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Traber Giardina

Houston VA HSR&D Center for Innovations, in Quality, Effectiveness and Safety, Michael E. DeBakey Veterans Affairs Medical Center and the Section of Health Services Research, Department of Medicine, Baylor College of Medicine, traberdt@bcm.edu

Varsha Modi

Houston VA HSR&D Center for Innovations, in Quality, Effectiveness and Safety, Michael E. DeBakey Veterans Affairs Medical Center and the Section of Health Services Research, Department of Medicine, Baylor College of Medicine, vmodi@bcm.edu

Danielle Parrish

Graduate College of Social Work, University of Houston, dparrish@Central.UH.EDU

Hardeep Singh

Houston VA HSR&D Center for Innovations, in Quality, Effectiveness and Safety, Michael E. DeBakey Veterans Affairs Medical Center and the Section of Health Services Research, Department of Medicine, Baylor College of Medicine, hardeeps@bcm.edu

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Cover Page Footnote

The authors would like to thank our participants for kindly sharing their experiences with us.

The patient portal and abnormal test results: An exploratory study of patient experiences

Traber Davis Giardina, PhD, MSW, *Houston Veteran Affairs Center for Innovations in Quality, Effectiveness and Safety, Michael E. DeBakey, Veterans Affairs Medical Center and the Section of Health Services Research, Department of Medicine, Baylor College of Medicine, Houston, Texas USA, traberdt@bcm.edu*

Varsha Modi, *Houston Veteran Affairs Center for Innovations in Quality, Effectiveness and Safety, Michael E. DeBakey Veterans Affairs Medical Center and the Section of Health Services Research, Department of Medicine, Baylor College of Medicine, Houston, Texas USA, vmodi@bcm.edu*

Danielle E. Parrish, PhD, *Graduate College of Social Work, University of Houston, Houston, Texas USA, dparrish@Central.UH.EDU*

Hardeep Singh, MD, MPH, *Houston Veteran Affairs Center for Innovations in Quality, Effectiveness and Safety, Michael E. DeBakey Veterans Affairs Medical Center and the Section of Health Services Research, Department of Medicine, Baylor College of Medicine, Houston, Texas USA, hardeeps@bcm.edu*

Abstract

Many health care institutions are implementing patient portals that allow patients to track and maintain their personal health information, mostly in response to the Health Information Technology for Economic and Clinical Health Act requirements. Test results review is an area of high interest to patients and provides an opportunity to foster their involvement in preventing abnormal test results from being overlooked, a common patient safety concern. However, little is known about how patients engage with portals to review abnormal results and which strategies could facilitate that interaction in order to ensure safe follow-up on abnormalities. The objective of this qualitative study was to explore patients' experiences related to abnormal test result notifications through patient portals. The authors conducted semi-structured telephone interviews with 13 participants, patients and primary caregivers, between February 2014 and October 2014. Using content analysis, the authors explored patient experiences accessing abnormal test results through their portals. Respondents strongly favored access to all types of abnormal test results, but they raised several concerns including need for more timely notification and not being able to interpret the exact relevance of the result. Respondents' personal experiences with physicians, test result notification, and the portal heavily influenced respondents' notification preferences. Patient experiences with portals could be improved by development of strategies to help patients understand and manage the information received. These findings suggest important considerations for health professionals and institutions aiming to better engage patients in follow-up of their test results.

Keywords

Patient portal, patient safety, patient experience, test results, communication, health information technology, personal health record

Introduction

With the passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act, nearly \$30 billion dollars have been committed to facilitating the adoption and meaningful use of health information technology.¹ The HITECH Act emphasizes the importance of providing patients with electronic access to their medical information and incentivizes patient engagement in health care as part of the meaningful use of electronic health records (EHRs).² The adoption of patient portals is an essential component of these national policy efforts to reduce costs and improve quality of care.

However, only about 28 percent of U.S. office-based physicians are currently using EHRs that offer patient access.³ Moreover, while patients are encouraged to take an active role in their care and have expressed interest in having electronic access to their health information,^{4,5} only 10 percent of American adults currently use a personal health record (PHR) or patient portal.⁶ Thus, there is much work to be done to bring these policy changes to fruition and a need to better understand the factors that facilitate patient portal use.

