Beyond the Patient Portal: Supporting Needs of Hospitalized Patients

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ABSTRACT

Although patient portals—technologies that give patients access to their health information—are recognized as key to increasing patient engagement, we have a limited understanding of how these technologies should be designed to meet the needs of hospitalized patients and caregivers. Through semi-structured interviews with 30 patients and caregivers, we examine how future patient portals can best align with their needs and support engagement in their care. Our findings reveal six needs that existing patient portals do not support: (1) transitioning from home to hospital, (2) adjusting schedules and receiving status updates, (3) understanding and remembering care, (4) asking questions and flagging problems, (5) collaborating with providers and caregivers, and (6) preparing for discharge and at-home care. Based on these findings, we discuss three design implications: highlight patient-centric goals and preferences, provide dynamic information about care events, and design for situationally-impaired users. Our contributions guide future patient portals in engaging hospitalized patients and caregivers as primary stakeholders in their health care.

CCS CONCEPTS

• **Human-centered computing** → **User studies**; **User centered design**; • **Applied computing** → **Consumer health**; **Health care information systems**.

KEYWORDS

Health; technology; patient portal; patient engagement; electronic health record; personal health record; hospital

1 INTRODUCTION

Patient engagement—the concept of patients, their families, and care providers actively working together to improve their health care—has been recognized as key to improving the quality and safety of medical systems worldwide [7, 9, 47]. Patients who engage in their care experience several benefits, including improved clinical outcomes, increased satisfaction and understanding of their health, reduced risk of experiencing medical errors, greater involvement in shared decision-making, and closer relationships with their providers [21].

Health information technologies are critical for encouraging patient engagement on a larger scale than what can be accomplished in face-to-face encounters with providers. These technologies have demonstrably increased levels of engagement across a breadth of patient populations, including those living with diabetes, HIV, and mental health challenges [59].

The patient portal is one such technology that has received special attention in recent years, due to its great potential to increase patient engagement [16, 25]. The purpose of a patient portal is to give patients convenient access to their current health information, and generally offer features such as viewing medication lists and test results, scheduling appointments, paying bills, reading doctors' notes, and messaging providers [1]. In the United States, patient portals are typically made available through health care networks or

clinics and are most commonly used by patients who manage chronic or complex conditions [24, 30].

However, patients undergoing overnight treatment in a hospital (hereafter referred to as **inpatients**) historically have not been afforded this same level of access to their health information [54]. To address this problem, researchers have newly shifted focus toward developing and deploying **inpatient portals** within hospitals to better support this patient population [19].

Despite the growing area of research on inpatient portals, we still have a limited understanding of how to design these portals to align with the informational and experiential needs that patients have during their hospital stay. Prior work has shown that the current design of patient portals and similar technologies do not fully meet the needs, or support the health work, that patients manage in the hospital [29, 31, 48]. Acceptance of patient portals is mixed among patients, often due to poor design and usability issues [3, 34]. Although commercial inpatient portals are readily available in some hospitals today, they are insufficient in meeting the needs of inpatients, offering few useful features beyond the clinical information that is pulled from provider-facing Electronic Health Records (EHRs) [72]. Thus, instead of a tool that encourages patient engagement, inpatient portals represent a small, locked window into the inner workings of the hospital care that inpatients receive.

To address this knowledge gap, we explored how a new class of inpatient portals can support inpatients' needs and engagement in the hospital environment. As the consolidation of commercial health technologies becomes commonplace and customization for individual health conditions becomes rare, the design and deployment of these technologies are increasingly standardized across health care systems [33]. Therefore, our study examined how these technologies should meet the needs of patients across a range of ages in two settings: a pediatric and adult hospital.

We conducted semi-structured interviews with 30 pediatric and adult patients and caregivers. During these interviews, participants viewed and responded to feature cards that represented different aspects of a futuristic inpatient portal. In reacting to these cards, our participants offered their perspectives on what role they wanted an inpatient portal to have in their hospital care, and how they envisioned using an inpatient portal to further engage in their health care.

In this paper, we make the following contributions: (1) a detailed understanding of the informational and experiential needs that a new class of inpatient portals must meet; and (2) design implications for future inpatient portals, based on the needs identified. These contributions will help guide the design of effective inpatient portals that better address the values and priorities of patients in the hospital, promote

their engagement, and elevate them as equal partners in their care.

2 BACKGROUND

Patient-Facing Technologies in Clinical Settings

Technologies for patients take on many forms and exist in a variety of health contexts. For example, researchers have studied the design of information and social support tools for patients managing their health in their daily life [2, 32, 37, 38]. Others have studied technologies for patients to use in preparation for clinic visits. One such technology was created by Jacobs et al., which offered breast cancer patients customizable resources, including links to informational websites, calendars, a nutrition tracker, and relaxation tools [27]. To help adolescent patients and their families communicate with their providers about radiology results, Hong et al. created an interactive radiology report that contained explanations of results, definitions of medical jargon, and places to document notes and questions [22]. In a study by Mentis et al., patients diagnosed with Parkinson's disease were given activity trackers for 4 weeks. The graphical summaries of the activity tracker data fostered collaboration and shared decision-making in their appointments with providers [39]. These contributions demonstrate how technologies can support patients in managing their health and interacting with their providers in the outpatient (non-hospital) setting.

