



# HHS Public Access

Author manuscript

CSCW. Author manuscript; available in PMC 2015 July 02.

Published in final edited form as:

CSCW. 2015 ; 2015: 1488–1499. doi:10.1145/2675133.2675259.

## Clinical Questions in Online Health Communities: The Case of “See your doctor” Threads

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### Abstract

Online health communities are known to provide psychosocial support. However, concerns for misinformation being shared around clinical information persist. An existing practice addressing this concern includes monitoring and, as needed, discouraging asking clinical questions in the community. In this paper, I examine such practice where moderators redirected patients to see their health care providers instead of consulting the community. I observed that, contrary to common beliefs, community members provided constructive tips and persuaded the patients to see doctors rather than attempting to make a diagnosis or give medical advice. Moderators' posts on redirecting patients to see their providers were highly associated with no more follow up replies, potentially hindering active community dynamic. The findings showed what is previously thought of as a solution—quality control through moderation—might not be best and that the community, in coordination with moderators, can provide critical help in addressing clinical questions and building constructive information sharing community environment.

### Keywords

Online health communities; moderators; H.5.2 User Interfaces; J.3 Life and Medical Sciences; Medical information systems

## INTRODUCTION

The canonical role of online health communities discussed in the literature includes providing psychosocial support, where peer patients exchange emotional, informational, and appraisal support [23,24,28]. Websites' policies generally discourage the sharing of clinical advice [40,41,42] due to liability issues. Although medical professionals agree with psychosocial benefits of online health communities, they are still concerned with potential misinformation being shared among patients [20].

This perception against potential misinformation around clinical questions is also reflected in moderators' roles in online health communities. In addition to moderators' positive, facilitating roles for building online communities, moderators also shy people away from

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asking for uncensored medical advice from the community by redirecting patients to see their providers instead of consulting the community [17]. Such response might discourage further participation by community members on the thread because the moderator has declared clinical questions, such as those requiring diagnosis or prescription of medications, are not something the community should answer. The possible assumption embedded in this practice is that patients have not consulted their providers when they ask clinical questions; patients want easy and quick diagnosis from the Internet; and peer patients might respond with health information they are not equipped to provide.

However, moderators might not know that patients already have seen or are planning to see their providers about the issue. Patients might want to talk to peer patients and receive additional information beyond just a diagnosis, empowering themselves as informed patients. Community's peer-knowledge has a great potential to provide such information, including patients' experiential knowledge largely unavailable in traditional clinical settings offered by health care providers.

In this paper, I challenge the widespread notion that online health communities are not an appropriate place to receive clinical help. I studied cases of online health community conversation threads where moderators redirected patients to see their providers instead of talking to the community. By studying these threads, I was able to investigate the context of the patients' clinical questions and how these questions are handled in the community by the moderators and peer patients. Furthermore, I learned how to better manage patients' clinical questions in online communities by observing what worked and did not work.

My overall goal is to examine how peer patients' and moderators' roles should be in addressing clinical questions in online health communities. To get to this goal, I examine current practice around threads where moderators redirect patients' clinical questions. My specific research questions are as follows: (1) In what contexts do moderators redirect patients to see their providers? (2) How do other community members work with moderators in this context? (3) How does the moderator redirecting patients to see providers relate to the patients' and other community members' participation with the community? The results will contribute to the state of clinical information sharing in online health communities from a quality control standpoint. Further, the findings will shed light on online health community development, specifically in defining the roles of moderators and the community members in providing help to patients' clinical questions.

## BACKGROUND

The role of community members in online health communities has been discussed as researchers presented social and clinical effectiveness of online health communities. Maloney-Krichmar and Preece [25] found strong group norms and reciprocity, membership, and strong sub-groups as critical elements in building sustainable community that positively influences members' offline lives. Frost and Massagli [12] studied patientslikeme.com and found that members who shared similar health conditions benefited from each other through questions and answers. The authors further emphasized the importance of patients' sharing health information, which worked as a catalyst for peer patient support in their case. Hartzler

et al [14] have been investigating mechanisms to match peer-mentors who can provide well-coordinated support among peers. Peers' emotional support has been shown to satisfy cancer patients' questions regardless of their purpose and content [36] and further prolong community participation compared to information support [38].

Select online health communities use moderators—an external governance, such as health professionals and staff moderators who moderate community discussions. Literature shows mixed perspectives toward the role of online health community moderators. Maloney-Krichmar and Preece [25] found that strong group norms made externally driven governance, such as moderators, unnecessary, further illustrating the importance of community members' roles over moderators. A randomized controlled trial showed that peer mentors were significantly more effective than nurse mentors in improving diabetes [16].

Other researchers, however, found moderator roles as helpful for online health community dynamic. Resnick et al. [31] found staff moderators facilitating online health forum to be crucial in moving lurkers into posters and bootstrapping an active community. Through a meta-analysis, Eysenbach [9] found that most studies of online health communities showing clinical effectiveness involved health professionals—the external moderators—making it difficult to tease out the effectiveness of “pure” peer to peer support on the outcomes. Huh et al. [17] studied moderators' roles in WebMD online health communities and found that moderators went beyond purely moderating the community content and attempted to build rapport and supply useful resources to the patient members. At the same time, moderators redirected patients to see their doctors instead of consulting the community. Such moderators' acts contrast with other kinds of moderating practices, because these acts could drive members away from the community.

