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Weaving Clinical Expertise in Online Health Communities

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Abstract

Many patients visit online health communities to receive support. In face-to-face support groups, health professionals facilitate peer-patients exchanging experience while adding their clinical expertise when necessary. However, the large scale of online health communities makes it challenging for such health professional moderators' involvement to happen. To address this challenge of delivering clinical expertise to where patients need them, we explore the idea of semi-automatically providing clinical expertise in online health communities. We interviewed 14 clinicians showing them example peer-patient conversation threads. From the interviews, we examined the ideal practice of clinicians providing expertise to patients. The clinicians continuously assessed when peer-patients were providing appropriate support, what kinds of clinical help they could give online, and when to defer to patients' healthcare providers. The findings inform requirements for building a semi-automated system delivering clinical expertise in online health communities.

Keywords

Online health communities; moderator; support group; health informatics

INTRODUCTION

A recent study with WebMD.com's most active online health communities [11] showed 62.1% of patient posts could benefit from clinical expertise. However, the portion of patients' posts that received replies from health professional moderators was only 4.7% (median value among 6 communities). The rest of the threads were left unmoderated, when a portion could have benefited from clinical expertise. Such moderating patterns pertain to other health communities, such as dLife.com—another popular moderated diabetes community [13]. Furthermore, according to a study conducted in 2011, only 19% of major online health communities provided health professionals as moderator staff. No non-profit online health communities provided health professional moderators, showing potential limitations in time and cost in hiring health professionals as moderators [12].

Although many Websites offer health information (e.g., Mayoclinic.org), patients still come to online health communities to get information that could benefit from clinical expertise. This phenomenon especially holds true because clinical issues and patients' experiential

knowledge are intricately intertwined [11]. For instance, in the context of diabetes, other patients can provide recipes appropriate for diabetes based on their experience and clinicians can advise on the ideal after meal blood sugar number that patients should maintain. Accordingly, it is helpful for patients to exchange experiences and support with peers while receiving the clinical perspectives of clinicians. Realizing such benefits of weaving clinical expertise and peer-patient support, many hospitals offer moderated support groups, but such resources are scarce for all illnesses, especially in rural areas.

Delivering clinical expertise to online health communities is a much needed but unavailable feature in current online health communities. We interviewed clinicians to examine the ideal practice of providing clinical expertise to patients. The results helped to develop requirements for a new online health community paradigm, where clinical expertise is delivered semi-automatically within peer-patient conversations.

ONLINE HEALTH COMMUNITIES: PEER-PATIENT AND CLINICAL EXPERTISE

Online health communities have been shown to provide immense social support among peer-patients in cancer [23], diabetes [10], rare diseases [19], infertility [25], and HIV/AIDS [22]. The term *peer-to-peer health care* has emerged to refer to peer patients' "pioneering new ways of pursuing health by banding together and sharing knowledge" [6].

Many hospitals have acknowledged the benefit of peer-patient interaction due to their level of social support and patients' experiential knowledge. Hartzler and Pratt [8] distinguished patient expertise from clinical expertise, highlighting the unique advantages that patients' own expertise brings to illness management. For instance, patients discuss where to find wigs or how to manage one's spousal relationship. Clinicians cannot provide such knowledge about managing the everyday experience of illness as well as peer patients can.

In hospital-led support groups, health professionals, such as dietitians, nurses, or medical doctors moderate peer-patient conversations. These clinician moderators provide clinical expertise when necessary while facilitating peer-patient exchanges of their experiences. The clinician moderators might clarify any questions requiring clinical expertise that come up, redirect potential misinformation, or add a clinician's perspective [15]. However, hospital-led support groups are scarce resources, especially to those living in rural settings where access to clinical facilities requires hours of traveling [9].

Similar to the idea of health professionals moderating peer-patient support groups in hospital settings, online health communities have also begun to incorporate health professional moderators, who can provide medical information to the community members [11]. However, only 19% of major online health communities provide health professional moderators, potentially due to monetary and time resources [11]. This study also found that no non-profit online health communities provided health professional moderators. Even though a community might provide health professional moderators, the level of moderators' participation was extremely low—health professional moderators only answered 4.7% of patient posts (Median value of the 6 most active communities on WebMD.com) [11].

Although automated medical question and answering systems have been investigated for clinicians' use [16], no studies have looked at automated ways to add clinical expertise within peer-patient online forum threads. We can learn about informal peer-patient leaders in online health communities from prior studies looking at general forums [4,18]. However, moderating with clinical expertise presents unique challenges that other expertise might not have (e.g., liability issues). Accordingly, studying the dynamics of health professional moderators and peer-patients presents unique research problems that have not been well explored before.