Aside from homes and clinics, hospitals present their own unique design challenges, including—but not limited to—few options for patients to communicate with providers, and physical or social isolation [62]. To overcome these challenges and support patient engagement in this hospital context, researchers have explored using mobile health (mHealth) applications to benefit patients during their hospital stay. These applications were intended to help patients understand aspects of their care [17, 51], identify care inconsistencies or safety concerns [10, 53], and improve communication with their providers [36]. In other work, Virtual Nurse Agents ensured patients were informed about their discharge information before leaving the hospital [5]. Jackson et al.'s patient engagement consult service connected patients to digital resources that addressed their medical, logistical, and social needs [26]. Bedside safety toolkits and screen savers have also allowed patients access to their tailored health and safety information [14, 28].

Although these solutions offer many ways for inpatients to engage in their care, most are designed to deliver information to inpatients, rather than to support the active exchange of information with their care team. Furthermore, previous research has warranted exploration of additional design opportunities—such as supporting the many roles inpatients take on during their hospital stay [42], facilitating

care coordination and decision-making between inpatients and their caregivers [40], and promoting self-efficacy and self-management before discharge [52]—that have not yet been addressed through inpatient-facing technologies.

The Inpatient Portal

Inpatient portals are a subset of patient-facing technologies that have prompted a growing area of research. This growth is partly due to a series of United States government mandates requiring health care organizations to increase patient access to their health information [6], and partly due to their potential to help patients overcome the many challenges they face when attempting to engage in their hospital care [11, 13]. However, compared to commonly available outpatient portals, inpatient portals are a relatively recent technology with limited adoption.

In prior work, Wilcox et al. investigated the design of an early version of an inpatient portal for Emergency Department patients in the hospital. The study generated large, paper-based information displays that contained details about the patient's care (e.g., names of care team members, lab results) [69]. Since the conclusion of that study, tablet-based portals have given patients real-time access to their medication history [65]. In addition to medical information, researchers have incorporated educational resources, spaces to take personal notes, and instant messaging features so patients can send questions to providers [30, 71]. Others identified opportunities to make OpenNotes—a program allowing patients to view their doctor's notes about their care—accessible to inpatients via their portal, and found this feature not only helped patients identify and report mistakes within their record, but was most frequently used compared to other features within the portal [18].

These research advancements suggest promising new avenues for engaging inpatients and improving access to their health data. However, inpatient portal use during a hospital stay remains relatively low, and researchers have acknowledged the importance of expanding the features of inpatient portals to offer greater benefits for inpatients [8, 58, 67]. Moreover, we know less about what hospitalized patients need and how to reflect these needs within inpatient portals. Many features in current inpatient portals are restricted by what data can be imported from current provider-facing clinical systems. Instead of designing and deploying inpatient portals based on what EHR data must be made available to patients, researchers in Human-Computer Interaction and Health Informatics fields have an opportunity to reframe this perspective by identifying what needs inpatients have—beyond the data contained in the EHR—that future inpatient portals should support.

3 METHODS

We conducted semi-structured interviews with 30 inpatients and caregivers to explore patient and caregiver perspectives on how designs of future inpatient portals should meet their needs during their hospital stay. Our study took place at two hospital sites: one pediatric, and one adult tertiary care hospital. Both hospitals are located in an urban area of the United States and admit over 10,000 patients annually from wide-ranging geographic and demographic populations. The study was approved by the authors' and hospitals' Institutional Review Boards.

Semi-Structured Interviews with Feature Cards

To understand what features patients and caregivers might value in technology to support their needs, we created a series of 48 paper-based feature cards to use as a design probe during interviews (examples of cards are shown in Figure 1). Each card represented feature ideas that emerged from an analysis of our prior research on the design of technologies for inpatients [40, 42, 52]. During the semi-structured interviews, we gave the cards to each participant and explained their function. We then asked participants to design their own app based on those features, describe their thoughts about each card, and which cards they valued most, least, and why. The cards served as tangible artifacts to engage participants—particularly pediatric patients—and scaffold the interview process, similar to Hong et al.'s Visual ODL approach [23]. We offered participants pens and markers, encouraging them to sketch on the paper-based cards. This process gave the participant control of the cards and helped us understand how they envisioned improving the cards, as well as what new ideas they had beyond those represented in the cards.
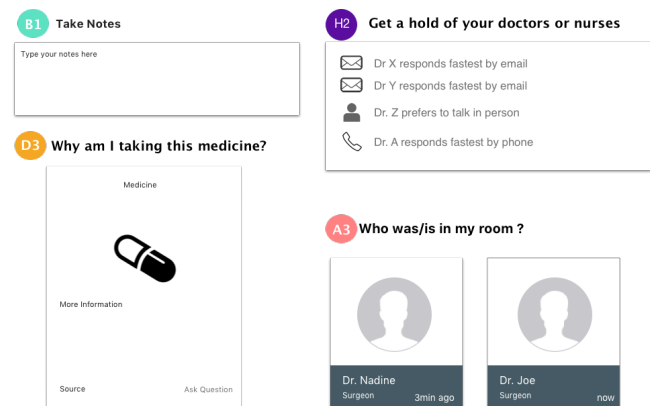

Figure 1: Examples of feature cards that participants responded to during interviews (e.g., take notes, who was/is in my room). Note: card H2 originally contained names of research team members that have been anonymized.