According to the literature so far, the role of community members has been heavily focused on psychosocial support [2,27,32], whereas the role of moderators has been focused on dealing with misinformation and community management in general [8,25,39]. Such dichotomous roles between community members and moderators place moderators as those who should play the “policing” roles, where moderators have to prune discussions that potentially produce misinformation. The canonical policing situation occurs when patients ask for medical advice or diagnosis, which could potentially result in misinformation if answered by non-health professionals. However, I do not know how such moderation impacts the constructive sharing of health information in online health communities and the dynamic among the community members. How other community members—who are known to focus in socially supportive roles—work with such situation is also unknown.

In this paper, I address such gap in the literature around dichotomous roles of peer patients and moderators around clinical questions. I challenge the notion that peer patients' help is only beneficial in the case of psychosocial support. To do this, I examine the threads handling clinical questions that the moderator evaluates as something the community could not immediately answer. I will then study how clinical questions can be handled both by moderators and peer patients, maximizing the benefit of peer patients in online health communities.

## RESEARCH SITE SELECTION, SAMPLING, AND ANALYSIS

Only a few online health communities have used moderators due to various resource limitations [18], but more online communities are adopting moderators as part of their growth. Moderators can help with answering questions that are not replied to, welcoming new comers, and providing useful information and resources [3]. WebMD.com is one of the few online health communities that offer moderated forums. Thus, studying WebMD will help us to understand the role of moderators in the large number of communities that will begin to use them.

I chose the WebMD diabetes community as a research site for this study. The moderators as well as patients at the WebMD diabetes community are more active—regarding total posts and update frequency—than other disease communities under WebMD. Managing diabetes is about changing lifestyle. Accordingly, the peers' discourse around diabetes as illness revolves around accepting the disease as part of daily routine and examining various aspects of everyday life as opposed to involvement in activities of serious problem solving and medical decision making like cancer. Such characteristic of a diabetes community might have influenced a study finding that the topic of diabetes allowed diverse moderator responses to be shared with patients, such as sharing clinical expertise, building rapport, and urging to see providers [17]. Because I was studying situations where moderators redirected patients to see providers compared to other moderating situations, having access to enough diverse moderator posts was important.

In February of 2014, I scraped publicly available forum data of the WebMD diabetes community dating from its beginning, which was June of 2007 to a secure MySQL database. The Institutional Review Board at my institution determined my project as unregulated by the review board. The community had 5,196 unique posters and 15 moderators (only two of them were actively posting hundreds of messages, which is common for all WebMD communities), and 711,777 total posts under 9,576 conversation threads.

### Identifying “see your doctor” posts

From this big corpus, I had to find reasonable ways to identify the relevant conversation threads connected to my study purpose, which is to examine threads that clinical questions are being asked and moderators redirect patients to go see their doctors instead. The following are representative examples of moderator responses that tell patients to “See your doctor” after patients ask clinical questions:

“Talk to your doctor and pharmacist about it.” (Moderator, WebMD diabetes community)

“You should call your doctor. No one here can tell you how to adjust your insulin or whether you need to go to the ER to have it brought down in a safe, monitored, setting.” (Moderator, WebMD diabetes community)

In these posts, the common languages used included “see your doctor,” “call your doctor,” and “talk to your doctor.” Other ways of conveying similar content include “consult your provider” or “Have you seen your diabetes educator?” However, I learned from querying

various keywords within the database that these variations do not return as many results as the first three phrases mentioned. Querying “your doctor” returned too many results that included unrelated posts outside the scope of this study to be useful.

Our main goal was to qualitatively study in-depth situations where moderators and community members managed threads when moderators urge patients to see their providers moderators’ first replies (first occurring reply from a moderator in a thread) to the initiator<sup>1</sup> of the thread, I queried from the database the exact match of the three phrases: “see your doctor,” “call your doctor,” and “talk to your doctor.” Out of 1,700 threads that had replies from 12 unique moderators, the query resulted in 109 total threads that contained replies from the two most active moderators.

### Further identifying “see your doctor”

The phrase, “See your doctor,” can mean many things. It could mean that moderators ask patients to see their doctors because the problem noted seems to be urgent needing immediate help from the health care providers, which is not within the scope of my study.

To identify the relevant threads pertaining to my goal, a coder (myself), performed an open coding analysis [35] of the moderators’ posts of the query results (109 threads). From this analysis, this coder generated a codebook for identifying various situations of what “see your doctor” phrase could mean. The coder then discussed the codebook with a second student coder to revise the codebook using 10 moderator post examples. The second coder then used the revised codebook to code a randomly selected half of the moderators’ posts in those 109 threads excluding the examples used in the codebook discussion. Cohen’s kappa between the coders was 0.6. Main disagreements occurred in distinguishing posts about moderators telling posters to go see their doctors because “the community cannot help” versus “the poster should see the doctor right away.” For the results that the coders disagreed with, the two coders discussed and collaboratively revised the analysis to what both coders can agree. The agreement for the problem in distinguishing “See your doctor because we cannot help” versus “See your doctor because the problem you state is dangerous,” the coders decided to find explanations in the Seedoc posts for why the problem is dangerous enough to see a doctor to code the post as the latter case.

