“Where am I?” Finding Patients in the Process of Navigating a Complex Clinical Information Space

Tera L. Reynolds, MPH, MA;1 Emma McGregor, BSE;2 Kai Zheng, PhD1
1University of California, Irvine, CA; 2University of Michigan, Ann Arbor, MI

Abstract

As a central component of healthcare quality improvement efforts in the United States, patient participation in care has become increasingly common. However, along with the benefits, increased participation often requires significant patient effort – for example, to learn enough to be able to have productive discussions with their healthcare provider. Building upon our previous work, in which we identified online health forum posts containing users’ laboratory test results and preliminarily analyzed relevant posts, here we report the results of additional qualitative analyses. The goal of this paper is to propose initial characterizations of patient information and knowledge needs in different situations. These results will inform future work. Eventually, we hope that this line of research will offer insights that will improve patient-provider communication channels, especially those supported by healthcare technologies, as well as informal sources of support, so that they provide more personalized information that better meets patients’ needs.

Introduction

Healthcare in the United States, and beyond, has been shifting towards a patient-centered model in an effort to improve quality of care, as well as to decrease unnecessary healthcare spending.1 One of the central components of this model is empowering patients to be partners, along with their healthcare providers, in their health.2 This partnership often involves sharing responsibility for managing any health conditions and making healthcare decisions.3,4–6 While such patient participation offers patients more control over their health, it also tends to require a significant amount of patient work, such as learning to interpret one’s clinical data (e.g., laboratory results) or about the trade-offs in different treatment options.

As a result of this shift, and combined with evidence of decreasing levels of traditional healthcare supports – i.e., on average, fewer visits to healthcare professionals per year4 and less time per visit5 – the bulk of the process of navigating clinical information is taking place outside of formal healthcare settings (see our conceptualization of this process in Figure 1). In addition to healthcare providers, this process may include a variety of offline (e.g., friends/family) and online (e.g., medlineplus.gov) sources of social support. Today, more and more patients are choosing the latter. In fact, according to the last report from the Pew Research Center’s Health and Technology series, 72% of internet-using adults reported searching for online health information in the past year.6

While there may be benefits to using online sources of information to supplement traditional healthcare resources, such as ease of access7 and increased patient participation in care,8 there are also often inherent challenges to this patient work. These challenges can include finding information that satisfies the patient’s needs, assessing the quality of information discovered and, ultimately, making sense of this information so that it may be used in decision-making. For example, several studies have found that online health information seekers tend to have limited search skills (e.g., ask full questions).8–9 and do not review past the first two pages of results.8–9 This is particularly worrisome as Berland et al. discovered that, among fourteen search engines, only 20% of English and 12% of Spanish links in the first page of results lead to relevant webpages.9–10 These same researchers also studied 18 English-language and 7 Spanish-language health websites, and found that less than 50% of clinical elements on these sites were both entirely accurate and at least minimally covered.10 Finally, many patients have low health literacy, or limited “capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions;”11 thus, even if they are able to find relevant content, they may still struggle to understand the information. In addition, it has been suggested that those with low health literacy may be more susceptible to information overload.12 Information overload may contribute to some of the aforementioned issues (e.g., cause patients to accept lower quality information, incorrectly process information).13

Given these constraints and challenges, how can we better support patients as they navigate a complex clinical information space? To answer this question, we first need to “find,” or in other words observe, patients as they experience this process – as they encounter health information and knowledge needs and seek to fill these gaps. Our conceptualization of this process, presented in Figure 1, includes both offline and online resources where patients
may seek support. However, we focus on online sources because they are commonly used, and reach far more people than other types of communication. There are many types of online resources, but health forums (purple box in Figure 1) are particularly suited to generating insights into question formulation, and other upstream processes such as better understanding patients’ information and knowledge needs. This is because many online health forums offer a public platform for patients to provide and receive support, users ask full questions (as opposed to search terms), and users often include key medical and contextual information with these questions.

We have previously discussed the results of a qualitative content analysis of questions containing users’ laboratory test results, and the threaded replies, posted in an online health forum (MedHelp.org). This analysis revealed a typology of patient confusion about their clinical data, what patients were seeking and receiving from the online community, and key situational factors. In this paper, we take our analyses a step further to try to understand the types of information and knowledge patients need in different situations. We believe that this could enable healthcare organizations, as well as other types of health resources (e.g., online health forums), to provide more personalized information that better meets patients’ needs. Towards this end, we further analyzed the forum posts identified through our previous work, and report the results below.