Patients and caregivers at both hospital sites were considered eligible for the study if they were well enough to participate in the interviews and could communicate comfortably in English. To gather a diverse sample of hospital experiences, we recruited participants across the medical and surgical services of both hospitals.

We approached, consented, and conducted interviews with participants at their bedside during their hospital stay. Assent was obtained from all pediatric patients, and their perspectives were foregrounded in the interviews. Of the pediatric patients in our study, five had a caregiver present who spoke during the interviews to help their child understand our questions or occasionally contribute their own ideas. In all cases, input came directly from the pediatric patients.

One research team member acted as the lead interviewer, while a second research team member was present to take observational notes and ask follow-up questions as needed. Interviews lasted approximately 45 minutes, and participants were compensated $25 for their time.

Participants

In total, we enrolled 30 participants in our study: 12 pediatric patients between the ages of 7-17, 3 people between the ages of 25-44 who were caregivers of pediatric patients, and 15 adult patients between the ages of 18-75. Participants were equally divided among gender (15 females, 15 males).

The hospital services of our participants were as follows: orthopedic surgery (n=9), medical (n=6), oncology (n=4), general surgery (n=3), cardiology (n=2), bone marrow/transplant (n=1), otolaryngology (n=1), pulmonary (n=1), neurology (n=1), urology (n=1), and hyperbaric (n=1).

Regarding our participants' ethnicity, 26 individuals identified as White/Caucasian, 1 as Black/African American, 3 as Hispanic/Latinx, 1 as Native Hawaiian/Pacific Islander, and 1 as Asian/Asian American. Twenty six of our 30 participants (86.7%) reported they had previous experience as a hospitalized patient or caregiver. At the time of their interview, participants' lengths of stay ranged from less than 24 hours to over one week in the hospital.

Data Analysis

Our interviews were audio recorded and transcribed for analysis. A qualitative, open-coding approach was used to analyze the data in Atlas.ti (v.8.2.4 for Mac) [63]. Several members of the research team participated in multiple rounds of initial coding, identified themes, and formulated the codebook, based on a subset of the transcripts. When thematic saturation was reached within this subset, one member of the research team continued coding the remaining transcripts. Any subsequent analytical discrepancies were brought to the research team for discussion and reconciliation.

4 FINDINGS

We identified six needs that participants wanted an inpatient portal to support: (1) transitioning from home to hospital, (2) adjusting schedules and receiving status updates, (3) understanding and remembering care, (4) asking questions and flagging problems, (5) collaborating with providers and caregivers, and (6) preparing for discharge and at-home care.

Each section below contains quotes and illustrative examples from participants. We use the following nomenclature to differentiate our participants: the first letter (P or A) indicates whether the participant was at the pediatric or adult hospital site, and the second letter (P or C) indicates whether the participant was a patient or caregiver. The letters are followed by a number assigned by the research team to uniquely identify each participant.

Transitioning from Home to Hospital

Our participants described the difficulty of transitioning from the comforts of home to the newness of the hospital environment, and discussed what information an inpatient portal could provide to make the transition easier. Key to this transition is the ability for patients to orient themselves within the hospital. AP07 explained how, on the morning of our interview with him, he was unable to recall what day and time it was and had to consult his phone to determine how long he had been in the hospital. PP08 also wanted information about her room number, as her caregiver had previously gotten lost when attempting to find her in the hospital. Other participants like AP09 mentioned the importance of having maps and wayfinding instructions to find locations of tests and procedures, as well as cafeterias, laundry, showers for caregivers, nearby parking lots for visitors, and other services.

Participants also expressed the need for information about hospital resources to make them feel more at home during their hospital stay, and the need to infuse aspects of their personal life into their hospital stay. Younger pediatric patients wanted information on how to watch their favorite TV shows, and borrow their favorite movies or games, from the hospital's library. Others wanted a centralized place within an inpatient portal to provide information about themselves—such as their most and least favorite foods, at what times they preferred to sleep, and how they usually received their medications at home—to mitigate the redundant paperwork and questions they received upon admission. PP11 wanted access to the hospital's food menu to help with the confusing process of placing a meal order: *"when you order lunch...they always ask you what do you want...and you don't really know what they can make for you and the options."*

Patients and caregivers thought that having access to information about hospital resources and documenting their

personal preferences in an inpatient portal would not only ensure a smoother adjustment to the hospital environment, but would also give them another way to find out this non-urgent information without bothering their providers. PC13 explained why she valued making this information easily available: *"[Y]ou don't always know [what] they have to offer necessarily unless you've been to the whole hospital, and you don't always make it everywhere. I think just knowing where stuff is and where things [are] can be better to help your situation..."*

Adjusting Schedules and Receiving Status Updates

Beyond knowing hospital resources and conveying personal personal preferences for treatment, adolescent and adult patients spoke about finding time within their hospital schedule to rest, plan for visitors, and work in their room. PP03 explained, *"sometimes [the doctors] come in a lot and I just don't feel good and I just want to lay down...just let me be alone for a while."* Another patient, PP04, had a friend who wanted to visit her in the hospital, but her friend had a fear of needles. PP04 wanted to use an inpatient portal to schedule a time for her friend's visit that did not overlap with changes to her intravenous (IV) line. AP05 was a frequent hospital visitor who spoke to us about finding time to run his law firm from his hospital bed:

