

Understanding Patient Information Needs about their Clinical Laboratory Results: A Study of Social Q&A Site

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Abstract

Clinical data, such as laboratory test results, is increasingly being made available to patients through patient portals. However, patients often have difficulties understanding and acting upon the clinical data presented in portals. As such, many turn to online resources to fill their knowledge gaps and obtain actionable advice. In this work, we present a content analysis of the questions posted in a major social Q&A site to characterize lay people's general information needs concerning laboratory test results and to inform the design of patient portals for supporting patients' understanding of clinical data. We identified 15 information needs related to laboratory test results, and clustered them under four themes: understanding the results of lab test, interpreting doctor's diagnosis, learning about lab tests, and consulting the next steps. We draw on our findings to discuss design opportunities for supporting the understanding of laboratory results.

Keywords:

Consumer Health Information, Information Seeking Behaviors, Patient Portals.

Introduction

Advances in personal health record technology, such as online patient portals, empower patients with easy and full access to their clinical data (e.g., laboratory results, radiology reports, and clinician notes) [0]. This access, in line with general interest in patient-centered care, has proven to foster patient engagement, enhance patient-provider communication, and ultimately, improve health outcomes [2]. These potential benefits, along with the financial incentives provided by the U.S. government [3] and the OpenNotes initiative [4], encourage healthcare organizations to increase patients' access to their clinical data via patient portals.

Among the many portal functionalities, access to laboratory test results is an area of high interest to patients; growing evidence suggests that patients are increasingly interested in timely and easy access to laboratory test results [5]. However, patients' current use of test result data is significantly limited due to several reasons [6]. For example, many portals present clinical data to patients in the same way as it is shown to healthcare providers, while patients may not have sufficient health literacy to process and understand the technical nature of the language (e.g., medical jargons) used in the laboratory test reports [7,8]. In addition, patients hope to find useful information, such as actionable knowledge, in online portals, rather than just reviewing the data [9,10]. These findings suggest that while healthcare organizations are increasing patients' access to their

clinical data via patient portals, this technology has not adequately met patients' information needs.

Therefore, patients often turn to online resources (e.g., search engines, health forums, and social media) to fill their knowledge gaps. In fact, a recent Pew Research Center study reported that over 70% of adult Internet users in the U.S. searched online for health information [11]. As one of the most popular activities online, health information searching has been the focus of many studies over the past decades [12]. However, to date, only a few studies have started looking into patients' online health information seeking behaviors in the context of understanding laboratory results. For example, Reynolds et al. [8] examined the type of supports patients need related to their laboratory data through analyzing questions in an online health forum (medhelp.org). In particular, they found that patients tend to ask questions pertaining to several topics: diagnosis, management/treatment, laboratory report, test, risk, and prognosis. Their study also preliminarily assessed the feasibility of identifying and characterizing the nature of patients' questions related to laboratory results. Building upon their work, we conducted an explorative study to gain further insights into patients' general information needs concerning laboratory test results.

In this paper, we analyzed the questions that users posted on a major social Q&A site, Yahoo! Answers. Among various online forums containing health communities, Yahoo! Answers allows patients to seek information through raising questions and receiving answers from others (e.g., peer patients, health professionals) who are willing to share their knowledge and opinions [13]. Unlike queries submitted to search engines, the questions posted on these platforms are expressed in natural language. These questions also tend to contain more contextual information, such as patients' medical histories and symptoms. Therefore, Yahoo! Answers is a good resource for examining lay people's health information needs [12,13]. As this study is exploratory in nature, we chose to focus on a specific chronic disease, i.e., diabetes, rather than many conditions. Diabetes is an ideal condition for us to investigate lay people's information needs regarding laboratory test results. That is, diabetes is recognized as one of the most important public health problems with escalating health concerns [14], requiring long-term management and regular laboratory tests. Addressing the barriers of understanding laboratory test results will benefit a broad population and the society at large. Furthermore, laboratory tests vary across different types of conditions and diseases. Thus, focusing on one condition allowed us to generate comprehensive search terms for data collection.

In this study, we began our inquiry by asking: What are lay people's information needs in making sense of their laboratory

test results? We identified 15 information needs related to laboratory test results, and clustered them under four themes: understanding the results of lab test, interpreting doctor’s diagnosis, learning about lab tests as a source of information, and consulting the next steps. This study highlights the need to address the gap between patient knowledge and limited contextual information presented on their lab reports.

