Patient Moderator Interaction in Online Health Communities

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Abstract

An increasing number of people visit online health communities to share experiences and seek health information. Although studies have enumerated reasons for patients' visits to online communities for health information from peers, we know little about how patients gain health information from the moderators in these communities. We qualitatively analyze 480 patient and moderator posts from six communities to understand how moderators fulfill patients' information needs. Our findings show that patients use the community as an integral part of their health management practices. Based on our results, we suggest enhancements to moderated online health communities for their unique role to support patient care.

Introduction: Patients' Information Needs and Online Health Communities

One in four Internet users with a chronic illness have gone online to find others with similar health problems.[1] Because of the ability to connect patients with others with similar experiences, online health communities have gained attention as sources for patients to obtain emotional and informational support. Studies have confirmed a positive effect on social support for people with various diseases,[2–7] investigated the kinds of support that patients bring to one another,[2,3,8] and presented the effects of being a lurker as opposed to an active poster.[3]

While their core value remains peer-support, online health communities have increasingly incorporated 'health experts' who provide clinical knowledge to the community. Although only a few communities engage health experts as moderators,[9] the idea of including health professional moderators in patient forums has gained increasing interest. Because the role of health professional moderators is still evolving, we have much to learn about the relationship between patients and moderators, including both health professional and traditional administrative moderators.

We report findings from our analysis of six online health communities to understand the interaction between patients and moderators. More specifically, we studied patients' information needs portrayed in their posts and how moderators responded to those posts. We found some challenges in generating empathic support through moderating styles, coordinating moderator roles, providing the right kinds of expertise, and connecting online health communities back to a clinical care context. We provide implications for the medical informatics community to build moderated online health communities that play a strong supportive role in patient care.

Background: Online Health Communities and Their Next Step with Moderators

Research evidence suggests a critical role of online health communities for providing patients and caregivers with emotional and informational support in various illness contexts, including: cancer,[2,3,8] rare diseases,[4,5] diabetes,[6] HIV/AIDS,[10] and infertility.[7] In addition to peer support, online health communities (e.g., WebMD.com, MedHelp.org, alliancehealth.com) have begun to employ 'health experts' for patient education purposes,[11] for clinical support,[12] and for asking doctors' opinions (e.g., Healthtap.com).

The expertise offered by 'health experts' and peer patients can play distinctive roles. Hartzler and Pratt[8] compared health-professional-authored and patient-authored online forum posts. They found differences in the domain knowledge each author group shared. Health professionals provided *clinical expertise*—expertise that came from their clinical training and experience, whereas patients and caregivers shared *patient expertise*—expertise emerging from personal experience of daily self-management. Because both patients' and health professionals' expertise play these important but distinctive roles, online health communities should consider how patients and health professionals can provide synergetic efforts to create and sustain vibrant communities. However, few studies have described how patients, health experts, and administrative moderators, interact in online health communities.

The role of administrative moderators in online non-health communities has been studied in depth in the field of computer supported cooperative work. Researchers found that good leadership and effective moderation play critical roles in the success of these communities.[13] Tasks involved in good leadership and moderation include recruiting new members, moderating discussions, and encouraging an engaging and respectful community culture.[14] Researchers investigated various interventions to help facilitate community participation, such as community membership design,[15] reward systems for increased motivation[16,17] and social interventions including volunteerism

and group uniqueness. We expect online health communities to share similar moderation issues. However, whether the role of moderators in online health communities is different from online non-health communities and how administrative moderators interact with patients and health experts remain open questions.

We examine the case of WebMD online health communities, in which both staff (i.e., administrative) moderators and health professional moderators team up to support patients and caregivers. We study how these different moderators respond to patients' information needs and how online health communities can support those moderators.

Methods: The WebMD Community, Data Collection, and Analysis

We qualitatively analyzed posts from select WebMD.com online communities for themes on patient-moderation interaction. WebMD.com features over 35 online health communities and is one of the few communities that offer both health professional and staff moderators. Health professional moderators at WebMD have clinical training in medicine, nursing, or nutrition. Staff moderators do not necessarily have clinical training, but participate as staff moderators of conversations. Each community has one to three assigned health professional moderators, while staff moderators often participate across multiple communities.

We selected communities with characteristics that could influence community dynamics. We ensured that the communities were active with sufficient participation from both patients and moderators. Our principle inclusion criteria included: the community should (1) be a chronic illness community to make sure participants could be engaged over the long term, (2) rank within the top 20 communities for the highest total number of threads, and (3) have at least three health professional moderators. Six WebMD communities met the criteria: diabetes, attention deficit hyperactivity disorder (ADHD), pain management (pain), multiple sclerosis (MS), sexual health, and heart disease. We downloaded all publicly available posts from these six communities. All of the quotes in this paper have been de-identified. We sought review by University of Washington Institutional Review Board (IRB). Our IRB determined that our study was exempt from review because it uses only publicly accessible data.