"[B]ecause I work while I'm in the hospital – I would like to know when I have a big block of uninterrupted time...when you're in a hospital [there's] just a continuous stream of people in and out...But if I had on my app where I could schedule quiet time, that would be the absolutely single most useful thing with my current condition and what I do for a living." (AP05)

Beyond scheduling personal time in the hospital, participants wanted to be informed of care-related events, shift changes, and appointments that occur over the course of their hospital stay. At home, AP15 would check her patient portal to find out about the timing of her upcoming doctor's appointments. Her experience in the hospital, however, was completely different: *"you usually don't know what's going on during the day. Once you're here [in the hospital]...if the doctor's coming in, you don't know what time."*

Participants such as PP08 thought that being aware of the schedule of upcoming care events could alleviate concerns about fearful procedures (e.g., blood draws, tube removals) and help prepare for encounters with providers. For patients like PP03 and PP06, fatigue from treatment caused them to sleep through early morning rounds with providers, which resulted in the patients having fewer opportunities to learn about their progress and ask questions. AP10 was recovering from a surgical procedure, and explained how a calendar-like reminder feature within an inpatient portal would help her to know when the doctor was coming to her room, and why:

"[S]ometimes I'm sleeping or whatever, and then they show up and I'm like – crap, they're here already. And then it's a therapy session and I'm not even ready because I'm super exhausted. So a reminder might be helpful to kind of wake me up like 15 minutes before...Especially the first couple days, I wasn't really sure what they were doing, they had to explain themselves." (AP10)

Receiving status updates about the progress of specific events was also important for some participants, because it would allow them to be 'in the loop' and aware of any changes to their schedule, and consequently, their hospital care. PP04 was transferred from another hospital to receive treatment for her rare, chronic condition. The results of a test she had done at the previous hospital had not yet been sent over to her current care team. She explained to us that having some way within an inpatient portal to track the status of these results would be useful:

"Since we transferred hospitals, like the lab over there can have the information and it would be nice to know when that lab has the results and when they're going to send them over. Because that's what we're waiting on now...it would be nice to have that just at our finger tips" (PP04)

Giving patients real-time status updates of their test and lab results would allow them to process how their results will impact their next stages of care, and ultimately, their progress toward discharge.

Understanding and Remembering Care

Both pediatric and adult patients described a substantial lack of information they receive about the reasoning behind care decisions that providers make. Participants wanted to know what to expect for upcoming procedures, including what the procedure was for, the risks and benefits associated with it, and how long it might take. Others wanted information about their medications, why they were prescribed, and what potential side effects they might experience. AP04 was undergoing hospice care. She spoke about the difficulty of taking her medications in a particular sequence at various times throughout the day, and about her desire for an inpatient portal to help her keep up with the complicated regimen: *"there needs to be something, an indicator which tells me you take this [medication] before everything else."*

In addition to understanding procedures and medications, participants wanted to educate themselves about other aspects of their care and hospitalization. For example, PP11 wanted an easily accessible glossary of medical terms that her providers regularly used because she did not know what those terms meant. AP14 also expressed a need for additional information, outside of what she was receiving in the hospital. She often conducted independent research on her condition via online resources and journal articles, but could only gain access to articles by requesting them through her

providers. AP14 wanted an inpatient portal feature that was comparable to her phone's weather alerts, to notify her of new, relevant articles about her treatment options. Having this feature would help her remember to follow-up with her providers and obtain the information she needed.

Participants also spoke extensively about how multimedia resources (e.g., video, graphs, picture, text, audio) could further their understanding of their care. Pediatric and adult patients thought accurate videos would be helpful to learn more about what to expect from an upcoming procedure. AP10's curiosity motivated her to search for online videos about her surgical procedure, although she had difficulty determining which videos were accurate. A different subset of patients discussed the use of graphics and visual summaries to interpret their test results. AP13 was managing diabetes and regularly tracked his A1C levels. He explained his need to have a graphical representation of his test results that indicated baseline levels, and whether a result was within a normal or abnormal range.

For patients undergoing X-rays, MRIs, and CT scans, gaining access to the image results was thought to be extremely valuable, and not something typically made available to them in the patient portal they accessed at home. Others mentioned opportunities to incorporate drawings, pictures, and diagrams into the inpatient portal. Some caregivers explained how, in preparing for their children's surgeries, their providers would draw diagrams explaining the procedures on stray napkins and papers. PC14 explained why he wanted a more permanent, secure place to store these diagrams:

"[D]octor's drawing would help because we did get a copy of the X-ray and he draw it on there what the procedure would look like. However, sometimes you lose those papers that get handed to you, even though you try not to. So having an app that you can revisit would be very helpful." (PC14)

However, AP08 preferred a text summary of her results, as she found such images to be *"scary"*. AP02 favored receiving explanations verbally, so as not to detract from the *"personal contact"* with his providers. Other participants raised the idea of an inpatient portal having audio explanations of their care, to recall complex conversations between themselves, their caregivers, and the care team. This feature was thought to benefit patients who have hearing problems, or who might be asleep when providers visit their room to explain results. AP12 was groggy after her procedure and missed several conversations between her husband and provider. She explained why a recording of these conversations would have been useful to her:

