

Social Features in Online Communities for Healthcare Consumers – A Review

Annie Y.S. Lau¹ and Trevor M.Y. Kwok²

¹ Centre for Health Informatics, ² Faculty of Medicine
University of New South Wales,
UNSW Sydney NSW 2052, Australia
{a.lau, t.kwok}@unsw.edu.au

Abstract. This review provides a snapshot of the literature in online communities for healthcare consumers. It summarizes the features commonly used by healthcare consumers in online communities: seeking and sharing personal experiences, opinions and answers, and exchanging social support. This review also identifies behaviors that are commonly practiced by healthcare consumers but are not readily supported in current online communities. These include collaborative healthcare decision-making, conducting social comparison, and lurking in online communities. This review concludes by emphasizing the importance of trust, privacy and safety when designing an online community for healthcare consumers, particularly in the age of Web 2.0.

Keywords: Online community, healthcare consumer, social features.

1 Introduction

An increasing number of people turn to the Internet for healthcare-related information and advice. At the same time, studies have reported that other people are one of the most important sources of information that influence healthcare consumers' actions when confronted with a health-related matter [1-6]. Online communities provide a means for people to share information and interact socially over the Internet. In the United States, 30% of the 90 million people who have participated in online communities have accessed such communities for medical or health-related purposes [7].

An online community that allows healthcare consumers to share information, interact with fellow consumers and provide support is not a new idea. Prior to Web 2.0, online communities for healthcare consumers existed in many forms, such as discussion forums, chat rooms, newsgroups and mailing lists [8]. Researchers have also made suggestions on ways we can use Web 2.0 technologies, such as using blogs, wikis, mashups and RSS feeds, to enrich the online experience for clinicians and healthcare consumers [9-13]. With the role of the Internet as a platform for social networks, typified by the growing interest in sites like Wikipedia, Facebook, and MySpace, we can envisage more consumers seeking health-related information and advice from online peer networks. How do we design online communities that meet

our healthcare information needs, and promote social interaction and information sharing in a safe manner without jeopardizing the privacy of our personal health information?

This review takes a different approach from previous reviews by identifying behaviors that healthcare consumers practice when confronted with a health-related matter that are not supported effectively in current online communities. The aim of this review is to examine literature from multiple disciplines to identify key social features and issues to consider when building an online community for healthcare consumers. It is not intended to be a comprehensive review, but rather a snapshot of recent literature in the various fields that are relevant to online healthcare communities. It will start by reviewing social features that are commonly found in these online communities, proceed to compare this feature set with the set of behaviors consumers actually practice when facing a health-related matter, and then identify needs that are currently not being met. The review then discusses the importance of trust, privacy and safety when designing an online community for healthcare consumers, particularly in the age of Web 2.0.

2 Current Features in Online Healthcare Consumer Communities

Online communities for healthcare consumers often exist in the form of interactive health communication applications, providing health information with at least one of the following features: social support, decision support, and behavior change support [14]. At present, the most common forms of social behavior in online healthcare consumer communities are seeking and sharing personal experiences, opinions and answers, and providing support and empathy [15].

2.1 Seeking and Sharing Personal Experiences, Opinions and Answers

In online communities, healthcare consumers access stories of fellow consumers' experience to help them understand their condition, normalize and make sense of their personal experience, manage their fears and maintain hope [16]. They also seek and share opinions and answers to questions that aid in decision-making. Consumers more likely to search for help online are those with illnesses that have a limited number of standard treatment options, have an uncertain etiology, or are considered embarrassing, stigmatizing or disfiguring [17, 18].

Common types of questions asked and information sought from online communities include: (i) asking questions and seeking advice from others who have had the experience, e.g. "can anyone help...?", "does anybody know ... ?" [19]; (ii) comparing the course of treatment and validating symptoms with others, e.g. "were you feeling X ... at stage Y?" [19]; (iii) seeking self-care information and day-to-day coping strategies, especially with side effects of treatment and recurrence of disease [19]; and (iv) looking for other sources of information written by and for people in the same or similar situation to themselves [16].

