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Patient-Peer Support to Improve Quality and Safety in the Hospital

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Abstract

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Patient safety is a critical and persistent problem impacting health care systems around the world. Despite major financial and technological investments to improve this problem, medical errors remain a leading cause of death in the United States. As experts in the care they receive, patients offer unique insights about the source of these problems and have key roles in their prevention. However, most interventions have not included patients as equal partners in safeguarding their own care.

Peer support is one type of intervention that recognizes the valuable insights patients could provide for each other to improve the quality and safety of their care. In many other health care settings, digital peer interventions have been implemented, and have demonstrated benefits such as increased knowledge, empowerment, and self-efficacy—many factors that also influence patient involvement in safety. Yet, we know little about how peer support might translate into the context of patient safety, particularly in a hospital setting.

In this thesis, I investigate how peer support technologies can improve the quality and safety of a patient's hospital stay. I first examine what opportunities exist for peer support in the hospital and articulate design recommendations for technologies to enable this support. I then describe my design, implementation, and deployment of a fully-functioning patient-peer support technology for the hospital setting. Finally, I show how patients used this technology and how it impacted their hospitalization. My findings reveal that peer support can be a powerful tool that equips patients with the support they need to navigate their hospital stay and can help patients take proactive steps toward improving the quality and safety of their care.

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1

INTRODUCTION

For two decades, patient safety has been recognized as a critical problem in health care systems around the world. In the United States alone, medical errors are the third leading cause of death, accounting for over 200,000 deaths each year (Makary & Daniel, 2016). As primary witnesses to the care they receive in the hospital, patients have unique perspectives on the problems that emerge during their stay, and could have a meaningful role in identifying, preventing, and reporting these problems. However, few resources are offered to patients during their hospital stay to fulfill this role. Many past interventions have either not aligned with patient perspectives on safety or have demonstrated limited efficacy.

Peer support could help patients engage in their safety in ways that past interventions have not. Research has consistently shown the positive effects of patient participation in peer support programs, including self-efficacy, knowledge, and empowerment in their care. Indeed, several components and benefits of patient-peer support have also been acknowledged as factors that influence patient involvement in their safety. Yet, little is known about the opportunities, value, and impact of peer support within the context of patient safety.

Technologies to facilitate peer support exist in many forms—such as mobile applications, short messaging service (SMS) pairings, online health communities, and social media—and have allowed patient-peers to easily exchange beneficial support. But most of these technologies are designed and developed for patients managing chronic conditions, or for patients interacting with peers in a non-hospital setting. Due to the high-risk, high-stress, and information-poor nature of

the hospital for patients (Kendall, Mishra, Pollack, Aaronson, & Pratt, 2015; Skeels & Tan, 2010), a number of unique design considerations must be made when creating peer support technologies for this type of clinical setting.

In this dissertation, I investigate how inpatient peer support technologies can serve as an intervention and resource to help patients improve the quality and safety of their hospitalization. I examine the opportunities for, and value of, inpatient peer support. I then design, build, and deploy a functioning inpatient peer support technology. I study how patients use this technology and what impact it has on their hospital stay. Findings from this research uncover inpatient peer support as a novel patient-centered safety intervention that can help to empower patients and elevate them as equal stakeholders in the quality and safety of their health care.

1.1 DISSERTATION AIMS

Over the course of this dissertation, I address the following aims:

Aim 1: Understand Patient and Caregiver Experiences with Undesirable Events. I focus on gaining a rich understanding of the types of quality and safety problems (which I refer to as Undesirable Events, or UEs) that patients and their caregivers (i.e., the family members and friends who care for patients) experience in the hospital. Based on their experiences, I reveal opportunities for effective patient-centered interventions.

Aim 2: Explore Needs and Design Recommendations for Inpatient Peer Support Technologies. I set out to explore what role patient-peers might have in improving the quality and safety of hospital care. I research what, if any, needs patients and caregivers have for engaging and exchanging support with their peers. I describe how these needs might improve

the overall quality and safety of their hospital care. I then identify design recommendations for technologies to enable peer support in the hospital environment.

Aim 3: Examine the Design, Use, and Impact of an Inpatient Peer Support Technology. I examine how the design recommendations identified in Aim 2 could be implemented in a real-world hospital setting. Through implementing and deploying a functioning inpatient peer support technology among hospitalized patients, I investigate how these patients use the technology, the nature of the peer support they exchange with each other during their hospital stay, and what impact this peer support might have on their hospital experience and the quality and safety of their care.

1.2 DISSERTATION SETTING

To achieve the three aims mentioned above, I conducted three studies—a survey study, interview study, and technology probe study—that I present in subsequent chapters of this dissertation. Each of these studies took place at two sites: one pediatric hospital, and one adult hospital. Both sites are located in a metropolitan area of the Pacific Northwest region of the United States. They collectively maintain over 800 beds and serve more than 25,000 patients per year from broad demographic and geographic backgrounds.

For each of the three studies, participants were eligible for enrollment and participation if they met the following criteria: were at least 7 years old, were comfortable communicating in English, and were well enough to provide informed consent. When applicable, parental consent was obtained for pediatric patients. All study procedures were approved by the University of Washington's and both hospitals' Institutional Review Board.

1.3 DISSERTATION OVERVIEW

I begin this dissertation in Chapter 2 by summarizing the related work in the Patient Safety, Medicine, Personal Health Informatics, and Human-Computer Interaction fields. Based on this review of the literature, I identify three key areas for future research, including the need to understand how patients experience quality and safety problems in their hospital care, the potential for peer support to serve as a patient-centered intervention to improve quality and safety, and the opportunity to study the design, use, and impact of inpatient peer support technologies in a real-world hospital environment.

In Chapter 3, I detail the methods and findings of a survey study with over 200 patients and caregivers. I reveal the range of quality and safety problems that these individuals experience, many of which are not communicated, or are invisible, to providers and hospital staff. I present a conceptual model derived from these patients' and caregivers' experiences and highlight the need for interventions that help these individuals take a proactive—rather than a reactive—stance toward quality and safety problems.

In Chapter 4, I integrate a subset of my findings from the survey study with results from a follow-up interview study. I show that patients and caregivers not only demonstrate a willingness to share advice with their peers regarding quality and safety problems, but also have several informational and emotional peer support needs during their hospital stay. In considering these needs and the complexity of the hospital, I develop a series of design recommendations for technologies to facilitate peer support in this setting.