**Methods**

Details on the dataset and identifying potentially relevant question posts – those containing questions about laboratory results that seem to be copied from a MedHelp user’s medical records and pasted into the forum (we refer to this as copied/pasted) – have been published elsewhere. However, briefly, the full dataset includes all MedHelp posts (> 2 million) and their threaded replies (> 8 million) as of September 2016. We developed an iterative, two-stage approach to retrieve potentially relevant posts in this dataset: (1) a keyword-based method, which aimed to identify a reproducible, unbiased set of potentially relevant question posts for the second stage; and (2) a natural language processing-based method to retrieve potentially relevant question posts without relying on keywords.

We took a random sample of 1,000 of the 64,922 questions posts identified as potentially relevant. Starting with the first question post in this sample, two researchers independently evaluated it for relevance – i.e., presence of the MedHelp user’s laboratory results. If the question post was relevant, both researchers independently analyzed it using inductive qualitative content analysis and grounded theory approaches. If the question post was deemed to be irrelevant, it was excluded. This procedure was repeated until no new categories/themes emerged (theoretical saturation). In total, 146 relevant question posts were analyzed as detailed below.

Figure 1. Working conceptualization of patients’ (blue outline) process of understanding complex clinical information. In this paper, we focus on the dark green paths – information and knowledge needs – and the purple target (health forums). The light green paths represent answers, which we analyzed in our previous work, and we will also study further in future research. Finally, the dotted line indicates that action does not always occur.
Specifically, the grounded theory approach to coding typically consists of an “open coding” phase and an “axial coding” phase, in which a single open coding category is selected as the “core phenomenon,” and then additional categories related to this phenomenon are identified. An inductive qualitative content analysis approach was taken to identify emerging categories during the initial, open coding phase. Due to the nature of the dataset, the coding naturally centered on MedHelp users’ information and knowledge needs (their questions), which were coded during this phase. The other overarching categories that emerged – including type of condition (e.g., thyroid-related), topic of question (e.g., management/treatment), requesting (e.g., opinion, personal experience), and situational factor (e.g., undiagnosed/diagnosed), as well as broad versus specific question formulation – naturally aligned with the types of categories typically identified through the axial coding phase of the grounded theory approach. For instance, the situational factors may contribute to the “causal conditions” (i.e., what caused the information need), and the “intervening conditions” (i.e., situational factors) that affect the actions taken as a result of the information need (i.e., “strategies”). In this case, the “strategies” include choosing the target of their question (in our case MedHelp), formulating the question, and what they are requesting. Figure 1 was developed through this coding process.

Additionally, the detailed questions asked in the posts were mapped to more general “underlying questions” (see Table 1). This coding aimed to identify the fundamental information need (underlying question), across different formulations of the question. Patterns emerged in these underlying questions, which may suggest challenges that patients experience in the process of understanding clinical information (underlying question themes).

Table 1. Underlying question themes and descriptions, underlying questions, and an example(s) detailed question.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Theme description</th>
<th>Underlying questions</th>
<th>Example(s) detailed question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessing risk</td>
<td>Understanding whether they are at risk or their level of risk.</td>
<td>Do I have [condition]?; Do I need to worry about this?</td>
<td>Am I at risk for [condition]?</td>
</tr>
<tr>
<td>Determining action</td>
<td>Determining what they can or should do.</td>
<td>What can I do [to find diagnosis]?; What should I do [diagnosis]?; What are my treatment options?; Why was this treatment recommended?; What option is right for me?; What questions should I ask?</td>
<td>What action should I take?; Would you recommend more testing [to identify cause]?; Is [side-effect of treatment] better than [current condition]?; What do I ask [doctor]?</td>
</tr>
<tr>
<td>Establishing location</td>
<td>Identifying the cause of their symptoms, abnormal test results, etc.</td>
<td>What caused this?; What is my diagnosis?; What is the explanation for this abnormal result/symptom/condition?</td>
<td>What is causing [condition/symptom(s)]?; What are the possible diagnoses?; Why is [laboratory value] [high/low]?</td>
</tr>
<tr>
<td>Identifying destination</td>
<td>Understanding the likely course of their disease.</td>
<td>What is my prognosis?</td>
<td>What are my chances of recovery?</td>
</tr>
<tr>
<td>Reading map</td>
<td>Interpreting their laboratory results.</td>
<td>What do my laboratory results mean?</td>
<td>Please explain my laboratory report(s).</td>
</tr>
</tbody>
</table>

Finally, “information journey” themes, also referred to as “question pattern” themes, emerged after mapping the broad versus specific formulation of each question in a given post. Posts with similar question patterns were grouped together. This process resulted in five themes, as summarized in Table 2.