To facilitate delivering a combined peer-patient and clinical expertise to patients, we investigate the idea of semi-automatically weaving clinical expertise into online health communities. We ask how we can automatically insert clinical expertise into online health communities. When and how should clinical expertise be added? What clinical expertise should be added? We interviewed clinicians to understand the ideal practice in delivering clinical expertise to patients, which can then aid answering these questions and building a new online health community paradigm where both clinical and patient expertise are delivered to the patients.

METHODS: INTERVIEWS AND EXAMPLE THREADS

Our goal was to use the ideal practice in clinicians' delivering expertise to patients as a potential gold standard in building requirements for the new online health community system, where clinical expertise is automatically weaved into peer-patient conversations. We sent emails to our social network in the northwestern U.S. and recruited 14 clinicians (Gender: 11 female, 3 male; Occupation: 8 nurses/nurse practitioners, 5 physicians, and 1 psychiatrist; Age: from mid 20s to late 60s). We interviewed the clinicians from 30 minutes to one hour.

Considering the short time (30 minutes) we can spend with each clinician, we prepared three example online health community threads for the clinicians to read and comment on how they would provide their clinical expertise. To accommodate the general expertise of the clinicians, the threads would need to cover common illnesses (e.g., diabetes) that have different causes for disease (e.g., lifestyle versus family history) and population (e.g., pediatric versus older adults). Accordingly, we chose the diabetes, ADHD (attention deficit hyperactivity disorder), and pain management communities. These three disease communities were also the most active communities at WebMD.com, a publicly available online health community, which supports over 35 disease communities. We randomly selected one thread from each community among patient-only threads (with no moderators) with at least two replies to include enough peer-patients' replies per thread but no more than four replies to keep the participant's required reading time low. We de-identified the authors of the posts before presenting the threads to the clinicians. We received approval from our institutions' Institutional Review Board for this study. The content of the example threads were typical threads of WebMD communities in terms of asking for clinical expertise, according to prior work in understanding what kinds of questions patients ask in online health communities [11].

We asked the clinicians to read one example thread at a time and think aloud as they read the threads. We then probed further on what kinds of advice they would provide to both the thread initiating patients and the repliers, if they were moderating the community. We also explained our envisioned system and asked what the system should ideally do. Below are the example threads we showed to the clinicians. Due to space constraints, we only give one full example from the diabetes thread, and we will paraphrase the other two example threads:

Diabetes community example thread: "Blackening feet"

Jane (the thread initiator) wrote: "*I have been trying to find anything to tell me what this means. My feet have been changing colors for about 2 years. Sometimes they are almost black. My podiatrist just shook his head. I also have pain if you just touch certain places. What can this be? :frown: Thank you, Jane (sic)*"

Hall replied: "*All kinds of things come to my mind, none of them good. You really need to get to your doctor. Neuropathy and circulatory problems could bring dire results. Get it checked out right away. (sic)*"

Amy replied: "*My feet turn really red when I stand for awhile and sometimes when I am shaving my legs and prop one foot on the side of the tub it looks darker to me until I put it back down, I guess a circulation problem with me, My dr, did not think I needed to worry, Just try to get this weight off, she said, slipper: :smile: (sic)*"

Pain management community example thread: "Methadone side effects?"

Jesse's thread initiating post (126 words) described taking Methadone and potential side effects that are "killing" him. Jesse asked for others who had similar experiences. To this post, Manny, also on Methadone, described (in 119 words) her experiences of becoming sick from her regular dose. She suggested that "fentanyl patches are by far the best medication for pain relief." The second replier, Eric, replied (304 words) with his experience of pain medications for the past 6 years—since he was 12. He described his significant others' experiences as well around Methadone for many years after recovering from taking Heroin. Eric noted "99% sure" that Jesse's descriptions of side effects are not those of Methadone. Eric suggested talking to the doctor about the symptoms and reassured that "Methadone is a safe, effective and proven medication."

ADHD community example thread: "A niece with ADD help!!"

Acary, an aunt of a girl who has ADHD, asked the community (49 words) what kinds of foods her niece needs to eat and if the pills she is taking are right for her. She says "I want her to grow up normal." To this post, Ashley responded (89 words) sharing her daughter's experience of changing diet and medications not making any difference. Ashley talked about her daughter going to college and working full-time and suggested Acary to just provide full support. Jes replied (233 words) congratulating Ashley's daughter and also shared her 4-year-old daughter's experience of having problems at home and at school. Jes described how treating children with ADHD as normal is important. She also mentioned her grandmother's quote of making an analogy between ADHD and cold medications.

