

Emerging themes in health literacy

Autor(en): **Schulz, Peter / Nakamoto, Kent**

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Guest Editors' Introduction

PETER SCHULZ* & KENT NAKAMOTO**

EMERGING THEMES IN HEALTH LITERACY

The issues of health and healthcare dominate social, political, and economic discourse around the world both because of their human impact and because of their enormous cost. In the United States, for example, healthcare costs in 2003 amounted to over 15% of GDP (\$1.7 trillion). According to the OECD in 2002, healthcare costs represented 11.2% of GDP in Switzerland, 10.9% in Germany, and 8.5% in Italy.

From advertising for diet programs, exercise videos and equipment, nutritional supplements, and in some countries, pharmaceuticals, to health promotion and social marketing campaigns launched by non-profit and government organizations, people are inundated with information related to health and wellness. Moreover, as patients, people receive health information and recommendations from a variety of healthcare professionals including physicians, nurses, social workers, occupational and physical therapists, and psychologists. Beyond western medical regimens, consumers engage practitioners whose specialties include numerous alternative approaches such as homeopathic remedies, herbal supplements, acupuncture, yoga, and meditation, to name but a few.

How do people cope with this avalanche of information? Addressing this question has been a focus of research on health literacy. Since the 1970's, a stream of descriptive research has sought to examine the concept of health literacy, its measurement, and the problem of low health literacy. In addition, a large body of research has focused on the development of interventions to improve health literacy or to limit the problems posed for people with low health literacy.

* HCCL, Faculty of Communication Sciences, University of Lugano, peter.schulz@lu.unisi.ch

** Marketing Department, Virginia Tech University, nakamoto@vt.edu

In this topical section of *Studies in Communication Sciences*, we seek to enrich both the breadth and depth of understanding of health literacy. We have assembled a set of papers that represent a range of issues and perspectives related to health literacy. The cases examined come from around the world. For the most part, the papers focus on themes already prominent in the literature. However, the diverse approaches represented encompass not only the medical and social science views but also humanities (or human science) perspectives on health literacy.

Enhancing Health Literacy through Communication

The twelve papers in this thematic section explore a range of issues related to the interface of communication and health literacy. All of the papers address the problem of promoting health literacy but adopt diverse perspectives on this issue.

Health literacy has been variously interpreted to include a range of knowledge and skills exercised in a variety of settings. The paper by Eagle et al. focuses on functional literacy and examines the prevalence and difficulties posed by textual health material that is beyond the comprehension level of the average reader. This is consistent with a sizable body of work that focuses on functional health literacy primarily in medical settings (e.g., Parker 2000). Nutbeam (2000) broadens this view, both in terms of the range of skills and of settings. He identifies three levels of skill: functional literacy, interactive literacy, and critical literacy which endow the consumer with increasing autonomy and empowerment. Functional literacy refers to basic reading and writing skills; interactive literacy adds to the functional level the consumer's ability to "extract information and derive meaning from different forms of communication". Critical literacy invokes a consumer's ability to analyze information and to use the analysis to gain control over "life events and situations." Eriksson-Backa seeks to incorporate in her view of health literacy some of these additional competencies.

The next two papers address the issue of commercial communication and its impact on health literacy, again highlighting two different approaches. The paper by Tedesco and Holloway reports an experiment examining the potential issue of bias in online health information and the relative insensitivity of website users to information regarding commercial sponsorship. The paper by Rubinelli applies a very different analysis—the analysis of argumentation—to direct-to-consumer adver-

tising of prescription drugs. Drawing on rhetorical analysis introduced by Aristotle as well as recent developments in argumentation theory, Rubinelli suggests that these advertisements might be misleading not because of the information presented but because of plausible logical fallacies employed. These papers point to the potential value of both social science and humanities approaches to this problem.

Turning to social advocacy and health literacy promotion, we include two papers examining health literacy in specific populations. The paper by Fleming, Balch, Towey, and Madamala examines health literacy among adolescents based on interviews with literacy educators and physicians and needed research in this area. The paper by Smith examines the development of culturally and linguistically appropriate health education materials—specifically prenatal information adapted for Spanish-speaking women in the United States.

