Tackling Dilemmas in Supporting "The Whole Person" in Online Patient Communities

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Abstract

Online health communities that engage the patient as a *whole person* attend to personal and medical needs in a holistic manner. Whether current communities structure interaction between health professionals and patients to address the whole person is an open question. To gain insights into this question, we examined a sample of online patient communities to understand health professionals' involvement in bringing in medical advice into peer-patient conversations. We found the communities fall short in supporting the whole person, because (1) patient expertise and clinical expertise generated by health professionals are shared separately, and (2) patients' quantified data are separate from narrative experiences. Such separation in the design of these systems can lead to limitations in addressing patients' interwoven medical and personal concerns. We discuss dilemmas and design implications for supporting the whole person in online patient communities.

Author Keywords

Health; online patient communities; the whole person; collaborative help

ACM Classification Keywords

H.5.2 User Interfaces; J.3 Life and Medical Sciences; Medical information systems

Introduction

Consider a scenario about a breast cancer patient whose information needs are not fulfilled by online communities:

> Sally started hormone therapy for breast cancer a few weeks ago and is now experiencing sexual dysfunction. She is wondering whether it could be a side effect of the hormone therapy that her doctor did not mention. Sally turned to an online breast cancer community, but there was not a convenient way to share her symptom-tracking logs along with the post. Patients shared their similar experiences, strategies for communicating with their partners about the issue, and treatments they found helpful. However, patients began having conflicting opinions about the suggestions. Sally turned to an expert Q&A section to ask about her

situation. The health expert suggested asking her doctor about vaginal estrogen therapy. Sally did not feel comfortable about the vaginal treatment. She wished the patients who were participating in her post were part of the conversation with the health expert so that the expert and patients can comment on one another's posts.

Sally's scenario illustrates limitations in current online patient communities. Sally ended up getting conflicting experiences from other patients and medical advice that she was not satisfied with. Sally wished she had a better way of conveying her experience in her posts using symptom logs. Sally's case portrays how online patient communities fall short in addressing patient's experience of a disease as a closely interwoven matter of both the medical and personal side of an individual, as suggested by the "whole person model" [8].

To examine how online patient communities currently engage the whole person model, we studied 27 online patient communities. We found two limitations: (1) patient and clinical expertise are not interwoven and (2) quantified and narrative experiences are disconnected during patients' experience sharing. With the findings, we discuss implications and challenges in improving online patient communities.

Background

Patient-centered medicine promotes exploring both the disease and the personal experience of that disease [8]. The field further suggests the importance of understanding not only medical issues but also *the whole person*—including details about the world in which he or she lives, such as family, friendship, employment, religion, and culture [2, 14]. Health professionals who respond to the whole person's needs provide care that integrates knowledge of patients' values and life circumstances, rather than only medical facts [14].

As designers of consumer health technologies, we also should consider what it means to support the whole person through design. Online health communities are an example of a technology that could potentially support whole person needs. On the personal side, online patient communities have been shown as great resources for providing patient expertise and empowering patients to learn from one another [5]. Furthermore, researchers examined online patient communities as a way for patients to give and receive emotional support [12] while also enhancing self-efficacy and self-management [10].

Although the main benefit of patient communities comes from peer-patient interaction, studies have also shown the importance of health professionals' roles in online support groups for behavioral changes [3,9]. A growing number of health organizations offer online patient communities together with medical information (connect.diabetes.org, www.juvenation.org) to address medical issues. However, users' interaction with medical information is independent from patient forums, making it difficult to weave together both peer and professional advice.

Another emerging area in patient communities is capturing aspects of illness experiences through personal informatics tools [16]. These tools enable patients to share quantifiable information that they can use to reflect and monitor their health. Websites such as Patients Like Me and Cure Together (www.patientslikeme.com, www.curetogether.com) support such a notion from patients' perspectives. However, such exclusively quantifiable information lacks context for appropriate interpretation [4]. Researchers explored ways to combine quantifiable experiences with contextual information, such as adding photography with glucose measurements [13] and capturing patient histories of both physiological data and events [11] for individual reflection. However, close integration of quantifiable information within patient conversations in community settings is still under-supported.

The whole person model provides a framework for examining how online patient communities can support delivering clinical and patient expertise to patients and what form this should take.