"I think right after my surgery, I was still in recovery – my husband got into a conversation with [the doctor] and I heard it again in the morning. Those two conversations were probably not the same...the one I didn't get to hear, maybe [I] would want to hear...I lost a lot of blood [during the procedure]...I

might have wanted all the detail I could possibly get...like how do you grow blood back? What should I be doing after all of that?" (AP12)

Finding ways for an inpatient portal to support patients in understanding and remembering their care was important for our participants. Incorporating features—such as detailed explanations of medications and procedures, medical term glossaries, alerts for relevant articles about treatments, and supplementary multimedia resources—can help reduce uncertainty about their health.

Asking Questions and Flagging Problems

Asking questions is sometimes necessary to fully understand the care provided in the hospital. However, our participants encountered challenges when attempting to ask questions, including not wanting to overburden their care team, and not knowing who on their care team was the right person to answer their question. Despite PP09's considerable experience in the hospital due to her chronic condition, she had frustrations about directing her questions to the proper care team member: *"I still don't know who to talk to, because I talk to a doctor and...sometimes they say 'you gotta ask this one, you gotta ask this doctor' and I don't know which doctor is which."*

To address this problem, participants wanted features within an inpatient portal that would recommend which care team member is best equipped to answer a question that a patient might have, augmented with information about individual providers (i.e., rank among hospital staff, credentials, department). Others like PC15 wanted an 'estimated time of arrival' feature for each provider's visit to prepare appropriate questions in advance. PC06 wanted the ability to document questions and send them to specific providers before the following morning's rounds. AP09 explained why such features would be important to him during his hospital stay:

"Why be wasting the doctor's time if they're not the person that should be answering the question...I think sometimes things can get lost in the wash and I want them to know that I consider this very important. And if it's not conveyed, it might be misinterpreted as not that important." (AP09)

Some participants also explained their need to ask for second or third opinions about their care while in the hospital. For example, PP11 asked multiple providers the same questions about her surgical procedure, to ensure the answers were consistent, and to gauge which providers she was most comfortable interacting with. For these participants, it was important to easily request these multiple opinions, without causing conflict among the care team. AP14 said: *"I wonder if in the app you could...type in a question and say, 'I just want to follow up with someone about this particular issue,' so that way I'm not sitting face to face saying 'I want a second opinion'."*

Conveying the urgency of a question or safety concern was important when a medical error or other safety issue might emerge. As AP05 said, *"I may need ice water, I may need to be revived."* Patients wanted an inpatient portal to offer multiple methods for reaching providers (e.g., messaging, paging, requesting an in-person meeting) to report problems such as dramatic spikes in pain levels or the onset of negative side effects. PP12 was in the hospital for epilepsy treatment, and wanted to get in touch with providers rapidly in the event of a seizure: *"I can't have just my mom take care of me during a seizure while I'm in the hospital...she'd have to call the nurse and then a nurse or two or more would come in."* In these emergency situations, patients envisioned a voice-activated feature within the inpatient portal that connected to the nurse's station to get quick help. Patients thought this strategy of obtaining help would be faster than existing nurse call buttons, because it would remove the patient's uncertainty of whether the nurse would respond to their request in-person or remotely. In differentiating between the urgency of requests, future inpatient portals could help provide more context when patients request assistance from their providers.

Collaborating with Providers and Caregivers

For several participants, cultivating a partnership with patients and providers was a high priority for receiving good quality care, and improving their health. PC13 was a nurse, caring for her son in the hospital. Her role as a practitioner and caregiver allowed her to verify the care team's understanding of her son's health history and bring attention to any gaps in his care. Regarding an inpatient portal's function in cultivating this partnership, PP02 thought having a space within the portal to take notes would encourage other pediatric patients like herself to actively participate in conversations with providers: *"Like you could say what your opinion might be or you could disagree with the doctor or agree with the doctor."* AP05 also saw his inpatient portal as a way to share information and work with his care team members inside, and outside, the hospital: *"the patient needs to be empowered...any information that I give or is taken needs to be readily accessible to me and transferable and be in some other format that other institutions could use."*

Collaboration between patients and their caregivers was also valued by our participants. Caregivers were often described as *"advocates"* on whom patients relied to communicate their needs to providers, obtain more information about their health, and protect against medical errors. For example, AP11 had two caregivers—his wife and daughter—who often exchanged, compared, and verified the information they received from providers. A few participants discussed how an inpatient portal could better foster this collaboration between patients and their caregivers. AP13 favored the idea

of his wife having shared or joint access to his portal, so she could *"know everything"*. AP10 contemplated how a portal that supported separate accounts would benefit her and her caregivers: *"[my parents] definitely always have a lot more questions than me...So yeah, that'd be kind of nice...they can [access the portal] by themselves and then ask the doctors."*