We transcribed the interview data and analyzed it using open coding analysis [24]. We iteratively refined and grouped the codes using an affinity diagram to find common as well as contradicting themes that emerge across participant data [2].

Next, we present our findings in two parts. In findings 1, we describe how the clinicians would provide clinical help to the patient who initiated the thread. In findings 2, we focus on the clinicians' reaction to peer-patient interaction. These findings provide implications for how we might envision semi-automatically weaving clinical expertise in online health communities.

FINDINGS 1: MOVING CLINICAL PRACTICES ONLINE

Clinicians used their existing clinical practices as a way to think about how they would respond to patients' posts in terms of *triaging*, *clinical questioning, partnering with patients, and deciding what to tell patients*.

Triaging

Triage refers to a commonly used term in health settings for prioritizing treatments based on the severity of the problem. The clinicians described a similar process, attempting to first understand the severity of the problem and decide how to respond accordingly—whether to tell them not to worry at all, to try simpleinterventions at home, or to go see a doctor immediately:

> In medicine, […] we always get trained [how to determine] sick or not sick. Sick you've got to deal with right away. Not sick, you can take a little bit longer to kind of figure it out. So, I think the first thing is to really categorize these posts in sick or not-sick. (P3)

The clinicians noted they would be extremely careful about overlooking severe problems. P5 said she would not come to a quick conclusion about the patient's problems, and would defer any medical opinion that does not have the expertise in (P14). Almost all clinicians mentioned that they would tell the patients to go see their doctors to ensure liability of the moderators (P14) or to help patients understand the severity (P3) and the cause of the problem (P9).

To understand severity, the clinicians focused on symptoms described in posts:

> If the [foot] color is red, you have to go to the doctor because this person already started color going dark and red—that is called Necrosis, a severe vascular injury. It can develop pressure ulcer or sometimes it can develop MRSA, a severe infection in the skin. (P1)

The clinicians considered detecting serious problems as an important task in moderating communities. Once the clinicians figured out how severe the problem was, the clinicians would then want to know further details about the patient's history and context to give better help.

Clinical questioning

Clinicians presented the lack of information about patients' medical history as one of the biggest barriers to providing appropriate help for patients in the thread examples. In their existing clinical practices, the clinicians would ask probing questions or use documents to understand patient history, context, and specifics of the problem. Based on the context gained, they would continue to further evaluate if necessary. Below shows examples of how clinical questioning can be applied in online health communities.

Eliciting patient history—The following shows an example of clinical questioning to elicit patient history: "[I would ask] something more specific: How long has she been a diabetic? Is she taking insulin? What's her diet like? Because all of those things will impact the skin and the circulation and the tissue too." (P11)

Gaining objective data—Sometimes the clinicians wanted to further gain objective data about the person since they could not trust what the patient was reporting: "I am not very convinced of her response in general. So I would like to run a lab test again on her. I want to get more objective data from her." (P12)

Gaining context—While P12 considered lab tests as a potential trustful source of data, others considered asking probing questions to gain further context from the patients: "[We could assess] a simple pain level, like 0 to 10 scale … Does it change what you do during the day? How has it changed your quality of life?" (P4)

By asking what else is going on and understanding the family context, such as who are the caregivers and what is their relationships with the caregivers, would clinicians be able to assist further with informational needs that the patients might have. During this process, the clinicians noted the importance of building trust with the patients.

Partnering with patients: Building connection and trust

The clinicians noted how patients' mistrust of clinicians can hinder the delivery of effective clinical help, especially in online settings where no personal relationships have been established. In their practice, the clinicians would attempt to first connect with patients and establish trust by attempting to *translate* what patients present into what makes sense to clinicians, *exchange* questions and answers, and *be transparent*.

Translating patient posts—Clinicians set up an analogy of moderating online communities to being on call, translating patients' words into what makes sense to clinicians, using patients' perspective: "When I'm on call, I have to just listen to what the patient is telling me over the phone and try to interpret through their eyes and their experiences." (P3)

A clinician showed how she would reinterpret patients' presented symptoms to what makes sense to her: "Opioids are known to have urinary retention, so he might be describing it as hesitant urination but it could be that he's actually experiencing some urinary retention." (P7)

Instead of disputing patients' presented symptoms, attempting to understand what really happens from a patient's perspective can help build further connections between patients and clinicians.

Increased back and forth interaction—To further build trust, the clinicians would exchange questions and answers back and forth to understand patients' knowledge and respond accordingly:

> A health professional would want to […] really find out what they (the patients) know, what they think they know, where they've learned it. (P13)

To interpret patients' situations more accurately, exchanging questions and answers will help the clinicians further understand the patients, leading to a better partnership with patients.