The rest of the posts were coded by the first coder based on the discussion. As a result, the coders identified 39 threads out of 109 threads as relevant to this study—threads that involved clinical questions and moderators redirected patients to go see their doctors instead of consulting with the community. These threads contained in total of 186 messages. For qualitative studies, 186 often provides reaching saturation point [26]. Only one moderator was present in the 39 threads. This moderator was the most active moderator in the diabetes community, meaning the moderator had posted most messages in the community.

From exploring other WebMD disease communities, the coders found “See your doctor” posts come from other moderators as well, showing that the “See your doctor” posts are not unique to this one moderator on the WebMD diabetes community. However, due to each

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<sup>1</sup>Initiator: A person who started the conversation thread

disease having because the community cannot help them. Thus, extracting a few, representative cases was more important than identifying all possible relevant cases. Accordingly, within unique cultural norm built around patients' relationships with peer patients as well as care providers and other helpers, the findings should not be interpreted as such that requires generalization. The goal should be to deeply understand community dynamic around the practice of "See your doctor" posts by moderators, particularly in the WebMD diabetes community. The applicability of the findings to other communities should be tested through reexamination of other communities as future work.

From now, I will call these 39 threads, *SeeDoc threads*. I will use *SeeDoc posts* for the moderator's replies that ask the thread initiators to see their doctors because the community cannot help.

In the remaining 70 threads, the coders found three other ways in which the phrase "See your doctor" was used. 37 cases showed moderators urging initiators to see their providers because the medical problem was a serious one to be checked out immediately. 26 cases showed moderators explaining initiators how to communicate with their providers. 7 cases showed moderators informing when initiators should call their providers. Compared to SeeDoc posts, these other cases were more inviting for the initiators and encouraged the community to provide useful information around the clinical question.

### Research questions and analysis methods

Using inductive coding [35], the coders qualitatively examined the whole thread of those 39 SeeDoc threads, including the thread initiating posts and replies to the thread, 186 posts in total. My goal was to answer three research questions: (1) In what contexts do moderators redirect initiators by asking clinical questions to see their providers? (2) How do other community members work with moderators and initiators in this context? (3) How do moderators redirecting initiators to see providers relate to the initiators' and other community members' participation with the community?

In addition to (1) and (2) requiring qualitative analysis, I added (3) to gain objective measure of community participation related to Seedoc threads as a supplement to my main questions of (1) and (2). To further understand (3), I quantitatively examined: (a) how often initiators replied back to the thread; (b) how many replies followed after the moderator's SeeDoc post; and (c) how often initiators returned to the community after receiving the SeeDoc posts. I descriptively compared (a), (b) and (c) with the rest of the cases where initiators received moderators' first replies in general using Wilcoxon Rank Sum test because the data were not normally distributed.

Next, I will talk about what sorts of problems initiators brought to the community in the case of SeeDoc threads. As I introduce initiators' posts, I will give context around how the community and the moderator responded to the post. I will then examine more in depth the kinds of help that the community provided before and after the moderator's SeeDoc post and how the initiators interacted with them. Lastly, I will quantitatively examine what potential relationship there might be between SeeDoc threads and initiators and other community members' participation with the community.

## INITIATORS' POSTS: WHEN DID INITIATORS GET THE "SEE YOUR DOCTOR" RESPONSES?

In this section, I will describe the kinds of questions SeeDoc thread initiators asked in the community and the context of how they were followed up by the moderator and the community members.

### Initiators asked for clinical expertise

Initiators did ask specific questions that needed someone with clinical expertise to respond to. Initiators asked whether the symptoms they were experiencing were related to the medications they were taking, whether the symptoms they were experiencing was something they should be worried about, which medications to take, and what should be done for the severe medical problem they were having at the moment.

For instance, one initiator asked whether the pain on the side of his torso and vomiting episode was related to Byetta he started taking:

I was diagnosed with type 2 diabetes approx. 3 years ago. I am currently taking byetta 10mg 2x day & 2000 mg of metformin. In the last week I have noticed a hard area on my right side as well as vomiting and diarrhea. Could this be complications from the byetta.

To this post, the moderator responded with a typical SeeDoc post:

There is no way for us to diagnose over the Internet. You need to see your doctor.

And then another community member responded with more detail what the problem could be while emphasizing why the initiator should go see his doctor:

This could be a complication of BOTH byetta and metformin. HOWEVER... you need to report this to your doctor and see what he says about it. But the hard area I don't believe is one of the side effects of either unless you are talking about injection sites... If it is the injection site that you are talking about.. make sure you alternate where you inject. But you really should be seen by your doc.