In Chapter 5, I explain how I implemented my previously mentioned design recommendations to design and implement a fully-functioning inpatient peer support technology probe. I provide details about several important features that this technology probe enables, and what steps I took to prepare for its deployment at both hospital study sites.

In Chapter 6, I describe findings from the technology probe study. I show how patients used the technology probe and the nature of the advice that they exchanged with each other. I then report on the different ways in which the technology probe impacted the participants in this study.

Finally, Chapter 7 contains a summary of my key findings and contributions, as well as how they fulfill the three aims of this dissertation. In this chapter, I also acknowledge my study limitations, point to new areas for future research, and provide a concluding statement about my work.

2

RELATED WORK

I draw upon several knowledge domains in order to inform and guide my work, including from fields such as Personal Health Informatics (PHI) and Human-Computer Interaction (HCI). In this chapter, I describe the primary motivation of this dissertation. I summarize the problem of patient safety, what patient perspectives are on this problem, and their involvement in improving safety. I also examine the potential for peer support—and digital forms of this support—to involve patients in their safety, as evidenced by prior literature. I then highlight opportunities for further investigation within the overlapping research areas of patient safety and peer support.

2.1 THE PROBLEM OF PATIENT SAFETY

In 1999, the Institute of Medicine (IOM) published a landmark report, *To Err Is Human*. This report revealed that **medical errors**—defined as "the failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim"—were a silent but severe problem in the United States (US) health care system (Kohn, Corrigan, & Donaldson, 2000). The IOM estimated that between 44,000-98,000 people each year died in US hospitals as a result of these errors, while a great deal more suffered non-fatal harms. Not only were the personal costs of these errors considered incredibly high, but the financial and opportunity costs were thought to be upwards of $20 billion dollars. Moreover, the report called attention to intangible costs, such as patients' loss of trust in their health care system, and the psychological consequences of the errors they

experience. *To Err is Human* represented both a warning siren and a call to action for the US health care system.

In the two decades since the IOM issued their report, medical errors continue to be a problem in health care systems around the world. In 2002, the World Health Organization (WHO) deemed **patient safety**—defined as "the prevention of errors and adverse effects to patients associated with health care"—a mandatory area of improvement for global health care systems ("WHO | Patient safety," 2019). Yet, research as recently as 2016 strongly suggests the magnitude of medical errors is much greater than what was originally calculated by the IOM (James, 2013). Medical errors have been recognized as the third leading cause of death in the US (Makary & Daniel, 2016), and an estimated 1 in 10 patients are harmed while receiving hospital care (World Health Organization, 2017). By some conservative estimates, approximately half of the harm that patients experience is preventable ("WHO | Patient safety," 2019).

Despite billions of dollars spent and several resources invested since 2000 (World Health Organization, 2017), the problem of patient safety persists. A critical step towards improvement is in understanding the perspectives of those who encounter these problems firsthand: patients, and the friends and family members who care for them in the hospital (hereafter referred to as **caregivers**).

2.2 PATIENT PERSPECTIVES ON PATIENT SAFETY

Historically, patient and caregiver perspectives on safety have been gathered through two primary methods: incident reports that are submitted to the hospital (Howell et al., 2015), or survey instruments used to measure safety at different health care organizations (Khan et al., 2017). In many cases, their perspectives have been interpreted using clinicians' judgements to categorize the reported errors and to determine their severity (Daniels et al., 2012; Fowler et al., 2008; Solberg

et al., 2008). This approach has helped to identify errors such as needle injuries, poor pain management, nausea, and preventable infections.

However, patients and caregivers have much broader perceptions of what constitutes an error, beyond what is captured by the clinical lens. In addition to care-related problems, these individuals have been known to report problems dealing with miscommunication, unprofessional conduct, and the physical environment of the hospital (Montini, Noble, & Stelfox, 2008; O'Hara, Reynolds, et al., 2018; Southwick, Cranley, & Hallisy, 2015). These quality- and safety-related problems are sometimes collectively referred to as **Undesirable Events (UEs)**, and are rooted in the patient's overall hospital experience (Agoritsas, Bovier, & Perneger, 2005; Davis, Sevdalis, Neale, Massey, & Vincent, 2013; Schwappach, 2008). Research has repeatedly shown that patient experience is positively associated with patient safety (Doyle, Lennox, & Bell, 2013). Thus, for patients and caregivers, the concepts of quality and safety are tightly intertwined.

Patients and caregivers have valuable perspectives regarding quality and safety, but the range of problems they identify have been inadequately documented in hospital incident reporting systems (Weingart et al., 2005; Weissman et al., 2008). Studies have demonstrated that patient perspectives have minimal overlap with those of providers; and are largely missing from federal standards for safety event reporting (Collins, Couture, Dykes, et al., 2018; Lawton et al., 2015; Levtzion-Korach et al., 2010). Furthermore, patients and caregivers often face barriers—such as not wanting to question or burden their provider—that prevent them from speaking up and submitting reports about the problems they face (Fisher et al., 2018; Rainey, Ehrich, Mackintosh, & Sandall, 2013). As a result, several of the quality and safety problems they experience go unreported and are unacknowledged (Harrison et al., 2015). Surfacing these hidden problems and recognizing the perspectives of patients and caregivers is essential to improve the quality and safety of their hospital stay.

2.3 PATIENT INVOLVEMENT IN IMPROVING QUALITY & SAFETY

To solve the problem of patient safety, researchers and health care organizations have traditionally used the "find and fix" approach derived from James Reason's Swiss Cheese Model, where efforts are focused on identifying linear patterns between hazards and harms, and implementing top-down procedures to prevent these events (Reason, 2000). Because this approach yielded only limited improvements in niche areas of medical care, the field has more recently adopted a preventative "system resilience" approach to improving quality and safety (Braithwaite, Wears, & Hollnagel, 2015). System resilience involves the health care system's ability to flex and adapt to the dynamic risks of hospital care, and consists of developing solutions that optimize the system's successes rather than focus on its failures (Hollnagel, 2014).

