involves many complex issues, and individuals choose not to be active participants in their care for a variety of reasons.

### Navigator Model

A recent report of the American Medical Association’s Council on Medical Service provides a summary of the current state of patient navigators. They provide historical background as well as current manifestations and address the various roles that patient navigators play (reducing health disparities, improving clinical outcomes, streamlining care and managing cost growth, and health care advocacy consultants). In the report, they define a patient

navigator as “someone whose primary responsibility is to provide personalized guidance to patients as they move through the health care system” [61].

While there is no one approach that is guaranteed to improve the nation’s health literacy, adopting the navigator model across multiple disciplines, including library and information science, may meet with greater success than some other strategies, since it seeks to improve the health care experience for each individual while supporting the overarching goal of the collective whole. Navigator models go beyond the well entrenched “buddy” programs that match survivors of a dread illness with patients currently undergoing treatment, in that navigators are professionals who work within the health care arena.

In terms of a national program, patient navigation was first instituted by the American Cancer Society (ACS). The Illinois division of ACS led the way beginning in September 2003. Three sites in Illinois—a large oncology practice in Peoria, the cancer center at the University of Chicago, and the Health Learning Center at Northwestern Memorial Hospital—served as “proof of principle” pilots for the concept. The program in Illinois was not a pilot for national ACS. Illinois was simply a pioneer in this concept, and national ACS quickly followed suit and endorsed the development of navigation programs in all of their divisions (e-mail message to author from Tim Volpe, Associate Director for Administration, Robert H. Lurie Comprehensive Cancer Center of Northwestern University, August 9, 2011). ACS rolled the program out nationally beginning in 2005. Typically, navigators are licensed clinical social workers and bring all the resources of the American Cancer Society to bear on the needs of people who are in active treatment. Oncology nurse navigators, not associated with ACS, provide a support system for the patient and family by acting as educators, advocates, health system navigators, care coordinators, and community ambassadors. Oncology nurse navigators are available to patients through the entire course of treatment and survivorship. Today patient navigation has become a popular model that is being implemented in settings beyond oncology. Patient navigators, while serving at the individual level, seek to enhance the overall quality of care while helping to contain costs.

Various electronic tools have been developed to assist with patient navigation. Some have been developed to assist health care providers in assuring continuity of care; others have been developed specifically with the patient in mind. Although electronic tools have been developed to assist with patient navigation in the health care setting, these do not negate the need for human involvement nor do they address issues germane to limited health literacy; in fact, they completely ignore health literacy.

The federal government has recognized the value provided by the pa-

tient navigator model and, by way of the Patient Protection and Affordable Care Act, has committed to providing funding for it. However, the navigators described in PPACA only extend to navigating health insurance selection and do not take into account the many other components of the health care system. Before committing further resources, though, methods such as community-based participatory research could provide initial avenues to explore more appropriate applications of the navigator models using, for instance, populations identified as having low health literacy.

Extending the patient navigator model to include LIS professionals would address the ongoing need for human involvement while allowing for further integration of support related to the multitude of information systems (e.g., clinical, directional, educational, financial, informational, referral) encountered by patients and their caregivers. Having LIS professionals tasked with the selection and dissemination of understandable, relevant, culturally appropriate information allows other members of the navigation team to focus on their areas of expertise. For example, librarians in hospital and clinic settings are skilled at filtering resources, selecting a variety of sources to reflect different literacy levels, responding to routine queries or requests, and triaging more complex questions that require intricate knowledge of subject matter. Nurses and social workers, on the other hand, are experts at counseling, handling complex social issues, and serving as health care advocates. By integrating discipline-specific expertise and skill sets, the navigation team is allowed to operate more effectively. Moreover, health literacy issues are more easily addressed in this person-to-person model.

## Conclusion

Limited health literacy has been identified as a contributing factor to the struggles for more effective delivery of health care, improved health outcomes (including reducing readmission rates to inpatient care), and reduced costs of health care in the United States. With a potential estimated cost approaching \$4 trillion annually, addressing limited health literacy has gained an economic foothold among policy makers within the health care establishment, focusing their attention on any means of reducing the percentage of the US economy dominated by expenditures for medical care. The movement to improve health literacy rates and develop health communication tools that address all levels of literacy has been fashioned fundamentally from a top-down perspective. This is in contrast to the consumer health information movement, which was forged as a groundswell movement originating primarily from the bottom up. Groundswell movements, by their very nature, garner broad public support. Employing a top-

down approach to decision making and implementation, on the other hand, often generates resistance rather than acceptance.

Instead of continuing to employ a top-down approach, the health literacy movement would likely garner more support from affected individuals if they were included as stakeholders in identifying problems, developing solutions, implementing those solutions, and evaluating implementation strategies. Given their role as health information consumers and disseminators, librarians are well positioned to contribute significantly to this process within an expanded navigator model and other innovative approaches identified by community stakeholders.

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