Because we were interested specifically in how patients and moderators interact to exchange information in online health communities, we focused the analysis on threads in which staff moderators and health professional moderators posted. We extracted moderated threads from each community, grouping them separately into staff and health professional moderated threads. To understand the differing roles played by staff and health professional moderators, we excluded threads in which both types of moderators responded. We sampled 20 staff moderated threads and 20 health professional moderated threads from each community, resulting in 240 total threads from the six WebMD communities. To ensure a variety of response rates in each set of posts, we randomly sampled 10 threads with under 3 replies as well as the 10 longest threads. We then analyzed the thread initiating post—the post made by a patient, and the first moderator's reply to the post, resulting in 480 total posts for the qualitative analysis. We did not analyze other posts in the thread.

All authors first examined a subset of the data to develop preliminary codes that describe patient information needs, including the types of questions patients ask and moderators' responses. Next, all authors together discussed and negotiated the appropriateness of codes. The first author used the agreed codes to continue analyzing the data using open coding analysis,[18] while allowing the codes to continue to evolve as new themes emerged. During the analysis, the first author shared the progress with other authors, revising the codes through negotiation given different interpretations among the co-authors on the data. The codes were not mutually exclusive. After the analysis, we used affinity diagramming to find common and distinctive themes across all codes. We also counted the themes per moderator group (posts responded by health professional moderator versus staff moderator) to understand the prevalence for each theme.

Results: Patients' Information Needs, Moderator Responses, and Community Differences

We first present characteristics of all six communities to understand the overall participation dynamics. We then present themes that emerged on patients' information needs and moderators' responses to the patient posts. Lastly, we describe how the themes vary across the six WebMD communities.

1. Overall Activity of the Communities

The overall activity of the six communities (Table 1) varied from 2,313 to 10,278 total threads, and the average number of posts varied from 2.9 to 15.0 posts per person. The total number of staff moderators per community varied from 7 to 15. The pain community had the most unanswered patient posts (i.e., "threads with no replies") (9.4%) and the diabetes community had the fewest unanswered patient posts (0.8%). The diabetes community was

the most active, and ADHD the least active, according to average posts per day. Patients initiated the majority of threads in all six communities (90.5% ~ 96.8%). Among patient initiated threads, non-moderated threads (i.e., threads in which moderators did not respond) were more frequent than moderated threads. Staff moderators responded to patient initiated posts more frequently than health professional moderators in diabetes, pain, and ADHD communities. However, the opposite was true for MS, sexual health, and heart disease communities.

Table 1. Activity of six WebMD online health communities

	Diabetes	Pain	ADHD	MS	Sexual Health	Heart Disease
Dates	6/07-5/12	9/07-6/12	7/05-6/12	3/08-1/13	1/09-1/13	5/08-5/12
Total number of threads	8,549	4,656	2,313	4,943	10,278	4,146
# posters	4,401	5,855	2,997	2,721	13,634	3,825
Average posts per poster	14.98	4.67	2.9	10.3	5.0	3.2
# Health professional moderators	3	3	3	3	3	3
# Staff moderators	15	9	10	9	10	7
Threads with no replies	0.8%	9.4%	5.1%	2.1%	1.7%	4.2%
Average posts per day	48.0	20.5	7.3	18.6	39.4	9.3
Patient initiated threads	90.5%	96.1%	95.6%	96.8%	96.6%	94.8%
Health professional moderated threads (number of threads)	3.7% (319)	4.3% (198)	6.4% (149)	5.1% (254)	2.3% (241)	32.4% (1343)
Staff moderated threads (number of threads)	17.6% (1506)	14.1% (656)	21.1% (488)	1.3% (64)	1.8% (187)	2.7% (111)
Health professional and staff moderated threads (number of threads)	1.6% (129)	1.2% (57)	0.4% (10)	0.2% (9)	0.1% (7)	0.6% (24)
Non-moderated threads (number of threads)	66.1% (5,650)	78.5% (3653)	67.7% (1565)	90.2% (4,459)	92.3% (9,491)	59.1% (2,452)

2. Patients' Information Needs

We found that the content of patients' posts that moderators responded to was largely categorized into the following four themes: *questions that can benefit from clinical expertise, questions that can benefit from community expertise, conversation starters, and desperate calls for help*. Table 2 shows themes frequencies across the six communities.