Although creating system resilience to improve quality and safety is widely viewed as the responsibility of the health care system, patients and caregivers have a key role in helping to achieve resilience. This role can take on many forms, from reaching an accurate diagnosis, choosing an appropriate care provider, ensuring a treatment plan is adhered to, and identifying quality- and safety-related problems (Vincent & Coulter, 2002). Indeed, patients and their caregivers are frequently the first to detect lapses in their safety (Gallagher & Mazor, 2015), and successfully intervene in quality and safety problems that emerge in their care. For example, patients independently check their medication labels, self-disinfect hands and wounds when they notice a lack of hand hygiene among providers, coordinate information handoffs between providers, monitor their health status, and detect procedural errors (Schwappach, 2010; Unruh & Pratt, 2007). Patient participation in safety has been positively linked to quality of care and associated with a reduced risk of experiencing a quality or safety problem (Weingart et al., 2011).

Despite these benefits, numerous factors can inhibit patients' and caregivers' willingness to be involved in improving quality and safety. These factors include the societal norms and culture of the hospital, a lack of prior experience of illness and hospital visits, the severity of their health condition, the risk to their relationships with providers involved in their care, literacy levels, and the degree of perceived urgency of the problem (Davis, Jacklin, Sevdalis, & Vincent, 2007; Hrisos & Thomson, 2013; Longtin et al., 2010). To address these factors, researchers have called for patient- and family-centered interventions that enable and encourage their participation (Entwistle, 2007; O'Hara & Lawton, 2016). However, most of the patient-centered interventions that have been implemented to date are either designed to resolve problems that are unaligned with the breadth of UEs that patients and caregivers experience, or are insufficient in helping patients overcome the participation-inhibiting factors that they encounter (Bishop & Macdonald, 2017; Hall et al., 2010). Therefore, a substantial gap exists between patients' and caregivers' potential to be actively involved in improving their quality and safety, and the interventions made available to them.

2.4 IMPROVING QUALITY & SAFETY THROUGH PEER SUPPORT

Peer support is one type of intervention that can help to bridge the aforementioned gap but has not yet been explored in the context of improving quality and safety. **Peer support** encompasses the informational, emotional, or instrumental help that patients and caregivers exchange with each other in order to manage a health condition (Civan & Pratt, 2007; Dennis, 2003; Helgeson, 2003). This support is distinct from, and complementary to, the information that patients receive from their providers (Hartzler & Pratt, 2011).

Patients who participate in peer support programs consistently demonstrate positive outcomes such as increased self-efficacy, self-management, knowledge, empowerment, and improved

overall health (Campbell, Phaneuf, & Deane, 2004; Dale, Williams, & Bowyer, 2012; Embuldeniya et al., 2013; Heisler, Vijan, Makki, & Piette, 2010; Høybye, Johansen, & Tjørnhøj-Thomsen, 2005; Verheijden, Bakx, van Weel, Koelen, & van Staveren, 2005). Particularly, self-efficacy and self-management have been noted as outcomes that influence patients' participation in safety (Bishop, Baker, Boyle, & MacKinnon, 2015; Hibbard, Peters, Slovic, & Tusler, 2005), and can reduce the likelihood of experiencing a quality or safety problem (Panagioti, Blakeman, Hann, & Bower, 2017). Two pillars of peer support—a patient's experiential knowledge and their relationships with other patients—are also key variables that determine the patient's involvement in improving quality and safety (Duhn & Medves, 2018).

2.5 PATIENT-PEER SUPPORT TECHNOLOGIES

Patients and caregivers mainly participate in peer support through online information resources (Cline & Haynes, 2001; Fox & Jones, 2009). Online health communities and social media platforms are vehicles for peer support that help these individuals conveniently search and find relevant health information, share ideas about managing their care, and build up the emotional strength needed to cope with their health condition (Preece, 1998; Sarasohn-Kahn, 2008). This digital form of peer support allows patients and caregivers to share information within and across health conditions, geographic locations, and demographic characteristics (Frost & Massagli, 2008; Moorhead et al., 2013; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). In the context of patient safety, researchers have explored social media as a way to engage patients in improving quality and safety, as proxy reporting systems that capture the breadth of the patient and caregiver experience, and as measurements for quality and patient satisfaction (Campbell & Li, 2017; Nakhasi et al., 2016; Rozenblum, Greaves, & Bates, 2017).

Despite great potential for peer support technologies to involve patients and caregivers in improving quality and safety, this type of digital intervention is nonexistent in the hospital (i.e., **inpatient**) setting. Patients and caregivers have been known to get in-person help from peers when alerting providers to a problem (Duhn & Medves, 2018), and to ask their peers about medication side effects and other information during informal conversations and overlapping hospital visits (Kaziunas et al., 2015). In the medical literature, patient-peer support programs usually take place face-to-face or over-the-phone instead of online, and aim to measure a patient's clinical outcomes—such as readmission rates and treatment adherence—rather than their involvement in improving quality and safety (Dennis, Hodnett, Gallop, & Chalmers, 2002; Parent & Fortin, 2000; Patterson, Fleming, & Doig, 2018; Wodinski et al., 2017).

Research in the Personal Health Informatics and Human-Computer Interaction fields have extensively studied and implemented technologies that facilitate peer support (Friedman, Trail, Vaughan, & Tanielian, 2018; Huh, Liu, Neogi, Inkpen, & Pratt, 2014; Mamykina, Nakikj, & Elhadad, 2015; O'Leary, Schueller, Wobbrock, & Pratt, 2018), but these tools are typically designed for patients managing chronic conditions, are meant for use in every-day, non-hospital (i.e., outpatient) settings, or do not foreground the concepts of patient safety and UE prevention. Although peer support via online health communities and social media are theoretically accessible within the hospital, in reality, using technology and seeking out relevant peer information across thousands of online resources presents cognitive and physical burdens for patients who are experiencing side effects from their hospital care (Haldar, Mishra, Khelifi, Pollack, & Pratt, 2017; Morris & Karlson, 2011). Thus, more work is needed to inform the design of peer support interventions for patient and caregiver use in the hospital.

2.6 FUTURE RESEARCH IN PATIENT SAFETY & PEER SUPPORT

Based on the above review and analysis of the literature, I identified three key research areas that warrant further investigation. The first research area is understanding patients' and caregivers' experiences regarding the quality and safety of their care. While past studies have specified the types of UEs that patients and caregivers might notice over the course of their hospital stay, less is known about how these types of events unfold from their perspective. Additional research in this area could help to pinpoint when patient- and caregiver-centered interventions should be introduced during their experience to maximize the effectiveness of these interventions.