Patient portals are increasingly being deployed with the underlying belief that they will empower patients and

improve health outcomes.^{7,8} However, there is little evidence drawn from controlled studies indicating that personal health record access supports improvement of patient empowerment⁹ or improves health outcomes.^{10,11} One key type of medical information that is increasingly available in portals is patients' test results (e.g., laboratory, imaging, and pathology results). To ensure that this tool is used in a patient-centered manner and follow-up delays are minimized,^{12,13} it is important to better understand patients' expectations and experiences with test result-related notification through portals. Despite policy incentives to increase patient access to information, evidence of the benefits, limitations and challenges involved in implementing this approach is limited.

Two recent studies examined the benefits and risks associated with patient electronic access to test results. A 2013 survey of patients at Kaiser Permanente, an integrated health care organization, found that a large percentage of patients who had used their portal to access a laboratory result in the last year experienced primarily positive feelings when viewing laboratory results online.¹⁶ Less than 7 percent of patients experienced worry, confusion, or felt afraid. A UK study published in 2014 looked at renal patients using a portal offering access to test results.¹⁷ Most patients used the portal to monitor their kidney function. Specifically, 81 percent checked creatinine, 57 percent checked potassium, and 50 percent tracked their hemoglobin. Ninety-three percent indicated that, overall, the system helps them manage their condition; however, 32 percent of the patients reported experiencing worry after seeing their test results in the portal.

Ultimately, the HITECH Act policy initiatives will support innovative methods to improve test result notification. However, before designing new methods supporting these functions, it is essential to improve our understanding of how patients experience and use their online health records and how they perceive the electronic notification of their medical test results. The purpose of this study is to explore patients' experiences using a portal to manage their medical care specifically as it relates to receiving abnormal test results. This study provides essential information regarding the views of patients using this technology to inform future system development.

Methods

Sample

Adults 18 years or older who have or have had access to a patient portal and have previously received any abnormal test result through their portal for themselves or while acting as a primary caregiver were eligible to be included in our study. Initially, the authors contacted patient advocates to share the study information with active national patient email listservs. The first author also posted

fliers at two ambulatory clinics and one with established patient portals actively releasing abnormal test results. Due in part to low recruitment, study information was also shared through Facebook and LinkedIn accounts of the first author. The local IRB committees approved this study.

Data collection

Recruitment began in January 2014 and ended in August 2014. Thirteen participants were interviewed from February 1, 2014 to October 30, 2014 by the first author. Individual interviews were conducted over the telephone, as many of the respondents were not local. The semi-structured interview included three sections: management of medical information, discussion of a specific abnormal test result, and test result notification preferences. The interview length averaged 45 minutes, ranging between 15 minutes and 90 minutes. The shortest interview was a respondent without perceived health issues whose portal use was limited to annual physician visits. Verbal informed consent was obtained for all participants.

Data Analysis

All interviews were audio recorded and transcribed by the first author. Using content analysis,¹⁸ the first and second author conducted independent analysis of the transcripts to create an initial code book. Codes that conveyed similar meanings or ideas were combined to form new categories. The authors met to discuss and refine codes and categories and any additional emergent codes. Categories were shared with the research team for further discussion and disagreements were resolved by consensus.

Results

Thirteen respondents agreed to participate in our study, two primary caregivers and eleven patients. Ages ranged from 30 to 80 years old and nine participants were female. Race/ethnicity was not collected. Eleven of the respondents indicated having at least one chronic illness. Our analysis explored two major categories: health-management practices and notification preferences related to review of abnormal results. Respondents were enthusiastic about their access to abnormal test results, but they raised several concerns that limited their positive experience.

Managing Health Information

All respondents indicated that they use their patient portal to review test results. Many of the patients and caregivers dealing with chronic conditions, such as diabetes, cancer, and kidney disease, indicated that they also used their portal to manage and keep track of their medical information. Some of these respondents additionally kept paper records of test results and

imaging reports, medication lists, and some kept digital copies of their imaging. There were various reasons; either this information was not made available in the portal or the portal was not up-to-date.

"It is a constant challenge to keep the electronic records accurate so I certainly do not rely on what's in the electronic, what's available to me through the patient portal" (Respondent (R) 3).