Methods

We analyzed 27 publicly accessible online patient communities for patients with cancer or diabetes, reported as U.S.'s leading causes of death and disability (http://www.cdc.gov/chronicdisease). We gathered lists of patient community websites from U.S. based representative organizations and medical help portals (e.g., National Cancer Institute). We excluded listservs and chose the top 9 community websites that had the most posting activities in the preceding week of data collection for cancer (cancerconnect.com, breastcancer.org, cancerforums.org, mylifeline.org, forums.networkofstrength.org, mycrcconnections.ning.com, cancerforums.net, cancer-forums.net, rare-cancer.org), diabetes (dlife.com, diabeticconnect.com, diabeticgourmet.com, childrenwithdiabetes.com, tudiabetes.org, juvenation.org, connect.diabetes.com, diabetesforum.com, diabetesdaily.com), and multi-disease communities (patientslikeme.com, webMD.com, inspire.com, healingwell.com, healthcentral.com, medhelp.com, dailystrength.com, curetogether.com, ehealthforum.com). Among the 19 communities that explicitly showed the total number of registered members, the number ranged from 583 to over 600,000 members (average 54,866). There were 15 communities that were run by for-profit companies and 11 by non-profit organizations.

We used iterative coding [14] to understand features of these communities that could be important for our analysis. The codes included the presence of: *administrative moderators* including patient advocates who regulate discussion content; *health professional moderators* that participate in patient forums to give medical advice; *expert Q&A feature* where patients can directly ask questions to health professionals; *medical advisory board*, an official board of members from business and medical field that shape the community; *a discussion place for health professionals only*, a place for health professionals to share information; and *quantified experience sharing*, features that patients can share quantifiable health experiences. We used these codes to analyze communities' "About Us" sections, disclaimers, and introductions.

Findings

We report three main findings. First, health professionals' engagement was largely separate from peer-patients interaction. Second, whether a community is non-profit or for-profit shaped the level of health professionals' involvement. Lastly, none of the communities that allowed patients to share their quantified experience supported linking that quantitative data with illness narratives.

Separation of Medical Advice from Patient Expertise

As Table 1 shows, although 81% of the online communities had administrative moderators, only 19% had moderators that were health professionals. Rather than directly engaging in patient conversations, most of these communities claimed that health professionals regularly monitor patients' conversations. The other 81% of the communities claimed no responsibility for the credibility of the content and suggested that patients should consult their primary care doctors for medical advice.

In one community that enabled health professionals' direct engagement in the patient forums, the posts showed that the patient forum became similar to expert Q&A sessions,

where patients and health professionals conversed and patients rarely interacted with one another.

Although 48% of the communities had advisory boards with medical professionals, only 30% had expert Q&A features where patients can directly ask questions of health professionals.

For-Profit Versus Non-Profit Online Communities

When we broke down findings into subcategories (Table 1), interesting findings emerged about the link between being a for- or non-profit online community and health professionals' engagement. Among the codes shown in Table 1, how much health professional moderators and expert Q&A features were offered showed a significant difference between for-profit and non-profit online communities at a 5% significance level using a two-tailed proportion test. None of the non-profit sites offered health professional moderators and fewer non-profit communities supported some forms of health professionals' engagement in all categories than for-profit online communities.

Quantified Experiences and Narrative Experiences

Five online communities (19%) offered patients' sharing of quantified experiences. Meanwhile, 26 communities (96%) offered free-form discussions among patients. However, none offered explicit ways of connecting quantified experiences with narrative experiences in forums. Given that all but one of the communities supporting quantified experience sharing were for-profit, a possible assumption is that a community needs resources to develop tools for sharing quantified experiences. In addition, these for-profit sites often sell anonymized versions of that quantified data.

Discussion and Design Implications

Below, we discuss two points for considering the whole person model in designing online patient communities..

Point 1: Dualistic View Towards Patient and Clinical Expertise

Only a small number of online communities supported health professionals' involvement with the communities. Even when supported, communities separated out where patients ask for medical questions and where patients share experiences. The health professional moderators' engagement was minimal. In one case where health professionals' engagement was bigger than other forums, it seemed to discourage peer-patient interaction. This result is congruent with a previous study; In patient support groups, unless the leader of the group actively promotes discussion among patients, it becomes a Q&A session between health professionals and patients [6].