The second research area is examining peer support as a patient- and caregiver-centered intervention that could involve patients and caregivers in improving the quality and safety of their care. Findings from prior research suggest that core tenets of peer support—such as self-efficacy and self-management—could influence patients' and caregivers' participation in their safety. Yet, the explicit links between patient safety and peer support have not been fully studied. There exist opportunities to explore the value of peer support as an intervention that better aligns with patients' and caregivers' broader perspectives on quality and safety.

The third research area is investigating how a digital peer support intervention should be designed and implemented in the inpatient setting. Much of the literature regarding digital peer support takes place outside the hospital and connects patients who are managing chronic conditions (e.g., diabetes, cancer) or pursuing long-term health goals (e.g., weight loss). Because peer support is difficult to access and largely unavailable for patients and caregivers in the hospital, these individuals do not receive the benefits of peer support during what can be a disempowering and stressful care experience. Furthermore, digital peer support has not yet been implemented in the inpatient setting, and we know little about its value, use, and impact in this environment.

3

UNDERSTANDING PATIENT AND CAREGIVER EXPERIENCES WITH UNDESIRABLE EVENTS

A critical step towards building system resilience is in understanding patient and caregiver experiences with quality and safety issues in the hospital. Specifically, characterizing their experiences in managing UEs can reveal important insights for developing interventions that can support patients and caregivers in preventing UEs (O'Hara & Lawton, 2016). A number of frameworks have been produced to assess the problem of safety (Bouwman, Bomhoff, Robben, & Friele, 2016; Montini et al., 2008; Reader, Gillespie, & Roberts, 2014). These frameworks—which are used as taxonomies to identify and classify patient-reported events—largely rely on data contained in formal complaints that patients and their family members submit or use clinical definitions of medical errors as a lens to interpret this data. However, as described in Chapter 2, this lens has minimal overlap with patient perspectives, and patients often face obstacles in speaking up about UEs and reporting their concerns to their care team or hospital (Fisher et al., 2018; Rainey et al., 2013), suggesting that these frameworks do not fully reflect the nature of UEs that patients encounter. Therefore, less is known about patient and caregiver experiences with UEs, and when or how during their experience can interventions support them.

In this chapter, I answer these questions by presenting findings from a survey study with over 200 patients and caregivers. I describe how UEs manifest from the perspectives of patients and caregivers, their harmful impacts, and what actions these individuals take in response. Based on these findings, I introduce a conceptual model that surfaces new opportunities for interventions to support patients and caregivers during their experiences.

3.1 METHODS

I conducted a survey study to answer my research questions regarding inpatients' and caregivers' experiences with Undesirable Events, a term used in prior studies to capture patients' broader interpretations of errors (Agoritsas et al., 2005; Davis et al., 2013; Schwappach, 2008). In this study and in communications with participants, I defined the term **Undesirable Event (UE)** as satisfying the following three criteria: (1) a small or a big concern, (2) something that was unpleasant or caused harm, and (3) could have been avoided. Because my goal was to elicit patient and caregiver perspectives, I did not compare data from medical records, formal reports, or provider accounts of events.

3.1.1 Survey Instrument

I created a web-based, anonymous survey instrument consisting of 30 questions, asking details about patients' and caregivers' UE, overall hospital experience, and demographics (Appendix A). Survey participants were asked closed-ended questions such as, *were you a patient or caregiver at the time of the UE?* and *how long was your hospital stay at the time of the UE?* I also included three free text questions where respondents could describe (1) the event in their own words, (2) their opinion on what caused the event, and (3) the outcome of the event. Participants could write about an event that occurred during any previous hospital stay, not necessarily at the study site. The instrument was pilot tested several times to ensure readability and comprehension for participants of various ages—including children as young as 7 years old—and a range of education levels.

3.1.2 Recruitment and Procedure

I recruited a convenience sample of inpatients and caregivers across the medical and surgical services of both pediatric and adult hospital sites. I, with the help of a research team, approached patients and caregivers after they had spent at least one night in the hospital. Those who accepted participation and provided informed consent were administered the survey on an iPad. I and other research team members were available to answer questions and help the participant take the survey, if needed.

3.1.3 Data Analysis

I led a multi-stage qualitative analysis of responses to the three free text survey questions previously mentioned. An open-coding approach was used to develop a preliminary codebook of types of UEs and harms (Strauss & Corbin, 1998). During recruitment, I regularly met with a colleague—Sonali Mishra—to discuss new survey responses, identify emerging themes, and iteratively edit the codebook. This analysis continued until saturation was reached and recruitment concluded. We both then tested the codebook's validity by deductively assigning codes to a random sample of 20% of responses. The codes and definitions were revised, another random sample of 10 responses were coded, and interrater reliability was achieved (Cohen's kappa=.815, percent agreement=96.3%). The entire data set was re-coded with the revised codebook. I then examined which codes appeared together in individual responses, identified patterns of coappearing codes, and developed a conceptual model characterizing the relationships between these codes.