Preparing for Discharge and At-Home Care

Finally, participants described their need for an inpatient portal to support their preparation for discharge from the hospital, and continuing recovery at home. Some patients wanted a place within the portal to learn more about when they might be discharged, while other participants talked about the goals they are required to meet before leaving the hospital. The discharge goals varied by individual patients, and included strengthening immune systems, increasing physical endurance, and drinking a specific amount of fluids. PP11 summarized the checklist items she needed to accomplish before discharge, according to her providers:

"I have to have no fears, I have to have a good diet, I need to be able to take big pills before I can actually go home so I don't have to have the IV anymore. So I think it's important to have goals...so they can make sure everything is okay before you go home." (PP11)

A feature to track the patient's progress toward these goals emerged as an important one to include in an inpatient portal, as their documentation is irregular in the hospital. For example, AP09's providers only ever communicated their expectations verbally. Written goals were not always useful for other patients, as the provider's handwriting was often difficult to read, or the progress toward the goals were not updated regularly. Thus, digitally documenting and tracking progress toward goals was generally well-received.

In addition to discharge goals, patients and caregivers described information that would help in their transition home. They wanted the inpatient portal to capture the information communicated verbally or via paper handouts about rehabilitation exercises, medications, medical equipment maintenance, and follow-up appointments that were required to continue after discharge. Other participants wanted to know how long they must wait until they could return to regular activities (e.g., driving). AP14 explained that when patients are ready to leave the hospital, *"everyone's in a hurry to give you your discharge orders and the prescriptions."* Having access to discharge information beforehand would give patients more time to understand their instructions and ask important questions about their recovery and self-management of their care at home.

5 DESIGN IMPLICATIONS FOR INPATIENT PORTALS

Relative to EHRs, inpatient portals are new technologies, and thus inpatients are new end users that systems must support. Past work studied inpatients' use of portals, but these portals are typically designed from the 'top-down', adapting systems designed for clinicians as primary stakeholders. Building upon prior research identifying needs of inpatients [35, 68], our 'bottom-up' approach surfaced unique needs of hospitalized patients that are unmet by—and extend far beyond—the current features of existing inpatient portals. Participants in our study envisioned the inpatient portal as an empowering tool for managing their care and interacting with their care team, as well as a resource to support them before, during, and after their hospital stay. These needs should be considered in expanding the role of inpatient portals as a type of patient-facing technology in the hospital setting. Moreover, our study revealed new ways to support pediatric inpatients in directly engaging in their own care, in addition to supporting their caregivers' portal use.

Based on our findings, we discuss the following design implications for future inpatient portals: (1) highlight patient-centric goals and preferences, (2) provide dynamic information about care events, and (3) design for situationally-impaired users. In the first two sections below, we include figures of example prototype mockups, to demonstrate how these suggestions could be incorporated into prospective versions of inpatient portals.

Highlight Patient-Centric Goals and Preferences

In addition to the various health goals patients must meet before discharge, (i.e., exercise, nutrition, and medication self-management), our participants discussed their personal goals during their hospital stay. For example, patients and caregivers saw themselves using an inpatient portal to achieve a good working relationship with their providers (PC13), to accomplish care tasks correctly (AP04), and to conquer fears about upcoming procedures (PP08).

Surfacing these health and personal goals connects to an emergent idea in the medical field of shifting toward a goal-oriented health care model to promote long-term health and wellness, and moving away from a disease-oriented health care model that focuses on treating short-term symptoms [55]. Reframing the inpatient portal in terms of goals is also an opportunity to interpret EHR data in a patient-centric way and prioritize the patient's life values [45].

Researchers have previously explored goal-setting and goal-sharing with providers as a design opportunity within patient portals [12, 49]. In the hospital, however, an inpatient's health goals are often predetermined by providers, focusing on short-term recovery, and are disconnected from the personal goals that patients have. Moreover, the health information that patients need to track their progress toward these health goals are stored in provider-facing tools, and remain inaccessible to inpatients [43]. Thus, current goals intrinsically emphasize provider-centric values that are prescribed to patients, instead of patient-centric values that arise from true collaboration between patients and providers. This provider-centric emphasis further inhibits the ability of technologies to fully meet the needs of inpatients that we identified in our study.

To give inpatients greater ownership of their goals and to encourage active participation in their hospital care, inpatient portals could offer tools for patients to articulate their health and personal goals, track their progress toward meeting these goals, and communicate these goals to their providers. For example, upon logging into their portal account, an inpatient could have the option to create a series of health and personal goals they want to achieve during their hospital stay, such as "walk up and down the hallway by myself", "have no pain after surgery", or "talk to the nurse about what's worrying me". These goals could be edited by the inpatient and shared with the caregiver as they progress through their hospital stay, to adjust for unexpected health setbacks or improvements. Such a feature could help inpatients adjust their care schedules to better align with their goals (e.g., rescheduling middle-of-the-night procedures to get sufficient sleep). This feature could also help the patient monitor their progress toward their own goals, document their providers' verbally-communicated goals for their care, and visually compare these goals within the interface. As shown in Figure 2, a patient-centric goal-oriented interface can also explicitly help inpatients prepare for their discharge and at-home care.

