Crowdsourcing Health Literacy: The Case of an Online Community

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ABSTRACT
Drawing on data from 31 semi-structured, in-depth interviews, participant observation, and online archives analysis, this paper examines the health information interactions that participants in an online breast cancer community experienced as they progressed through breast cancer and survivorship. This research highlights patients’ perceptions of information gaps, how patients navigated through their information gaps with the help of the community, and the significance of peer interaction in the comprehension of medical information and medical decision-making. The findings reveal that participation in this online health community played an important role in the acquisition of health literacy.

Keywords
Health literacy, health information, online communities

INTRODUCTION
Over the last forty years, health literacy and consumer access to health information have become major concerns to a variety of constituencies, including medical professionals, government and community agencies, librarians, and consumers themselves (Kouame, Harris, & Murray, 2005; Murray, 2008; Rubenstein, 2012a). At the same time, the availability of health information on the Internet has grown exponentially; the Pew Internet and American Life Project reported that 80% of Americans who use the Internet use it to access information related to health issues (Fox, 2011). However, although health information is readily available, consumers do not necessarily know how to interpret, process, and evaluate this information (Chobot, 2004; Gillaspy, 2005; Kwon & Kim, 2009; Oelschlegel, Earl, Taylor, & Muenchen, 2009).

According to the U. S. Department of Health and Human Services (2011), health literacy encompasses “the ability to understand health information and to use that information to make good decisions about…health and medical care” (para 1). In an environment where patients are increasingly expected to engage in participatory health care, individuals with low health literacy are at a major disadvantage (Rudd, 2007). If patients are unable to understand and act on the health information they receive, they are unable to follow through with management and treatment, resulting in reduced health, increased chronic illness, decreased quality of life, and even premature mortality (Berkman et al., 2004; Schaefer, 2008). Currently, only 12% of the population has high enough levels of health literacy to make appropriate decisions related to their health, making “limited health literacy…a major public health problem” (Johnson, Baur, & Meissner, 2011, p. 22).

This poster reports on a subset of findings from a larger study that investigated the information and social support exchanges of an online breast cancer community (Rubenstein 2011; 2012b). Some of the findings from the study indicated that being part of this community had a great impact in how participants made medical decisions and proceeded through their breast cancer treatment. One aspect of this that is yet to be addressed is how being part of this community, or any community whether online or not, results in greater opportunities to increase individuals’ and groups’ health literacy. This research makes the argument that health literacy can be attained collectively through social, collaborative resources. In the same way that online health communities offer patients direction and support in coping and making health care decisions, they also garner the knowledge of the crowd to promote greater health literacy among participants.

BACKGROUND
Conceptualizing Health Literacy
Health literacy is a subset of information literacy, “the ability to know when there is a need for information, to be able to identify, locate, evaluate, and effectively use that information for the issue or problem at hand” (National Forum on Information Literacy, 2011, para 1). Library and
information science scholars have long studied the processes of information literacy in order to develop effective teaching programs for libraries, educational institutions, and community-based organizations. Much of the current research on health literacy focuses on measures such as reading comprehension, brochure and website design, computational ability, and patient-provider communication. However, few studies have examined the impact of social support on health literacy.

The National Institutes of Health (NIH) and the National Library of Medicine (NLM) (2011) have issued calls for research to identify and examine the underlying processes that contribute to health literacy. Health literacy comprises multiple components, some of which are easily tested, but others that are not immediately apparent or easily situated with a quantifiable framework. Health literacy includes such skills as reading and understanding prescription instructions, appointment slips, medical consent forms, and doctors’ instructions as well as having “the ability to negotiate complex health care systems” (National Network of Libraries of Medicine, 2011, para 3). Prior research has emphasized developing quantitative assessments to address reading and comprehension with the goal toward developing appropriate written materials, or formal communication within medical contexts (Nielsen-Bohlman, Panzer, & Kindig, 2004). Issues related to social support, information seeking, and health information resources outside of clinical settings are seldom addressed in regard to health literacy.

Adopting a holistic interpretation, the Committee on Health Literacy (at the Institute of Medicine, part of the National Academy of Sciences) takes the stance that health literacy is composed of the interactions among individuals’ skills within health contexts, health care systems, the educational system, and social and cultural factors at home, work, and in communities (Nielsen-Bohlman et al., 2004; Paasche-Orlow et al., 2006). Thus, health literacy transcends the ability to acquire and implement specific skills – it is an intricate integration of cultural awareness, interpersonal and technological communication, and access to appropriate and relevant information (Paasche-Orlow et al.). Furthering the discussion of a more integrated model of health literacy, Lee, Arozullah & Cho (2004) state that research agendas should include inquiries into the relationships among social support, health literacy, and health service utilization, noting that “social support may moderate the impact of low health literacy” (p. 1310) and provide patients with confidence and tangible help in navigating medical systems.