The theme, ***Questions that can benefit from clinical expertise***, comprised 62.1% of all patient posts (See Table 2). As will be further described below, the subthemes included: clarification of medical knowledge or drug information; explanations for symptoms and concerns; seeking solutions; and seeking second opinion. The following is a canonical example of a patient asking for clarification on a medical issue:

> *I will start Lisinopril because Carvedil has given me too many side effects. Should I wait until Carvedil is out of my system? If so, for how long before I start Lisinopril? (Heart disease)*

Patients also described their symptoms and concerns to ask if they pose serious risks:

> *Recently I have been experiencing spasms or cramps in my upper back area. Now I have pain in the back side of my right arm. The pain comes and goes and my feet feel like the are swollen. [What is going on?] (Diabetes)*

Patients asked for additional explanation or interpretation for the information given by their health care providers. Patients also sought second opinions from the community to compare, with their health care provider's advice:

> *I have an 10-year-old daughter that was diagnosed with ADHD about two months ago. Brought her to our family doctor […] after meds the grades are mostly in their A's. The problem is the attitude. Little things seem to throw her off. Can the extreme mood swings come from incorrect dosage or medication? My family doctor says to up the dosage and keep her medicated longer...is that the right thing to do? (ADHD)*

Table 2. Theme frequencies in patient posts (n=240) and moderator posts (n=240): 'All' refers to both staff moderated and health professional moderated threads, 'Staff' refers to staff moderated threads, 'HP' refers to health professional moderated threads.

	Diabetes All (Staff/HP)	Pain All (Staff/HP)	ADHD All (Staff/HP)	MS All (Staff/HP)	Sexual health All (Staff/HP)	Heart Disease All (Staff/HP)	Total staff threads (n=120)	Total HP threads (n=120)	Total (n=240)
PATIENT POSTS									
Benefits from clinical expertise	60% (45%/75%)	50% (50%/50%)	57.5% (55%/60%)	50% (25%/75%)	65% (60%/70%)	90% (90%/90%)	54.2%	70%	62.1%
Benefits from community expertise	17.5% (20%/15%)	25% (30%/20%)	40% (55%/25%)	35% (30%/40%)	20% (5%/35%)	12.5% (15%/10%)	25.8%	24.2%	25%
Conversation starter	22.5% (30%/15%)	7.5% (10%/5%)	7.5% (10%/5%)	22.5% (45%/0%)	17.5% (35%/0%)	10% (20%/0%)	25%	4.2%	14.6%
Building rapport	2.5% (5%/0%)	2.5% (5%/0%)	5% (5%/5%)	2.5% (5%/0%)	0% (0%/0%)	0% (0%/0%)	3.3%	0.8%	2.1%
Desperate calls for help	2.5% (0%/5%)	7.5% (15%/0%)	2.5% (0%/5%)	0% (0%/0%)	0% (0%/0%)	0% (0%/0%)	2.5%	1.7%	2.1%
MODERATOR POSTS									
Provides clinical expertise	65% (50%/80%)	50% (5%/95%)	60% (30%/90%)	42.5% (0%/85%)	75% (55%/95%)	55% (15%/95%)	25.8%	90%	57.9%
Talk to your doctor	15% (25%/5%)	15% (25%/5%)	17.5% (10%/25%)	7.5% (5%/10%)	17.5% (30%/5%)	47.5% (45%/50%)	23.3%	16.7%	20%
Moderating	15% (20%/10%)	32.5% (65%/0%)	12.5% (25%/0%)	17.5% (35%/0%)	20% (40%/0%)	10% (20%/0%)	34.2%	1.7%	17.9%
Building rapport	22.5% (30%/15%)	15% (15%/15%)	10% (15%/5%)	10% (20%/0%)	27.5% (55%/0%)	20% (40%/0%)	29.2%	5.8%	17.5%
Pointers to outside resources	22.5% (25%/20%)	7.5% (15%/0%)	17.5% (35%/0%)	17.5% (30%/5%)	17.5% (30%/5%)	12.5% (25%/0%)	26. 7%	5%	15.8%
Provides community expertise	7.5% (15%/0%)	2.5% (5%/0%)	15% (30%/0%)	10% (0%/20%)	2.5% (0%/5%)	12.5% (25%/0%)	12.5%	4.2%	8.3%
Technical help	0% (0%/0%)	2.5% (5%/0%)	2.5% (5%/0%)	7.5% (15%/0%)	10% (20%/0%)	2.5% (5%/0%)	8.3%	0%	4.2%
Advertisement	0% (0%/0%)	0% (0%/0%)	2.5% (0%/5%)	0% (0%/0%)	5% (0%/10%)	0% (0%/0%)	0%	2.5%	1.3%