Another respondent indicated that paper records were necessary to exchange health information among providers,

"And I use that portal as soon as the results, the labs and x-ray, as soon as that stuff becomes available. Download, print to PDF and then share with providers" (R 6).

Interestingly, some respondents used their portal to avoid redundant testing. A respondent who had multiple blood transfusions while hospitalized was asked to take a hepatitis C test by her gastroenterologist. She assumed the test had been completed during her hospitalization, but upon checking the hospital portal she found the test had not been.

"There were some questions about whether or not I was tested for hepatitis ever in the hospital, even with all of the blood transfusions. And it turned out I was not and that came in handy for that" (R2).

Another respondent, anticipating his physician's request for certain tests, prints out copies from his portal to bring to his appointments.

"Like so I'm gonna go over to my heart doctor at [clinic name] and I'll take him a copy, if it's something I know he always [wants], I'll take him one" (R7).

Another respondent, a primary caregiver to his wife, routinely requests copies of all her imaging. Having access to the imaging and the reports helped his wife avoid redundant testing thereby avoiding delays in care. Finally, a respondent with multiple chronic conditions explained that having access to the portal at her neurologist's office allowed her to provide her medical history to other physicians.

Try coming up as a teenager when, with 10 medical conditions and going to your doctor and the routine of questions they ask you over and over again. It's just easier to pull out the spreadsheet and hand it to them. Here you go. Like let's move on to the real questions. Here's all the numbers you want... (R10)

There was one exception. One respondent, who considered herself to be healthy, did not use the portal to manage health information.

My general health information, I don't know that I manage it except for when I actually go to the doctor for like a yearly checkup and then I look at the test results. I just look at what they recorded in there... I didn't really track anything. (R 8)

Notification Preferences

Overall, the majority of respondents felt that abnormal test results should be available to review on the portal. However, seven of the respondents felt that some abnormal results, those with high emotional impact or 'sensitivity', should be communicated verbally prior to being released on the portal. Some examples of sensitive tests given were life-threatening illnesses, any diagnosis that cannot be treated or cured, cancer diagnosis, and genetic testing.

So maybe, you know, we don't put the results of the cancer test that says you're going to die of cancer without the doctors interpreting it for you to the patient (laughs). But for those of us, you know, in my case I've got anemia and sodium and hyponatremia ...that I need to monitor. (R3)

Another respondent said,

"For me personally, let's say like the doctor runs this test and the doctor found something suspicious of cancer. I would like to have a call to come by and reschedule and talk about it. But to have it just posted on there [the portal], nah, personally I wouldn't want that" (R5).

Five respondents, with varying severity levels of chronic health issues, felt that all test results should be released at the same time they are available to the physician, regardless of sensitivity.

"It is what it is. I'm not going to go shoot myself if I see an abnormal result... I mean it's always better to know. Especially if you're getting something that you really want to know about like cancer." (R12)

Another respondent echoed this:

"It's my body, my result and despite what it is, it doesn't matter what it is. I still want to see it. I'd like to see it when the doctor sees it ... You know, I'm a grown up." (R9)

One of these respondents indicated that she wanted to receive all results regardless of sensitivity because she had experienced a delayed notification from her doctor.

Well in my case with the oncology they, he gets it, it's stat. So he actually gets it by 11 o'clock that day. But I don't hear from him for days so that's why I started getting it so I can look myself. The one time...I ended up in the hospital for 5 days is because he didn't look at it. He didn't call and I had no white blood cells and no neutrophils and I had a very bad infection. And that was and that's really what started the whole thing because no one called. (R2)

There was one exception. One respondent indicated that most abnormal test results should not be released prior to verbal contact.

"I make sure to tell the doctor ahead of time - when these test results come back, I need a phone call. I need to talk live about it, if there's a problem." (R13)

However, she indicated being comfortable with receiving abnormal results related to her present health issues, diabetes and anemia,

"Something that I'm already diagnosed with and I'm familiar with, is fine...If my A1c is abnormal, I don't mind knowing that without the doctor calling. I don't need to talk about it...because I know what to do about it."

For this respondent, all abnormal test results are potentially sensitive if she's not sure what the abnormal result means in context.