Being transparent—The clinicians also pointed out how being transparent about what they do not know can gain patients' trust and break boundaries:

> I am upfront about [the lack of knowledge] and I say, "So, let's look it up, if that's something that's common." I feel like it's good for my relationship with the patients, because I think it humanizes me too […] it means I drop or break boundaries… (P6)

As the clinicians establish trust and connect with patients, they would then recognize patients are dealing with difficult conditions (P14). They would then provide a supportive environment (P14) and personalized help by giving modified information based on patient types (P9) and context of knowledge (P13). This process would lead to mutually agreeable outcomes (P3). It is not just telling patients what to do (P3), but aligning expectations with the patients (P2).

Deciding what to tell patients

Once the clinicians established an in-depth understanding about the patient's problem, the next question would be what information or help to give to patients. The clinicians would first try to give patients a *bigger picture* of what is common while highlighting *individual differences*, explain *what to expect*, *clarify* medical information, and advise how to *manage relationships*.

Bigger picture, individual differences, and what to expect—The clinicians would explain to patients in online health communities what are common treatments or side effects, and what are the unknowns and atypical situations. The clinicians would then explain the individual differences, depending on the patient type. For instance, P14 below would explain what common side effects are and what should be communicated with providers:

> I would say, "Most of these symptoms that you're describing are typical side effects of Methadone. If they last more than a few days you might want to consider consulting your physician. […] The foot symptoms you're experiencing are not symptoms I've typically heard as a side effect of Methadone." (P14)

Using numbers and statistics can also help patients or caregivers understand the scale of problems:

> This is something I will say—Some alarming percentage like perhaps 25% or 30% of all males under the age of 25 in jail have untreated ADHD (P8)

While showing what is common, addressing individual differences would help patients have a proper understanding of their health:

> I just get worried when I see these specific numbers this person's going to think that they're just like someone else. While they can get support from each other, each person should expect that their symptoms might be different. (P2)

The clinicians feared that not knowing patients' complete health situation could incorrectly lead patients to think their experiences were similar to each other's potentially unrelated experiences. P9 was concerned that patients would think that Jesse, the thread initiator, and Eric's situations were similar, because Eric may have had addiction problems in the past:

> We don't know if Jesse was on methadone. […] People [like Eric] who were on methadone because they were former heroin addicts—that's just different. Their experiences are going to be probably slightly different in terms of expectations. (P9)

The clinicians considered their role to be telling patients about the unknowns and expectations for what could happen next. This way, they saw the new online health communities as a platform for prevention and additional help not provided by existing clinical care. The clinicians also noted the importance of helping patients not to be anxious about warnings but to be prepared for potential harm.

Clarification of medical information—The expertise the clinicians would share with the patients included clarifying medical information, such as an overview of drugs and foods (P2, P3, P9, P10, P14), the definition of medical terms (P9), and clarifications about any information unaddressed by peer-patients (P14).

P13 emphasized that clinicians are not in the same position as a parent or caregiver who provide social support. Instead, clinicians should give evidence, medically sound facts, and reasoning. The clinicians also suggested providing other helpful medical resources online, such as WebMD.com, MayoClinic.org, MicroMedex.com, PubMed.gov, and other physician drug references.

The challenge was when there were no right answers to a patient's questions. P1 below described how existing clinical practices work when no clear solutions exit for a patient's problem:

> When there are no right answers, and when side effects are coming up, we tell patients to call back right away. When nurses cannot solve the problem, then she would ask the doctor. If the doctor is not sure either, then the doctor and the nurse would talk about notifying times, like every two weeks to call back about updates. (P1)

The anecdote helps us think about how our system might work through new problems without clear answers.

Managing relationships—The clinicians also discussed how they should help patients in online health communities manage their relationships with their healthcare providers and their family members.

<u>**With providers:**</u> To help with patient-provider relationship, the clinicians first wanted to know the existing relationship:

> Are people really telling [the provider] when they come in? Does the provider take the time to listen? Are they too afraid to really bring it up because they're so worried that they don't really bring it up in a way that gets the attention of the healthcare provider? (P10)

Knowing existing relationships with their healthcare providers could allow clinicians to assist patients of online health communities in what to ask or include when calling their providers (P9, P14). Further, the clinicians would teach patients what to do before going into appointments with their providers—to keep a list of what is happening, how long it has been happening, and what is the intensity of the symptoms (P10). The clinicians were careful in providing such help, because they did not want to diagnose but to explain the problem the provider should examine (P3) and "just help [patients] to be able to seek appropriate help" (P10). P7 was worried that patients will print out their suggestions and bring them to their providers.