Questions that can benefit from community expertise comprised 25% of all patient posts. This theme refers to patients' information needs that can benefit from expertise that peer patients and caregivers in the community can offer better than the moderators, similar to Hartzler and Pratt's notion of "patient expertise."[8] The subthemes included: asking for doctor recommendations; asking for guidance and support; and seeking similar experiences. In the following quote, the patient explains why she visited the community after consulting her health care provider:

> *Lately, I have been dealing with the thought that I can no longer work. I feel very useless. … I have been sick on and off for eight years and got disability in 2004 for Acute Myelogenous Leukemia … I did talk this over with a psychologist and that has not helped me so far. So I am coming to others that I know have had to face this same situation for guidance and support. Thank you for any info you can help with! (Pain)*

In addition to guidance and support, some patients asked for similar experiences from peers:

Anyone have experience with a newly released drug, Amlyge, and how long until it will be available? I thought I would share the news for those of you who have not already read about the drug. (God, please let this drug work for me!) (Multiple Sclerosis)

Conversation starters was the next most frequent theme in patient posts *(*15%). This theme refers to ways that posters engage the community with informal chat regardless of the topic. The subthemes included: venting frustrations about their status or current health care providers; seeking others' opinions on news articles; giving personal updates; and asking for what others did over the weekend. For instance, a patient asked what others have done over the weekend:

I went a tone of walking half the morning and afternoon to XX Park with camera equipment. It was around 80 degrees and beautiful, but too sunny to be conducive to great photos. The beauty of the Japanese garden was so enjoyable though. I did zumba Friday morning, ballroom dancing that night to the point of having soaking hair … What are your plans for exercise this weekend? (Diabetes)

Desperate calls for help were infrequent (2% of all patient posts) and occurred when a patient or a caregiver seemed to be in panic when asking for information from the community. These posts were mostly unfocused and did not have any specific questions. In one example, the patient posted problems with a patch on her/his 7-year-old child while waiting for the clinic to open:

My 8 year old has been on the 20mg Daytrana patch for about 2 weeks now and things have been super crazy. I personally hate the patch, I hate how it makes him act, I hate the redness it leaves when I take it off. [explains behavioral issues after school] is this just the adjustment period or is this what life will be like if he continues with the patch? I will call as soon as the office opens, I would just like some thoughts now. (ADHD)

3. Moderators' responses

For the moderators' responses, the categories largely fell into the following themes in the order frequency: *provides clinical expertise, "talk to your doctor," moderating, pointers to outside resources, building rapport, provides community expertise, technical help, and advertisement.*

The theme, ***Provides clinical expertise***, comprised most (58%) of moderator posts. Subthemes included: clarifying medical concepts; explaining current clinical practice; challenging the patients' health care providers' suggestions; providing outside resources; providing potential solutions; and advising how to talk with health care providers. Depending on whether the moderator was staff or a health professional, the amount as well as the kinds of clinical expertise shared differed. While only 26% of all staff moderator responses provided clinical expertise, 90% of all health professional moderator responses contained clinical expertise. The following shows an example of how a staff moderator and health professional moderator shared clinical expertise:

Eating sweets does not cause high blood glucose the next day in people without diabetes. It would not have caused your test results during pregnancy as long as you had followed the fasting guidelines before the test. (usually 8-12 hours or nothing after midnight) … You are at higher risk for developing type 2 diabetes because of your history of gestational diabetes. You will want to avoid becoming overweight or sedentary and adding to your risk factors. Work on your other risk factors as well to stay healthy. (Diabetes staff moderator)

Adderall can cause a stomachache and much more rarely, vomiting. However, that would tend to be dose-related and only during the days that he takes the medication. Simply, I do not think his vomiting was related to the Adderall the day before whatsoever. (ADHD health professional moderator)

The unique ability of health professional moderators that differed from staff moderators was their clinical training and experience with other patients. While staff moderators did not, health professional moderators sometimes challenged the advice or information shared by the patient's current health care provider and advised the patient on how to talk with their health care providers:

Some preliminary data suggest that elevating low Vitamin D levels will reduce the number of exacerbations over time. I have my patients take Vitamin D supplement, but I also keep them on the other MS therapies. I think you might want to get another opinion about therapy since being on Vitamin D alone for MS is not an established therapy. (MS health professional moderator)