This community member's post nicely assisted the moderator's SeeDoc post with why the problem is something that the community cannot answer—that we do not know the answer to the symptom unless the initiator gets checked out by a medical professional. More importantly, the member was giving tips for insulin injection sites that could avoid potential hardening of skin, which might have been the cause of pain.

In two other instances, initiators replied to the thread to report they saw the doctor after getting the response to go see the doctor. Here, the SeeDoc posts indeed motivated some initiators to see their providers. From their providers, the initiators received answers to their medical problems or they were able to change the dosage of the medication to solve the problem they were having.

In most cases, however, the initiators already had seen or were planning on seeing their providers by the time they initiated the thread. Even though initiators did not explicitly say

they have seen their providers in the initiating post, when I examined the returning replies of the initiators (which was only 11 out of 39 threads), 9 of the 11 clarified they already had seen the doctor or have doctor's appointment.

### **Initiators' providers confirmed they do not have medical problems, but initiators wanted more knowledge**

Initiators either did not feel it was an "ER call," which refers to calling an emergency room, or their doctors have already told them that there were no problems with their health. For both of these cases, the initiators were not diagnosed with diabetes, but they have been having symptoms that were unusual, such as feeling "woozy" after eating food, have "low blood sugar occasionally," or their fasting blood sugar was high. This initiator who monitored blood sugar only started to do so because he had a strong family history of diabetes. A few months ago, his doctor had confirmed he did not have diabetes. Thus, this initiator needed more information than his status with diabetes— why he has been having such symptoms and blood sugar levels even though he did not have diabetes. To his post, the moderator replied and told him to see a doctor because the community cannot make any diagnosis:

It sounds like time to see your doctor. We are here to support you, but no one can diagnose over the Internet. This article contains more information on Diagnosis of Diabetes and Pre-Diabetes.

To this standard moderator's SeeDoc post, the initiator responded again clarifying that he was not looking for a diagnosis but was seeking knowledge, which he expressed as his understanding of the purpose of WebMD:

Obviously I didn't make my question clear.... First and foremost, I am NOT looking for a diagnosis, I am simply seeking knowledge and that is what I understand to be the purpose of WebMD. I'll rephrase my question as follows: Is it unusual for fasting levels to be elevated, yet to see otherwise normally acceptable levels throughout the day.

To this reply, the moderator again responded with more detailed information on what factors could lead to high fasting blood sugar and again stressed that he should see his doctor. The initiator did not respond again, but three other community members shared their personal experiences around how to measure fasting blood sugar correctly and when they tend to have unusually high reading of fasting blood sugar according to their own experiences.

This thread shows a typical problem that SeeDoc posts might have in online health communities. At least in this thread, the initiator responded back to the moderator and clarified the purpose of his post—not wanting a diagnosis but peer-knowledge—and ended up getting informative responses from both the moderator and other community members. However, if the initiator did not clarify, the thread could have been left with the moderator defining the initiator's post as a diagnosis question and potentially ended without further helpful responses from the community.



### **Initiators already have a doctors' appointment scheduled but need somebody to talk with them about it**

Initiators knew they needed to see a doctor and had an appointment set up in the upcoming few weeks. However, they either wanted to get more community feedback on the problems they were concerned with or they asked how sick should they be before they call the emergency room instead of waiting for the appointment.

For instance, one initiator wanted to know why he was having certain symptoms, such as shaky hands, feeling light-headed, or always feeling hungry. He had an appointment scheduled in a few weeks with an endocrinologist. He described his health history and symptoms at length and what food makes the symptoms worse or better. However, he did not receive any replies for three days and received only one response from the moderator:

Your symptoms [can come from] a number of health conditions. The best way to find the reason is to see your doctor. Unfortunately, it is impossible for any of us to diagnose over the internet. Even your own doctor could not tell what the problem is without lab work. The Symptom Checker might help you organize your thoughts for your doctor. You also may want to keep a food/symptom journal until your appointment. Let us know what your doctor has to say.

The thread ended this way without any further responses.

### **The problem was beyond setting up a doctor's appointment**

The problem was not whether initiators should see their providers or are attempting to get a diagnosis, but they wanted to get second opinions about the solution they received from their providers.

For instance, an initiator replied and clarified that she was concerned whether she will be "ok" until the appointment and wanted further information on what to prepare for the appointment:

Have an appointment scheduled all the way on the 20th of next month. Hopefully I'll be ok in that time? I have to fast for the test right?

When the initiators responded back to their own threads, a prevalent response was that they already talked or will talk to their providers. The initiators had intentions that were beyond getting answers to their medical problems—such as preparing for their appointment, getting second opinions about what their doctors have told them, or wondering whether to see a specialist since they were not satisfied with what their doctors have told them. One initiator had symptoms similar to heart palpitations but the initiator's doctor had told him it was stress related. The initiator came back from the appointment without any diagnosis or treatment while still having the worrisome symptoms. Thus, the initiator posted to get more help from the community. Instead, the initiator only received the SeeDoc post and no other community members chimed in.

### Initiators wanted other patients' personal experience and second opinion

Other initiators explicitly asked for personal experience and opinions from the community members about their medical problems. Still, the moderator responded with a SeeDoc post.

