Health Literacy and Information Seeking: Poised for Convergence

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Health literacy is essential to achieving a healthy society and an informed and empowered citizenry. Health literacy research is evolving from an approach that focuses on the transfer of factual knowledge from the provider to the patient, to one that views the patient as an information seeker and a partner in decision-making. In this paper, the authors suggest that this shift resembles one that took place in the field of information science. Using two examples from our previous work, this paper explores whether the two fields—information science and health literacy—will at some point converge and suggests implications for future research.

Keywords
Health literacy, information seeking, health information seeking

1. Introduction

Health literacy has been identified as essential to achieving a healthy society and an informed and empowered citizenry [1-3]. It has been defined 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” [1]. The growing importance of the role of the individual in making informed health decisions has spurred efforts to improve health literacy, especially among vulnerable populations characterized by disparities in health status and access to care. At the same time, the field of health literacy has continued to broaden and evolve to accommodate the changing health information environment, presenting new opportunities for research and demonstration, e.g., [4]. While many of these opportunities have naturally arisen from health research, the field of information science has much to contribute to understanding of the ways in which individuals seek, acquire, understand and apply information of all kinds, including health information. The purpose of this paper is to explore whether the two fields—information science and health literacy—will at some point converge and to suggest implications for future research.

2. Current state of health literacy

Health literacy is a concern of many communities—clinical medicine, public health, and education for the health professions. While this list reflects a U.S. centric focus, similar activities can be found world-wide, and indeed, the World Health Organization promulgates an inclusive view of health literacy by including the motivation and ability to gain access to, understand and use information to promote and maintain good health [5]. In the United States, health literacy is a central component in achieving the goals of national health policy as expressed in Healthy People 2020, and in the National Action Plan to Improve Health Literacy [6, 7]. The Institute of Medicine (IOM) recently established a Health Literacy Roundtable to address issues related to educating providers in culturally competent communications, and numerous instruments currently exist to help clinicians and researchers screen for health literacy and use appropriate techniques when talking with patients [8-12]. The Plain Writing Act of 2010 supports...
opportunities for computational approaches to creating more understandable medical texts to aid groups suffering from low health literacy [13-15]. The American Medical Association, among others, recommends not only screening of patients for health literacy but also providing more training for medical professionals to improve their communication with all patients, especially those who suffer from low literacy [16].

That the relationship between limited health knowledge and the differential use of health resources frequently results in poorer health outcomes has been well established in the research community [17]. Recently, there has been increased interest in using digital technologies such as the Internet and mobile phones to ameliorate low health literacy, especially amongst vulnerable populations where chronic diseases such as diabetes and hypertension are especially prevalent. Most of these studies are conducted from the perspective of the provider in that they address the problems that arise when individuals fail to understand their disease or their provider's recommendations, and thus do not comply with the prescribed treatment regimen. As a result, many of these provider-centric solutions aim at training health professionals to use “teach back” techniques when communicating with patients [18].

Today, issues of low health literacy have become even more widespread and complex, as societies have become information-intensive. The multiplicity of resources available to the patient or consumer can vary in credibility (much of the “information” available on the Internet and through social media may be misinformation or hearsay), understandability (much published information contains complex language and providers often use similar words and concepts when talking with patients) and reliability (other people's opinions, experiences and stories). In addition, the provision of health services has increasingly moved beyond the walls of institutions into everyday life. Treatments, especially for chronic illness, are frequently administered in outpatient settings or at home. Sources of health information can be both external—published information, other people, including health providers—and internal—one’s own beliefs, knowledge, skills and beliefs, attitudes and values. In this environment, patients and consumers need help extracting and evaluating this information to determine what is accurate and relevant to their situation.

In such an environment, Nutbeam’s work in public health that includes both health literacy and health information seeking is particularly relevant [19-21]. Nutbeam proposes three levels of health literacy: 1) basic understanding or functional literacy which consists of reading, writing, and understanding; 2) communicative/interactive health literacy which consists of communication and social skills to derive meaning and to apply new information as situations change; and 3) critical literacy, which consists of higher-level cognitive and social skills needed to analyze information and to use it to exert control, over life events and situations, thus exercising autonomy and empowerment in health decision-making. Rather than focusing on the transmission of information from provider to patient in a clinical environment, Nutbeam argues for a broader, more complex understanding of health literacy that views health literacy as supporting greater patient autonomy and empowerment in health decision-making [21].