Notification preferences appeared to be highly patient specific. Personal experiences with physicians, abnormal test result notification, and the portal heavily influenced respondents' notification preferences. For instance, two respondents received a suspicious mammogram through their patient portal. One of the respondents, a two-time breast cancer survivor perceived these results to be sensitive and not in the normal scope of abnormal test results and was angry receiving her results this way. Of note, her result was released on Friday afternoon, making it difficult for her to reach her doctor.

I was a little shocked that they would post anything on [the portal] without talking to me and sure enough Saturday morning, woke up 6 o'clock, I went on [the portal] on my iPad and there it was, um, and the result was 'suspicious finding right breast. Possible problem' ah, the wording was something like that. 'Need a recheck.' You know, 'need to have patient come back in.' ... You never tell a patient about something serious like that in either an email or a voicemail or on a portal, because you want to talk directly to the patient and let them know, um, and give them reassurance... I mean the shock of having received that news on the portal opened my eyes to the fact that this could be happening to a lot of people and I think it's totally wrong. It was wrong for me and I

think it's wrong for everybody. And it's influenced the fact that I think there are limits to which portals should be used. (R1)

Alternatively, the other respondent, with no history of cancer, felt it was an ideal way for her to receive this information and was able to quickly schedule a follow-up.

I know I had a mammogram come back iffy... like a shadow or something...and had to redo it and I got an email and, you know, from the portal, and it was just 'hey, don't be alarmed but we'd like to just redo it just to be safe' and I think that was faster than ... they call the house and you're at work so by the time you get home from work you get the message late so then you're going to stress all night. Whereas you get the email, you can pick it up anywhere and reschedule and go in right away. (R11)

Concerns Related to Test Result Access

Without prompt, eleven of the respondents spontaneously expressed concern or acknowledged the complexity of receiving abnormal test results through the portal, despite indicating it is a helpful patient tool. Some respondents were concerned about patients' reactions to receiving abnormal test results through the portal. Concerns ranged from patient anxiety and confusion to self-harm.

Now personally, I have a great support system and I've been chronically ill since I was a child but to somebody that's newly diagnosed with a situation that might seem you know, um, horrendous or something that they might not be able to overcome, you know this is my third brain tumor but to somebody a brain tumor might seem detrimental and this is my third. You know, I could see somebody overreacting to an abnormal test result and thinking their life is over and taking a negative action and that's not a good thing. (R10)

Respondents were also concerned about issues of health literacy and computer literacy.

But what I have realized joining a couple of support groups and talking with other caregivers and patients is there are a lot of people that really don't comprehend how the lab things work. And I mean all of those values, people just don't understand that they're not trivial...but I also understand how patient education when it comes to labs is going to be over the next decade a bid deal. (R6)

It's a really good tool just, you know, some things do need to be a little bit better or a little bit easier because, you know, some people don't really understand computers at all and... Like I said the website is a little bit tricky for me, I haven't quite, you know, mastered everything on there but I'm pretty sure once you learn it, it's a good tool. It's a really good tool. (R5)

Three of the respondents thought that some patients just do not want to know about their medical information or be involved in their care.

I mean some people don't really want to know. I mean they really don't. I don't know. They really don't want to know the what? The gory details? I don't know what it is with people, but they don't want to know. You know, you're supposed to make me better so I don't need to know. (R7)

Despite expressing these concerns, most were unequivocal about receiving their own test results electronically. These respondents indicated that they should have access to their test results.

"I don't know that all people should do that. Especially elderly people or people that don't even have a clue about what it means then I think they should wait to hear from the doctor but I would, I would like to have mine" (R2).

Of note, only three respondents indicated feeling anxiety or confusion about an abnormal result they received through the portal.

Discussion

This exploratory qualitative study examined patients' experiences using their patient portal to access abnormal test results. Though respondents favored access to abnormal test results, there were several concerns. These included concerns related to the need for more timely notification and difficulty interpreting the relevance of a result. Notification preferences appear to be heavily influenced by past interactions with physicians and the health care system. Patients who have received an abnormal result and didn't understand it or it caused concern preferred that sensitive test results be verbally communicated by a health care professional.