For instance, an initiator was recently told by her doctor that her body started rejecting her insulin due to many complications she had. She wanted to hear whether others had similar problems who could share any second opinions. She also asked whether she would be qualified for social security disability benefits:

... THE DRS ARE NOW THINKING THAT SINCE I HAVE HAD HCV AND CELIAC SPRUE THAT MY BODY TENDS TO REJECT THE INSULIN DUE TO AUTOIMMUNE. DOES ANYONE ELSE HAVE THIS PROBLEM? ALSO SINCE OBVIOUSLY I CANT WORK LIKE THIS WOULD I QUALIFY FOR ssd?  
[sic]

To this post, the moderator responded and told the initiator to talk to her doctor and lawyer about the qualification of the benefits. Two other community members replied afterwards to inform the initiator to talk to an endocrinologist to change the dosage of the insulin or consult changing medications. It was unclear whether the advice of the community members came from those who also have HCV and Celiac sprue, and the initiator ended up not getting a second opinion on her issue. It would also have been helpful if somebody with the disability benefit responded and gave her tips for what process is involved in talking to lawyers or doctors about being qualified for the disability benefits. However, such interaction did not happen in this thread either.

### Initiators had concerns in seeing the doctors

Initiators had reasons for not wanting to call their doctors. One initiator asked for help because he was afraid seeing the doctor would “end up in either an appointment or buying meds [costing extra money that I do not have]” and another 13-year old teenager said he was “afraid of needles.” In both cases, after the moderator told the initiators to see their doctors instead, other community members gave the initiators convincing explanations for why their concerns are not something to be worried about.

For instance, the first initiator lost a sliding scale for his insulin, which helps him determine how much insulin to take depending on the food he eats. The initiator was afraid that calling his doctor will cost him money to set up an appointment or had to buy another medication. To this post, the moderator responded that the community cannot help with how much insulin he should take but he should call his doctor to get the sliding scale again. Another community member clarified that there will not be any additional charges for getting a new sliding scale and explained how to talk to the clinic about it.

This case showed how other community members can add helpful clarifications to why seeing the doctor makes sense to the initiators, when the moderator's SeeDoc posts on its own cannot fully clarify the initiators about their concerns.

### **Summary: The initiators needed something more than “See your doctor”**

The topics of initiators’ posts mostly included clinically related questions that the initiators should get answers from their providers instead. However, the findings showed various reasons initiators wanted to talk to the community instead of their own providers. The initiators already had seen their providers about the problem or had a doctor’s appointment set up unlike what the moderator had assumed. The initiators needed more information, such as what the community members were giving to the initiators. Still, moderators responded with SeeDoc posts to these initiator posts. Some were because the moderators did not have a full understanding of the initiators’ context.

### **THE COMMUNITY’S WORK AROUND “SEE YOUR DOCTOR”**

In this section, I will further examine the posts that were posted before and after the moderator’s SeeDoc posts to understand how other community members interacted with the initiators and the moderator.

On average, the moderator’s first replies in SeeDoc threads were positioned 1.9<sup>th</sup> (Median: 1st) out of 3.8 replies (Median: 2.0 replies). There were 1.6 other unique members replying per thread on average (Median: 1 member), where 1.9 unique members (Median: 1 member) on average replied after the moderator’s SeeDoc post among those threads that had replies following the moderator’s SeeDoc post (54% of the SeeDoc threads). Below I describe what these 1.6 unique community members said in the thread before and after the SeeDoc posts.

#### **Encouraged initiators to see their doctors**

Medical professionals fear misinformation being shared among community members [20]. Contrary to their worries, even before the moderator told the initiators to see their doctors, the community members clarified with the initiators that “none of us can diagnose this” and urged the initiators to see their providers just “for the peace of mind.” Also, the members provided their own experiences around similar medical problems where visiting a doctor prevented what could have been a severe problem.

Similarly, after the moderator’s SeeDoc posts, community members supported the moderator and encouraged the initiators to see their doctors by explaining that it will help the initiators let go of their concerns:

A very simple blood test will confirm or dispel any thoughts that you have about this. Go to your doctor.

Some missed the initiator’s reply that the initiator has set up a doctor’s appointment thanks to the community and continued to urge the initiator to see his doctor because “we care about your health and life”:

Stacy, are you just funin’ us? Or maybe you are just playing a game of “yeah but” YEAH you hear us BUT you aren’t intending to pay any attention. This is not a game. We really care about you and your health and life and the life of your unborn baby. Do you care enough about yourself to make that doctor’s appointment?

### Discussed medical information

Community members discussed possible phenomenon or symptoms that the initiators might be experiencing, which the initiators could clarify with their doctors. For instance, a member explained what the initiator could potentially be experiencing, called Dawn Phenomenon, which the initiator could ask his doctor about:

There is something called the Dawn Phenomenon which is stronger in some people than in others. Your body (through the liver) releases glucose early in the morning to help your body prepare for the stresses of the day. This is possibly what is happening. If your A1C and post prandial levels are ok and you maintain contact with your physician...