These papers are followed by several shorter presentations. In the first of these papers, Stokes discusses the use of rhetorical analysis of web-based health information and the “hidden” persuasive approaches in a site providing ostensibly objective information. The other five papers in this section highlight the global interest in the interplay of health communication and literacy. Erramilli, Sharma, Chung, and Sivakumaran discuss challenges surrounding sex education and contraception in Singapore. Duff, Witte, and Singhal examine the impact of a soap opera oriented to reproductive health in India. Howe, Remmes, Kellin, and Timmons review a project and method for producing health information that matches patient culture and education level in a rural community in the southern United States. Van Leuven describes a community-based program to improve health literacy of disadvantaged, homeless, and Spanish-speaking schoolchildren in a small, rural town in Northern California. Consistent with the literature on promotion of health literacy, cultural factors, language barriers, education level, and socio-economic status all figure prominently in the success of these health literacy promotion programs.

Our final papers turn to the issue of health literacy from the perspective of healthcare professionals. Schwartzberg, Fleming, Van Geest, Vergara, and Oliver analyze a program focused on educating physicians and other providers on the problem of low health literacy and techniques to improve communication between physicians and low literate patients. The commentary by Wunsch closes this thematic section by highlighting the roles and responsibilities of patients and providers in enhancing health literacy and health in general.

Enriching Visions of Health Literacy Research

Underlying almost all of the papers in this issue is a conception of health literacy that grows out of work on the general concept of literacy. For example, the NIDCD, one of the National Institutes of Health in the U.S. offers the following description of health literacy:

Similar to our traditional understanding of literacy, health literacy incorporates a range of abilities: to read, comprehend, and analyze information; decode instructions, symbols, charts, and diagrams; weigh risks and benefits; and, ultimately, make decisions and take action. However, the concept of health literacy extends to the materials, environments, and challenges specifically associated with disease prevention and health promotion.

Within this conceptualization, health literacy might be viewed as competence with increasingly complex skills (Figure 1). Certainly, traditional literacy abilities in terms of reading and numeracy form a base on which health literacy must be built.

