Sharing Clinical Notes with Hospitalized Patients via an Acute Care Portal

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Abstract

Though several institutions offer hospitalized patients access to their medical records through acute care patient portals, no studies have assessed the potential impact of patients' access to physicians' notes through these systems. We employed a mixed-methods approach, including patient surveys, system usage log analysis, and qualitative interviews, to describe patients' perspectives on receiving their clinical notes and usage of the clinical notes feature in an acute care patient portal. Patients visited the clinical notes feature more frequently and for longer durations than any other feature. In qualitative interviews, patients reported improved access to information, better insight into their conditions, decreased anxiety, increased appreciation for clinicians, improvements in health behaviors, and more engagement in care. Our results suggest that sharing notes with hospitalized patients is feasible and beneficial, although further studies should investigate the magnitude of benefit and explore the unintended negative consequences associated with increased transparency of clinical information.

Introduction

Increasingly, healthcare institutions offer inpatient access to the medical record through acute care patient portals. Several medical centers, including Brigham and Women's Hospital,[1-12] NewYork-Presbyterian Hospital / Columbia University,[13-18] Michigan Medicine,[19-27] the Ohio State University Wexner Medical Center,[28-30] Northwestern Memorial Hospital,[31-33] and the Veteran Affairs Medical Centers[34] have trialed or currently maintain acute care patient portals.[35] The Libretto Consortium is composed of five institutions that have implemented or plan to implement an acute care patient portal.[36]

Acute care patient portals offer various features, including medical record viewing, patient-provider messaging, care plan and safety information, educational materials, and amenities such as food ordering. To our knowledge, no studies have evaluated the impact of a feature that enables inpatients to view their clinicians' notes, despite evidence that most patients (over 90%) report wanting access to their complete medical record.[13, 16, 17, 37] In the outpatient setting, the OpenNotes consortium has enabled nearly 10 million patients to access their primary care physician's office notes.[38-40] Research suggests that OpenNotes increases patient satisfaction, trust and safety,[41] and the project has attracted considerable media coverage.[42-46]

Given the acceptance of OpenNotes in the outpatient setting and patients' enthusiasm for increased transparency of their medical record, the expansion of note-sharing to the inpatient setting is a probable next step. To date, few data exist[16] regarding the benefits and risks of inpatient note-sharing, because few institutions have embraced the practice. To address this gap, we designed a mixed-methods study to evaluate usage of a clinical notes feature in an acute care patient portal and describe inpatient perspectives regarding receiving their clinical notes.

Methods

Study Design

Using purposeful sampling, we recruited study participants from a single cardiac step-down unit at NewYork-Presbyterian Hospital / Columbia University Medical Center. Each participant received access to their hospital medical record via a previously described acute care patient portal.[18] Participants accessed the portal using a hospital-provided iPad with internet. A new "Clinical Notes" feature provided participants with real-time access to all clinical notes written about them by either medical doctors or nurse practitioners. Patients maintained access to the portal throughout their hospital stay, even if moved to another unit. Each participant completed a survey as well as a semi-structured interview. Additionally, we recorded and analyzed system usage logs for each participant. The Columbia University Institutional Review Board approved the study.

Recruitment

Inclusion and Exclusion Criteria: We included adult patients admitted to the cardiac step-down unit. Although the portal offered information in both English and Spanish, we included only English-speaking patients because our clinicians write notes in English. We excluded patients with severe cognitive impairment or major psychiatric illness, patients unable to provide written informed consent, patients actively participating in another research study, and patients placed in contact isolation.

Recruitment Protocol: The research coordinator identified potential participants through discussion with attending cardiologists on the unit. The coordinator typically invited patients to participate within 1-2 days of admission. Patients agreed to provide survey data and to participate in an audio-recorded interview. After participants provided written informed consent, the coordinator conducted a brief training session to familiarize the participant with the iPad, the portal login procedure, and the portal layout. For the first five days following recruitment, the coordinator visited each participant daily to troubleshoot any issues with the network, iPad, or portal. After the first five days, the coordinator visited the participant twice weekly until discharge. For infection control purposes, the coordinator used antibacterial wipes to clean the iPad between participants.

Measurements

To collect participant demographics, assess technology literacy, and determine health literacy, we used our previously described patient survey.[18] We used the Patient Activation Measure (PAM) to assess patients' knowledge, skills, and confidence in managing their health and healthcare.[18, 47-56] To measure portal usage, we recorded each user action in a detailed system usage log.