In addition to surfacing patient-centric goals, our participants expressed the importance of having a place to convey their own personal preferences for their care and hospital experience (e.g., preferred meals, sleep routines, and delivery of medications). Future inpatient portals could incorporate a personal profile feature to support patients in communicating this information. Previous work described the opportunity for a shared profile that patients and caregivers could use during their hospital stay to disseminate important information about themselves to providers [41]. Having such a personal profile feature within an inpatient portal would provide a centralized place for patients and caregivers to input information—such as their medical history, known allergies, preferred flavors of medicine, and other likes or dislikes—that might be important to share with the care team. This feature could also help reduce the burden of responding to repetitive questions and paperwork that our participants described.
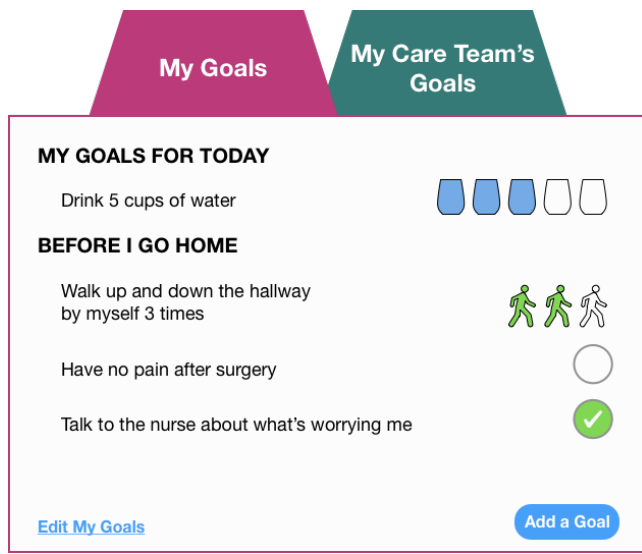
Figure 2: Example of how patients' health and personal goals could be incorporated into an inpatient portal. Patients could add or edit their own goals (e.g,. talk to the nurse about what's worrying me) and track progress toward their goals during their hospital stay.

Highlighting these patient-centric goals and preferences as part of future inpatient portals could give patients greater motivation to meet their health goals and assert their personal point of view to their care team [57]. These features would support collaboration between patients, caregivers, and providers by serving as a shared communication artifact that allows them to compare their goals and resolve potential discrepancies in expectations of their hospital care. This approach could help patients and caregivers ask questions, flag problems, and convey any disagreements they might have with their providers. Thus, future inpatient portals could help to foreground what actions can be taken to meet patients' goals and increase the patient's self-efficacy before leaving the hospital [52].

Provide Dynamic Information about Care Events

Patients and caregivers wanted information beyond the details their hospital care, and the reasons behind major care decisions. In particular, knowing the schedule of upcoming events was important for participants in our study.

Researchers have previously explored ways to present this 'Plan of the Day' information to inpatients [51, 69]. A distinction that emerged in our study, however, was the need for inpatients to edit and contribute to their daily schedule. AP05 and PP03, for example, wanted to designate time for themselves during their hospital stay, while others expressed a desire to schedule visitors around care appointments. Future inpatient portals could implement an adaptive schedule of

the day that not only reflects upcoming care events, but also allows patients and caregivers to manually add their own events, similar to a shared calendar. Incorporating this function into an inpatient portal would surface this often invisible information, ease the patient's and caregiver's transition to the hospital, and give them an opportunity to provide input on their care schedule.

In addition to *when* care events happen, participants like PP04 needed to know *where* their health information was. This frustration is a common experience for inpatients and caregivers: many government and health care organization policies restrict data sharing with other institutions, or delay the release of test results to the inpatient for an extended period of time without offering a clear explanation [46, 50].

To fill this information gap, inpatient portals should provide dynamic updates about the progress or status of specific health information, and its impact on care events. In PP04's case of not knowing whether her lab results had been transferred from her previous hospital in time for her scheduled discharge at her current hospital, an inpatient portal could contain a feature analogous to a package shipment and delivery tracker (Figure 3a). This feature would address inpatients' need to receive status updates and monitor their evolution during their hospital stay. It also facilitates asking questions and flagging problems (e.g., if a lab result did not get transferred in a timely manner). If a provider decides to hold specific results for a later, in-person conversation, the system could reflect this, so the patient and caregiver are fully informed about the reason for the hold (Figure 3b).

Inpatient portals could also push a notification to the patient when an important care event is approaching or has occurred (e.g., a shift change, a medication dose has been adjusted, a new event has been added to the schedule of the day). These notifications could emulate micro-explanations, which distill complex medical information from care events within the EHR and are tailored to individual patients [70]. Similar notifications could be created for non-urgent requests, such as AP14's desire to access academic articles about her treatment. For example, a notification could be generated when the article she requests from her provider is ready for her to view. Ensuring such timely access to an inpatient's health information is an important way for them to understand and remember their care during their hospitalization.