When responding to patient posts that can benefit from clinical expertise, instead of directly providing clinical expertise, staff moderators generally provided pointers to other forums, websites, or health professionals' blogs (see theme "moderating" below). In contrast, health professional moderators provided medical information, not necessarily medical consultation, such as making diagnosis or prescribing medication, since giving an actual medical consultation is against WebMD's policy. Accordingly, moderators tended to suggest that patients talk to their health care providers

The theme ***"Talk to your doctor"*** occurred in 20% of all moderator posts–23% of staff moderator posts and 17% of all health professional moderator posts. This theme differs from moderators advising patients on *how* to talk with their health care providers previously described. The purpose of moderators' posts captured in this theme relates more to liability issues than information sharing. For instance, moderators would ask patients to discuss the provided suggestions with their doctor:

> *I cannot comment on whether guanfacine could be considered as a possible alternate treatment for your high blood pressure, although it is a reasonable question. On the other hand, if you have ADD, then short-acting guanfacine generally is an inexpensive and well-tolerated medicine. However, it typically needs to be taken 3 times a day. You should speak with your physician about adding guanfacine and then try tapering your beta blocker. Guanfacine may take 2-3 weeks to fully work. Do not start or discontinue any prescription drug without discussing with your prescribing physician. (ADHD health professional moderator)*

Another frequent case of "*talk to your doctor*" was when moderators asked patients to talk to their health care providers instead of attempting to find answers from the online community:

> *Do you have heart disease history or other medical issues? I am not the medical expert on this board but an immediate call to your physician seems appropriate. (Heart disease staff moderator)*

The ***Moderating*** theme occurred in 18% of all moderator posts, 34% of all staff moderator posts, and only 2% of all health professional moderator posts. The theme *moderating* refers to moderators' responses attempting to: reinforce participation etiquette and forum rules; redirect patients to more relevant forums; warn patients about the limitations of WebMD communities regarding policies around medical consultation; and encourage participation. Following is a canonical example of moderating to encourage participation:

> *Happy Belated Birthday Cindy, I wanted to let everyone know that we do have a Sexuality Chat Room that would probably be a better place for you to chat back and forth. Sometimes on boards when two people alone are having a continuous conversation it takes away from the board itself, excluding others. If you want to have a "private" conversation we do offer a platform for that, in the form of our chat room. I hope everyone finds the chat room ok and enjoy themselves there! Take care, (Sexual health staff moderator)*

Aside from sharing expertise or moderating, moderators also attempted to ***build rapport*** with the community members by asking for future updates by calling out a specific patient name, sending encouragement to struggling patients, or even sharing hobbies. This theme consisted of 18% of all moderator posts, including 29% of all staff moderator posts and 6% of all health professional moderator posts. For instance, moderators followed up on patient members to ask how they are doing:

> *Hi Lee, Crud! What a horrible experience! How are you doing now? Any other feedback or follow-up from the hospital? (MS staff moderator)*

Instead of directly providing clinical expertise, moderators often provided pointers to websites, blogs, features in WebMD, and other forum posts. This theme, ***Pointers to outside resources***, consisted of 16% of all moderator posts, 27% of all staff moderator posts, and 5% of all health professional moderator posts. The following is an example:

> *Did you explore support groups through the hospital or rehab center that you and your husband could attend together? Here's also a link to Heart Disease Resources from the WebMD Heart Health Center: [link] I cannot imagine the impact this would have on my relationships. Whew! Please let us know how you are doing and keep checking in here! (Heart disease staff moderator)*

The theme, ***Provides community expertise***, consisted 8% of all moderator posts. Staff moderator posts contained more community expertise (13%) than health professional moderator posts (4%). The moderators provided community expertise particularly from those who had experience being a patient or a caregiver. For instance, one of

the moderators who had a personal experience of a daughter with ADHD shared the following reply to a patient asking what to do with her 18-year-old daughter who was refusing medication:

> *My daughter just graduated from XX. She never had to take medication for her ADHD, but she did for Bipolar (she is not currently taking anything) and GAD (Generalized Anxiety Disorder). She had support from a therapist, psychiatrist, her family, her roomies, her job, and the university she went to. Things were not perfect, but we've learned to ignore the minor and cheer on the major things. (ADHD staff moderator)*

The moderators also suggested non-medical solutions for overcoming the situation, enhancing relationship issues with family, lovers, and friends. For example, a health professional moderator responded with community expertise to a patient who asked why his wife cheated:

> *If you want to save your marriage and to have a healthy relationship, you need to have open conversations, which is, of course, a risk. The only other alternative is to live in a distressing limbo as things slowly get worse. If it feels too difficult to do on your own, you might need a third party to help you. I hope you find the inner strength you need to find your way through this. (Sexual health health professional moderator)*