A content expert used an iterative process to develop a semi-structured interview guide. Briefly, the content expert developed a preliminary five-question guide based on patient interviews from a separate study.[16] Then, the content expert incorporated feedback from each study team member to develop the final interactive interview guide. The interview topics included general experience with the iPad and portal, and the usefulness, comprehension, emotions, and behavior changes associated with reviewing providers' notes.

Data Collection and Management

The research coordinator (LVG) collected the patient survey and PAM responses at the time of recruitment. The semi-structured interview took place either two weeks after enrollment or one-to-two days before discharge. The research coordinator received training prior to interaction with participants and followed specific guidelines to ensure consistency of data collection. The coordinator continued enrollment until thematic saturation occurred, meaning participants discussed no novel themes.

Data Analysis

Quantitative: We conducted a descriptive analysis of the patient survey data, PAM data, and system usage log data in R Studio. For the purposes of comparison, we conducted a descriptive analysis of the age, sex, employment status, race, and ethnicity of all patients admitted on the cardiac step-down unit during the study period.

Qualitative: A professional service transcribed the audio-recordings of the interviews verbatim. Transcripts were imported into NVivo Version 11 (QSR International) for thematic analysis. The authors analyzed the transcripts in multiple steps using a qualitative descriptive approach to uncover common themes regarding patients' perspectives on receiving their medical record information, particularly their clinical notes. The analysis included three steps. First, two authors with training in qualitative methods (LVG, RMC) independently read each transcript, and defined codes in a dictionary for the remaining analysis. In addition to codes that emerged from the data, the dictionary included *a priori* codes based on the research questions, interview guide, and literature.[16, 40] Second, the two authors independently coded all transcripts using nodes corresponding to the coding dictionary. We conducted one round of inter-coder comparison queries in NVivo11. Kappa scores ranged from 0.74 to 0.94. The coders met to review, discuss, and arrive at consensus for the content coding. Third, additional experts reviewed codes for accuracy and to identify common themes. Themes emerging from four or more interviews were identified as common.

Rigor: One author (LVG) conducted all the interviews and confirmed the content of the audio recordings and transcripts to ensure accuracy. All authors reviewed the coding procedure to ensure dependability and credibility, and both coders stringently adhered to the coding procedure. To further enhance dependability and credibility, the coders shared an audit trail and notes on the application of each code with the research team to illustrate the process that led to their conclusions. The authors triangulated multiple sources with the interview data to confirm accuracy, including patients' comments through the portal and during daily visits.

Results

Study Population

Out of eleven patients approached to participate in the study, ten consented to and completed the study, including five congestive heart failure patients, four post-heart-transplant patients, and one post-kidney-transplant patient. The eleventh patient declined to participate due to feeling too ill. Participants spent an average of 13.3 days with access to the portal (range: 4-38). The mean age of participants was 49 years (range: 27-60), comprised predominantly of men (n=9). Table 1 compares the study participants' demographic characteristics with the overall demographics of the cardiac step-down unit. The study population was representative of the employment status, race, and ethnicity of the unit, but was more predominantly male and younger.

Table 1. Demographic Characteristics of the Study Population

	Study Participants	**Entire Unit**
Age in years: *median (range)*	49 (27-60)	65 (20-102)
Sex: *n (%)*		
Female	1 (10.0)	247 (45.8)
Employment status: *n (%)*		
Employed or Self-Employed	3 (30.0)	84 (15.5)
Retired	1 (10.0)	135 (25.0)
Unemployed	6 (60.0)	320 (59.4)
Race or Ethnicity: *n (%)*		
White	4 (40.0)	155 (28.7)
Black or African American	4 (40.0)	79 (14.7)
Asian or Pacific Islander	1 (10.0)	10 (0.02)
Hispanic, Latino, Spanish origin	1 (10.0)*	155 (28.7)
Education: *n (%)*		
Some High School	1 (10.0)	--
High School Graduate	2 (20.0)	--
Associate's Degree	3 (30.0)	--
Bachelor's Degree	3 (30.0)	--
Master's Degree	1 (10.0)	--

* Non-English Speakers excluded from study because cannot read notes
-- Data not available for the unit

Technology and Health Literacy: The majority of participants reported previously using the internet to look up health information (n=7). All participants reported previously using the internet through another device, and half reported previously using an iPad or another tablet. Three participants reported needing frequent help to read and understand hospital materials or medical information.

