Health Literacy and the Tailoring of Health Information.  
A Dialogue between Communication and (AI)Technology

Sara Rubinelli1, Peter J. Schulz2 and Kent Nakamoto3
1 Seminar Health Sciences and Health Policy, University of Lucerne/Swiss Paraplegic Research  
2 Institute of Communication and Health, University of Lugano, Switzerland  
3 Department of Marketing, Virginia Tech, USA

sara.rubinelli@paranet.ch  
peter.schulz@lu.unisi.ch  
nakamoto@vt.edu

Abstract
By moving from a health communication perspective, this paper addresses the issue of how to enhance consumers’ health literacy through virtual health environments. More specifically, the paper is structured in two parts. Firstly, we present a conceptualization of health literacy which takes into consideration the complexity of its components. Secondly, we show how this concept was used to design the website ONESELF targeted to consumers affected by chronic low back pain. Findings from our paper are expected to highlight important dimensions of health literacy that virtual healthcare systems – designed to enhance health literacy – will have to operationalise.

ONESELF works through a bottom-up approach where users can ask for all information to build or reinforce their level of health literacy. This approach presupposes the physical presence of the content manager who assures the delivery of the information requested through the website. Here the main question arises of how AI systems can assure the same level of tailored information by standing, however, from a genuinely human-computer perspective.

Health Literacy and Empowerment
Health literacy is widely regarded as critical for managing personal health and is an important socio-political issue in that limited health literacy can result in enormous burdens to healthcare systems (Ratzan 2001). Lack of specific skills and knowledge associated with health literacy has been shown to affect negatively people’s understanding and use of information provided by health professionals.

Much descriptive research has sought to elucidate the concept of health literacy, its measurement, and the problem of low health literacy. The term “health literacy” was first used by Simonds in the context of school health education. Simonds argued for the importance of students becoming as “literate” in health as they were in other disciplines. This view crystallized an understanding of health literacy as “functional literacy”, as exemplified by the American Medical Association report where health literacy is conceived as «the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials» (Ad hoc committee on health literacy 1999).

This functional approach to health literacy assumes epistemic objectivity; that is, reading skill and comprehension are objectively measurable. Certainly, deficiencies in reading and numeracy skills represent a major barrier to health education and management, and this has given rise to a large body of research on proposing tests for assessing literacy levels and strategies for improving the accessibility of materials such as patient education leaflets and informed-consent documents. In recent years, however, an expanded view of health literacy has been motivated by evidence of an at best weak link between the ability to read and understand health communication and patients’ actual performance. This gap
between functional skills and patient practice created the need to extend the definition of health literacy to include factors that can influence health decisions (Nutbeam 2000) as reflected in the WHO 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”. (World Health Organization 1998)

Some recent definitions of health literacy have expanded the concept to the point where literacy becomes the ability to make sound decisions in all domains—from home and the workplace to the political arena (Kickbusch et al. 2005). However, with these skill-based enrichments of the concept (especially in health promotion oriented visions), health literacy has grown broader in extension but impoverished in its intension. Factors that extend the limited definition of functional literacy have been incorporated but, at the same time, have lost focus on the central link between the person’s goals and actions, reducing health literacy to a set of skills and taking for granted motivation and the meaning of “good health”.

Several current discussions of health literacy hold that its purpose is to enable the individual to use knowledge as an independent agent, thus “empowering” him to make choices that preserve, improve or manage health. This view has enriched the concept of health literacy by including essential dimensions of medical knowledge and a varied set of skills that people need to find, evaluate, negotiate on and apply health information. Nutbeam, for example, encapsulates these skills as functional, interactive and critical literacy that incorporate psychological, social and environmental factors (Nutbeam 2000).

Apart from the difficulty of grasping what some of these skills actually involve, a serious concern arises in that, given the skills that being empowered implies, it is no longer clear how the competences that patients need to acquire differ from those of physicians. The literature does not address this issue but attempting to clarify this distinction between literacy and professional expertise leads to paradox.