The way healthcare consumers interact with others in online discussions can depend on the health condition they are experiencing. In a three-month study analyzing the content of postings in online support groups for consumers with breast cancer,

fibromyalgia and arthritis—diseases that can be associated with chronic physical or psychological pain and suffering—postings were most often made to share personal experiences, provide empathy and support, and share information on what the condition feels like and what to expect next [15]. It was noted that the style of postings varied depending on the disease. Consumers in the support groups for breast cancer and fibromyalgia—diseases that are often incurable or unable to be treated effectively—often used ‘chit chat’ [15], establishing and contributing to a community offering trust, warmth, concern and a normalizing experience among group members. On the other hand, consumers in the arthritis group used relatively less ‘chit chat’, and postings were more matter-of-fact in style, with discussions centering on treatment, medications and restrictions on daily living imposed by the disease [15]. During the study period, only a small number of postings contained actual medical information, and none of the postings contained medical information considered potentially dangerous to other consumers [15].

Practical information on how to manage day-to-day life in the context of disease is often not available from clinicians but can be obtained from fellow consumers who have lived through the experience [20]. By reading fellow consumers’ opinions and advice, consumers gained knowledge on how to manage and accommodate their condition, and felt better informed to ask important questions to their clinicians [19]. In fact, studies have found there is an emerging cohort of consumers who feel the need to be—or at least appear to be—experts in their disease, locate effective treatments for themselves, and be able to question the advice and decisions of health professionals [21].

2.2 Seeking Support, Empathy and a Sense of Belonging

Healthcare consumers using online communities commonly seek support, empathy and a sense of belonging amongst people experiencing a similar situation. Consumers sharing comparable experiences and facing similar challenges report experiencing significantly less loneliness and withdrawn behavior, developing a sense of camaraderie with fellow consumers, and experiencing less anxiety and resistance towards their treatment [7].

Men and women have been observed to seek support from online communities in different ways. While men participating in online discussions are more likely to ask for information directly relating to a health condition, women are more likely to share personal experiences and provide encouragement and support [17]. In addition, men appear to prefer to participate in online communities than face-to-face support groups, and have been reported to be twice as likely to use online communities for support than face-to-face groups [17].

The development of ‘virtual factitious disorder’, or ‘Munchausen by Internet’, has demonstrated the importance that some individuals place on the support and sense of community they can obtain from online health groups. In this phenomenon, named by analogy with the real-world factitious disorder and Munchausen syndrome, members of online communities intentionally deceive others by feigning illness in order to obtain sympathy and attention [17].

More research is needed to explore the impact of online communities on managing health and making healthcare decisions, in particular to influences on compliance with medical treatment, health behaviors and health outcomes [17].

3 Social Behaviors Not Yet Supported in Online Healthcare Consumer Communities

Current online healthcare consumer communities do not directly address or facilitate all forms of social conduct that people tend to employ when faced with a health-related matter. Examples of social activity not well supported currently include: (i) recognizing that healthcare decision-making is often a collaborative process that involves seeking opinion and having discussion with multiple parties before reaching a decision; (ii) conducting social comparison, the process of comparing the self with others who are similar or dissimilar [22], which includes comparison with the self and others at different points in time [23]; and (iii) lurking in online communities, the process of reading an online discussion without contributing to the discussion. These processes are practiced by consumers at different stages of their health journey; for example, lurking is more likely during initial information gathering in the early part of a journey, while collaborative decision-making is likely to occur later in the journey.

3.1 Supporting Healthcare Decision-Making as a Collaborative Process

Management of a health condition and the related decision-making is a collaborative process, often involving not only the experience of the consumer but that of his or her family and other close associates [19]. However, a paucity of research attention has been given to the information needs of caregivers, family members, and friends who are involved in the process [24]. In particular, few, if any, studies have looked at the interactions between consumers and those helping them to manage their condition [25].

The *influence* of a consumer's close social network on the health decision-making process needs to be explored with further research [25]. One study found that only 4.8% of cancer patients personally accessed the Internet for health information, but 50% of them receive information from the Internet via their family [26]. When consumers find information online that they do not trust or believe, they ask their close network and clinicians to evaluate the information and provide advice [19]. During the decision-making process, consumers often consult online information and integrate it with offline advice from friends, family and clinicians before being able to reach a final decision with confidence [16].

A consumer's close network can also reduce consumers' use of online information and involvement in online communities. For example, some consumers are discouraged from participating in chat rooms and online bulletin boards by family members who believe that they are poor sources of factual information [19]. Other consumers feel that the support of their friends and family members is sufficient, and do not seek further information from the Internet [19].