Methods

Data Collection

Using the application program interface (API) of Yahoo! Answers, we collected a total of 58,422 questions in the diabetes category between 2009 and 2014. The questions were downloaded in a csv format to a MySQL database. We then extracted 8655 posts using keywords suggested by the guidelines and recommendations for laboratory analysis in the diagnosis and management of diabetes, such as HbA1c, glucose, and creatinine [15]. The complete search terms and the number of posts retrieved by each term are listed in Table 1. The terms “glucose” OR “blood sugar” yielded the most posts (87.1%). The study was approved by the institutional review boards at Pace University and Florida State University.

Table 1. Search terms and the number of retrieved posts.

| Search Terms | Number |
|---|--------|
| “lab” OR “laboratory” | 243 |
| “A1c” OR “HbA1c” OR “hemoglobin A1c” | 427 |
| “glucose” OR “blood sugar” | 7,536 |
| “blood pressure” OR “systolic” OR “diastolic” | 338 |
| “creatinine” | 111 |

Data Analysis

We generated a random sample of 1,619 posts of the potentially relevant question posts (8655 posts containing keywords). Then two researchers independently reviewed posts for relevance. Duplicate or irrelevant posts were discarded. The posts were determined to be irrelevant if they did not contain any laboratory results or questions related to laboratory tests. This screening resulted in 967 posts eligible for further analysis. The relevant posts were then transferred into NVivo, a program for organizing, storing, and manipulating qualitative data. The research team performed content analysis on these relevant posts. The analysis was performed independently by three researchers and consisted of multiple steps (Figure 1).

The first step was to iteratively develop a codebook using the open coding technique. Two coders, C1 and C2, independently analyzed 240 randomly sampled posts until saturation was reached. The initial list of codes was generated and then discussed in a group session to determine which codes to keep, merge, or remove. After the list of codes was set, we created a data dictionary defining each code to standardize the coding process. Our final coding scheme contained a total of 15 codes, which were clustered under four themes: understanding the results of lab test, interpreting doctor’s diagnosis, learning about lab tests as a source of information, and consulting the next step (see Table 2).

Next, a third coder (C3) coded 100 randomly sampled posts from the rest of the posts to check for exhaustiveness of the themes. Once confirming that the themes were comprehensive, C1 and C2 independently coded another set of 100 posts to check for inter-rater agreement using Cohen’s Kappa coefficient. The resulting kappa value was analyzed using the

kappa interpretation scale suggested by Landis and Koch [16]. The coders presented “Almost Perfect” agreement (kappa value of 0.851). The disagreements were mainly due to the interpretive differences attributed to “Confused about doctor’s suggestions or diagnosis” and “Seeking confirmation of doctor’s diagnosis” codes; all the disagreements were resolved through discussion. Once resolving all disagreements, C1 and C2 coded the rest of the posts to conclude the analysis.

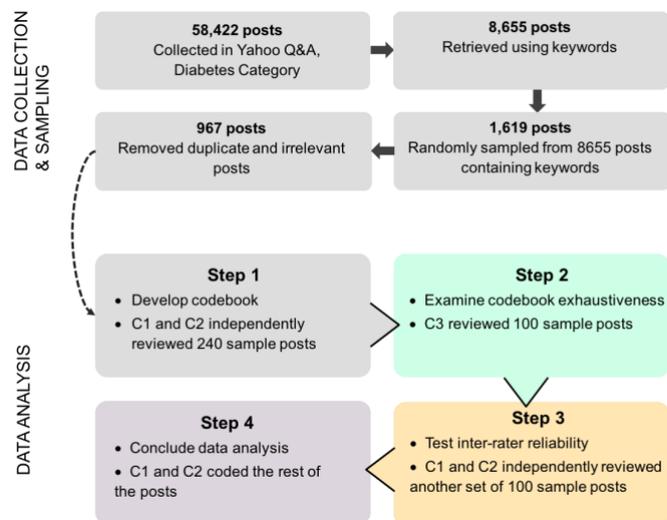


Figure 1– Data Collection, Sampling, and Analysis Process

Results

People come to Yahoo! Q&A to request advice, suggestions, information pertaining to laboratory test results. Their information needs are multi-faceted, manifested in their multiple different but related questions. In this section, we will describe these information needs that people expressed in the questions. We will use representative quotes to illustrate the salient themes.