Patient Activation: The Patient Activation Measure (PAM), which assesses individuals' knowledge, skills, and confidence in managing their health and healthcare,[18, 47-56] categorizes patients into four distinct levels of activation: (1) disengaged and overwhelmed, (2) becoming aware, but still struggling, (3) taking action, (4) maintaining behaviors and pushing further. The PAM categorized our study participants as level 2 (n=3), level 3 (n=6), and level 4 (n=1). The high level of activation is consistent with the selection of five participants as transplant candidates.

Portal Usage

Based on system usage log analysis, all ten patients accessed the portal independently, without the research coordinator present. Eight out of ten patients viewed their clinical notes. Patients logged in an average of 2.19 times per day (range 0.375-7.2). Patients typically accessed the portal in the morning, prior to rounds, or in the afternoon, when new test results or clinical notes tended to appear.

Patients navigated to the clinical notes feature most frequently, followed by the laboratory test results and the medications. Patients spent the longest time viewing the clinical notes feature (mean: 7.2 minutes, max: 34.1 minutes), compared to the laboratory test results feature (mean: 3.0 minutes, max: 31.4 minutes) and the medication feature (mean: 1.25 minutes, max: 20 minutes).

Usefulness of Clinical Notes

Participants spoke of reading clinical notes as an informational experience that supplemented their verbal communications with their physicians. Participants felt the notes allowed for communication outside of potentially intimidating or rushed one-on-one situations. One participant discussed how important the written information felt to him, because he felt overwhelmed in one-on-one situations:

"A lot of times, the docs say all this stuff. It's really intimating. I don't always understand everything they're saying. I get an idea, if things are good or bad, or if they're concerned or not concerned. But this is a different kind of communication that I've never seen before. It's bringing everybody [the patients] in, putting us on the same page." [Pt.1]

Another participant discussed how important the written information felt, given the short amount of time devoted to verbal communication with his physician:

"On average, I get to spend about a minute-and-a-half with my doctor a day, and so when I go back after the doctor writes the report, I get a more detailed account. Although it's not a personal one-on-one, it at least comes from her mind that she has seen me and these are the more detailed things." [Pt.7]

Participants viewed notes as objective indicators of both their health condition and their progress while in the hospital. Multiple participants (n=3) used the metaphor of seeing information in "black and white" through the notes. The participants explained:

"It's different, when you see the note. It's like a report card, I guess. When you see it; it hits you a different way. It's not as emotional, it's more objective. And it's there. It's right there in black and white so you can totally track like, "Oh, I'm good, I'm good, I'm good, I'm in trouble, ok now I got back on my feet." So I find that that's very good information." [Pt.1]

"To be honest, I can't always believe the doctors. I think that sometimes they sweet-talk you, excuse me for saying that. They don't want you to stress, and it's not like they lied to you, but sometimes they don't tell you the whole truth." [Pt.7]

Participants expressed a sense of ownership over their data, and wanted access independent of plans to read or use it. One participant who did not view his clinical notes still wanted the notes to be available:

"Even though I didn't look at them [the notes], it's just nice to have them. You can't go wrong with it. More information is always better. Maybe if I had gotten sick, maybe it would have been different, or if something had changed, I would have looked." [Pt.5]

Half the participants (n=5) asked for access outside the hospital, unprompted. One participant even offered to pay for outside access. Two patients reported photographing information in the portal on their personal devices, to avoid fees associated with requesting their medical record from the hospital after discharge. Multiple participants (n=4) expressed the desire to review notes from prior hospitalizations.

Comprehension and Insight

Participants spoke of clinical notes as "truth tellers" that improved their insight about their progress and condition. One participant, after reading his notes, asked for a family meeting:

"My sister and I didn't realize that what I'm going through is as bad as it is. Basically, reading the notes, we felt it [my condition] was more serious. For some reason we weren't getting that in the room. We needed to know what our goals are. Which direction we're heading and how we're going to get there." [Pt.9]

After the family meeting, the patients' care team involved the palliative care service, who arranged the participant's discharge to home hospice care.