(a)

Complete Blood Count (CBC)
Ordered Friday September 14, 2018

Sample Drawn — Received by Lab — Testing in Progress — Result Available

(b)

X-ray

Comments from the Doctor

Your doctor has decided to explain your X-Ray results to you in-person later this afternoon.
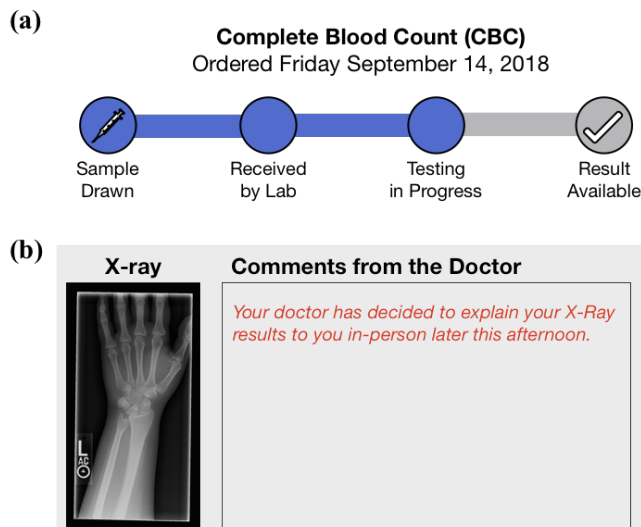
Figure 3: (a) Tracking the status of a blood test, from when the sample is drawn to when the result is made available in the inpatient portal. (b) An X-ray image next to a comment describing a provider's intention to explain the results to the patient in-person before releasing them in the inpatient portal.

Design for Situationally-Impaired Users

Aside from the informational and experiential needs that our participants expressed, many patients in the hospital encounter situational impairments: when the environment or context contributes to the existence of impairments, disabilities, or handicaps that might not otherwise exist [60]. Examples of situational impairments in the hospital include grogginess or fatigue from medications, pain from conditions or treatments, emotional distress from being in the hospital, and physical constraints from connections to equipment or effects of procedures [44]. Without specific prompting on this topic, our participants mentioned their experiences with situational impairments. For example, PP03 and PP06 experienced treatment-induced fatigue that caused them to miss updates about their care. AP12's grogginess after her surgery resulted in her forgetting her provider's explanation about managing her post-procedure blood loss. Thus, new technologies must be designed to explicitly accommodate for these factors.

To help patients manage situational impairments, future inpatient portals could support multiple methods for capturing and interpreting information about their hospital care. On top of text-based explanations, a system could provide audio explanations of their care, or support audio recordings of conversations with providers. This practice is common in other clinical settings (e.g,. consultations with cancer patients) and has positively impacted patients' ability to recall

and understand their medical information [4, 64]. Audio recordings could help patients such as AP12 capture verbal information and reflect on this information in a later, more lucid mindset. For visual learners like AP10, and younger pediatric patients, the inpatient portal could embed vetted videos depicting their upcoming procedures and answering common questions about treatment. Offering these resources within an inpatient portal could give patients a central place to access information, without them taking on extra cognitive and physical burdens to search for this information independently. As inpatients experience rapid changes in their emotional state and information processing capabilities, presenting multimedia educational resources would help them to understand and remember their care.

Inpatient portals could also address situational impairments through the improved graphical representation of lab and test results, to help patients understand these results in terms of the 'big picture' of their health. Most patient portals currently present this information in table format, which impedes patients' ability to interpret their data [15]. Lab results plotted on a graph, coupled with visual cues for what is considered a normal or abnormal result, helps patients make sense of their data in a more meaningful way, without requiring excessive cognitive work [73]. Incorporating these graphical data representations into inpatient portals would offer greater value to patients such as AP13, who specifically wanted baseline values to better understand his test results. Patients might also benefit from comparing their results to other patients like themselves, to determine the normalcy of their experience [20, 56]. The inpatient portal could aggregate similar patients' data and present it as an optional data point on the same graph as the patient's, to help them gauge their recovery and progress relative to their peers. The use of such accessibility and visualization tools could allow inpatient portals to serve a broad range of patients that experience situational impairments during their hospital stay.

6 LIMITATIONS AND FUTURE WORK

Our findings reveal new opportunities to improve the design of future inpatient portals and address the unmet needs of patients in the hospital. However, we recognize some limitations to our study. For example, our study sites were based in an urban area of the United States and might not reflect findings from other geographic regions. Our participants' views also might not be representative of a larger, more diverse sample. Selection bias may have a role in our findings, as participants who chose to enroll in this study might be more engaged in their care than a typical inpatient.

Although incorporating the perspectives of other stakeholders (e.g., providers, hospital staff, EHR vendors) was out of our scope, the next phase of this work is to understand

these stakeholders' perspectives and determine how such technologies can incorporate the voices of patient without increasing the workload of other stakeholders. In addition, as inpatient portals become more prevalent in the hospital setting, researchers should explore how the design of these portals can overcome complex data privacy and access policies for specific patient populations (e.g., adolescents [61]) and reduce known disparities in their availability, adoption, and use [66].

7 CONCLUSION

In this paper, we present findings from a semi-structured interview study with 30 hospitalized patients and caregivers. In using feature cards to elicit our participants' perspectives on their informational and experiential needs in the hospital, we uncovered several ways in which existing inpatient portals do not meet these needs. Based on our findings, we discuss three major design implications for the future of inpatient portals to support patients in the hospital: (1) highlight patient-centric goals and preferences, (2) provide dynamic information about care events, and (3) design for situationally impaired users. Addressing these design implications in new versions of inpatient portals will help to guide the design of such technologies and could ensure their success among hospitalized patients. Furthermore, our design implications point to new avenues for patient-facing technologies to engage patients and recognize them as primary stakeholders in the quality and safety of their hospital care.

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