The growth and ubiquity of the Internet as a frequently-used source for health information, addresses another facet of health literacy, namely health information literacy. Health information literacy has been defined by the Medical Library Association (MLA) as “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” [22]. While the IOM definition and the MLA definitions have much in common, they have different emphases. As noted earlier, health literacy is primarily concerned with the individual’s acquisition of specific health knowledge and the ability to navigate a complex system in which he or she is rarely the one in control. Health information literacy, however, implies greater agency and autonomy and, we argue, most often takes place outside the clinical

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encounter. Health information literacy is therefore highly relevant to that aspect of information science that focuses on information seeking. To the extent that information seeking is mediated through computer technology, health information literacy is relevant to health informatics.

Increased interest in using digital technology to address problems of low health literacy presents an opportunity for health informatics researchers to contribute to the amelioration of low health literacy. (Here we view health informatics as the application of information science to the health domain.) Despite the vastly improved access to digital health information, significant barriers exist for individuals to fully benefit from such information and present new challenges for research [23-26]. Work on chronic disease management, for example, found that web-based media improve knowledge and understanding as well as social support, behavior change, and clinical outcomes for a variety of diseases [27]. To address the perceived potential of mobile phone messaging interventions for self management of chronic illness, a Cochrane review of 4 randomized controlled trials concluded that despite the enthusiasm with which mobile health (mhealth) interventions are being implemented, further research is needed [28].

In this paper, we present a view of health information literacy that stems from our positions as information scientists and informaticians. To support that view, we review key studies selected from both the health literature and the information science literature that have relevance to information seeking. We describe our work and place it in a theoretical framework drawn from both spheres. Using examples from our previous work, we examine how information seeking manifests in communities of varying socio-economic status (SES). While these are small studies, they advance our understanding of health literacy and illustrate both opportunities and challenges for information scientists and Informaticians. Much is to be gained by adopting a multidisciplinary approach to understanding--and ultimately affecting--the ways in which individuals can become more engaged in understanding and improving their health status.

3. Literature Review

3.1. Health literacy

The ability to seek, understand and use health information has long been a concern of the U.S. National Library of Medicine (NLM) as evidenced by services such as MedlinePlus and MedlinePlusConnect, as well as their numerous funded research and demonstration projects aimed at improving health information literacy in various populations [29-33]. In 2010, NLM introduced the MeSH term “health literacy” to assist researchers working in the field. As a result, several hundred articles and over 50 systematic reviews of health literacy published since 2009 can be easily retrieved from PubMed. For this reason, we do not include a full review of the literature here.

Martensson and Hensing reviewed the earlier literature from 2000-2008 and identified two different approaches to health literacy [34]. The traditional approach is functional and clinical, focused primarily on the patients’ ability to understand and act on information presented in a clinical encounter. They term this health literacy as a “polarized encounter” in which high health literacy is associated with positive health outcomes, while low health literacy is associated with the opposite. The newer approach presents health literacy as a complex construction in which individuals call upon a broad spectrum of skills to interact with their social world and which may vary across time and situation. In this view, health literacy is complex and context-dependent [35]. That is, one may be highly illiterate in one context and much less so in another context. This view, which is ecological in nature, leads the authors to conclude that health literacy is a heterogeneous phenomenon with important implications at both the individual and at the societal level.
This shift from viewing health literacy as the ability to receive and understand information, which is essentially a passive role, to one in which health literacy is seen as active and engaging broadens the range of theoretical perspectives through which to examine it. Chinn describes this perspective as “critical health literacy” terming it a “second wave” of health literacy research [36], that draws on Nutbeam’s conceptual framework, but makes a subtle distinction by using the phrase “users of literacy.” The “users of literacy” apply skills and resources as they act in different roles to exert more control over their health—indeed, to engage in purposive behavior change in order to achieve positive health outcomes.

Similarly, our view of health literacy is grounded in a public health perspective and draws largely on Nutbeam’s theoretical work which specifies asking questions and seeking information as a stage of health literacy. Sorensen et al., have further developed Nutbeam’s model and created an integrated model that positions health literacy and patient activation in a situational, contextual framework [37]. Sorenson’s model identifies four health literacy competencies—accessing, understanding, appraising and applying health information—in three health domains: health care, disease prevention and health promotion.