Recent research has focused on patient portal use but few studies have explored patients' experiences of accessing their test results. The findings from this study provide important considerations for health care professionals looking for ways to engage patients and their families in health and health care management. While exploratory, to the best of our knowledge, this is the first study of its kind to qualitatively explore patient review of their abnormal test results through their portal. The passage of the HITECH Act and the Meaningful Use requirements has prioritized patient engagement in health care through the use of health information technology. While consumers generally want access to their health information, very few are currently taking advantage of this access. However, it is expected that the number of patients using health information technology will increase exponentially in the next decade.⁶ As more health care organizations adopt a

standard of care of releasing results within four days to meet the MU requirements, physicians would be expected to contact patients with abnormal and sensitive results before they are automatically released. Currently, some health care systems are withholding release of certain test results (e.g. pathology, genetic testing) through the portal or allowing physicians to release the results themselves to ensure verbal contact has occurred.

Notification of abnormal test results via portals might face implementation challenges. In a recent survey of U.S. and Australian primary care and specialist physicians, the authors found that 78.7 percent of physicians were not comfortable with direct patient notification of clinically significant abnormal test results (test results that are not immediately life threatening but require short-term follow-up).¹⁹ Akin to the findings in our study, physicians expressed concerns about patient anxiety and confusion when patients access abnormal test results online. To alleviate these concerns, standardized good clinical practices in portal-based test result notification should be developed and accompanied by strategies to help patients understand (e.g. explanation of abnormal result and instructions for next steps) and manage the information they receive.

Though concerns tended toward confusion and anxiety, very few patients in this study experienced these emotions themselves. Those who did experience anxiety received results they considered to be sensitive, or of high emotional impact, because they were related to suspicion of cancer. Most respondents believed that some sensitive tests should require a telephone call prior to release in the portal - including, with some variation, new diagnoses, cancer-related testing, and untreatable or deadly diseases. The sensitivity of test results was an issue of contention for The CLIA Program and HIPAA Privacy Rule.¹⁵ The Rule addresses this issue directly, stating that patients have a right to their information under HIPAA and laboratories cannot withhold test results "*based on the sensitive nature or potential for causing distress to the individual*" (p. 7296). Further the rule states that laboratories categorizing tests into sensitive and non-sensitive is a subjective process and not in the best interest of patients. Interestingly, the rule does include a 30-day window for physicians to follow-up and even a 30-day extension. Moving forward, health care providers should consider both sensitivity and significance of the result when deciding which tests are released in what timeframe. Based on the preferences of the patients in this study, they may also consider the timing of release, for instance avoiding release of test results just before or during weekends or other off hours if no staff is available to answer questions.

Patients who are empowered about follow-up actions on abnormal test results could add a layer of redundancy to reduce delays in care related to abnormal results being overlooked. While the theme of empowerment, advertised

proposed benefit of the portal, did not emerge directly in the narratives, it was implicit in the patients' desire for access to their test results. If the underlying purpose of empowerment is to increase patients' autonomy,²⁰ providing access to test results allows patients to exert control over their health in ways they find meaningful. For some patients, that means keeping track of their results to avoid error, delay, or testing redundancy. It can also mean the ability to closely monitor changes in health for patients with chronic conditions or simply to better understand a condition. Though a recent review of controlled trials found insufficient evidence to support increased empowerment,⁹ it may be an issue of how empowerment is conceptualized (i.e., self-efficacy, control, activation). Despite patient empowerment being ubiquitous, in the literature related to health information technology, there is no consensus on the definition.^{20,21} Further work is needed to understand how patients can be empowered in relation to follow-up of abnormal test results and how this can be leveraged to improve health outcomes and patient safety.

This study has several limitations. Our sample size is small due to difficulty in locating patients that have received an abnormal result through their portal. However, the sample is diverse with regard to experience. Moreover, our goal was not generalization, but to explore the experiences of a distinct purposeful sample. The method of analysis may also be influenced by the researchers' own biases. However, researcher triangulation was used to reduce these concerns. Finally, convenience sampling is the least rigorous qualitative sampling technique.

In conclusion, our study provides one of the first qualitative studies examining a new area of research – patients' experiences of receiving abnormal test results through the patient portal. Our findings have important insights and implications for the future implementation of the use of patient portals for automatic notification of abnormal test results, and how patient engagement providers could leverage to reduce the number of test results overlooked.

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