	n (% total)		
	Pediatric Site	**Adult Site**	**Total**
Completed Responses	146 (59.3)	100 (40.7)	246 (100)
Patients	*56 (22.8)	79 (32.1)	135 (54.9)
Caregivers	90 (36.6)	21 (8.5)	111 (45.1)
Gender Identity			
Female	108 (43.9)	53 (21.6)	161 (65.5)
Male	37 (15.0)	46 (18.7)	83 (33.7)
Other/No Answer	1 (0.4)	1 (0.4)	2 (0.8)
Age in years			
7-18	48 (19.5)	0 (0.0)	48 (19.5)
19-24	12 (4.9)	2 (0.8)	14 (5.7)
25-44	67 (27.2)	17 (6.9)	84 (34.1)
45-64	16 (6.5)	45 (18.3)	61 (24.8)
65+	1 (0.4)	36 (14.6)	37 (15.0)
No Answer	2 (0.8)	0 (0.0)	2 (0.8)
Education			
8th Grade	17 (6.9)	0 (0.0)	17 (6.9)
High School/GED	25 (10.2)	19 (7.7)	44 (17.9)
Some College	18 (7.3)	19 (7.7)	37 (15.0)
Two- or Four-Year Degree	44 (17.9)	36 (14.6)	80 (32.5)
Graduate/Professional	17 (6.9)	24 (9.8)	41 (16.7)
None/No Answer	25 (10.2)	2 (0.8)	27 (11.0)
Race/Ethnicity**			
White/Caucasian	109 (44.3)	79 (32.1)	188 (76.4)
Black/African American	8 (3.3)	5 (2.0)	13 (5.3)
Hispanic/Latin American	16 (6.5)	5 (2.0)	21 (8.5)
Asian	17 (6.9)	6 (2.4)	23 (9.3)
Native American/Pacific Islander	12 (4.9)	4 (1.6)	16 (6.5)
Other/No Answer	17 (6.9)	7 (2.9)	24 (9.8)
Overnight hospital stays within the last 5 years***			
Less than 10 stays	84 (34.2)	69 (28.0)	153 (62.2)
More than 10 stays	58 (23.6)	30 (12.2)	88 (35.8)
No Answer	4 (1.6)	1 (0.4)	5 (2.0)
Type of stay at the time of UE			
Planned	45 (18.3)	39 (15.9)	84 (34.2)
Unplanned	101 (41.1)	61 (24.8)	162 (65.9)
Length of stay at the time of UE			
7 days or less	94 (38.2)	69 (28.1)	163 (66.3)
8 days or more	45 (18.3)	29 (11.8)	74 (30.1)
Unsure	7 (2.9)	2 (0.8)	9 (3.7)

Table 1. Summary of survey participant demographics across hospital study sites.
**Two caregivers of pediatric patients submitted responses about their experience as a patient.*
***Participants could select more than one category.*
****At the time the study was conducted in 2016.*

3.2 PARTICIPANTS

Over the course of 5 months, I approached 606 hospitalized patients and caregivers across both pediatric and adult hospital sites. Of those approached, 312 (51.5%) were considered eligible for the study, 70 of whom declined participation due to illness or privacy concerns. The remaining 242 patients and caregivers agreed to participate and completed the survey, yielding a response rate of 77.6%. I received a total of 246 responses, as some individuals provided more than one response about separate UEs. Table 1 summarizes the participant demographics.

3.3 RESULTS

The participants in this study reported their encounters with a broad range of UEs and their resulting harms. Specifically, the analysis process drew out four distinct stages that patients and caregivers experience with regards to these UEs and harms. In the following sections, I describe each of these stages and the types of UEs and harms involved. I also include illustrative quotes and examples from participants (noted with the unique identifier S#).

3.3.1 Stage 1: Occurrence of Undesirable Events

The first stage consists of patients and caregivers recognizing that one or more UEs have occurred in their care. These UEs largely fell into two categories: clinical and non-clinical. Clinical UEs refer to problems in the administering of the patient's hospital care, and can include a patient identifying faulty medical equipment, a mistake in a medication prescription, a misdiagnosis, inadequate diet or nutrition, and an unexpected deviation from agreed-upon treatment protocols. Non-clinical events, on the other hand, involve quality-related aspects of a patient's hospital stay that can sometimes impact clinical care. These non-clinical events were made up of three subtypes that were present in my analysis: miscommunication, institutional barriers, and lack of respect.

Tables 2 and 3 provide summaries of the subtypes, definitions, and particular examples of both clinical and non-clinical UEs. Although the combinations of events were unique and varied, I found their subtypes to be interrelated and to exacerbate each other's occurrence.

One miscommunication event can lead to further miscommunication among patients, caregivers, and providers. For example, participants recalled breakdowns between providers that resulted in patients and caregivers not receiving critical care information. Others thought that *"poor bedside manner"* led providers to convey inaccurate or misleading information about the patient's care. S78 was caring for her child when a doctor she had never met entered the room. She described, *"[the doctor] discussed worse case scenario treatment options in a very casual fashion without consulting the rest of the [care] team. He was not a doctor in charge of making treatment decisions but more of a consult however didn't identify himself that way."*

Miscommunication events are also interconnected with institutional barriers, which are defined as UEs originating at the organizational level of the hospital, of which patients and caregivers experience the downstream effects. These barriers involve logistical or scheduling failures between hospital departments, poor use or design of Electronic Health Records (EHRs), and policies that burden patients and caregivers. S102 brought her diabetic mother to the hospital to treat abnormally high blood sugars. During the hours spent in the Emergency Room, providers repeatedly forgot to measure the patient's blood sugar levels. This miscommunication between providers resulted in S102's mother's delayed insulin treatment, long after she was assigned a hospital bed. In another example, S246 witnessed a planned upgrade to the hospital's EHR system that went poorly and caused communication breakdowns between her providers. She wrote, *"[N]urses and docs were unable to chart patient info and their communication with each other and other departments was severely impaired…it was outrageous."*

Types of clinical UEs	% Total Responses	Definition	Representative Quote
Medications	24.0	Mistakes in prescribing or administering medications to patients	***[Patient] was administered IV chemotherapy at over twice the prescribed rate***. (S162)
Medical equipment	17.9	When medical equipment used in patient care malfunctions or is mishandled	***High flow not working properly because of loose connections and faulty parts***. (S33)
Treatment protocol	10.2	Unexpected deviations in treatment protocols	***Nurse did not remember to put on gloves or sanitize hands prior to dispensing medication.*** (S198)
Delayed or misdiagnosis	6.9	Uncertainty or incorrect judgement regarding the patient's diagnosis	***A [provider], unfamiliar with my child's complex medical history, made a misdiagnosis*** *about my son's absolute low neutrophils.* (S103)
Natural cause	8.9	Natural, and sometimes unexpected reactions patients have to treatment	***Treatment caused unknown reactions*** *and trip in night to [the ER].* (S80)
Hospital Acquired Conditions (HACs)	6.5	Additional medical conditions that the patient experiences due to their presence in the hospital (e.g., falls, hospital-specific infections)	***Staph infection following surgery****…required an additional surgery to patch a bursa sac on my shoulder.* (R227)
Inadequate diet or nutrition	3.3	Deficiencies in nutrition or hydration during patient or caregiver's hospital stay	***I bit into the [meal] and it was like eating pure salt…I'm on a salt restrictive and water restrictive diet. I didn't eat for the rest of the night.*** (S287)

Table 2. Summary of clinical UEs identified through a qualitative analysis of free text survey responses.

