The Value of Patient-Peer Support in Improving Hospital Safety

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Abstract. Healthcare systems worldwide have dedicated several years, special attention, and action toward improving safety for their patients. Although many innovative technological solutions have helped providers reduce medical errors, hospitalized patients lack access to these solutions, and face difficulties in having a proactive role in their safety. In this paper, we examine how patient-peer support can be a valuable resource for patients in the context of hospital safety. Through semi-structured interviews with 30 patients and caregivers at a pediatric and an adult hospital, we identify the potential benefits of incorporating patient-peer support into patient-facing technologies. Facilitating such support can provide patients with new avenues for engaging in, and improving, the quality and safety of their hospital care.

Keywords. Patient safety, peer support, human computer interaction; user centered design; consumer health informatics; hospital; medical errors; technology.

1. Introduction

Every day, patients in hospitals around the world are impacted by medical errors and experience avoidable, and often deadly, harm. Ensuring the safety of patients has therefore been a priority for governments and healthcare organizations around the world [1]. To reduce medical errors, hospitals have implemented technological interventions—such as medication barcode scanners and Computer-Physician Order Entry—into their clinical workflows [2]. Although these interventions have demonstrated some degree of success, hospital safety remains an ongoing concern in healthcare systems. More work is needed to understand why these problems persist, and to explore additional opportunities for effective interventions.

In recent years, policy makers, organizational leaders, and researchers have increasingly acknowledged the importance of engaging patients in improving safety [3,4]. Indeed, patients have expressed willingness to be involved in their safety during their hospitalization, and have demonstrated proactive measures they take to protect against avoidable harm (e.g., double-checking medication labels, asking providers about hand sanitation) [5,6]. However, patients still face several systemic barriers when speaking up about concerns, and lack access to sufficient resources to help prevent errors [7].

The support of patient-peers is one potential resource that could help remove the barriers that patients encounter when attempting to engage in their safety. Patients who

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participate in peer support programs experience a number of benefits, including improved health outcomes, self-efficacy, knowledge, and empowerment, all of which can impact their participation in safety [8,9]. Moreover, previous studies have observed and identified opportunities for patients to exchange support addressing quality and safety issues in their care [10–12]. Despite great potential for patient-peer support to improve safety, systems that scaffold this support *within* the hospital are nonexistent. Thus, understanding patients' peer support needs in the context of hospital safety, and exploring ways to facilitate this support, are important next steps towards including patients as equal partners in improving hospital safety.

In this paper, we explore inpatient perspectives on how support from patient-peers could improve their safety during their hospital stay. Our findings from a semi-structured interview study with 30 inpatients and caregivers reveal new opportunities for patient-facing technologies to help patients take on a greater role in their safety.

2. Methods

Our study took place at two hospitals in the Pacific Northwest region of the United States: one children's hospital, and one adult tertiary care hospital. As part of a larger project to investigate the information needs and design requirements of a patient-facing mobile application, we conducted semi-structured interviews with 30 participants (12 pediatric inpatients, 3 parents of pediatric inpatients, and 15 adult inpatients). All participants were approached, consented for the study, and interviewed during their hospital stay. The study was approved by the authors' and study sites' Institutional Review Boards.

To prompt and motivate discussion during interviews, the research team developed a series of paper-based 'feature cards'. Each card represented a hypothetical feature of a futuristic patient-facing technology (e.g., setting reminders for medical events, estimated arrival time of providers coming to the patient's room) and were based on themes relating to the patient's hospital experience (e.g., patient-provider communication, learning more about my health). During the interviews, participants were asked to review and respond to each card. The research team member conducting the interviews asked follow-up questions—such as which cards they valued most, least, and why—as appropriate.

Each interview, lasting approximately 45 minutes, was audio recorded and transcribed for analysis. A research team member did an inductive, qualitative analysis of each participant's transcript to identify themes. These themes underwent discussion and iteration with other members of the research team. Below, we present findings for one particular feature card: "Frequently Asked Questions (FAQ) by patients like me". We focus on this card because it was specifically created to (1) explore design solutions for conveying useful safety information to patients, and (2) understand patient perspectives on peer information about hospital safety.

3. Findings

Twenty-nine out of thirty participants (97%) responded positively to the idea of having access to information from patient-peers on the subject of hospital safety. In the following paragraphs, we describe our how participants envisioned using this information to improve their safety. Each quote from a participant is accompanied by a unique identifier: YP# (Youth Patient), YC# (Youth Caregiver), and AP# (Adult Patient).

YC13, YC14, and AP9 believed that having FAQs from patient-peers would help them think of questions or concerns that they might not have otherwise considered. YP7 spoke to us about his desire to have the FAQ feature, and real-time, up-to-date information about his health, within the same mobile application. He saw FAQs from peers as a resource to think of questions for his care team, verify information that he received from his providers, and fill knowledge gaps that he might have about his care.