Understanding the Results of Lab Test

Requests for understanding laboratory test results were by far the most common in this sample (85% of the total posts). That is, posters shared parts of the report content and asked the community to explain their lab test results. As Table 2 shows, posters needed help in understanding different aspects of their lab content, including the meaning of lab value, specific terminology, and the effects and causes of abnormal and/or inconsistent results.

The most common questions in this category were related to understanding the meaning of lab values (74% of the total posts). We found that people had different needs in making sense of their lab results, which may be due to different levels of health literacy, knowledge and experience [17]. For example, a post sought a clarification whether a specific lab value falls into the normal range: “Is GFR of 73 and creatinine 1.1 normal?” In other cases, posters often asked the community for diagnosis or opinions, by providing substantial portions of their reports and relevant medical history, medication information, and symptoms. For example, a post sought opinions on what the lab results indicated:

“I am an 18-year-old male. [...] Some of the statistics from the report were as follows: high alkaline phosphatase levels, elevated T3, elevated Hbg levels. [...] My AbC1 level was 6.1. What do these elevated levels seem to point to? Can anyone make sense of what might be wrong from my lab results?”

Posters also requested explanation of technical jargon, i.e., terminology. For example, a post asked for the clarification of a specific term: “Does anyone know what is the meaning of ‘Lymph’ on blood labs?” This observation suggests that people have difficulty understanding medical terminologies, even though some patient portals have started implementing consumer-friendly vocabularies [18].

Finally, people wanted to know the effects and/or causes of abnormal lab results. For example, a post asked for advice on the consequences of high creatinine level: “A recent pathology test states that my creatinine is 6.28. [...] What are the effects of such high levels?” In other cases, people expressed concerns about inconsistent lab results they received from different laboratories or over a period of time, as one post stated: “My creatinine level increased from 1.0 to 1.1 with a span of 10 days’ period. What is the reason?”

Table 2. Summary of themes. Some posts fell into multiple themes, so percentages add up to more than 100%.

| Theme | % (n) |
|--|-------------|
| Understanding the results of lab test | |
| Meaning of lab value | 74.3% (418) |
| Specific terminology | 1.7% (9) |
| The effect of abnormal/inconsistent results | 1.1% (6) |
| The cause of abnormal/inconsistent results | 7.3% (41) |
| Interpreting doctor’s diagnosis | |
| Confused about doctor’s suggestions/diagnosis | 1.6% (9) |
| Seeking confirmation of doctor’s diagnosis | 4.6% (26) |
| Concerned about doctor’s misdiagnosis | 0.7% (4) |
| Learning about lab tests as a source of information | |
| Inquire information about a specific lab test | 34.1% (192) |
| Ask for lab test recommendations | 1.2% (7) |
| Look for comparison among tests | 1.6% (9) |
| Concerned about lab procedure | 2.1% (12) |
| Consulting the next steps | |
| Healthcare consultation | 27.7% (156) |
| Treatment options | 4.1% (23) |
| Taking medication | 4.1% (23) |
| Life-style | 21.3% (120) |

* The percentages are calculated using the number of posts in each category divided by the total number of posts (N=967).

Interpreting Doctor’s Diagnosis

Sometimes people posted questions after they discussed the results with their physicians and cited several reasons for doing this. First, people may have doubts about, disagree with, or mistrust their physician’s diagnosis, thus seeking a second opinion on their physician’s conclusions and/or interpretations (referred to as *seeking confirmation of doctor’s diagnosis* in Table 2). For example, in one post the person stated:

“My 4-year-old [child] had all the symptoms and signs of type 1 diabetes so his doctor run test for him. What came back was Glucose, Blood 71, Insulin, Fasting 1.2, Low, C Peptide 0.4

Low. Doctor says there are a few low things, but nothing to worry about. I in my gut don’t think that is right. Can someone else help me out?”

Second, people seemed to be confused about their physician’s diagnosis or suggestions as to what to do next and whether or not the treatment is needed. Therefore, they turned to online forums to seek clarification or explanation regarding the information they received from their physician: “Why do I need to test my creatinine level every three months as being suggested by my doctor?”