If the patient’s knowledge and skills (literacy) are not commensurate with those of the doctor, then the skill attainment vision of health literacy leads to the patient as a pale shadow of the physician. Such literacy might empower the patient and make him more independent in the health system, but results in a dangerous independence. Empowerment might lead the patient to overestimate his real competences and to favour deleterious health choices inspired by insufficient expertise. If, on the contrary, the patient’s knowledge and skills are “close” to those of the doctor then health literacy is tantamount to making the patient into a health professional—a goal that is unrealistic and unreachable.

We believe that the concept of health literacy should be re-framed in a way that avoids this paradox but at the same time preserves its important value as a key component of individual self-healthcare. To do so, we argue that health literacy must be re-grounded in the individual’s existential experience.

**The Goal of Health Enhancement**

Consider the following example. Andrew, who works in an institute of preventive medicine, has been asked to design an anti-smoking campaign. He has all knowledge necessary to design the campaign: numerous medical reports on the risks of smoking and techniques to quit smoking. Nevertheless, he himself is a smoker and has no intention of giving it up.

Would we claim this smoking behaviour constitutes a failure of health literacy? Traditional definitions of health literacy would give an ambiguous response. His literacy includes all competences that “being literate” in health implies but his choices belie his expertise.

What our example shows is that, first and foremost, although there is a link between health literacy and behaviour, that link is neither necessary nor sufficient. What is needed to forge this link is the primacy of an existential goal of health-enhancement. It is this goal that would motivate Andrew to quit smoking. The problem, of course, is that people have multiple goals, among which health is one, certainly not the only one, and in some cases not even the most important one. Thus, the behaviour of highly functionally literate people who do not act accordingly can be explained by the fact that for these people the pleasure of smoking or the importance of the maintenance of a relationship take priority over health.

On the other hand, prioritising the health-enhancement goal as part of the definition of health literacy would fail to consider the richness of the existential dimensions of the individual and ultimately deny the importance of freedom of choosing how to live one’s own life. It might well be the case that specific life events lead people to change their goals, e.g. the occurrence of an illness might motivate a person who has so far enjoyed smoking to seriously think about stopping his habit. But this goal revision is rarely made a priori against the status quo—more often it is a function of the salience of health at specific moments of life. Moreover, it arises while reflecting on a complex of individual and social factors that form a context in which the importance of health enhancement is either prioritized or diminished.

Provided that health enhancement is the goal, then, how does a person capitalize on his health literacy to advance this goal? This leads us to re-consider the nature of health literacy.

**Health Literacy and its Components**

As Schulz and Nakamoto explain (2005), patients’ health literacy is a competence that integrates factors working at three main levels. On the first level, health literacy is made up of the kind of knowledge technically labeled
The Website ONESELF

As part of a project financed by the Swiss National Science Foundation, we designed and implemented a website to support low back pain sufferers in their online searches, and enhance their self-management abilities. The website, titled ONESELF and currently available only in Italian at www.oneself.ch, is run by the Institute of Communication and Health of the University of Lugano in collaboration with health professionals of the Lega Ticinese per la Lotta contro il Reumatismo.

We derived the rationale of ONESELF by reflecting on what constitutes and stimulates people’s health literacy (Schulz et al. 2007 and 2009) [8]. The following text explains how our core concept of health literacy was taken in consideration in the orchestration of ONESELF.

Based on the assumptions made above, we first decided to make available online basic texts on back pain. These texts are expected to meet users’ range of needs for declarative information, thus forming a basis for understanding and interpreting more complex information about this condition. To fulfill this task, we designed a section of the website – called “Library” (Biblioteca) -, where we initially inserted a series of texts selected by the health professionals involved in the project. In particular, they reached a consensus on some key information on low back pain that they normally deliver to patients during face-to-face interaction, e.g. the nature of back pain, its etiology, the vertebral column and the importance of postures and physical activity. To further favor users’ search for personalized information, we provided the Library with a form headed “Propose a topic” where they can suggest topics of interest and request contributions that they would like to read.

By exploiting the audio channels that internet supports, we created a further section - titled “The radio” (La Radio) - where we recorded 10 two-minute lessons given by health professionals on further basic contents including “Sport and back pain”, “The perception of pain” and “Manual medicine to mobilize/stabilize the spine”. These contents were chosen by reflecting on the questions that health professionals receive more often during consultation. Here, again, users can request a specific contribution on the topics they are most interested in.