Research suggests correlations between social support and health outcomes, but rarely expands these connections into health literacy constructs. Research has described the influence of social support on such diverse areas as HIV treatment adherence (Gordillo, Amo, Soriano & Gonzalez-Lahoz, 1999; Simoni, Frick & Huang, 2006) and healthy eating practices among low-income African Americans (Sloane et al., 2003). Studies of online communities addressing a range of health conditions, such as breast cancer, heart disease, and other chronic illnesses, have also offered evidence of the positive health implications of social support, noting better management of illness (Hill et al., 2006; Lieberman & Goldstein, 2006; Lindsay et al., 2007; Maloney-Krichmar & Preece, 2005). These studies speak to the importance of social support in fostering better health practices, but they do not specifically link the support participants received to health literacy. Because health literacy comprises multiple skills and circumstances, it is important to understand how community support plays a role in the development of health literacy.

Inspiration for this study grew from theory and practice related to the idea of “local literacies” (Barton & Hamilton, 1998), which argues that literacy builds through social networks, based on the interactions among people who either purposefully or incidentally learn from each other. Referencing these ideas, Mehra, Merkel, and Bishop (2004) studied how various local grassroots groups learned from each other and became empowered as they were building community. In addition, Papen (2013) makes the case for information literacy (although not health literacy per se) as being ingrained in social practices. Although not specifically related to health literacy, other scholarship also emphasizes the importance of information exchange in social settings (Maloney-Krichmar & Preece, 2005; McKenzie, 2010; Prigoda & McKenzie, 2007). This current study takes the stance that even an online community can be considered “local,” and based on that, looks at the way health literacy was built through the online social practices of a breast cancer community.

Study Context

This research sought to extend current concepts of health literacy by identifying interconnections between peer social support, exchange of information, and the development of health literacy. Drawing on data from an earlier study of an online breast cancer community (Rubenstein 2012), the research looked at the processes that occurred as participants gained health literacy through the social support of others and social practices among members of the forum. The research questions were: 1) What kinds of relationships exist between peer social support interactions and health literacy? And 2) How does peer social support build capacity towards health literacy? The goal of this research was to identify and illustrate linkages between the social support that online community members exchanged and how these events contributed both to their understanding of their conditions and their subsequent treatment.

Research Design and Methods

The original research that this work is based on took an ethnographic approach, using analysis of the online community’s archives, participant-observation, and 31 interviews (Rubenstein, 2012). The findings of the original study led to an investigation of how health literacy might be
achieved through online peer social support. For this current study, the archives and interviews were re-analyzed to see how, if at all, health literacy was achieved through the process of collaboration and social interaction. This analysis took a broad view of health literacy based on the National Network of Libraries of medicine definition, “being able to negotiate complex health systems” (2011, para 3) and the ability to “acquire and use new information” (Baker, 2006, p. 878). Doing this covered the ability to recognize a need for information, the ability to know how to find it, understanding how to use it, and, in using it, being able to use it to access and navigate through medical establishments. Primarily, this research looked for how understanding and actions were based in social practices.

FINDINGS AND DISCUSSION

This paper reports on preliminary results linking online social practices to health literacy. In particular, social support as a phenomenon is very much related to social practices. The online breast cancer community in this study was abundant in both expressions of social support and in information exchange. The challenge was to understand where in the spectrum of these exchanges did instances of health literacy lie? How could these be identified within the rich corpus of interactions that members of the forum exchanged?

Going back to the working definition for this research, including being able to navigate health systems and knowing how and when to acquire and use information, several instances were identified that related to these ideas.

Questioning

The action of questioning, while simple, indicated recognition of information gaps. Individuals understood that they needed to know more in order to understand and act. Questioning occurred from an individual perspective, but evolved into one-to-many and many-to-many conversations. For example, a participant asked for advice about chemotherapy treatment, which spurred multiple responses directed to her as well as inciting other related conversations among other participants. These interactions resulted in the original poster gaining information that she had not had previously, allowing her to make decisions about how to negotiate chemotherapy treatment. On a group level, there was a greater awareness of the different issues and considerations one must think about when pursuing treatment. Thus, the action of one person (questioning) evolved into a group activity (social practice and social support), contributing to more detailed group understanding and health literacy.

Providing and Receiving Information

Health literacy was further promoted through information provision in two particular categories. Exchanges included technical and medical information, often based on provider interactions, but also from various media including scholarly and popular publications; and personal information, which included comparative information, where participants discussed their own treatments with each other and vetted information among others. Participants also updated each other as to status of medical appointments, tests, etc. In these instances, social interactions were well integrated into how participants learned more about their own conditions, about others’ conditions, and about health information in general. Over and over again, conversations about breast cancer and other health information prompted participants to interact more with medical providers and be more proactive in their health care decisions.

Providing and Receiving Social Support

Social support occurred in several ways, encompassing informational support (sharing information), emotional support (words of caring and encouragement), and tangible support (providing goods or services). Most pertinent to the health literacy process was a combination of informational and emotional support, because they both provided feedback and camaraderie that interacted together to help in the learning process. Although potentially either could provide impetus toward better health literacy, encouragement paired with information gave participants confidence that they were learning and acting upon what they were learning.

CONCLUSION

Conceptualizations of health literacy as a construct are slowly moving away from strict assessments of reading and numeracy levels, but much more work needs to be done to draw stronger connections between the value of social interaction in the health literacy process. Although the results of this study are preliminary, they suggest that there is a direct connection between being able to process health information in a supportive environment as being a route to being able to understand and act on health information, which is key to acquiring health literacy.

REFERENCES