Lastly, a few posters talked about perceived misdiagnosis by their physicians. Often the language used by these patients indicated some level of distress, fear, or other negative emotions. In one post, for example, the poster wrote: “My wife’s doctor, at a prominent San Diego hospital, failed to notice her declining kidney function until she was in end stage kidney failure. [...] Is it common for physicians to ignore kidney function and obsess over diabetes labs?”

These findings reveal a communication gap between health care providers and consumers. Misunderstanding or confusion about doctor’s diagnosis may adversely affect patients’ access to health information, resulting in poor patient understanding, trust, and satisfaction.

Learning about Lab Tests as a Source of Information

This category concerns questions related to lab test itself. For example, lack of sufficient knowledge about lab tests led people to inquire general information about them (referred to as *inquire information about a specific test* in Table 2), as shown in one post: “What is creatinine cholesterol?” In other cases, people asked for some other general information about lab tests, including relationship between lab tests and symptoms (e.g., *why are urea and creatinine levels raised with dehydration?*), how often taking a specific lab test (e.g., *how often should creatinine and eGFR levels be checked?*), and treatment options (e.g., *my creatinine is 1.6, what is the treatment for it?*).

People also inquired about the diagnostic abilities of a specific test and sought recommendations on which lab test to take (referred to as *ask for lab test recommendations* in Table 2). As this data sample focused on a diabetes online community, the questions therefore were related to lab recommendations for diabetes: “Which laboratory test is diagnostic for diabetes?” Similarly, people also sought comparison among different types of test (referred to as *look for comparison among tests* in Table 2): “Advantages and disadvantages of creatinine clearance test vs. plasma creatinine?”

Lastly, posters asked questions about the lab procedure. Sometimes, they posted questions while they were waiting for the tests. At this stage, posters asked questions concerning various aspects of the lab procedure, such as what they will go through during the test: “I am going to the lab to get tested for hypoglycemia (low blood sugar) tomorrow, what exactly will they do?” Others looked for information as to what they should do or not do to prepare for the upcoming tests: “This is a lab test for diabetes, blood sugar, cholesterol etc. And I am wondering how long should I fast and can I drink water?” Similarly, people also posted questions after taking their tests to inquire the turnaround time of their test results: “How long should it take for a doctor office to call you about lab results?” These posts tended to exhibit language indicative of distress: “I had lab work done last Thursday and I am still waiting to hear what my A1C and all else [the doctor] had me tested for. Shouldn’t they call you with results sooner? What if something is really wrong?”

Consulting the Next Steps

Sometimes people also consulted the community about what they should be doing next. One reason was that people may be waiting for an appointment to discuss the results with their physician, but they wanted to obtain actionable suggestions from the online community first: *“I have lupus [and] my routine blood work shows the ck enzyme at 271 (ref range is 26-192). I have an upcoming doctor appoint. What can I do?”*

They also asked for the community’s assistance in assessing the need for a healthcare consultation or further lab test (referred to as *healthcare consultation* in Table 2). For instance, a poster expressed the lack of confidence in the accuracy of lab results and asked for advice as to if it is necessary to re-do the test or take a different test: *“High blood sugar – should I get a second opinion from a different lab? This is too important not to double check with a different lab; last reading was 6.4. This doctor was wrong before about different things.”*

Of these posts, people also asked for treatment advice (referred to as *treatment options* in Table 2). For example, one poster wrote: *“A recent pathology test states that my creatinine is 6.28. Does it require dialysis to be done? What can cure this high level?”* In such cases, people also wanted to know what medication and/or whether changing life style (e.g., diet and exercise) could be of any help (referred to as *taking medication and life-style* in Table 2), as one post stated: *“My mother aged 45 and has only one kidney. [Her] creatinine level [is] 4.2, Urea [is] 50. What diet she should take and what medicine?”*

Discussion

In the study, we characterized lay people’s general information needs related to laboratory test results, such as understanding test results, interpreting doctor’s diagnosis, learning about lab tests, and making decisions on the next steps. This study presents an early investigation for our long-term goal of guiding the design of patient portals that can provide more informative and personalized healthcare information. Building upon prior work [8], our study provides a more comprehensive, fine-grained description of lay individual’s information needs about their laboratory test results. For example, Reynolds et al. [8] highlighted that patients have confusion about the laboratory report; our study further revealed the aspects of laboratory report that patients had difficulties with, such as the meaning of lab values, medical terminologies, and the causes and effects of abnormal lab results. While this study only examined a subset of questions in an online forum setting, our findings reveal that people need support in interpreting and acting on clinical data, as well as making personalized decisions. Below, we draw on our findings to discuss five design opportunities for supporting the understanding of laboratory results in patient portals.