The clinicians also saw themselves as helping patients in online health communities be heard by the providers, advising patients how to describe further details (P10). Also, clinicians in online health communities could help patients make a commitment to see their providers or help figure out how the patient can be evaluated (P3, P7).

In the case of patients who have other issues that prevent them from having access to care, another clinician would volunteer other ways to give help, such as "sending them to a website that they could look at and compare with their own situation" (P13). A more common perceived challenge by the clinicians, however, was that patients "just do not go see the doctor" (P10) and might be "afraid to see the doctor because [they're] afraid of what [the doctors are] going to tell [them]" (P3). Accordingly, our system can attempt to understand where patients develop such perceptions about their providers and help patients either find an appropriate provider to talk to or advise on communication skills.

<u>**With family:**</u> Similar to the patient-provider relationship, the clinicians would first try to understand the patient's existing relationship with their families to help it improve. For the ADHD thread example, the clinicians wanted to understand the motivation of the aunt for being involved with care of her niece and why the aunt challenged what was prescribed to the child. A clinician described how he would suggest the poster to talk with the direct caregiver:

> Since you're the aunt, talk with the parents and go, 'How can I be supportive and how can I be helpful?' (P14)

So far we described the first part of our findings on how the clinicians applied their existing clinical practices to infer how they would moderate online health communities. This next section provides insights on how to design the semi-automated system that weaves clinical expertise into online health communities. The clinicians, however, had to expand their usual boundary—patient-provider relationship—and further think about how to work with peer-patients who are also providing help to the patients.

FINDINGS 2: ABOUT PEER-PATIENT REPLIES

Peer-patient interaction presents a unique dynamic of online health communities distinct from regular patient-provider interaction. In response to peer-patients' replies in the example threads, the clinicians first talked about their perspectives on peer-patient sharing information in general. Furthermore, the clinicians discussed how they might work with peer-patient repliers to provide better clinical help.

About peer-patient interaction

From the clinicians' perspective, peer-patient interaction was a double-edged sword. While they saw concerns arise around peer-patient interaction, the interaction could also provide unique support that cannot be earned from other places.

Being online, misinformation, and individual differences—When the Internet started to become widely available to the public, a series of studies examined the quality of information online with an apprehensive view toward uncensored exchange among patients [3]. Over time, researchers have shown that patients generate norms that would discourage sharing misinformation to one another [21], similar to other areas of online community activities [1]. Yet, the older, reserved view toward peer-interaction persisted in the clinicians, showing concerns about peer-patients who are 'strangers' interacting online. They were concerned with the misinformation that peer-patients might share, considering that individual differences can be unnoticed. For instance, P6 below described how unrecognized individual differences among peer patients can lead to misinformation:

> This is one of the things that's dangerous about peer discussions online. What that might mean for somebody healthy or [those with] a different set of comorbidities means something very different and the conversation doesn't include that level of complexity. (P6).

P12 further described how misinformation can be harmful, especially because "people tend to find it hard to filter out information and be objective about them" and that education is crucial in community-based settings. P1 was concerned with a random solution becoming a 'hot topic' and being misconstrued as an effective one without any evidence. P12 was also afraid that the differences in people's opinions can make people nervous and said that outdated experiences around medications have a lot of room for criticism. P5 also noted that experiences cannot simply transfer from one person to another, giving an example of Amy, who compared her red feet with Jane's black feet.

The clinicians showed stronger concerns for highly individualized regimens like medications than other topics:

> Treating of pain is not a cookie cutter thing. You have to try it, you have to check it out and see what works for you. … it might be working just fine for [some]. And other people, you can't give them enough and it's still not working for them. (P11)

Places that the clinicians pointed out as "red flags" were when dosages were mentioned (P2), generalizing experiences that come from a small sample size, such as "my family and friends" (P3), or when other patients suggested drugs to others (P1).

Ironically, while the clinicians were concerned about sharing specific experiences, they also considered sharing specific experiences as crucial in patients relating with each other, leading to increased social support. P2 wondered what patients' expectations were—whether patients wanted just support or clinical management as well. P2 would be concerned about the latter. If it were the former, then just finding appropriate peers to exchange support would work. P5, on the other hand, considered peers' suggestions as something that he would agree with.