The *needs* of a consumer's close network group, in particular the primary caregiver, also need careful consideration. Caregivers often take the responsibility of interacting with clinicians, asking questions on behalf of the consumer, managing the logistics of care plans, and finding information online for the consumer [19]. The caretaking process can be stressful and demanding that caregivers express the need to vent feelings of anger, frustration or helplessness [17]. Despite this, there are few, if any, online tools designed specifically to support the caregiving process. In particular, caregivers need to be supported when they are required to make high-impact or

otherwise difficult decisions on behalf of consumers who are unable to assert their will or lack decision-making abilities.

3.2 Facilitating Social Comparison

Consumers often take their own journey as a starting point and search for fellow consumers' stories and experiences for comparison and advice. Studies have reported that consumers often conduct 'upward' (i.e. comparing with others who are doing better than themselves) or 'downward' (i.e. comparing with others who are doing worse) comparisons with fellow consumers to help gauge their own progress and to seek comfort in the knowledge that there is hope and that they are not in the worst situation [27].

A few studies have examined ways to facilitate upward and downward social comparison. For example, Overberg and colleagues examined the information needs of breast cancer patients and proposed additional features on search engines that retrieve fellow consumers' stories based on the content of the stories or the medical history of the authors. They found that consumers want functions that: (i) conduct searches using content keywords to find stories; (ii) allow stories relevant to the consumer to be retrieved, by searching on personal data of the author such as age, treatment undergone, time since diagnosis, and presence of metastases; and (iii) retrieve stories based on writing style or story ending (e.g. to find stories that reflect the consumer's possible future disease states) [20]. More research is needed to investigate other mechanisms to facilitate social comparison.

3.3 Supporting Lurking Behaviors

Lurking in online communities (reading online discussions without contributing to the discussion) is an extremely common activity: it has been reported that 90% of users in online communities are lurkers [28]. However, few, if any, tools have been designed to support the information foraging and decision-making behaviors of this large group of users. Social features emerging in non-healthcare online communities may have a role supporting lurkers as they forage across different online communities, and may encourage them to actively participate in online communities. Examples of these features include: social rewarding (using mechanisms, such as a points or ratings system, to motivate users to contribute to the community to elevate their reputation and status in the community) [29], facilitation of social presence (the ability of a user to appear to be a 'real person' within the community by participating frequently and actively) [30], social roles and types (explicit titles and roles for users, such as member, leader, or mentor) [31] and social cohesion (mechanisms to help users in a community work together as a cohesive force to achieve a common goal) [32].

4 Trust, Safety and Privacy Issues

The importance of trust, privacy and safety when designing an online community for healthcare consumers cannot be overemphasized. Although trust models have been explored extensively in the field of e-commerce, they remain relatively unexplored in other domain areas. Trust models for online healthcare communities are likely to

differ significantly from those in e-commerce because consumers are particularly vulnerable, and activities in healthcare are more complex and more collaborative than commercial transactions.

Consumers participating in online healthcare communities often reveal personal information in intricate detail [33] without necessarily understanding the consequences of their actions [34]. In the age of Web 2.0, the opinion of popular peers and leaders in online communities has become the key determinant of the level of influence of information sources. Established mechanisms that promote safety and privacy in online discussion forums, such as utilizing a moderator to filter out ‘flaming’ and other aggressive behavior, may be more difficult to implement in online communities built using Web 2.0 technologies. Further, Web 2.0 encourages openness and sharing, yet in healthcare, issues of privacy and security are paramount, especially for people with health conditions that make them vulnerable to stigmatization and who find approaching traditional sources of help and information difficult. Although it can be argued that consumers should feel ‘safe’ by participating anonymously or under pseudonyms when revealing their personal health information, there is always the possibility that the identity of a consumer can be reverse-engineered by assembling data from different sources.

Healthcare consumers develop trust in online communities through exposure to social identification cues, such as the use of familiar sounding language and highly relevant or personalized content [16]. However, recent research shows that consumers who are least confident in their decisions are the ones most likely to be swayed by social feedback [35]. Studies have shown that consumers ignore medically credible sites simply because they do not contain sufficient social identification markers [16]. Research is needed to investigate ways to prevent online communities that are unreliable sources of information (such as those with a political or religious agenda against a certain medical treatment) from misusing social identification cues to mislead or misguide consumers and gain their trust.