Providing consumer-friendly and credible information to assist the reading of lab results. Our findings suggest that the design of test results in patient’s portal seems to assume that patients have sufficient medical knowledge about their test results. Consequently, patients often did not receive explanatory information or result interpretation in the portal at the time they received the result, and they would search online to make sense of their results. It is therefore crucial to provide more useful information that patients need at the point of viewing their laboratory results in patient portals. For example, patient portals could provide links to consumer-friendly and credible information sources (e.g., entries in MedlinePlus) to help patients better understand the lab results; the portal could also suggest basic healthcare management advices, such as diet and life style.

Accommodating people with different health literacy. People have different levels of health literacy and numeracy as well as potential biases and personal beliefs. For patients who were recently diagnosed, they may not be literate enough to understand the terminology and the results, and thus may ask basic questions such as whether a particular lab value falls into the normal range. In contrast, some patients who have had chronic conditions may have been self-educated on relevant health knowledge (e.g., medical terminology, normal ranges of a test) and therefore need help with more comprehensive questions (e.g., how to interpret the lab results in the context of their medical history). Given such a fact, patient portals need to be designed taking into consideration of people’s health literacy differences [19].

Considering the temporality and illness trajectory of patients. We also observed that patients’ information needs had a temporal dimension—the nature and extent of the needs may be different at different stages of patients’ illness trajectory [12]. For example, right before getting a medical test, patients may want to know how to prepare for the test and what they will go through during the test. Upon receiving their test results, patients may ask for interpretation of what the results mean and what they should be doing next (e.g., make an appointment with their physicians). This observation shed light on portal design with regard to temporal organization of information materials so as to provide relevant health information to patients according to their illness trajectory.

Facilitating shared decision making through personalized and contextualized information along with lab results. An interesting observation is that patients provided contextual information (e.g., medical history, symptom) along with their lab results in order to seek personalized advice and treatment options. This observation suggests that the same lab results may have different indications in different contexts (e.g., family history). In addition, prior work has recognized that personalized healthcare information within a shared-decision making framework leads to better patient engagement, better outcomes, and an increased level of trust between healthcare providers and patients [20]. As such, patient portals should provide more personalized content.

Supporting the sharing of personal stories between patients who are “in the same boat”. Sometimes, patients sought health information due to their suspicion about a certain diagnosis made by their physician. This means that patients not only need objective explanations of terms and values in test results, but also other patients’ opinions and experiences. Such behavior constitutes reflection upon and distrust in doctors’ explanations. It seems that when authoritative explanations lost credibility in certain cases, patients were in urgent need of a second opinion, especially from patients with similar symptoms and conditions. This observation suggests that a social network in patient portals could benefit patients by connecting them with peers who have similar conditions. This also suggests that patient portals should provide a more streamlined communication channel between healthcare providers and patients in order to resolve any misunderstandings in a timely manner.

Limitation and Future Work

Our study has several limitations. First, our study focused on one disease, namely diabetes, one type of health information, laboratory test results, and one health forum, Yahoo! Answers. While our findings pertain to the characteristics of the specific domain, the results may not be generalizable to other types of diseases and types of health information. Our future work will expand to other health conditions (e.g., cancers), other health forums (e.g., eHealth.com, healthboard.com), and include other

types of health information (e.g., radiology report, physician notes, discharge summaries) to assess the generalizability of our findings. Second, we only analyzed the question posts and therefore did not discuss how those questions were answered on this Q&A site. In our future work, we will synthesize the types of information people gain from the online communities and how these answers were constructed to meet their needs. Lastly, due to various constraints, we did not collect posters' demographic data, such as level of disease severity, gender, age, and different stages of life/illness trajectory. We will take these factors into consideration in our future work.

Conclusions

This study explored lay people's various information needs related to lab results through analyzing forum posts collected from a social Q&A site. Our results highlighted the need to address the gap between patient knowledge and limited contextual information presented on their lab reports, and provide essential insights into improving the design of patient portals to fully meet patient needs in understanding the lab results. Our findings provide a foundation for our future work, including qualitative studies (e.g., interview with clinicians and patients) and analysis of medical record data to understand how to best provide personalized information and present clinical data in patient portals.

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