Moderators also gave ***technical help*** in 4% of all moderator posts (8% of all staff moderator posts and none from health professional moderator posts), such as how to navigate the community forum:

> *Hi Lily, Regarding your name, please email xxx@webmd.net with the details of the problem you're experiencing and we will try to help you. :-) (MS staff moderator)*

The theme, ***Advertisement***, occurred from 1% of all moderator posts, although all came from health professional moderators (3% of all health professional moderator posts). Health professional moderators advertised their books that may help with the particular problem the patient expressed. In the following example, a health professional moderator responded to a parent's question about whether ADHD:

> *If your daughter has ADHD you two may want to read my book for girls with ADHD, [book title]. More information about girls with ADHD is on my website, [website link] (ADHD health professional moderator)*

4. Community Differences in Patient-moderator Interaction

Across all communities, *questions that can benefit from clinical expertise* was the most frequent information need in patient posts. However, the frequency of *conversation starters* varied across communities. *Providing clinical expertise* was the most frequent type of moderator response in all communities. For all communities, the kinds of information and the contribution style of staff and health professional moderators differed.

As you can see from Table 2, questions benefiting from community expertise ranked second in most communities except the diabetes community. In the diabetes community, *conversation starters* ranked higher in content (22.5%) than *questions on community expertise* (17.5%). The ADHD community and the MS community had most *questions on community expertise* (40% and 35%) compared to other communities. The MS community had a similar percentage of *conversation starters* (22.5%) in patient posts as the diabetes community.

Although the majority of moderator responses consisted of clinical expertise (58%), most of the results on clinical expertise were derived from health professional moderators' responses. Across all communities, health professional moderators were the dominant providers of clinical expertise. For instance, staff moderators in the pain community provided clinical expertise in 5% of responses while health professional moderators provided clinical expertise in 95% of responses. In the MS community, staff moderators did not provide any clinical expertise, while the health professional moderators provided clinical expertise in 85% of all responses.

Building rapport and *moderating* themes showed another common trend across all communities—staff moderators posted more messages to build rapport than health professional moderators did. Except for one response in the diabetes community, health professional moderators did not engage in moderating conversations. The staff moderators in the pain community performed the most moderating activities (65%) among all communities. Compared to other communities, the heart disease community had the most *talk to your doctor* theme (47.5% as opposed to under 17.5% for all other communities). Lastly, staff moderators posted most of *the pointers to outside references* and *technical help*.

Discussion: Challenges Identified in Moderated Online Health Communities

Our findings shed light on four main points: community differences in moderating, coordination between staff and health professional moderators, ambiguity in defining clinical versus community expertise, and ambiguity in giving

medical consultation versus medical information. We report how these points inform technical implication for building vibrant online health communities that support moderators in addressing patients' information needs.

1. Towards Empathic Community: Community Differences in Moderating

Moderating is a crucial activity for developing a healthy online participation culture.[13] At the same time, literature shows health professionals' empathy as a crucial component in patient care.[19] We saw that the staff moderator posts in the pain community showed high moderating content (65%). The staff moderators responded by asking patients to be careful when sharing clinical expertise, clarifying that diagnostic questions cannot be answered by the community, advising not to write in all caps, redirecting patients to more relevant resources, and advising appropriate community participation. On the other hand, only 15% of staff moderator posts in the pain community were rapport building. At the same time, the overall community activity (Table 1) shows that the pain community had the most unanswered threads among all communities. Such moderating activities with little rapport building and support could negatively impact the level of empathy perceived in the pain community. For instance, 40% of staff moderator posts in the sexual community moderated content, whereas 55% contained building rapport. In the diabetes community, many patient posts contained conversation starters (22.5%), showing that, in contrast to the pain community (7.5%), staff and health professional moderators responded more to conversation starters, engaging in informal conversations outside those on clinical expertise.

Ideally, every community should receive similar support from the moderators to create an empathic community culture. One potential solution can be automatically detecting affect to indicate emotional support provided by moderators, who could use this feedback as a monitoring device. Such a tool could, for instance, show correlations between moderators' affect and number of replies posted by other patient members to help moderators understand consequences in community participation. With such tools, moderators can monitor how much emotional support they provide to the community, about which they might otherwise be unaware, and adjust their participation accordingly. How moderators' rapport building and moderating activities influence community dynamics is still an open question that online health communities should be mindful of in facilitating a positive and empathic community culture.