The prevalent perception that interacting with other patients can be harmful sometimes was not grounded on the example threads we gave them. In fact, the clinicians agreed with many replies in example threads:

> it worries me, just because… I don't know, … But this one person says, "You really need to go to your doctor," which is reasonable. And the information they're giving is reasonable, […] But I don't really know how that's gonna… (P2)

P2 further noted that not being familiar with online communities might have pushed her to be more concerned about misinformation online, similar to the society's early reactions toward new technology, such as the Internet [17].

Uniqueness of peer-patient experience and support—During the discussions on misinformation shared among peer-patients, the clinicians acknowledged the unique role peer-patients play in online health communities, such as providing patient expertise, social support, and personal experiences. "Patients know what they are talking about" (P10). One participant noted that online health communities should provide patients information "they cannot get through their doctors" (P3). It is uniquely helpful when peer-patients suggest other things that worked or did not work for her (P4, P9) and recommend asking the provider about the suggestion (P4). P13 below also contrasted the kinds of support that only peer-patients can give compared to clinicians:

> [patients are] supportive in a way that a health professional doesn't necessarily need to be. Health professionals need to give evidence, medically sound facts and some kind of reasoning behind that (P13).

P11 also mentioned successful cancer communities and their unique support compared to healthcare:

> The cancer people have done a good job in that whole support thing […] But that doesn't happen in a lot of the way healthcare is delivered. So, support groups are fantastic resources (P11).

Even though the clinicians saw peer patients' reassurance as potentially harmful, they also agreed that reassurance coming from those who "actually [went] through the same thing" (P4) empowers other patients:

> That story can reassure Jesse that, gosh, you don't have to stay here. You can go and talk with physician in changing a dose. You're in charge here, and giving some ideas they might try. That's what I like about that interchange. (P4)

P5 stated that, although she has heard from lectures that peer support is important, seeing the example threads helped her further realize that family and friends can really help with the situation. Especially in situations where patients are "being blown off by providers," such as in the case of Jane in the Diabetes thread whose doctor shook his head, places like online communities could help patients feel supported (P10). Sometimes, just feeling supported by knowing that "there are other people struggling" (P9) suffices even at the cost of not getting their original questions answered. P6 also mentioned peer patients can influence each other in positive ways for interacting with their providers—letting each other know that they can contact their providers sooner, for instance. More experienced patients can also share well-known medical facts, such as side effects (P13).

Good replies versus bad replies

During the interview, we did not ask the clinicians to evaluate the replies. However, interestingly, all clinicians categorized replies into 'good' ones and 'bad' ones based on a variety of language style and content characteristics. In this section, we discuss what the clinicians considered as "good replies" versus "bad replies" and how they would respond to these replies.

"Good" replies: Balanced, focused, reassuring, and advising to go see the doctor—What the clinicians saw as "good replies" were balanced, focused, reassuring, and suggesting to go see the provider. P9 described the post characteristics that he agreed with:

> I really liked Ashley's response, because it felt like it was (A) respectful, but (B) it was also a balanced response in saying that there is no one best medicine, and there are a variety of things that could be done. (P9)

Balanced responses would not emphasize any one particular piece of information but would provide wider understanding around a problem. P5 saw repliers' comparing different treatment options using evidence was a helpful reply. *Focused* responses would be those that address the patient's specific problem instead of being "derailed" or "distracted" (P2, P9) with unrelated personal experiences. Reassuring responses would validate the approaches and attitudes of the patient or the caregiver:

> In saying, "Hey, you care about your child. You're a caring aunt." I think that was something really helpful to validate what she was saying. (P10)

However, P4 was concerned about peer patients reassuring themselves, such as in the case of the diabetes thread, where severe problems get overlooked. The clinicians considered peer-patients telling the poster to go see the provider as helpful. However, in many cases,

patients might already have contacted their providers [20] and they visited the community to receive peer support, not to be told to talk to their providers.

"Bad" replies: Underestimating or overstating—What the clinicians considered as "bad replies" were those that were either underestimating or overstating. The diabetes thread had a severe case of blackening feet and Amy's response that her doctor told her not to worry stood out as the underestimation problems of "bad replies" (P4, P5, P7, P8). The clinicians also considered one a 'bad' reply when they saw overstatements of a problem, such as "*mentioning his sister, brother, and being 99% sure about it*" (P12). P12 went on to explain that generalizing judgments with confidence could make people unnecessarily nervous.

Working with replies: Challenge, ignore, reassure, and enrich—As the clinicians shared their opinions about the replies, they challenged the repliers, stated they would ignore or reassure them, or said they would respond to the thread to help bring clinical expertise to enrich information shared in the thread.