Miscommunication events and institutional barriers can both lead to a lack of respect from providers or the healthcare organization. Patients and caregivers might be forced into making decisions that are incongruent with their values, feel disempowered due to their physical environment, or experience unwanted restrictions—or a lack of consideration for—their ability to engage in their care. S184's providers did not communicate with each other before calling her about an important care decision during her intravenous (IV) placement. She said this event *"made the process confusing and frustrating during a time when I really wasn't in a position to make big decisions."* Another participant, S26 was caring for her child in the Neonatal Intensive Care Unit (NICU) when her family was asked in the middle of the night to relocate and make room for another patient. This lack of care coordination disrupted their sleep and put the family in a room

that did not suit their needs. S26 explained, *"This transition would have been a lot more respectful and courteous with some warning…when we aren't sleeping and recovering from severe trauma."*

Types of non-clinical UEs	Subtypes of UE	% of Total Responses	Definition	Representative Quote
Miscommunication	Breakdowns between providers	19.5	Inadequate communication among individual members of the care team	*The hospital advertises the 'team medicine' concept but sometimes* ***the team members are not following the same game plan.*** (S171)
	Lack of information	14.2	Care-related information is not communicated to patients and caregivers	***No real information was provided*** *about [my son's] …****Large lack of parent/provider communication.*** (S105)
	Inaccurate information	7.7	Information is wrong or presented as more reliable than it actually is	*I thought I was coming in for a simple surgery…but really* ***it was more complicated than they let on.*** (S141)
	Lack of empathy	28.1	How a provider communicates is reflective of poor bedside manner or a lack of compassion	***The provider was mean and she tried to undermine my pain.*** *She was rushing and wasn't personal, not compassionate.* (S219)
Institutional Barriers	Lack of care coordination	17.9	Conflicting or delayed schedules; logistical failures	***Scheduled test delayed from 9:30am to 5pm but was delayed one hour at a time with no explanation.*** (S179)
	Poor use of EHRs	4.1	EHR design, usability, access, and dependencies that negatively impact care	***Nursing staff did heavy time for electronic documentation and very little attention to the patient.*** (S175)
	Burdensome policies	5.7	Organizational rules that negatively affect patients and caregivers	***I was denied service for 2 to 3 days*** *before they start[ed] on me* ***because of insurance****.* (S269)
Lack of Respect	Capacity to make decisions	2.4	Patients' or caregivers' ability to make critical care decisions is restricted or not considered by the care team	*I was given too much pain medication.* ***I was not competent after the procedure to be reliable when asked, 'is your pain still a 7?'*** (S96)
	Comfort of hospital environment	8.1	Physical surroundings of the hospital negatively affect patients' and caregivers' experience	***It was uncomfortable the whole time, bad blankets bad beds.*** (S18)
	Personal privacy	2.4	Patients and caregivers struggle to establish personal boundaries with hospital staff	***[I] just don't like people touching me without asking****…they think because I'm a kid they don't have to ask…*(S37)

Table 3. Summary of non-clinical UEs identified through the qualitative analysis of free text survey questions.

In some cases, these non-clinical events can trigger clinical UEs (e.g., a communication breakdown between providers can lead to an incorrect order for a medication that is later administered to the patient). When patients and caregivers experience both non-clinical and clinical UEs, the events heighten each other's perceived severity. Upon her admission, S21's request for a type of manual therapy was denied due to hospital policy. This negative experience worsened her impression of a series of clinical events that she later experienced (*"daily inhaled meds were missed"* and *"blood sugar was rarely checked"*). As these problems accumulated throughout her hospital stay, S21 felt her input was increasingly ignored by her care team. Her health did not improve, and after discharge, she was readmitted to another hospital.

3.3.2 Stage 2: Opportunity for Intervention

After patients and caregivers recognize UEs, they sometimes have an opportunity to intervene before harms emerge. Such interventions include expressing their concerns directly and repeatedly to providers, asking for justifications of care decisions, or requesting involvement from higher level staff and third-party representatives (e.g., patient-family representatives, legal counsel) to mediate conflicts. Caregivers also advocate on the patient's behalf to relay their worries to providers when needed.

After patients and caregivers intervene, one of two possible scenarios happen. The first is that the patient's or caregiver's intervention is recognized by their providers, prompting each party to collaborate efficiently, properly address the concerns that were raised, and reach a resolution together that avoids potential harm. S131 experienced this when he was in *"agony"* from a urinary retention problem and repeatedly asked for a bladder scan and catheter. After some persistence, a

nurse finally acknowledged the issue, conducted the bladder scan, contacted the attending doctor, and catheterized S131 *"within 5 mins"*, mitigating further unnecessary harm.

In other cases, the patients' and caregivers' attempt to intervene is not heard. Several participants alerted their providers to parts of their hospital care that did not seem right or questioned a decision that contradicted their own expertise. Pediatric patients who were skilled in managing their health requested treatment modifications to prevent anticipated harms. Despite these efforts, the participants' concerns were denied or unaddressed. S34 described a similar experience as her son's caregiver: *"the wrong medication was prescribed and given for 6 days. Despite my concerns of no improvement in my child's symptoms…[providers] were dismissive to my own experience and history with my child, leaving enormous room for error."* For S50, these unaddressed concerns led to additional clinical UEs. S50 requested a Peripherally Inserted Central Catheter (PICC) line due to her child's complicated medical history of being unable to hold an IV line. Her request was rejected, and the patient *"suffered multiple failed attempts to place new IV lines"*.

It is important to note that not all patients and caregivers experience this second stage, as opportunities to intervene do not always present themselves after UEs. Some participants did not have these opportunities because they felt too vulnerable to speak up, were not fully aware of their rights in the situation, or the urgency of care decisions meant the *"damage was done"* before any chance of prevention.

3.3.3 Stage 3: Emergence of Harms

When patients and caregivers are unable to bring attention to UEs, or if their concerns are not heard, harms will emerge as a consequence of these UEs. For example, S285 unsuccessfully tried convincing his providers that he had symptoms after a gallbladder surgery. When his concerns

were not addressed, he visited the ER and discovered severe damage that required three months of reconstructive surgery and blood clot removals.