The analysis team met weekly to discuss and merge category lists; all disagreements were resolved through discussion. Once these lists were finalized, one researcher recoded, as needed, so that the final codes were applied consistently to the sample. Finally, we looked at the relationships between variables for patterns that may characterize patients’ information and knowledge support needs in different situations.
Table 2. Summary of information journey, also referred to as question pattern, themes and descriptions.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lost</td>
<td>Only asks a broad question, possibly suggesting an earlier stage of knowledge or a point where they have exhausted their options along one path, and are searching for a new path(s).</td>
</tr>
<tr>
<td>Orienting</td>
<td>Asks a broad question, but also indicates that they have an existing idea or opinion. Often, they do not understand/trust their current information source(s), and are opening their line of inquiry back up.</td>
</tr>
<tr>
<td>Focused</td>
<td>Focused on a particular symptom, condition, or laboratory result, and are gathering information related to that focal point.</td>
</tr>
<tr>
<td>Flexible course</td>
<td>Focused on a particular laboratory result, condition, or symptom. These question posters are gathering information, but they are also checking or verifying a particular idea, hypothesis, or belief.</td>
</tr>
<tr>
<td>Directed</td>
<td>Have a starting point (idea, hypothesis, or belief), whether from their own experience or research, or from a knowledgeable friend/family member or a healthcare provider. However, they are open to other opinions, recommendations, or explanations.</td>
</tr>
</tbody>
</table>

Results

We considered a number of situational dimensions, including type of condition, but in this preliminary study clear patterns only emerged along two. We characterized patient states based on these two situational dimensions — whether the patient had (1) discussed their laboratory results with their physician (pre-/post- consultation), and (2) received a diagnosis. These two dimensions were identifiable in the majority of question posts. In this sample, question themes associated with being in undiagnosed and/or pre-consultation states were more often basic, foundational questions (although not necessarily easy to answer). These questions are usually essential to eventually finding answers and taking actions to improve one’s health. The question patterns of posts classified into these states also often included broader questions that provided all symptoms, laboratory results, and any other information the user deemed relevant, and then asked the community to return possible diagnoses or next steps. These posts tended not to single out a symptom or laboratory result, but be asking about the totality of their personal health information. If they did show specific concern for a given condition, symptom, or laboratory result (e.g., an out-of-range value), they usually asked questions meant to gather information (as opposed to confirming an idea, hypothesis, or belief). The opposite tended to be true of questions associated with being in diagnosed and post-consultation states. These results are summarized in Figure 2, and each state is further characterized in the following sections.

![Figure 2](image-url)

Figure 2. Preliminary summary of the processes (rectangle), topics (pill shape), and requests (circle) common in each state based on analyses of a sample of MedHelp question posts containing the user’s laboratory results. Thicker lines mean larger difference compared to the corresponding situational state.

**Undiagnosed State:** Perhaps unsurprisingly, those without a diagnosis tended to be focused on identifying the cause of their abnormal laboratory results and/or symptoms, and obtaining a diagnosis (establishing location theme). These posters were often requesting an opinion — i.e., for the community to take all of the information they provided, and suggest a diagnosis. Similarly, the theme assessing risk applied to patients having difficulty determining their level of risk with a particular laboratory result. These questions were equally likely to be asked
pre- and post-consultation, but were more commonly asked if the patient had not yet been diagnosed. Those in the undiagnosed state also tended to be in the pre-consultation state (and vice versa).

Posts made by patients without a diagnosis typically followed two question patterns. Some posts only included broad questions (e.g., “Where to turn from here?”), which we referred to as the lost question pattern. They did not indicate that they, or their doctor, had any hypothesis or idea of where they are (or where to go next). These patients could be at opposite ends of the information spectrum—some having exhausted the known possibilities and are now looking for new directions, while others are at the beginning of their journey and are looking for a starting point. On the other hand, some posts followed the orienting question pattern, which also includes a broad question(s), primarily about the cause/diagnosis, but the poster also has an existing idea or opinion. In other words, they seem to have some information, which could originate from a physician, friend/family, personal research, or elsewhere, but are also keeping their line of inquiry open by asking a general question as well.