P8 challenged Amy's suggestion to do weight off (to put legs higher up for blood circulation purposes), because doing weight off might not be safe depending on the poster's personal situation. P3 also challenged Manny's suggestion on trying Fentanyl patch in the Pain management thread, but could not think of the best way to identify P3's opinion that going from Methadone to Fentanyl patch is counterproductive. P1 also challenged common knowledge that people have around massaging—that massaging can be harmful for circulatory problems.

The clinicians would sometimes just ignore the replies that self-report and not address the problems of the poster, since they would not know how to respond to those. P6 said he would not know what he would respond specifically to Eric other than saying, "I agree with both Manny and Eric that if there's something that is going on, it does need to be addressed."

For good replies, the clinicians would reassure that "they have given a good reply" (P12). To further improve the conversation with better information, the clinicians would redirect, confirm, or suggest solutions:

> If I were a moderator, I might redirect them and say, "Black sounds like a big problem to me. It sounds like that's different from the darker red foot. Certainly neuropathy and circulatory problems are likely and they're common with diabetes. It will be important for you to carefully look at your feet, watch for signs of any kind of openings in your skin or problems" (P2)

Here, P2 explained that another reply about blackfoot not being a big concern was incorrect. P2 then briefly explained common background knowledge around diabetes regarding the problem and suggested the next step. P1 would add contingencies around peer-patients' suggestions, such as appropriately performing weight off (lifting the legs up high using cushions). P3 would even warn a replier about his potential danger. To enrich peer conversations, P11 saw repliers asking more patient history questions could help.

TOWARD SEMI-AUTOMATICALLY WEAVING CLINICAL EXPERTISE IN ONLINE HEALTH COMMUNITIES

So far we described the clinicians' ideal clinical practice and their perspectives on supporting patients in online health communities. In this section, we discuss how our findings translate into thinking about semi-automatically weaving clinical expertise in online health communities. Largely, we learned (1) what clinicians would do to prioritize patient posts to respond to, (2) how to further understand the patients to give better help, and (3) what to give help and how.

How to prioritize threads needing help

As discussed in the findings on *triaging*, to prioritize the threads that need clinical expertise, we could first go through a triage process, classifying whether a post contains any critical problems that need to be addressed directly. For instance, the clinicians often focused on numbers, biomarkers, names of medications, symptoms, and emotions. Such information can be picked up using natural language processing techniques, together with a database on medications, symptoms, and emotions. Existing work has looked at creating online patient profiles, based on detecting health-related phrases mentioned in patient posts in online community settings [7]. Using post content to predict whether the post will be moderated can also help to predict whether a post needs a clinician's attention [14]. It is an open question how much the severity of the problem can be delineated, and it might be challenging to automatically triage at greater detail as in the real world. However, detecting the "critical" or "flaggable" terms (e.g., 'urination retention', 'black feet') could help speed up the first pass at classifying whether a post is about non-medical or medical topic. A lower level triage process could be done manually by the community administrators or patients themselves (e.g., crowdsourced) or further sophisticated machine learning approach can be devised, using accumulating data produced by moderators and patients.

Similar to prior work in patientslikeme.com [26], detecting critical events of patients, such as onset of a new disease, disease progression, or recovery, can provide implications to not only patients themselves but to the healthcare infrastructure as well. Online health communities can collaborate with clinics and engage patients holistically, from prevention to after-care.

As discussed in the *peer-patient interaction* section, some repliers might present what clinicians consider as misinformation. However, what the clinicians called misinformation was often tied to lack of context—missing patient history and unnoticed individual differences, rather than the incorrectness of the information itself. The next point of discussion—how to further understand patients—will address how patients' detailed context can be further shared.

How to further understand patients

All clinicians continuously noted that the patient posts lacked information about the patients' context and history. Disambiguating patient history helps not only in preventing potential misunderstanding of information shared among patients but also facilitating better,

partnered help from moderators. Rich patient history can also lead to quality peer-patient interactions, as evident in studies attempting to match peer-patient mentors based on profiles [7]. The system should be able to respond in context to the person's knowledge as the clinicians do in their clinical practice.

The online health community system can devise methods to help patients further delineate their patient history and context related to the topic they are discussing. It could be a template that patients fill out or connect with personal health records. Privacy problems could emerge, in which case mechanisms around partial private communication features among moderators and peer-patients can be useful. Considering that patients generally find it hard to tell history and instead say, "I need help," providing a mechanism to produce probing questions for moderators and peer-patients to ask can also help, as learned from the findings around *clinical questioning*. Also, using the patients' past postings can add further context to the patient history.