S285's additional care is a type of a visible harm, which are tangible clinical consequences that are commonly recognized by providers. However, patients and caregivers can also experience invisible harms, which are typically unnoticeable by or unreported to hospital staff. S67's child, for example, was not admitted to the hospital despite orders from their primary care doctor. Without an opportunity to question the decision, S67 took on the additional burden of driving for several hours to admit his child to the next-closest hospital. More examples of both invisible and visible harms are provided in Table 4.

My analysis of the data also suggested an interplay between invisible and visible harms. Specifically, when participants described a visible harm, an invisible harm often followed. This relationship was most evident when participants described a decline in health or experienced pain or discomfort due to UEs. These visible harms led participants to feel negative emotions (e.g., fear, anxiety, helplessness, emotional trauma), and a deterioration of trust in their care team. S267 experienced several delays in receiving her medication that resulted in visible harm. She became frustrated with the situation and felt *"a huge amount of both physical and emotional pain, and loss of confidence and trust in my care team."*

After harms emerged, some participants described taking time to process or reconcile the experience that the just endured. Others mentioned waiting for a dependency—such as a test result, or a second opinion from a provider—before deciding to take action.

Types of Harms	Subtypes of Harm	% of Total Responses	Definition	Representative Quote
Invisible	Negative emotions	26.8	Feelings that patients and caregivers experience after UEs (e.g., fear, anxiety, loneliness, helplessness)	*I was in an extreme state of panic and* ***[the event] has made me fear other surgical procedures.*** (S129)
	Loss of trust	3.3	Patients' and caregivers' confidence in their providers and healthcare system is undermined	*I wasn't nervous until they put [on] the mask…I was rushed. All the doctors said different things.* ***Who are you supposed to trust???*** (S156)
	Life burdens	11.8	Aspects of patients' and caregivers' home lives that are affected by UEs (e.g., financial stress, finding child care for young siblings of patients)	*Our local hospital back home…is not equipped to handle such conditions that my daughter had…****My husband and I have since moved…with our kids for our daughter's treatments.*** (S148)
Visible	Pain or discomfort	27.6	Pain resulting from a procedure, poor pain medication management, and other forms of physical discomfort (e.g., bruising, lack of sleep)	*I went to get my port placed and [the nurse] jammed it in and* ***it hurt so bad…I was in pain and it left a bruise.*** (S181)
	Decline in health condition	24.8	The general health or condition of the patient worsens	***My dad's condition worsened*** *in my opinion due to a lack of nursing observation on the patient.* (S175)
	Delay in care or discharge	17.1	The delayed administration of time-sensitive, critical care; setbacks in the discharge process	*The pharmacy had difficulty obtaining my insulin…****medication was finally administered but it took at least 24 hours.*** (S223)
	Additional care or readmission	16.7	Patient requires more care than originally expected, or is readmitted for problems due to UEs	*Had infection in shunt fluid…****they needed emergency surgery to help defeat my infection****.* (S223)
	Affected diet or nutrition	3.7	Dietary consequences due to treatment or inadequate nutrition	*Patient was not given food until 1:30am…****was hungry*** *and distressed* ***as a result.*** (S218)

Table 4. Summary of invisible and visible harms identified through the qualitative analysis of survey responses.

3.3.4 Stage 4: Reaction and Response

After patients and caregivers make a decision to respond to the UEs and harms experienced, they take one of two actions. The first is that patients and caregivers take steps to transfer hospitals or request new providers to be involved in their care. Participants who had serious conflicts with individual care team members asked that they not be involved in their care for the remainder of their hospital stay. S201 was frustrated with the *"large highly matrixed organization with busy*

people," and this impression *"reduced patients [sic] confidence in patient care model. Patient switched to another hospital system with better communication to patients."* In some cases, however, this decision to change hospitals was forced upon the participant, rather than it being their choice. This scenario occurred when patients were denied additional care, like S243 whose providers thought she was *"faking pain. And literally kicked me out of the [hospital]."*

The second action is when patients and caregivers report harms to their providers or hospital. For example, many participants described bringing harms to the attention of their care team. Although participants were encouraged by hospital staff to submit formal complaints, they encountered barriers in doing so. S19 experienced a lack of empathy from a nurse who ignored her child's cries for help. She was told that her doctor would help her file a report about the UE, but *"it never happened."*

In a smaller subset of cases, providers involved in the UEs and harms would initiate apologies to the patient and make improvements in handling future harms. S124's child's *"heart stopped"* due to breakdowns between providers. After this serious event, S124 described *"improved communication among doctors and the teams were told to listen to the parent."* For other participants, these improvements were a direct result of their report. S135 was an adolescent patient who reported her experience to her local health department and news channels, prompting an investigation and retraining of hospital staff. However, not everyone who submitted a report was informed of how their feedback was addressed, if at all. S63 was a caregiver who successfully intervened in a UE by stopping her care team from administering treatment to the wrong patient in their shared hospital room. Although she submitted a report, she was disappointed in the lack of updates: *"I don't know at this point if [the] team has been talk[ed] to. It would be nice to know that the follow-up continued that far."*