5 Conclusion

Healthcare consumers’ social networks play a key role in their progress through healthcare journeys, and are vital sources of advice, recommendations, empathy and support. This has already been recognized on the Internet by the establishment and popularity of online healthcare consumer communities. Currently, these communities facilitate a range of forms of social interaction, such as sharing experiences, sharing opinions and providing support to fellow consumers. However, current communities are not designed to support important social behaviors such as collaborative decision-making, social comparison and lurking. Research is needed to explore whether and how Web 2.0 technologies can assist in the design and implementation of features to support these behaviors.

Issues of trust, safety and privacy are of the utmost importance, and new trust models need to be developed to safely enable these additional social behaviors online. In particular, it will be essential to understand how consumers most vulnerable to undue influence can be best supported when entering online communities.

References

1. Lorig, K.R., Laurent, D.D., Deyo, R.A., Marnell, M.E., Minor, M.A., Ritter, P.L.: Can a Back Pain E-mail Discussion Group improve health status and lower health care costs?: A randomized study. *Arch. Intern. Med.* 167, 792–796 (2002)
2. Lieberman, M.A., Golant, M., Giese-Davis, J., Winzenberg, A., Benjamin, H., Humphreys, K., Kronenwetter, C., Russo, S., Spiegel, D.: Electronic support groups for breast carcinoma: A clinical trial of effectiveness. *Cancer* 97, 920–925 (2003)
3. Dawes, M., Sampson, U.: Knowledge management in clinical practice: A systematic review of information seeking behavior in physicians. *Int. J. Med. Inform.* 71, 9–15 (2003)
4. Coumou, H.C.H., Meijman, F.J.: How do primary care physicians seek answers to clinical questions? A literature review. *J. Med. Libr. Assoc.* 94, 55–56 (2006)
5. Shaw, B.R., McTavish, F., Hawkins, R., Gustafson, D.H., Pingree, S.: Experiences of women with breast cancer: Exchanging social support over the chess computer network. *J. Health Commun.* 5, 135–159 (2000)
6. McGettigan, P., Golden, J., Fryer, J., Chan, R., Feely, J.: The sources of information used by doctors for prescribing suggest that the medium is more important than the message. *Br. J. Clin. Pharmacol.* 51, 184–189 (2001)
7. Johnson, G.J., Ambrose, P.J.: Neo-tribes: the power and potential of online communities in health care. *Commun. ACM* 49, 107–113 (2006)
8. Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., Stern, A.: Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ* 328, 1166–1171 (2004)
9. Kamel Boulos, M.N., Maramba, I., Wheeler, S.: Wikis, blogs and podcasts: a new generation of Web-based tools for virtual collaborative clinical practice and education. *BMC Med. Educ.* 6, 41 (2006)
10. Karkalis, G.I., Koutsouris, D.D.: E-health and the Web 2.0. In: *The International Special Topic Conference on Information Technology in Biomedicine, Greece* (2006)
11. Kamel Boulos, M.N., Wheeler, S.: The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education. *Health Info. Libr. J.* 24, 2–23 (2007)
12. Murray, P.J., Cabrer, M., Hansen, M., Paton, C., Elkin, P.L., Erdley, W.S.: Towards addressing the opportunities and challenges of Web 2.0 for health and informatics. *Yearb Med. Inform.*, 44–51 (2008)
13. Murray, P.J.: Web 2.0 and social technologies: what might they offer for the future of health informatics (2008), <http://hcro.enigma.co.nz/website/index.cfm?fuseaction=articledisplay&FeatureID=010608> (retrieved October 29, 2008)
14. Murray, E., Burns, J., See, T.S., Lai, R., Nazareth, I.: Interactive Health Communication Applications for people with chronic disease. *Cochrane Database Syst. Rev.* CD004274 (2005)
15. van Uden-Kraan, C.F., Drossaert, C.H.C., Taal, E., Lebrun, C.E.I., Drossaers-Bakker, K.W., Smit, W.M., Seydel, E.R., van de Laar, M.A.F.J.: Coping with somatic illnesses in online support groups: Do the feared disadvantages actually occur? *Comput Human Behav.* 24, 309–324 (2008)
16. Silience, E., Briggs, P., Harris, P.R., Fishwick, L.: How do patients evaluate and make use of online health information? *Soc. Sci. Med.* 64, 1853–1862 (2007)
17. White, M., Dorman, S.M.: Receiving social support online: implications for health education. *Health Educ. Res.* 16, 693–707 (2001)
18. Davison, K.P., Pennebaker, J.W., Dickerson, S.S.: Who talks? The social psychology of illness support groups. *Am. Psychol.* 55, 205–217 (2000)