This finding brings out an interesting social challenge. A study [5] found that 56% of the patients' posted content in a sample of online patient communities were medical in nature, 31% were personal, and 13% were for both medical and personal. This finding, along with literature in patient-centered medicine, points to the importance of weaving together clinical and patient expertise in online communities. However, involving health professionals could take away value that patients provide to one another. Also, depending on supporting organizations' resources to pay for health professionals' participation, the quality and amount of engaging clinical expertise can vary greatly.

Then the key becomes how we can bring in clinical expertise without hindering patient-to-patient interaction, and how we can minimize the effort of health professionals who usually

have limited resources to spend. Below we discuss potential automated and crowd-based solutions for this problem.

Design Implication: Linking Medical Advice with Patient Experiences

<u>Collaboratively elevate medical problems to health professionals:</u> We propose that online forums add a feature that allows patients to collectively vote on discussions that focus on the medical side. This thread could then be forwarded to health professionals' attention. In addition, long threads could indicate conflicting stories that could be flagged for health professionals to participate.

<u>Help patients become critical part of building clinical and patient expertise:</u> Once a patient receives advice from health professionals, the members can challenge, confirm, or augment health professionals' responses with their personal experiences. Patients could take an active role in sharing their illness narratives and collaboratively making sense of clinical and patient expertise [1].

<u>Outsource clinical expertise:</u> Not all communities have resources to hire health professionals to provide medical expertise. Currently, patients work around this problem by sharing related materials from health professionals who they have communicated with. Alternatively, an automated aggregator could bring in publicly available resources from other communities, websites, blogs, and medical articles for the threads that patients have voted for.

Point 2: Quantified Experiences as a Reduced View of Illness

Quantified experiences have advantages in scalability and efficiency in sharing patient experiences. However, our findings show quantified experiences are shared separately from patients' illness narratives. Quantified experiences fall short in capturing patients' holistic illness experience [4], and with narrative data the information can gain richness in context [7]. Below we explore ways to link quantified experiences with narrative experiences.

Design Implication: Integrating Quantified Information with Illness Narratives

<u>Link quantified data to forum posts:</u> Patients can link back to their tracking history during forum posts. The tracking history can also show links to forum posts. Linking tracking history with forum posts can help contextualize patients' medical and personal experiences.

<u>Allow easy sharing of narratives on tracking histories:</u> Similar to Willett et al's [15] work, patients can point to one's tracking history to discuss various interpretations. Furthermore, parts of tracking history can be pulled back into forum conversations. Such intertwined sharing of tracking histories within conversations can trigger rich stories to be constructed through peer-patient interaction.

Limitations

In discussing the whole person model, we examined intertwining medical and personal expertise and quantifiable and narrative patient experiences. Further work should explore other aspects of the whole person model, such as cultural and institutional constraints around patients' illness trajectories. Our work analyzes content from the information pages of the community websites, rather than patient exchanges. Future work will be necessary to understand patients' perspectives and evaluate design suggestions.

Conclusion

In this paper, we discussed design implications for better supporting the whole person in online patient communities. Given the improved design, our hope is to help Sally's case turn into a scenario as shown in the following:

> Sally turned to an online breast cancer community to share her log of this potential side effect. Patients shared their similar experiences using logs, strategies for communicating with their partner about the issue, and treatments they found helpful. After patients voted this issue as a top concern, an oncologist participating in the community replied that such natural remedies are good ways to begin treating side effects before diving into more serious treatments. Other patients began discussing their experiences of going through the treatments the oncologist mentioned, giving Sally an idea of what to consult with her doctor.

Acknowledgments

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Table 1

Breakdown of how non-profit and for-profit online communities support engagement of health professionals

Whether the online community had:	For-profit communities (15 total)			Non-profit communities (12 total)			All (27 communities)
	Cancer 11% (1)	Diabetes 67% (6)	Multi-89%(8)	Cancer 89% (8)	Diabetes 33% (3)	Multi-11% (1)	
Administrative moderators		73% (11 out of 15)		92% (11 out of 12)			81% (22)
Health professional moderators *		33% (5 out of 15)		0% (0 out of 12)			19% (5)
Expert Q&A feature *		47% (7 out of 15)		8% (1 out of 12)			30% (8)
Advisory board		53% (8 out of 15)		42% (5 out of 12)			48% (13)
Health professionals only		13% (2 out of 15)		8% (1 out of 12)			11% (3)

*
(Multi-: multiple-disease): There were significant differences between for-profit and non-profit communities at a 5% significance