Similar to this member, I saw that the community members emphasized initiators should continue to communicate with their providers about the issue.

### Supplemented discussion with personal experience and tips

The strength of online health communities that a clinical environment cannot provide is peer-patients' similar experiences and their everyday coping strategies in various aspects of managing illness. Examples range from saving money to finding ways to communicate with their providers. Community members added after SeeDoc posts what they personally experienced around a similar issue and provided useful tips, making the SeeDoc thread useful.

For instance, community members added to the moderator's SeeDoc posts how to talk to the providers. One community member explained how to talk with a doctor who is a "one-word answerer" and what kinds of doctors to choose:

Hi, [Jim], When you ask your doctor about this, make sure you ask him why this warning is on the package. It may be that using both insulin & Januvia might cause lows in some people but make sure he explains it to you thoroughly. My first doctor was a "one--word answerer" & that wasn't any help at all so I changed doctors. My new doctor spent one hour talking & answering my questions in detail before any lab work. That's the type of doctor you want—not one who can't wait to get you out of his office.

### Summary: Community members' active roles in medical questions

Community members attempted to actively help with topics sensitive to medical liability issues when they can. The members rarely attempted to share uncensored medical advice. Perhaps the moderator explicitly attempting to prevent any medical advice sharing might have been why other community members were not providing what could have been misinformation. However, the members provided distinct support compared with the moderator in the cases of SeeDoc threads—to help initiators communicate better with their providers, give convincing reasons for why talking to providers can be helpful, and share similar experiences that can help initiators to not feel alone.

## QUANTITATIVE ANALYSIS: “SEE YOUR DOCTOR” POSTS AND COMMUNITY PARTICIPATION

In this section, I will examine how the moderator’s SeeDoc posts can potentially be associated with initiators’ and community members’ participation with the community. To do this, I examined three things: the rate of initiators returning to the thread, the number of following replies after the SeeDoc post, and the rate of initiators returning to the community in general after having experienced the SeeDoc threads.

In examining these three phenomena, I compared SeeDoc threads’ results with those of *Other threads*, meaning all of patient initiated threads from the community where moderators have replied to the initiators, excluding the SeeDoc threads. A *moderator’s first post* refers to the first moderator post per thread. All SeeDoc posts were moderators’ first posts.

### How often initiators replied back to the thread?

Our findings showed that initiators tended not to reply back to threads in general, not just in SeeDoc threads. In SeeDoc threads, initiators on average replied 0.5 times back to their own threads (including before the SeeDoc posts), where only 11 out of 39 (28%) initiators replied after the moderator’s SeeDoc post. For Other threads, on average initiators replied back to their own threads 1.4 times, where 631 out of 1591 (40%) replied after a moderator’s first reply. Using Wilcoxon Rank Sum test, the difference between SeeDoc and Other threads on the initiators’ rates of replying back to the thread after moderators’ first reply was not significant ( $W = 27470.5$ ,  $p = 0.1482$ ).

### Did conversations end after the SeeDoc post?

I found that SeeDoc posts tended to stop conversations compared to moderators’ other first posts in general. On average, 18 out of 39 (46%) SeeDoc threads ended right after the moderator’s SeeDoc post. 450 out of 1591 (28%) Other threads ended right after a moderator’s first post. The difference in the number of following replies after moderators’ posts was significant between SeeDoc and Other threads when tested using Wilcoxon Rank Sum test ( $W = 21192$ ,  $p < 0.001$ ). I note that this result should not be interpreted as SeeDoc post cutting conversations, since the topic matter of the thread involved in SeeDoc threads versus Other threads might matter more than the SeeDoc post itself. Still, there is a strong association between SeeDoc posts and the number of replies that follow.

### How much initiators return to the community after receiving the SeeDoc posts?

I found that initiators tended not to come back to the community in general (by the time the data collection ended, which was February 2014), not just in SeeDoc threads. 82% of the initiators in the SeeDoc threads (31 out of 38 unique initiators) did not post again in the community after receiving the moderator’s SeeDoc post. Among the eight returning initiators, two initiators have already been active before they received the “See your doctor” post, and they continued to post 496 and 58 posts after experiencing the SeeDoc thread. Half of the returning initiators posted only once after the SeeDoc thread experience. The remaining two initiators posted two and three times after the SeeDoc thread.

Similarly, 76% initiators in Other threads (601 out of 793 unique initiators) did not post again in the community after receiving moderators' first replies. 9% of the returning initiators from Other threads participated once after receiving moderators' first replies. The Wilcoxon Rank Sum test showed no significant differences between the initiators who experienced SeeDoc threads and moderators' general responses in how often they participated in the community afterwards ( $W = 15679$ ,  $p = 0.5724$ ).

When looking at the general activity of the community, out of 5,213 total users, 3,290 users (63%) did not return after their first post in the community. 16% (853 users) of those who returned posted only once more.

This last finding further highlighted the prevalence of the lack of continuous participation throughout the community, following the typical long-tail distribution of community participation and the challenges of patients' sustained participation with online health communities.