**Pre-Consultation State:** Posts categorized as pre-consultation highlight a common workflow in health care: the physician orders a laboratory test(s) during a consultation, the patient gets the result(s) soon after the consultation (e.g., via mail, patient portal, telephone) and, depending on the results, a follow-up appointment may be scheduled. In other words, patients in this state seemed to have received their laboratory results outside of a healthcare visit, and were asking a question prior to discussing these results with their physician. Consequently, questions explicitly asking for an explanation of the laboratory results (reading map theme), and indicating general difficulties interpreting their results (e.g., “What does all this mean?”), tended to be more common. These posters often used language indicative of anxiety or distress, and requested emotional support/reassurance. In addition, questions about prognosis, referred to as the identifying destination theme, were also relatively common in pre-consultation posts.

As with the undiagnosed state, posts made by patients who had not yet discussed their results with their physician often followed two question patterns. The lost pattern (described above) was the most common. However, some posts contained questions focused on a particular condition, symptom, or laboratory result, but asked a general question about that specific item (focused exploring pattern). In other words, they had a narrow concern, but did not indicate that they had any hypotheses or ideas, most often, about the cause/diagnosis. In these cases, the person posting was usually missing key pieces of information (e.g., other tests that might be available and relevant).

**Diagnosed State:** Posts with a diagnosis tended to ask questions about treatment and/or their prognosis. They most often requested personal experiences from the community. In addition, patients in this state also tended to ask a specific question(s) to evaluate an idea or belief, but also asked a broader, more open question (flexible course pattern). In these cases, the patient may be less confident in their belief and, thus, explicitly invited alternative ideas.

**Post-Consultation State:** Questions associated with being in the post-consultation state tended to be action-oriented (determining action theme), and focused on either management/treatment or diagnosis. Posts in this state most often requested advice and generic information, possibly to inform their actions, from the community. They also tended to only ask specific questions that evaluated an idea, hypothesis, or belief (directed pattern). In other words, they seemed to be fairly confident in their idea, and were looking more for confirmation. This may be due to the fact that they had already discussed their laboratory results with their physician.

**Discussion and Conclusion**

Through our analyses of MedHelp question posts containing personal laboratory test results, we have preliminarily characterized patients’ information and knowledge needs, in terms of the level and type of support they may require, in different situational states. In other words, based on our analyses, we propose that two patients receiving results from the same laboratory test (e.g., thyroid panel) may have different support needs if, for example, one is in the diagnosed and the other undiagnosed state. On the other hand, two patients in the same situational states, but receiving results from different laboratory tests (e.g., thyroid versus liver panels) may require a similar level and type of support (although the content would likely be different).

This may be due to the relationship between the state and the level of uncertainty that the patient, and possibly the physician, is experiencing, which may in turn affect the type of support the patient needs (e.g., experiencing anxiety, and needs more emotional support). These states may also be related to the patient’s current level of knowledge. For example, while it likely depends on how long the patient has been living with the condition, someone with a diagnosis is likely to have at least basic information, which may help them with tasks such as processing their clinical data and information from their healthcare provider, evaluating information from other sources, developing ideas about why their test results are abnormal or the likely next steps. On the other hand, patients experiencing symptoms, especially those affecting their everyday life (e.g., “brain fog” making it difficult to focus), but that do
not have a diagnosis, may feel lost in the complex information space – like they do not know where they are or where to go. Patients in situational states associated with being lost, may need higher levels of support (e.g., more information and knowledge, more frequent support) – whether from their healthcare provider or supplementary sources such as patient peers in online health forums – to successfully navigate the complex clinical information and, ultimately, participate in their care.

The results of our follow-up studies, which will include larger samples, be more quantitative in nature, and involve additional types of clinical information (e.g., medications) and data sources (e.g., survey methods), could have implications for improving patient-provider communication channels, especially healthcare technologies (i.e., electronic health records and patient portals). Many healthcare technologies have elements that could be used to identify a patient’s situational states (e.g., problem lists, appointment dates/times), and personalize the type and level of information accordingly. Beyond traditional healthcare settings, the results of our follow-up studies could also have implications for informal sources of support such as by informing improvements to the information retrieval strategies of online health forums so that users can more easily find the content most relevant to them.

References