2. Managing Information Inequality: Coordination Between Staff and Health Professional Moderators

We found that staff and health professional moderators had distinctive roles in responding to patient posts. Health professionals provided clinical expertise, whereas staff moderators made sure patients talked to their doctors and pointed to outside resources in response to clinical questions. Both staff and health professional moderated threads had a high percentage of content that can benefit from clinical expertise. Such division of role is a helpful strategy, especially because of the limited participation that health professional moderators can offer. At the same time, such distribution of work may produce problems with patient user satisfaction, where some patient posts get personal opinions coming from health professional moderators and others only get links to related topics or told to talk directly to their current health care providers instead of being given any additional information from the community. Such selective clinical expertise distribution to patient members in the community allows for new forms of information inequality[20] in online health communities. Accordingly, patients specifically call out health professional moderators' names in their posts, although only a portion of them are answered by the health professional moderators.

One way to manage information inequality includes helping moderators efficiently distinguish posts that need clinical expertise from health professionals or staff moderators' response. For instance, using text mining techniques, a multi-classifier system can learn from existing patient posts which patient posts have been answered with clinical expertise, community expertise, or other forms of support, such as technical help. Such a system could then predict which type of help a given patient post needs.

3. Exploring the Right Expertise: Ambiguity in Defining Clinical versus Community Expertise

We found several instances where the boundary between clinical and community expertise was ambiguous. For those cases, we coded patient posts as those that can benefit from clinical expertise as well as community expertise. For instance, many questions from the sexual health community included relationship issues. The kinds of clinical expertise that health professionals provided did not limit itself to biomedical problems, but further social-cultural issues (e.g., "is oral sex cheating") and relationship issues (e.g., "did my husband cheat on me because of my physical appearance") for which peer patients can provide good advice. What could have been community expertise in other communities (e.g., how to manage relationship problems with family and work) were tightly coupled with

clinical problems in sexual health. Thus, as shown in the sexual health column in Table 2, we ended up with data showing that most expertise shared by both moderator groups resulted in clinical expertise.

Any posts can benefit from having moderators' clinical expertise as well as the community's experience. At the same time, patients may have specific needs for whom they want to answer their questions. We observed cases where patients directly called out health professional moderators' names in the posts for those that we consider as beneficial from community expertise. Similarly, we observed cases where patients directly asked the community to respond, even though the questions contained medical content that can benefit from other health professional moderators' second opinions.

Assessing whether a post requires clinical expertise or community expertise poses challenges—do health professional moderators decide which posts need clinical expertise, or do we allow patients to decide who will answer the question. If it is the latter, making sure that health professional moderators answer the question emerges as another challenge.

One way to address this problem is for automated systems to infuse outside clinical expertise as a link or flagged material into peer patient conversations. This way, patients not only gain community expertise but also clinical expertise as appropriate. Patients can also tag any parts of each post to alert moderators attention. Such an approach may resolve problems of moderators missing posts that need their attention. A tool can also be used to help identify related posts from previous community threads for each patient post that staff moderators can choose and link for the patient posts to offload some of their work.

4. Connecting Back to Clinical Care: Ambiguity in Giving Medical Consultation versus Medical Information

The WebMD terms and conditions of use states: "*The content [at WebMD] is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read on the WebMD Site!*"[1] However, the boundary between medical consultations and medical information shared by the WebMD moderators showed ambiguity. As shown in Table 2, health professional moderators suggested that patients to talk to their doctors 5%~50% of the time, depending on the community. We observed that health professional moderators asked patients to talk to their doctors to make sure that the clinical expertise they provided is confirmed by personal health care providers who know more about the patient's history. At the same time, in many cases, health professional moderators also presented their clinical expertise without asking patients to talk with their doctors about the shared information. In the sexual health community, where the boundary between clinical versus community expertise is ambiguous, very few health professional moderators (5%) mentioned that patients should also confirm the information with their doctors.

Health professional moderators even challenged what patients shared about their doctors' advice, in some cases asking patients to get second opinions from other health care providers. Health professional moderators provided tips and suggestions for what information patients can bring to their health care providers and what alternative treatments patients can consult with their own health care providers.

The patients appeared to use online communities as an integral part of their health management. Patients came to online health communities to not only gain community expertise, but also for the clinical expertise that they may not have been able to get from their existing health care providers, either due to time constraints or difficulty in communicating with them. This finding leaves a big implication on how we might support clinical care to address patients' information needs. Online health communities no longer should be considered as a dangerous third party information material on the Web, but its unique role should be devised in relation to clinical care.

A tool can either let moderators fill out a template message or automatically summarize what moderators have suggested. The message can be delivered in the forms that are easy for patients to use during the consultation with their health care providers.