Shifting to the publication of procedural-oriented information, this is delivered to patients in two main formats, namely as texts that verbally and visually show how to perform certain specific actions (e.g. to get out of bed in the morning) and as exercises found in a section of the website called “Gym” (Palestra). More specifically, the Library contains documents that illustrate with pictures and explanations the correct postures for performing certain actions considered by patients to be “difficult”, e.g. lacing up one’s shoes, carrying shopping bags, getting out of cars. In its turn, the Gym contains videos on exercises selected on the basis of the major disabilities reported by users of ONESELF. In particular, it contains stretching, stabilization and mobilization exercises. Each video is accompanied by photos and a written description of the exercise, its difficulties and correct execution. This area is maintained by two physiotherapists who guide users in the selection and performance of the appropriate exercises. The physiotherapists can be contacted by users directly through the form ‘Contact the team’ from the homepage of the website.

To foster users’ integration of the information delivered by ONESELF and, thus, enhance their third level of health literacy, the website offers a forum and a chat-room where they can meet and interact with both other users and the health professionals of the team. These are the sections where users can ask for further information on declarative and procedural levels, as well as discuss any information in synchronous (via the chat-room) or asynchronous (via the forum) ways. Once a week, at a specific time of the day announced on the homepage of the website and via a weekly newsletter, a health professional is available in the chat-room to address specific topics. The topics of each chat-room are selected by screening the messages published in the forum during the previous week. Users are also invited via the newsletter to propose any topics they would like to discuss.

To further enable the interaction between users and health professionals, in the section “The specialist answers” (Lo specialista risponde), users can find videos
and other kinds of electronic material (e.g. short PowerPoint presentations) on topics of interest collected during face-to-face consultation. Another section, titled "Tell a story" (Testimonials), invites users to edit and comments personal stories and experiences.

The Ingredients of ONESELF
At the time of publication approx. 900 people were using ONESELF. Considering the size of Ticino, with its population of approx. 315.000 people, this number counts as an external indicator of the success of the initiative.

We believe that this success is significantly due to the validity of the communication paradigm behind ONESELF. But for ONESELF to function as a resource for consumer, different types of expertise are needed. In addition to the technologists who design and develop the website, a prominent figure to assure the working of the health literacy - bottom up orientation of the website is the content manager. The content manager deals with a series of specific tasks:

1. He answers users’ non-clinical questions (concerning, for example, technological features of the website and instructions on how to navigate it).

2. He occupies an intermediate position between users’ clinically-oriented requests and health professionals’ response. Users can post requests (for example through the Library of ONESELF) on specific topics they would like to read online. The content manager receives all these requests, selects the health professional that will write the text and assures that it will be published in time.

3. He monitors and analyses users’ overall and individual activities. When a topic of interest has been identified, the content manager organizes the production of a new contribution.

4. He manages the sources for synchronous (chat-room) and asynchronous communication (forum). Concerning the chat-room it is a matter of checking whether users are interacting online without the presence of an health professional. As for the forum, the content manager verifies whether health professionals answer to users’ requests in a reasonably short period, and controls whether users’ requests and health professionals’ answers guarantee a constructive communicative exchanges within the online communities.

The second ‘ingredient’ for the functioning of ONESELF is represented by the health professionals and the role they play. ONESELF is currently monitored by 8 health professionals (5 rheumatologists and 3 physiotherapists) who have actively managed the interaction with users over the last two years.

A Concluding Question
In order to target consumers’ health literacy, initiatives such as ONESELF make use of technologies but as one of the channels to enable expert-to-lay communication. ONESELF is a tool that users can navigate to contact and speak to health professionals beyond face-to-face consultation. We conclude this paper by posing a question to the audience of this Symposium. How can AI systems reach a level of sophistication that enables addressing consumers’ health literacy in an in depth tailored perspective? Indeed, one of the topics of the Symposium concerns the tailoring of health information to low-literacy audiences. Given the complexity of what health literacy implies, can intelligent systems instantiate that interactivity that is at the basis of consumers’ disclosure of their informational needs? We fear that the pre-compiled set of arguments and messages which AI systems usually implement and deliver [Bickmore and Green 2006] risk missing the individuality of consumers and their specific needs at the very moment they use a healthcare system.

References