In the U.S., implementing the Affordable Care Act requires a new commitment to “person-centeredness” as a key feature of health care [38]. While much of this effort is directed to changes in health organizations themselves (becoming “health literate” organizations), this emphasis on the person at the center of health information and decision-making is reminiscent of the rise in the user-centered paradigm in information science.

As a result of this broadened view of health literacy, several disciplines can contribute to defining and exploring this complex phenomenon. The majority of the relevant literature currently emanates from health promotion, prevention, education, behavioral science nursing and health/medical care. While we acknowledge the contributions of these fields, we introduce here some foundational models from information science, many of which are gaining relevance because of the simultaneous movement of healthcare away from institutional boundaries and the broadening view of health literacy.

### 3.2 Information science

This section will briefly summarize the theoretical models employed by information scientists that are particularly salient to health literacy. The shift began as early as 1960 when Parker argued that “the system should adapt to the receiver or user, rather than the user of the system [39]. Later, in 1986, Dervin and Nilan reviewed the literature on information needs and uses. Their review became a touchstone for integrating communication studies into information science, and took a strongly user-centered approach to information seeking [40]. Dervin’s own work is best known for recognizing the complex tasks human beings face as they navigate daily life, encountering ever-changing environments and situations. This complexity and fluidity makes it nearly impossible for a single “package” of information to be sufficient to meet all situations, nor to meet the needs of all people. Dervin has applied her model in many domains, including health [41]. A user-centered approach has persisted as a central paradigm for information science research for over 30 years and has moved the focus of interest from the construction and evaluation of information systems to the users of those systems [42-44].

In the 1990s, Chapman’s “small world” approach used ethnographic methods to develop a theory of information seeking which is situation based. Her observations of individuals living on the margins of society showed that these occupants of a “small world” do not seek information for its own sake, or to improve life, primarily because their expectations that information has the power to do so are extremely limited [45]. Fisher-Pettigrew extended the situation-based metaphor to the concept of “information grounds” in which information seeking is seen more as information sharing that takes place in particular
time and in a particular environment. Known as the “people-place-information trichotomy,” the information ground is a social construct rooted in a person’s combined perception of place, people and information [46].

Overall, the information seeking literature suggests that for most people, information needs arise from everyday situations, many of which are related to health. Information needs and information seeking patterns are highly situation dependent and may cover an array of behaviors for an individual at any given time or place. This relationship between health information seeking and health literacy, although seemingly intuitive, has been less well investigated [47]. As greater responsibility for managing one’s health is placed on the individual, however, the need to seek information, understand and apply it is increasing. The evolving digital environment also changes where, how and when information seeking occurs, presenting opportunities for health informatics researchers who understand models of information seeking and use.

4. Information seeking research examples

The two studies presented here apply informatics to a prototype intervention aimed at increasing health information seeking amongst vulnerable populations. The setting for both studies is a university-affiliated urban neighborhood Health Center that uses a transdisciplinary model in caring for patients, most of whom live in public housing and are low-income, minority patients. The Center offers a variety of ancillary services such as cooking and fitness classes, dental and podiatry services, and an array of behavioral health screenings and interventions. Care is delivered by nurse practitioners, social service professionals and public health nurses. Approximately 5,000 patient visits are logged annually. Prior to our work with the Health Center, little was known about either the Internet capacity of the population or the health literacy of the patients. The first study here was influenced by Nutbeam’s model in which health literacy includes the ability to access health information; as informatics researchers, we focused on Internet access and information seeking.

4.1 Assessment of internet capacity

Using semi-structured interview protocol administered in the waiting area of the Center, we assessed the Internet capacity and “connectedness” of patients [48]. We found that 72% (38 of 53) of respondents (patients registered at the Center) reported accessing the Internet, but only 21% (8 of 38) reported searching the Internet for health information. This contrasts with the Pew study for the same time period that indicated that 80% of Internet users, or 59% of U.S. adults look online for health information [49]. In 2003, Pew reported that health information was one of the most frequently searched topics on the Internet, but at the time, few people verified online health information [50]. Recent reports from other sources are mixed, supporting the premise that there is still much to be learned about the general public’s capacity to seek and use health information effectively [51, 52].