In summary, SeeDoc posts were strongly associated with ceased community conversations, and patient participation with community was generally unsustainable.

## DISCUSSION

I first discuss how my work connects back to the previous literature on online health communities, particularly around the roles of peer patients and moderators in dealing with clinical questions. I then turn to how findings translate to practical implications for the CSCW community.

### What is really harmful in managing clinical questions in online health communities

Despite the increasing evidence that online health communities help with managing illness psychosocially [5,13,16,33], concerns toward misinformation being shared among peer-patients are common [20]. To emphasize the importance of peer-patient interaction, previous work illustrated what distinctive expertise patients can provide [15] compared to the medical expertise that health professionals provide to patients.

Studies emphasizing the importance of peer patient expertise, however, focused on non-clinical information that patients share. On the other hand, in this study, I focused on investigating how clinically oriented problems, not just psychosocial problems, were being moderated in an online community setting, and, more importantly, how peer patients helped with those clinically oriented problems. Peer patients helped to supplement information closely linked to their daily experiences and coping strategies and advised peers how to communicate with providers and motivated each other to talk to the providers as necessary.

Our results aligned closely with a survey result on online diagnosers [10]. The respondents in the survey stated that they did not visit a clinician to get a professional opinion (35%), medical professionals confirmed their diagnosis performed online (41%), or the respondents could not agree with the clinicians' suggestion (18%). Although my analysis showed that the primary purpose of the initiators was not online diagnosis, my results uncovered the process

by which online diagnosers could potentially get help from others in online community settings.

Still, I should not be concerned with the phenomenon that people look for clinical answers from online communities. My findings directly challenge the prevalent position of the medical community on what is considered harmful and helpful. My findings challenged the notion that clinical information shared by peer patients can be harmful and that peer patient help should be confined to non-clinical information. This finding is in line with Smithson et al [34]'s work where self-harm community members reciprocally provided “mundane” advice to go see health professionals and sought support with one another, reverting assumptions that online communities would promote self-harm. Also, my findings challenged the current practice of online communities, which relies on content moderation for quality control. Moderators posted Seedoc posts with good intentions, but it could lead to harmful results, hindering healthy community dynamic, as shown from the number of follow up replies in Seedoc threads. Liao et al [22]'s work supports this finding, where they showed, depending on the community culture, the tightness of governance should be adjusted.

No literature has looked specifically at how moderators and community members work together to address clinical questions. I showed how community members supplemented with information that moderators overlooked to share with patients. Accordingly, patients were able to get the benefits of both sides—information coming from patients and moderators.

Below, I discuss how the CSCW community can help patients and moderators take roles in online health communities in addressing clinical questions.

### **Moderators should focus on the inviting role rather than the governing role**

When people schedule an appointment due to concerns with their health, there are no other options to talk to their providers than to wait until the appointment, which usually takes from a few days to a few weeks. During that time, people can feel anxious and want to gain as much information as possible. The community was an outlet for them to fulfill this need. However, moderators' SeeDoc posts can potentially hinder this process of getting help and support from peers by making a conclusion to the thread that the only solution to the problem is to see their doctors.

Rather than a governing role, moderators should play an inviting role, even in circumstances where patients might be asking for answers that the community cannot answer. Moderators should respond to clinical questions as I observed in other cases of where “See your doctor” phrases occurred, such as helping patients to communicate with providers and informing them about when to call an emergency room. Furthermore, calling out other members who have similar experiences to share how they worked with their providers or what the process was like—any additional information regarding similar situation—can help initiators to feel welcome and not alone and direct them to make better decisions.

Depending on the culture of the community and the purpose of each thread, however, strict governance might be necessary. Liao et al [22] explained how properties of communities determine how tight governance should be. Content-centric communities, such as Flickr, tend to impose tighter management control, whereas social networking sites emphasize social transparency and self-governance to accommodate members' goals in community participation. In the case of Seedoc threads, I observed a mix of both content-centric culture (sharing resources around clinical questions) and social networking purpose (sharing social support among community members). While the quality of information they collect is critical and might need strict regulation, I saw collectively gathering socially supportive comments as effective in getting a message across. An example includes the case of community members being more successful than the moderator in convincing the asker to go see the doctor. Accordingly, some mix of appropriate governing and inviting roles should help, depending on how content-centric the community is.

### **The real value of online health communities that providers cannot provide**

The literature discussed community members' roles as focusing on psychosocial support, primarily in response to non-clinical questions. Community members' participation with SeeDoc threads demonstrated value in what peer-patients from the community could offer even in the cases of patients asking for clinical information, not just in non-clinical domains. Community members did not try to diagnose or give medical consultation. The initiators did not expect the community to answer their questions as their doctors would. Rather, the initiators wanted to see whether others had similar experiences and what they did to overcome the situation.

On the other hand, I did see cases where the initiator came back to the thread after talking with their doctors, asking questions that could have been consulted with their doctors. Literature shows the lack of communication between patients and providers. On average, patients in the U.S. spend 20 minutes with their providers [4], but depending on the purpose, it could last as short as 5 minutes [7]. During that time, it is difficult to remember all the questions they had and ask follow up questions [21], and even though they have questions later on, the process by which they get the answer is tedious, such as a long wait on the phone or waiting to get a call back. Studies demonstrated that the majority of online health information seekers benefited in changing their health behavior, learning something new that was useful, and their search has affected the way they decide treatments and care [11,30].