Many of our participants thought that the patient-peer FAQs could help patients and caregivers establish a 'baseline' experience to proactively recognize errors and avoid anomalies in their care. A subset of participants mentioned using FAQs to identify side effects, or allergic reactions, to medications that they might receive during their hospital stay. AP5 was undergoing chemotherapy at the time of his interview, and explained how FAQs from patients would reinforce the safety information that his care team had given him earlier during his extensive treatment. AP10, recovering from surgery, expressed interest in learning whether her medications *"make people feel nauseous or have like constipation..."* YC14 was caring for his two-year-old daughter in the hospital. He wanted to read FAQs from other patients who had similar medication allergies as his daughter, as the information would help him decide whether he should be more watchful for side effects, or outright refuse the administration of a potentially harmful medication.

Other participants interpreted this concept more broadly, seeing FAQs from peers as an opportunity to compare or align their own longer-term health experiences with other patients like themselves. YC15 was caring for her daughter with a respiratory infection, and wanted to determine patterns through general trends, such as, *"in the last 15 days or last one month, how many patients like that has been admitted, what is their experience, what kind of medications they got…I will be knowing that I'm not alone…"* AP13 was also interested in FAQs to understand the quality and safety of his long-term health. To manage his diabetes, he wanted to know the average patient's A1C levels, and what constituted a healthy blood count. He went on to say, *"I may want to know what happens if I go hypoglycemic, what happens if I do the opposite, and I'm too high."*

Related to the idea of long-term quality and safety of care, a few participants discussed the potential for FAQs from peers to be made available before, during, and after their hospital stay. AP12 suggested incorporating peer information as an educational tool into the pre- and post-surgery materials she received from her care team. AP8 mentioned having this information accessible before admission and after discharge, stating, *"I'd use that while I was in here [the hospital] and I'd use it while I was home."*

This information was considered valuable because, as some participants described, finding useful information from peers is burdensome and arduous for patients undergoing treatment from their hospital bed. AP15 was a surgical patient who talked about her unsuccessful attempts to seek out such information: *"I wanted to know how other people did, how [they] went through this [surgery]. Because…I was curious how other people dealt with this, and there's no way really to find that out."* (AP15)

Although most participants reacted positively to having access to FAQs from patient-peers, YP9 was not interested in this feature, and did not expand on her reasoning. AP8 spoke in more detail about the potential drawbacks of including such a feature in a patient-facing mobile application. She believed that keeping the FAQ content relevant, current, and accurate would be difficult. In addition, she thought that having someone available to answer all the questions that patients might have would be a technical and logistical challenge. Despite these concerns, AP8 still responded enthusiastically to the idea of exchanging support with other patients like herself.

4. Discussion and Conclusion

Our findings demonstrate the value our participants saw in FAQs from peers to improve hospital safety. Patients and caregivers thought their peers could help them discover new questions or concerns, verify their understanding about their care, and recognize when they experience a deviation from what is expected in their care. Although some drawbacks emerged from our discussions with participants, the benefits—such as proactively avoiding harm and maintaining long-term safety—were clear.

In previous work, we explored the needs, opportunities, and design recommendations for patient-facing technologies to enable peer support in the hospital [11,12]. The findings in this paper build upon that work by delving into peer support as an upstream patient-centered intervention to improve the quality and safety of hospital care *before* harms occur. Furthermore, patient-peer support is distinct from, and complementary to, the support that patients receive from their providers [13]. Thus, not only does patient-peer support help to underline the safety concerns that providers share with their patients, but it can be effective in ways that past safety campaigns and interventions have not.

Our participants discussed at length how experiential information from other patients could offer a form of emotional support (i.e., not feeling alone in their health journey) to help them feel safer in the hospital. However, patients face many challenges in seeking out this information through existing online health communities and other sources. For example, patients' cognitive and physical functions are negatively impacted by the medications, procedures, and equipment they manage in the hospital. Similar patients might be in rooms that are grouped closely within hospital units, but health privacy laws hinder their chances of meeting and interacting with each other. Patient-facing technologies that incorporate peer support features are uniquely positioned to overcome these challenges, and to make experiential information easily accessible to patients during their hospital stay. These features could accommodate shared experiences of past, present, and future patients, and connect patients across boundaries such as geographic location, diagnosis, and type of treatment.

Peer-support features can also help patients take proactive steps to improve their safety, before a medical error can cause serious harm. Our participants explained how practical advice from peers—including what side effects to watch for, recovery management, and care anomalies to be aware of—could help them avoid errors during their hospital stay. Such support goes far beyond the reactive measures (i.e., error reporting) that are sometimes triggered after emotional and physical harm have already occurred.

Patients have a key role in improving hospital safety, but need greater access to tools and resources that support their involvement in these efforts. Technologies that facilitate patient-peer support is one resource that can help patients identify, prevent, and report errors, while acknowledging them as experts and equal partners in their care.

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