What clinical expertise to give and how

Once we know which patient threads need help and learn more about the patient history, the next problem is providing clinical expertise. The kinds of clinical expertise that the clinicians envisioned to provide to patients included: giving a bigger picture, explaining individual differences, presenting what to expect, clarifying medical information, and giving advice on relationships. Some of this information can come from databases containing statistical facts stored in open government resources such as healthdata.gov. For instance, as in the case of Jane with blackened feet, in combination with the symptoms and patient history, the system could pull up national statistics around what that symptom might imply. Such information can be either directly presented to patients or filtered through moderators, who will use the information as a tool to better support patients.

The system can also devise a mechanism with which the community administrators and peer-patients can together make sure that information shared has added references to the original source. It could be in the forms of an automated trigger, asking the patient poster to clarify where the shared medical information came from. Or it could be peer patients or administrators tagging and asking the poster to further delineate the source of information. The interface should clarify that the suggestion is not required so that it does not hinder participation. Instead, if patients supply such information, their posts can receive badges for incentives.

In hospitals, as the clinicians mentioned, many roles and specialties exist—registered nurses, nurse practitioners, interns, residents, attendees, etc, multiplied by specialties. People with these various roles collaborate and create a working, holistic care for each patient. The point is not to replicate regular healthcare to online communities—but online communities can learn from the existing practice on how roles can be divided and coordinated. At current health professional moderated forums such as WebMD.com or diabeticconnect.com, mainly three roles exist: health professional moderators, staff moderators, and peer-patients. Emerging roles of community members have been defined in prior work in online communities, such as voluntary, informal leaders [4,18]. We could utilize such unique, emerging roles in online communities such as peer-patients. More specifically, we can use

various peer-patient dynamics structured around length of experience (e.g., mentor-mentee relationships [7]), degree of similarity (e.g., buddy system [10]), and community members' mini-experiences (e.g., collaging experiences [10]). These emerging social relationships, together with semi-automated clinical expertise, can extend what has been happening in regular healthcare settings to provide robust, enriched, and sustainable support for the patients coming to online health communities.

Further, for replier support, we could help repliers learn how to better compose message content to not under- or over-state their experiences, using similar mechanisms to computerized writing educational tools [5]. If the system detects any styles of language that show under- or over-statement of things, the machine can warn about it or suggest other ways of wording them. The machine can also prompt repliers to include references or sources of knowledge, or suggest helpful links to include in the content.

Not crossing the line: Rules around "Go see your doctor"

Unsurprisingly, the clinicians were especially careful of liability issues around providing clinical help online. The clinicians continuously reminded themselves of the limitations around not being the primary care providers of the patient posters and began formulating rules for "not crossing the line."

A number of questions around 'go see your doctor' began to emerge. That is, when are moderators going to tell patients to go see their providers? Are moderators going to help what patients ask their doctors about? Should moderators help understand what to expect, such as which work-ups patients would need to do? How should moderators tell patients to go see their doctors without scaring the patients? Why not just add to every post that they need to go see their doctors?

All clinicians mentioned that they would tell the patients in the example threads to go see their providers. If we were to build an automated health professional moderator, telling the patients to go see their providers to all posts would be an easy task. However, telling patients to go see a doctor can be a conversation stopper. Rather, addressing the implications built around why one would suggest to 'go see your doctor' better tackle potential needs of the patients. Possible tasks for agents would include finding key terms relating to diet, medication, emotions (P10), triggers (P8), and critical events (P2, P13). The automated agent can then provide related online health resources (P6, P7, P14), add words of support (P10), or attempt further evaluation, going back to gaining more history of the patient. As a result, online health communities can mediate patients in ways that augment existing clinical care systems, especially if collaboration with clinics can be established. Many clinical institutions have built online communities—however, such communities are limited to their registered patients. We would still need mechanisms supporting the more spontaneous, floating forms of patient crowd, such as finding related clinics and strengthening commitment to visit clinics.

CONCLUSION

Through interviewing clinicians, we found requirements for weaving clinical expertise into online health communities. We learned how to prioritize posts that need clinical expertise, how to further elicit patient context, what clinical expertise to provide, and how to provide that clinical expertise in online health communities. The clinicians came from a variety of academic disciplines thus sometimes perspectives differed or even contradicted. However, all clinicians considered online health communities as unique, supportive platforms from which patients can greatly benefit.

The findings help us move one step closer to improving emerging, unique peer-patient support systems, such as online health communities. Our work helps to enrich the peer-patient conversations and support by exploring a novel approach of automatically weaving clinical expertise with peer-patient conversations. By examining this research problem, we also engage studies of expert and novice relationships, machine learning, and social computing. This multi-disciplinary approach in online health communities supports patients' complex information needs that can benefit from a balanced expertise between patients and clinicians.

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