For another participant, the notes offered clarity about his condition's severity, and encouraged him to consider destination left ventricular assist device (LVAD) surgery:

"I was walking up and down that hall, going to the bathroom on my own. I really thought I was going to be able to go home, without any drugs, the Milrinone, all that stuff. But then you look at the notes. And they say it's the total opposite. I can see why I need this [LVAD]. I was glad that the doctors made the best decision… Every patient that walks through that door wants the raw deal of what's going on with their health situation." [Pt.10]

Participants spoke about "getting on the same page" as their physicians. Multiple participants (n=4) felt more able to converse with their physician, either because of better insight about their condition or increased comfort around the care team. The participants explained:

"It's very, very useful, because from the note we [I and my family] know exactly what's going on. And when we talked to the doctor, we were able to ask questions, and we know what the doctor is saying." [Pt.8]

"[The notes] help me keep track of who everybody is and who has seen me recently. Today, this older doc came in. And I was comfortable enough to be like, "Do I have to do a blood test every day?" And he was like, "No. We don't have to do that." And he totally changed it for me. If I was uncomfortable with him, I would never have broached that topic." [Pt.1]

Two participants reported that the portal answered questions they might otherwise ask their physician:

"It's better because you don't have to call [the doctor] to ask questions; you just go there [the notes] directly." [Pt.6]

All participants who read their clinical notes reported struggling to understand medical terms and acronyms, excepting one participant who had a Master's degree in a medicine-related field. One participant explained his struggle with interpreting acronyms:

"There were a lot of acronyms. Some of these acronyms, I knew what they were talking about just because I know my history… there were a lot of line items [e.g., HPI, PMH, ROS], that I didn't really get. But the parts that I could read and make my way through - that seemed pretty evident - I would just read." [Pt.1]

Emotional Reactions

Multiple participants (n=4) reported that viewing their notes decreased their anxiety. No participant expressed concern that seeing the notes increased anxiety. The notes reduced anxiety by providing new information, verifying known information, and offering additional processing time:

"Humans can make mistakes and even the input to these computers can be wrong. But when she [the doctor] tells me one thing and it's backed up with visual, it makes me feel a little bit better about it… and you feel more confident, seeing that at least whatever episode or what you felt was bothering you at the moment has been notated, and at least it's on their radar." [Pt.7]

"A lot of people get scared by this stuff. They're intimidated. They're in the hospital. They're scared. It's tough when there's a guy in a white coat with stethoscope and glasses. Standing on top of you and telling you, "your CBC level is blah-blah-blah." It's rough. This [reading the notes] is not as intense. It's a nice filter. It's like reading the paper." [Pt.1]

Participants reported increased appreciation for and trust in their clinicians. Seeing the amount of documentation prompted appreciation for the work physicians devoted to patient care:

" I don't really understand everything in the notes, but it's really amazing to see everything that goes into my care. I don't think I really appreciated how much gets done for me before." [Pt.3]

"When I read the notes, I feel that the doctors are following and that they care for you." [Pt.8]

"[The notes] grounded me in my whole being here. At first, I just want to get out of here. But when I got this, I was like, "Wait a minute, they're doing all this work for me." I really looked at all this. It kind of laid it out for me. And I was like, 'Maybe I should just settle in. Let them do what they got to do.' " [Pt.1]

" Sometimes there are just so many different things, and if your gout doesn't clear up, you feel like you're not being taken care of sometimes. But when you read in the note, 'pending talking to a gout doctor,' it makes you feel better. They're really trying to care for you." [Pt.7]

Health Behavior Change

Multiple participants (n=4) reported changing their health behaviors after reading the notes, including one participant who called a family meeting, and another who considered LVAD surgery, described above. Another participant began drinking the nutrition supplement (Ensure) that his nutritionist had prescribed:

"I started drinking the Ensure. Honestly, I never really gave it a shot before. It was just that my dad had to drink it when he was sick, so it bummed me out. But once I saw everything, I felt like, the nutritionist is trying and is giving me this food for a reason, so I should try too, and do what I can to make my numbers as good as they can be." [Pt.1]

Another participant reported feeling more likely to take his antihypertensive medications:

"When I saw that my weight went really down, that was an eye-opener. I mean, you know it, but then when you actually see it, it's different. Maybe when I get out, I'll be a little more careful." [Pt.3]

Participants described how reading the notes increased their ability to engage with their care, because the written information allowed for processing time to overcome anxieties:

"I was able to read it and then process it, and then when the doctor came in and talked to me, it was easier to talk about." [Pt.9]

"At first, to be honest, I was a little bit weirded out. I was so excited to get my heart. And I think of that moment, and it's just like 'do I really want to know any more?' But once I got into it, it was like a good book. You just want to

delve into it and learn more and more… The greatness of it is, knowing once you continue to read it [medical information], it's only going to help you to continue to stay well." [Pt.7]