19. Dickerson, S.S., Boehmke, M., Ogle, C., Brown, J.K.: Seeking and managing hope: patients' experiences using the Internet for cancer care. *Oncol Nurs. Forum* 33, E8-17 (2006)
20. Overberg, R.I., Alpay, L.L., Verhoef, J., Zwetsloot-Schonk, J.H.: Illness stories on the internet: what do breast cancer patients want at the end of treatment? *Psychooncology* 16, 937–944 (2007)
21. Ziebland, S.: The importance of being expert: the quest for cancer information on the Internet. *Soc. Sci. Med.* 59, 1783–1793 (2004)
22. Buunk, A.P., Gibbons, F.X.: Social comparison orientation: a new perspective on those who do and those who don't compare with others. In: Guimond, S. (ed.) *Social comparison and social psychology: understanding cognition, intergroup relations and culture*, pp. 15–32. Cambridge University Press, New York (2006)
23. Redersdorff, S., Guimond, S.: Comparing oneself over time: the temporal dimension in social comparison. In: Guimond, S. (ed.) *Social comparison and social psychology: understanding cognition, intergroup relations and culture*, pp. 76–96. Cambridge University Press, New York (2006)
24. Keselman, A., Logan, R., Smith, C.A., Leroy, G., Zeng-Treitler, Q.: Developing informatics tools and strategies for consumer-centered health communication. *J. Am. Med. Inform. Assoc.* M2744 (2008)
25. Mayer, D.K., Terrin, N.C., Kreps, G.L., Menon, U., McCance, K., Parsons, S.K., Mooney, K.H.: Cancer survivors information seeking behaviors: a comparison of survivors who do and do not seek information about cancer. *Patient Educ. Couns.* 65, 342–350 (2007)
26. James, N., Daniels, H., Rahman, R., McConkey, C., Derry, J., Young, A.: A study of information seeking by cancer patients and their carers. *Clin. Oncol. (R Coll. Radiol.)* 19, 356–362 (2007)
27. Bennenbroek, F.T.C., Buunk, B.P., van der Zee, K.I., Grol, B.: Social comparison and patient information: what do cancer patients want? *Patient Educ. Couns.* 47, 5–12 (2002)
28. Preece, J., Nonnecke, B., Andrews, D.: The top five reasons for lurking: improving community experiences for everyone. *Computers in Human Behavior* 20, 201–223 (2004)
29. Hoisl, B., Aigner, W., Miksch, S.: Social Rewarding in Wiki Systems – Motivating the Community. In: Schuler, D. (ed.) *HCI 2007 and OCSC 2007*. LNCS, vol. 4564, pp. 362–371. Springer, Heidelberg (2007)
30. Schimke, D., Stoeger, H., Ziegler, A.: The Relationship Between Social Presence and Group Identification Within Online Communities and Its Impact on the Success of Online Communities. In: Schuler, D. (ed.) *HCI 2007 and OCSC 2007*. LNCS, vol. 4564, pp. 160–168. Springer, Heidelberg (2007)
31. Turner, T.C., Fisher, K.E.: The Impact of Social Types within Information Communities: Findings from Technical Newsgroups. In: *HICSS 2006*. Proceedings of the 39th Annual Hawaii International Conference on System Sciences (2006)
32. Hu, C., Law, S.: PixelWish: Collective Wish-Making and Social Cohesion. In: Schuler, D. (ed.) *HCI 2007 and OCSC 2007*. LNCS, vol. 4564, pp. 80–85. Springer, Heidelberg (2007)
33. Frost, J.H., Massagli, M.P.: Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. *J. Med. Internet Res.* 10, e15 (2008)
34. Adams, S.A.: Blog-based applications and health information: Two case studies that illustrate important questions for Consumer Health Informatics (CHI) research. *J. Med. Inform.* (2008), doi:10.1016/j.ijmedinf.2008.06.009
35. Lau, A.Y.S., Coiera, E.W.: Impact of Web Searching and Social Feedback on Consumer Decision Making: A Prospective Online Experiment. *J. Med. Internet Res.* 10, e2 (2008)