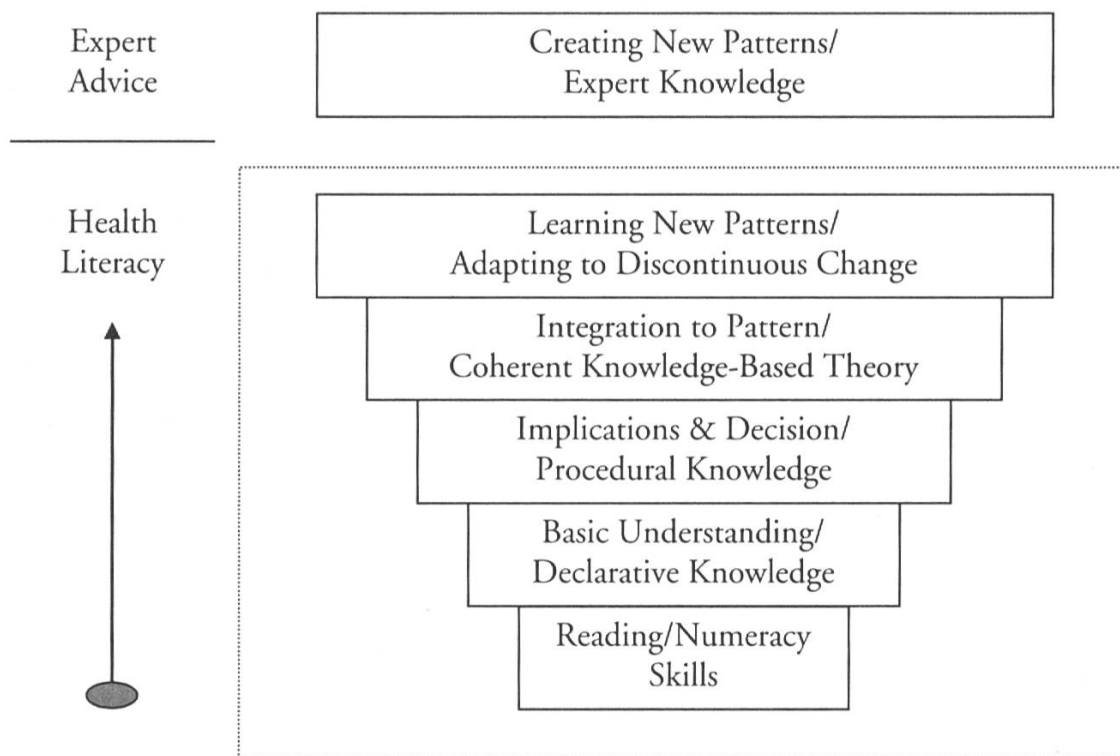


Figure 1: Skill Attainment View of Health literacy

Beyond these basic skills, as Nutbeam suggests, health literacy involves the attainment of more “advanced” skills. Basic understanding of health-related material as declarative knowledge is invoked. Knowing, for example, that pain signals an abnormal condition or that prescription medicine is obtained at a pharmacy forms a base for understanding and interpreting health-related information. Using such declarative knowledge to make informed decisions requires procedural knowledge regarding the appropriate application of health information. These skills might correspond to Nutbeam’s integrative health literacy. The most complex levels of health literacy involve the integration of knowledge and adaptation to changes in knowledge (cf. Nutbeam’s critical health literacy). It is easy to see how difficult these types of learning would be for individuals with limited health knowledge and limited exposure to analytical and critical thinking. Our point here is that, even accepting a “functional” perspective on health literacy, focus on reading, numeracy, and basic understanding limits the application of the concept to a significant but limited population. Research on the problems and biases that emerge as people seek to abstract, integrate, and apply health information is badly underdeveloped.

It is critical, in addition, to recognize that health literacy has limits. We would not expect even a highly literate layperson to be able to discover and identify new patterns or develop new theories of health and disease. New knowledge of disease—mechanism, diagnosis, and treatment—is the domain of medical research. The application of such knowledge, for example, in the initial diagnosis of disease—e.g., an initial diagnosis of diabetes—would not be an exercise in literacy. Rather, this would be a task appropriately performed by an expert—a physician—who has extensive training and experience in applying evidence-based tools and techniques to this task. One of the potential pitfalls of the skills conception of health literacy is the degree to which it leads to the portrayal of the health literate person as a “pale shadow” of the expert.

One example of the difficulties attendant on the model of literate person as pseudo-expert is a mistaken vision of “patient empowerment.” Certainly, it is easy to argue that the caricature of the physician as autocratic and paternalistic dictator of health behavior is unacceptable, but so too should be the patient as constant skeptic—doubting not only the judgment of the physician but also the value of his or her underlying knowledge. Beyond a vision of integrative medicine which seeks to involve complementary avenues to health—from improved nutrition to

alternative treatment approaches (e.g., acupuncture), this patient feels empowered to denigrate the expertise of modern medicine altogether.

The health literate person, then, occupies an admittedly ill-defined middle ground. However, we do expect a literate person to be able to recognize the need to consult an expert, not to become the expert. *A fortiori*, this means that literacy is not a function of ever-increasing amounts of content-specific (e.g., medical) knowledge. What sort of knowledge, then, is essential to health literacy?

Literacy and the Lived Experience of Health

Literacy in the traditional sense is based on the ability to read and comprehend specific texts. Many authors appear to have translated that into health literacy as the ability to read and comprehend health related textual material. While we recognize that these skills are foundational to a notion of health literacy, we believe that defining health literacy in this way creates a view that is overly objective. In a traditional sense, literacy would be measured objectively. The focus of traditional literacy assumes epistemic objectivity; that is, comprehension is objectively measurable. Ontological considerations play a limited role in this vision. With respect to health literacy, this epistemically objective knowledge is certainly an important component but ontological considerations (internalized ideas of good health) that are necessarily subjective play a central role. Indeed, health literacy can have no meaning separate from personal (internal) experience.