The community should not be an alternative place to get clinical expertise, but it can be a place where community members can help each other learn how to manage communicating with their providers and motivate positive behavioral change towards better health. Research shows the strong persuasiveness of self-referencing, involving communicators' personal experiences [19,29]. Peer patients' advice and suggestions coupled with personal experiences can have a big impact on patients. The initiators needed peers' similar experiences around the clinical problem and how they coped with the problem.



## Supporting the gray space between online diagnosis and community help

A gray space exists between what the community cannot do and what the community is supposed to do. The former being diagnoses or prescribing dosage of medication, which only providers are legally allowed to do. The latter—what the community is supposed to do—refers to the canonical role of online communities known in the literature—social support, including emotional, informational, tangible, and companionship support [6]. However, I saw that communities can offer help around clinically oriented problems coupled with personal experience and coping strategies. Moderators should be facilitating that process, instead of building boundaries for what an online community could or could not do.

Here are some implications for the CSCW community in supporting online communities to address this gray space:

- The challenges emerge when the community attempts to directly answer questions such as “Do I have diabetes?” Such questions should be considered as a starting point of discussion instead of responding based on the assumption that the forum is a Q&A site. For instance, the moderators or system features can highlight the topic being mentioned in the question. The community can talk further about what they experienced around the symptoms and share personalized knowledge around them.
- It is hard to know what initiators’ status in communicating with their providers is. We can help initiators share status with their providers, either through members’ follow up questions or the system pushing cascades of questions to reveal patients’ context.
- Showing guidelines in the new post submission screen for how to get supportive answers depending on the initiator’s purpose would help initiators better formulate initiating posts.
- SeeDoc posts can be portrayed as template responses. A system can help moderators include individualized advice or questions based on the context the initiator has provided. A system providing moderators with Webpage links or past conversations among peers related to keywords mentioned in the initiators’ posts can help moderators provide further helpful information.
- The persistent challenge of online communities in general is dealing with unanswered questions and lack of discussions. Notify community members with similar interests based on past posts to engage with the thread and facilitate sharing second opinions.

## CONCLUSION

Our study contributes to the online health community and CSCW literature in three ways: I challenged the existing notion of peer patients’ non-existent role around clinical questions; I demonstrated how shared roles among community members and moderators can provide benefits to discussing clinical questions; and finally I provided practical implications that the CSCW community can take away to help moderated online health communities better address clinical questions.

The quantitative analysis in this work was limited to descriptive, small-scale data. Compared to the overall size of the community, the proportion in which Seedoc threads occur is minimal. Thus, how important the effect that Seedoc threads have for the entire community is still unknown. However, the influence moderators have for the community could be bigger than that of regular members. For instance, moderator responded threads are weighted higher in featured threads. Also, in the case of WebMD, users see which threads were moderated, making users consider moderated threads as more special than unmoderated threads. Future work should address other factors, such as topic and similarity of posts together with Seedoc posting practices to see how these factors influence community dynamic. Furthermore, larger scale data beyond Seedoc threads can be harnessed through machine learning techniques, identifying moderators' posts that attempt to control conversations. Other disease communities should be examined to see how my findings theoretically generalize to other communities' cultures. I was not able to get in touch with the WebMD moderators to further understand what training they were given. I was informally aware of the fact that practices around Seedoc threads were similar across varying moderators. However, I did not systematically study all moderators' Seedoc threads. Future work should address how prevalent the Seedoc threads practices that I described in this paper exist in online health communities. The WebMD editing staff policy, however, states the following, illustrating that the moderator's Seedoc post practice I described in this paper is derived from the site-wide policy:

Be aware, however, that information on WebMD or any other web site should not be used as a substitute for professional healthcare. You should always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition [42].

The challenge here is how we can maneuver between medical liability and practical help. How do we facilitate peer patients to continue sharing content around unmet needs from their healthcare providers that peer patients could fulfill, such as how to choose care providers or how to communicate with physicians?

The preconception towards clinical advice sharing online should shift away from laymen discussing clinical materials as a taboo. We should rethink sharing medical information as something that a community together can actively help support one another.

Such paradigm shift applies to other domains where the validity of laymen knowledge becomes debatable, such as citizen science [1], fine arts [37], and education [39]. As social media provide large-scale platforms in which any lay person can participate and share knowledge, the constant battle for what is a valid information will continue to be present. How to manage content quality and to maximize benefits that communities of practice can offer will continue to be a reoccurring challenge for the CSCW community.

## ACKNOWLEDGMENTS

This work has been in part funded by NIH 1K01LM011980-01. I would like to thank the iCARE Lab and the BitLab, especially Katie Hoban, for their continuing support. I also thank Wanda Pratt, David McDonald, and Andrea Hartzler, who have been providing immense insights for this problem around moderator-patient relationships in online health communities.

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