Conclusion

From studying moderated threads in six WebMD online health communities, we learned that, for the participants of online health communities, moderators play a critical role in responding to patients' information needs. Patients at WebMD used the community to fulfill their information needs in addition to current clinical care. Moderators in

[1] http://www.webmd.com/about-webmd-policies/about-terms-and-conditions-of-use#part1

online health communities assisted patients with emotional support, links to resources, medical knowledge, and ways to communicate with health care providers. Such moderators' roles resemble caregivers who play a supportive, assistive role to patients' care. However, we saw a number of challenges in how online health communities should further play a role as part of the larger infrastructure of patient care. Our study is limited by its use of only one site, WebMD, although we reviewed six different communities within that site. Our work provides further understanding around patients' information needs and the support they receive from moderators when they visit online health communities. This new understanding and our suggested improvements should strengthen moderated online health communities and their unique role in the overall patient care.

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References

1. Fox, S., Peer-to-peer Healthcare. Pew Internet & American Life Project, Feb 28, 2011, http://pewinternet.org/Reports/2011/P2PHealthcare, accessed on March 13, 2013.
2. Meier, A., Lyons, E. J., Frydman, G., Forlenza, M. & Rimer, B. K. How cancer survivors provide support on cancer-related Internet mailing lists. *Journal of medical Internet research* **9**, e12 (2007).
3. Setoyama, Y., Yamazaki, Y. & Namayama, K. Benefits of peer support in online Japanese breast cancer communities: differences between lurkers and posters. *Journal of medical Internet research* **13**, e122 (2011).
4. Lasker, J. N., Sogolow, E. D. & Sharim, R. R. The role of an online community for people with a rare disease. *Journal of medical Internet research* **7**, e10 (2005).
5. Oprescu, F., Campo, S., Lowe, J., Andsager, J. & Morcuende, J. A. Online information exchanges for parents of children with a rare health condition. *Journal of medical Internet research* **15**, e16 (2013).
6. Huh, J. & Ackerman, M. S. Collaborative help in chronic disease management. *In the Proceedings of ACM CSCW* 853–862 (2012).
7. Malik, S. H. & Coulson, N. S. A comparison of lurkers and posters within infertility online support groups. *Computers, informatics, nursing : CIN* **29**, 564–73 (2011).
8. Hartzler, A. & Pratt, W. Managing the Personal Side of Health. *J Med Internet Res* **13**, e62 (2011).
9. Huh, J., Patel, R. & Pratt, W. Tackling Dilemmas in Supporting "The Whole Person" in Online Patient Communities. *In the Proceedings of ACM CHI* 923–926 (2012).
10. Mo, P. K. H. & Coulson, N. S. Exploring the communication of social support within virtual communities. *Cyberpsychology & behavior* **11**, 371–4 (2008).
11. Nordqvist, C., Hanberger, L., Timpka, T. & Nordfeldt, S. Health professionals' attitudes towards using a Web 2.0 portal for child and adolescent diabetes care. *Journal of medical Internet research* **11**, e12 (2009).
12. Grau, I., Grajales Iii, F. J., Gene-Badia, J., Siso, A. & De Semir, M. Forumclínic. *Studies in health technology and informatics* **183**, 271–5 (2013).
13. Robert E. Kraut & Paul Resnick *Building Successful Online Communities: Evidence-Based Social Design*. (The MIT Press: Cambridge, MA, 2011)
14. Wenger, E., McDermott, R. & Snyder, W. M. *Cultivating Communities of Practice*. (Harvard Business School Press: Boston, MA, 2002).
15. Bateman, P. J., Gray, P. H. & Butler, B. S. The Impact of Community Commitment on Participation in Online Communities. *Info. Sys. Research* **22**, 841–854 (2011).
16. Rashid, A. M. *et al.* Motivating participation by displaying the value of contribution. *In the Proceedings of ACM CHI* 955–958 (2006).
17. Lakhani, K. R. & Wolf, R. G. Why Hackers Do What They Do: Understanding Motivation and Effort in Free/Open Source Software Projects. *Perspectives on Free and Open Source Software* (2005).
18. Strauss, A. L. & Corbin, J. *Basics of qualitative research: Grounded theory procedures and techniques*. (Sage Newbury Park, CA: 1990).
19. Lelorain, S., Brédart, A., Dolbeault, S. & Sultan, S. A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psychooncology* **21**, 1255–64 (2012).
20. Lustria, M. L. A., Smith, S. A. & Hinnant, C. C. Exploring digital divides: An examination of eHealth technology use in health information seeking, communication and personal health information management in the USA. *Health informatics journal* **17**, 224–43 (2011).