Knowledge is only one element of literacy and if we focus on the knowledge component, the concept would give us limited leverage in seeking to promote good health. We want to make literacy something important to healthy choices and behavior and in that sense it has to be internalized; it has to be integral to the lived experience of the person. Being health literate therefore is not equal with propositional knowledge; it's not just declarative and it is even more than procedural; it is procedural as it relates to the person. It almost *is* the person in an existential sense. It's not only "what to do" but what doing something specific means for me "in my own world". We suggest, then, that:

P1: Health literacy is a characteristic internal to the individual—a form of practical wisdom—that reflects the individual's understanding of the implications of health knowledge for his or her own good health.

At the same time, it is critical to recognize the role of knowledge in health literacy. The concept may be, in Nutbeam's terms, "critical" and it is entirely legitimate for a literate person to weigh information in terms of his or her values. However, if literacy is to lead to better health outcomes and physical well-being, the literate person cannot distort or ignore relevant fact. To take but one example, not wearing a seatbelt while riding in a car because of a belief that being confined by the belt in an accident could increase the risk of injury (despite accident data to the contrary) would violate this consideration.

P2: Health literacy entails the use by the individual of information (as relating to the self) without entailing the falsification of knowledge.

As we noted earlier, though, health literacy does not imply omniscience. That is, while literacy requires acceptance of truth, it does not require complete information. In most, if not all, cases complete information is not attainable. This is most obvious in the medical arena, where not only the patient but even the physician can be unsure of a diagnosis. What health literacy does imply is an understanding of what is important to a health decision so that one can ask the right questions. Again, what is important is idiosyncratic and subjective—arising from the person's lived experience of health.

P3: Health literacy is reflected in an individual's knowledge of what questions to ask as much as what information he or she holds.

Finally, health literacy is not synonymous with healthy behavior or "good" health choices. Health literacy implies the *ability* to leverage knowledge to make competent choices. It may well be that an individual who is well aware of the hazards of smoking continues to smoke. It is not an issue of knowledge or decision skill but one of values and preferences that drives this "poor" choice. Health literacy skills are applied in the context of the individual's lived experience. Indeed, dictating health behavior (relying on greater expertise or public policy) could be argued to vitiate the value of health literacy. What is the point of having the skills to make informed choices if you are not allowed to exercise choice?

P4: Health literacy does not entail behavior consistent with knowledge. As such behavioral "failure" does not reflect on literacy.

Nutbeam (2000) uses the term *health literacy* as "a composite term to describe a range of outcomes to health education and communication

activities.” The work on health literacy that is reported in the present collection and more generally in the vast majority of work on health literacy to date is consistent with Nutbeam’s usage. There is, however, implicit in this outcome orientation an underlying promotional vision. The function of health communication is to improve health outcomes by improving access to information—both logistically and intellectually.

Certainly, it is difficult to argue against the benefits of enabling a consumer to distinguish among tubes of toothpaste, antibiotic ointment, and hemorrhoid cream (Van Leuven, this issue). However, it is limited to cases where there is a “right” answer—or at least where a consensus would be probable. Otherwise, we once again run the risk of imposing a bureaucratically convenient or paternalistic model of healthy behavior. In addition, it seems, as in this volume, that this view tends to focus attention on disadvantaged, marginalized, or handicapped populations. Perhaps this is natural in the face of the appalling morbidity and mortality statistics that characterize some of these groups.

Nevertheless, this view of health literacy tends to focus primarily on the person as recipient of information. If the provider or organization presents the information at the right reading level, in the right language, using the right culturally appropriate images, the recipient will respond appropriately. He or she will adopt healthier practices—eat more nutritious food, abstain from drugs, practice safe sex, etc. What is less salient to this analysis is the person as active respondent to the information. Yet, even in the understanding of the provider, success will be contingent on not only the person’s access to information but his or her interpretation and acceptance of it.

Conclusion

Health literacy is a relatively recent focus of study and, as such, appears still to be in a developmental rather than a mature stage of analysis. Even at this stage, research on health literacy offers significant value and importance in understanding and promoting healthy choices, behaviors, and lifestyles. However, to capitalize on potential of the concept of health literacy, we suggest there is a need to explore expanded visions, particularly a vision that highlights the ultimately subjective nature of a person’s interaction with health information. As the research stream grows and matures, we believe it holds great promise not only as theoretically inter-

esting but also as a valuable tool to inform health communication, provision, and policy.

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