Patient Safety

Participants reported incidents where access to their information improved their quality of care. One patient noticed a medication error:

"This morning I saw the prednisone had fallen off [of my medication list]. I showed the nurse, who agreed with me that something wasn't right. She called the doctor, and within a minute-and-a-half the prednisone was back on [my medication list]. And within another minute-and-a-half, my nurse was back with the [prednisone] pill." [Pt.7]

Another patient noticed a low calcium level which needed correction after plasmapheresis:

"In the afternoon something happened. It was about my calcium level. I went to the nurse, and explained to her, the normal is between this and this, and I'm here. The nurse wasn't sure, so I said look, I'm going to show you [with the portal]… She [the physician] doubled my calcium supplement. She said since I will have more plasmapheresis, we need the calcium to be higher. So [the portal], it saved me." [Pt.8]

Upon reviewing the chart, the participant's physician deferred his plasmapheresis until his serum calcium level returned to normal.

Discussion

A rapidly growing literature documents the benefits of acute care patient portals. Research suggests that bedside access to information may increase patient safety and satisfaction.[1, 13, 16, 57-59] To our knowledge, ours is the first study to elicit inpatients' perspectives on receiving their clinical notes through an acute care patient portal.

Although only ten patients participated, our results suggest that patients may benefit specifically from inpatient note-sharing. In our qualitative interviews, patients reported better access to information, increased insight into their condition, increased appreciation for their clinicians, changes in their health behaviors, and medical error prevention. The system usage log data demonstrated that patients used the clinical notes feature more frequently and for longer durations than any other feature. We achieved these results in a complex clinical practice setting, with variations in patients' conditions and treatments as well as heterogeneity among clinicians in education, experience, and motivation to share notes.

The lack of common negative themes surprised the research team. We expected that note-sharing might increase some patients' anxiety. However, we did not find evidence of increased anxiety among our participants, but we did find evidence of decreased anxiety. Given the study design, we do not know whether response bias existed which led to this conclusion. However, an alternative explanation is plausible, that information in any form counteracts the uncertainty and disempowerment patients feel when hospitalized. This explanation is consistent with prior OpenNotes research.[39]

One striking result was the intervention's apparent influence on health behavior change and hospital outcomes. In a sample of only ten patients, four reported significant changes to their health behaviors, and two reported preventing possible medical errors. This included one patient who changed his entire course of end-of-life care, and another who opted to pursue surgery. Because completing an interview allows patients to reflect on and verbalize changes, further research should explore whether note-sharing actually translates to increased illness understanding, medical knowledge, health behavior change, and error prevention.

Some clinicians fear that note-sharing may prompt mistrust, force unwelcome changes to documentation practices, require increased time with patients to alleviate concerns, and increase legal liability risk. In our study, physicians did not appear to change their documentation practices. Patients expressed surprise and gratitude at receiving their notes, and after reading them, voiced increased appreciation for and trust in clinicians. In some instances, patients reported answering questions using the portal rather than asking their physicians. Although the patients' perspective cannot serve as a proxy for the impact on clinicians, our results encouraged us to remain open-minded about note-sharing. Future research should identify the unintended consequences of inpatient note-sharing, and investigate the effects of note-sharing on consultation time.

Our study had several limitations. First, we enlisted patients from a single clinical unit in an urban academic medical center. Though our sample included only ten patients, we achieved thematic saturation. Consistent with the sample size, we introduced stringent criteria for identifying common themes, namely that the theme must exist in four or more interviews. Second, we did not select participants randomly. Although the attending cardiologists purposefully selected patients representative of the unit, a selection bias for younger, more technology literate patients existed. Third, the study used five transplant patients as participants. Transplant patients must demonstrate high engagement prior to receiving their transplants, and may exhibit more interest in their health care than other patients. To confirm our findings, this study should be repeated with randomly selected participants and a more generalizable patient population than transplant patients.

Conclusion

To our knowledge, this is the first study to assess hospitalized patients' perspectives about receiving their clinical notes through an acute care patient portal. In qualitative interviews, patients who read their notes described better insight into their medical conditions, better access to information, decreased anxiety, increased appreciation for their clinicians, improvements to their health behaviors, and engagement with medical decision-making. Although our patient population is too unique to draw broadly generalizable conclusions, our results suggest that further studies to explore the potential benefits and unintended consequences of inpatient note-sharing are warranted.

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