4.2 Text message intervention

In a second study thirty-one women attending prenatal classes at the same Center were enrolled in a study to test the feasibility of implementing a text messaging intervention that presented links to relevant, credible information found in pre-selected websites. Participants who received the messages reported that they looked at the websites and found them informative, enjoyable and supportive. While the findings are suggestive rather than definitive due to the small sample size, our experience demonstrated that combining Internet information retrieval with text messaging may serve as an “on-ramp” to effective health
information seeking on the Internet [53, 54]. Once again, we were influenced by Nutbeam’s model in developing an intervention designed to motivate the women to become active information seekers. In so doing, we chose to simulate information seeking rather than to assess acquisition of specific health knowledge or ability to pronounce medical terms—the measures that are commonly used in traditional health literacy studies.

**4.3 Ongoing Work**

We recently repeated our survey of Internet connectivity in four pediatric practices, two of which have a similar demographic profile to our previous study, and two of which are more mixed in character [55]. Preliminary analysis indicate that almost all respondents to our survey access the Internet regularly either through a desktop computer or a smartphone, and that the most frequent uses are for general information, social media or entertainment, not health information seeking. In our future work, we propose to move beyond a single topic such as prenatal care to focus our interventions on elucidating the barriers and facilitators to motivating individuals to adopt the pro-active stance described by Nutbeam’s second and third levels of health literacy—extracting, critically analyzing and applying information to exert control over life events. In so doing, we will address the relationship between health information seeking and health literacy, and bring our approach into alignment with the current priorities for improving health outcomes, the ultimate goal of both health literacy and health informatics.

**5. Discussion**

While our objective has relevance to one of the stated goals of healthcare reform in the United States—increasing patient engagement by enrolling patients in specially designed portals—as informatics researchers, we are also interested in applying the insights of information science to understand the role of health information-seeking in patient well-being. As noted, there is a vast literature on health literacy, yet models drawn from information science are sparse. Because managing chronic illness confronts a growing proportion of health care, greater attention must be paid to patient status in between clinical encounters—it must enter the realm of everyday life. Modern healthcare systems depend increasingly on the patients’ willingness to manage their health independently and to make informed decisions regarding when, how, and if a consultation with a health provider is necessary. Tapping the insights of information science which has typically examined information seeking and use across multiple situations can contribute to the advancement of new approaches to health literacy.

Broadening the view of health literacy beyond the patient provider encounter offers an opportunity for multidisciplinary research teams that include members conversant with models and insights developed in information science. New conceptual models and new measures are needed to fully appreciate the changing scope of health literacy. Framing health literacy as a public health goal with health information seeking as an indicator of patient engagement or activation may have greater predictive value for health status than health literacy alone. Such an approach may enable the measurement of health literacy to be separated from the assessment of health knowledge. Seeing health literacy as a contextualized variable that changes over time in relationship to external factors such as the presence of health and diseases, the presence or absence of informational resources and in response to an intervention, suggests that the study of health literacy has much in common with the study of information seeking in general.
6. Conclusion

The field of health literacy may be poised to adopt user-centered model in which individual needs, behaviors and use, gain greater traction than those which have been focused on the one-way transfer of knowledge from provider to patient. In this paper, we have suggested that the needs of the provider and the healthcare system itself have been paramount. In this view, patients are regarded as passive recipients of treatments, rather than as active contributors to their own health status. This shift parallels the shifts taking place in other sectors of society in which power and authority are increasingly mediated through social media, and “information” is seen as contextual and situation-based.

As this change takes place, frameworks of research will also undergo a shift toward greater participatory design and the use of mixed methods in frameworks derived from the social and behavioral sciences. As informatics researchers, we welcome this shift, as our own experience indicates that indicates that overcoming the current barriers to patients’ engagement in their own health is a complex problem, but one well worth pursuing, for if the individual is not engaged in the quality of his or her own life, no amount of “treatment” will result in optimal health and well-being.

Throughout this discussion of health literacy and health information literacy, it must be recognized that a revolution in information technology has taken place over the past 30 years. The information science research community has undergone several waves of technological change, while the health care field, it can be argued, is at only at the beginning of what promises to be an equally transformative period, one that will no doubt progress much faster than the one in information science. By bringing the two research streams together, we can expect greater progress toward ameliorating the poor health outcomes associated with low health literacy, and can expect to witness a more empowered patient community.

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