

Revisiting the concept of health literacy. The patient as information seeker and provider

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In the light of increasing user-generated online health information, the changing role of the patient, and the shift toward patient-driven care, it is timely to revisit the concept of health literacy by considering the twofold role of the patient as information seeker and provider. We claim that rather than limiting the patient's role to that of a passive information recipient, more attention should be devoted to the patient as an active information provider, particularly in the context of peer-to-peer communication. Consequently, individuals should not only be supported in developing their skills to search, evaluate, and apply health information, but also to share relevant health information.

The Patient as Information Seeker

Prior research in the field has conceptualized health literacy as a requirement to find, understand, evaluate, and apply health information to one's personal health situation (Altin, Finke, Kautz-Freimuth, & Stock, 2014). It has further been suggested that health literacy can be regarded as a measurable outcome describing a number of task and skill related capacities of an individual that are essential in different health contexts (Nutbeam, 2009). These capacities may be influenced by factors like health education (Nutbeam, 2000), aging, or

cognitive impairments (Baker, Gazmararian, Sudano, & Patterson, 2000).

Much research has focused on identifying the antecedents and consequences of health literacy, highlighting its crucial role in relation to individual health outcomes, access to and utilization of health care services, patient-provider relationships, and self-management (Sørensen et al., 2012). A number of different trait variables related to demographic, psychosocial, and cultural factors have been identified as antecedents of health literacy while authors have also recognized the role of individual characteristics and experiences (Sørensen et al., 2012). Interestingly, little attention has been paid to the impact of situational characteristics, or state variables, such as fatigue, fear, or physical discomfort. It is very challenging to communicate meaningfully to consumers of health care who are experiencing significant physical, cognitive, and psychological challenges due to their health conditions. We therefore believe that it is critically important to recognize such state variables that often limit consumer understanding when presenting complex health information to other consumers.

In order to assess health literacy, scholars have developed a variety of different measurement tools, such as the TOFLA, REALM, and HALS (Nutbeam, 2009). These tools, however, all focus on consumers' interpretation of health information rather than capturing their abilities to share health information. Indeed, our review of the literature suggests that, apart from a few noteworthy exemptions (Crook, Stephens, Pastorek, Mackert, & Donovan, 2016), current

efforts in the field of health literacy are predominantly focused on aspects related to individuals' capacities as information seekers or recipients, neglecting their role as information providers (Sørensen et al., 2012). When patients' communication skills were addressed, this was usually done in a formal context, such as patient-provider interactions, rather than looking at informal information exchange as found in the peer-to-peer context (Crook et al., 2016).

We believe that this is a serious limitation to research in this area, especially given the growing demand for effective peer-to-peer sharing of relevant health information among consumers to promote health and well-being. The demand for sharing health information among consumers has increased with the growth in consumer participation in online health networks. It is important for participants in these online health networks to be able to share health information in ways that other consumers will be able to understand and use this information, emphasizing the importance of health literacy skills in providing health information to others.

This paper contributes to the health literacy debate by drawing attention to the role of the patient as information provider in the context of peer-to-peer health communication. Prior research on health literacy does not account for situational influences resulting from an individual's health or emotional state nor does it adequately address issues arising from the role of the patient as information provider. The objective of this paper is therefore to highlight the importance of conceptualizing and operationalizing health literacy in the context of peer-to-peer health communication while taking situational factors into account.

The Patient as Information Provider

The idea of the patient as an information

provider becomes particularly relevant in the context of online information and the revolutionizing role of health information technologies (Kreps & Neuhauser, 2010). The ever increasing interactivity on the internet has supported the trend of user-generated content on an unprecedented scale and scope. In fact, everyone with internet access and the ability to navigate the online world can become a self-proclaimed expert. Plenty of health-related online communities exist where individuals openly share their experiences in a peer-to-peer format (Eijk et al., 2013). However, this information exchange does not come without risks. As pointed out by Chalmers (2001), "invalid health information is potentially lethal". This threat becomes more concrete when considering patients' suboptimal health literacy in terms of identifying and evaluating online health information (Morahan-Martin, 2004). Even the delivery of technically accurate health information that does not make complete sense or is misinterpreted by consumers due to health literacy constraints is problematic. Therefore, it is important to help consumers who share health information develop strategic health literacy skills to enable them to share messages that other consumers are likely to understand and apply effectively.

The push toward patient-driven health care (Swan, 2009) and the rise of patient-helpers who share their knowledge and experiences online with other patients (Ferguson, 2000) further underline the importance for recognizing patients as providers of information. To illustrate this, take Karen as an example of a highly health literate patient who shares important health information with other health care consumers. After being diagnosed with lung cancer, she sought help and information from an online support community. Once recovered, she decided to start her own website to share her knowledge and information resources with peers. Her

website is widely acknowledged as one of the top consumer-initiated websites for lung cancer (Ferguson, 2000). On the one hand, Karen was able to find, understand, evaluate, and apply health information to her personal situation. On the other hand, Karen possessed the necessary skills to produce knowledge with the purpose of helping others.

Patients like Karen are invaluable resources for other patients and their families who find themselves in similar situations. Their personal experiences coping with serious health issues provide them with a special level of experiential credibility when sharing health information. They have the ability to connect with other health care consumers on a very personal and experiential level. Often they have unique insights into strategies for overcoming the challenges that other consumers face when seeking care and managing their health conditions.

Strategies of Empowerment

Given the increased amount and popularity of user-generated content online, there seem to be at least three strategies of reducing the risk of peer-to-peer health communication leading to misinformation and causing harm; 1) increasing availability and accessibility of high-quality health information so consumers have easy access to the best, most up-to-date, and complete health information, 2) improving patients' health information searching and processing skills, and 3) improving patients' health information sharing skills. In the light of current debates on the quality of online health information, much research has been conducted on patients' information seeking behavior (Morahan-Martin, 2004), but only very little is known about their ability to make sense of the information they gather and to effectively share

relevant health information (Oh, 2012).

Patients can receive support in processing health information, particularly through educational efforts, but they often need more support to be able to make sense of the information they gather. Online forums, especially conversations with health care providers, educators, scientists, and other knowledgeable consumers can help improve their understanding of health information. Access to online health databases, health information portals, and reference works can further help to enhance access to and understanding of complex health information. In addition, consumers need to develop skills at evaluating the meanings, credibility, and applications of health information they gather, especially the information they find online. Once they find relevant health information, they also need to learn how to adequately share health information with others.

This suggests the need to develop strategic communication skills for designing health messages that match the communication competencies and orientations of the audiences that consumers share health information with. A key part of developing these competencies involves careful audience analysis so that messages can be adapted to meet the audience characteristics. In addition, it is important for communicators to become adept at seeking feedback from those they share health information with to determine how well they understand information provided.

We suggest that informed patients can take on a more active role in the health care process if they are well prepared to seek relevant health information, make sense of the information they find, and share that information effectively with others who may also need the information. Empowered by information technologies, patients can not only seek to exert control over their own health, but to also become health

advocates for others.

Conclusion

In the present paper we illustrate the power and potential of peer-to-peer health communication. We thereby draw attention to the role of the patient as active information provider and underline the importance of conceptualizing and operationalizing health literacy in the context of peer-to-peer health information sharing.

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