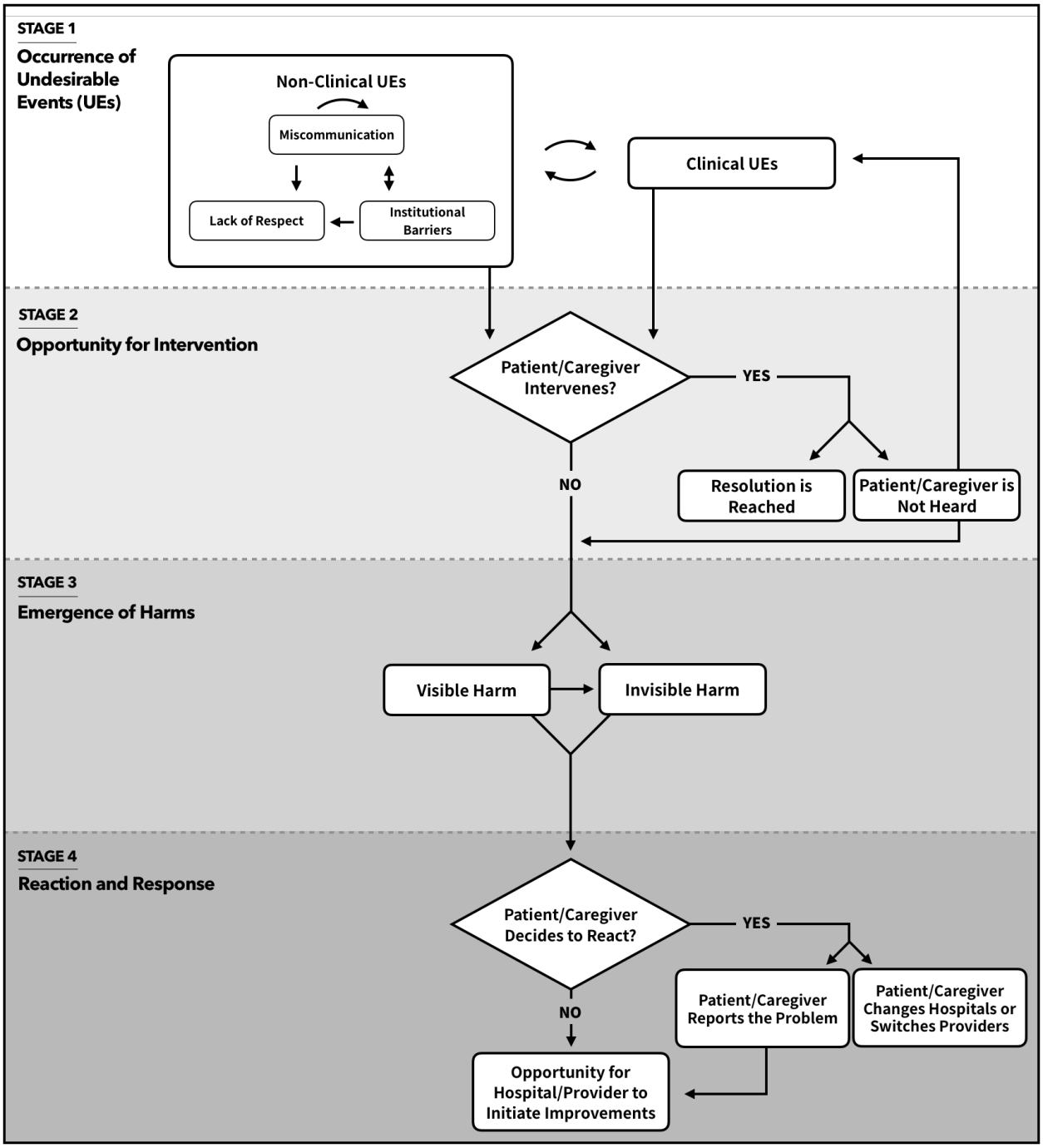

Figure 1. Conceptual Model of patient and caregiver experiences with UEs. Each of the four stages is depicted, in addition to the individual UEs, harms, and steps that patients and caregivers take to intervene and respond to these problems.

3.4 DISCUSSION

Based on the findings described above, I developed a conceptual model that depicts the events, harms, interventions, and responses from patients and caregivers, as well as the relationships between these elements (Figure 1).

The model builds on prior work by conceptualizing patients' and caregivers' experiences regarding hospital safety. Specifically, the model adds new knowledge in two ways. First, it reveals when patients and caregivers have an opportunity to intervene and respond to UEs or harms during their experience. Second, it describes the specific actions that patients and caregivers take and how these actions unfold after experiencing a UE. Some participants took actions—such as speaking up about a UE, requesting a second opinion or care preference, and submitting a report about harms—and were successful in mitigating negative consequences. However, many other participants' attempts were dismissed, or their feedback was ignored. Although patients and caregivers have been known to encounter barriers that prevent them from speaking up about mistakes in their care (Bell et al., 2018; Tarrant, Leslie, Bion, & Dixon-Woods, 2017), the model shows that barriers can also exist in spite of their speaking up, yielding additional UEs and harms, and increasing the challenge of their participation in safety.

Moreover, I demonstrate the breadth of UEs and harms, as well as their compounding relationships. This contribution moves us closer to understanding patients' holistic experience of quality and safety across the wider health care system (Lachman, 2019; Trbovich & Vincent, 2018). These findings also support the recognition of non-clinical UEs as "little" problems that—although typically overlooked—are early warning signs for negative downstream events (Armitage et al., 2017; Fitzsimons & Cornwell, 2018; Sahlström, Partanen, & Turunen, 2018). Moreover, negative emotions were the second most prevalent harm among participants, suggesting these invisible harms are comparable in severity to visible harms that patients endure. Despite this

high prevalence, emotional harms are rarely acknowledged, nor are they sufficiently captured in error reporting mechanisms (Sokol-Hessner et al., 2018). Inadequately addressing such emotional harms can negatively affect patients and caregivers for years after the event itself (Ottosen et al., 2018).

The goal of this conceptual model is to uncover new opportunities for patient- and caregiver-centered interventions that overcome the barriers to their involvement. Typically, patient-centered interventions have focused on soliciting feedback or optimizing the error reporting process, corresponding to the fourth "reaction and response" stage of the model (King et al., 2010; Mitchell, Schuster, Smith, Pronovost, & Wu, 2016; Sheard et al., 2014). In this stage, providers and hospitals occasionally take steps to resolve problems—with or without the patient submitting a formal report—but these steps are taken after harms have already caused their damage. Preventative solutions are increasingly available for healthcare organizations and providers to implement into their workflow (Gandhi et al., 2018). Yet, patients and caregivers are rarely offered a similar caliber of preventative tools in this context, beyond encouragement to speak up if they suspect a problem. Thus, the earlier "opportunities for intervention" stage of the model demonstrates a clear gap between what reactive resources are currently available to patients and caregivers, and what tools they need earlier in their experience to proactively intervene in UEs and prevent harms.

Patient-facing technologies—such as inpatient portals, and inpatient access to OpenNotes—are examples of interventions that have created opportunities for patients and caregivers to have a greater role in their safety, allowing them to alert providers about errors in their care plans (Grossman, Masterson Creber, Restaino, & Vawdrey, 2017; Woollen et al., 2016). Mobile applications that are co-designed with patients and caregivers can also serve as an opportunity to involve them in medication reconciliation, real-time error reporting, and surgical checklist processes (Couture et al., 2018; Prey et al., 2018; Stolk-vos, Steen, & Drossaert, 2018). Making

these interventions widely accessible to patients and caregivers could further include them in developing strategies to avoid harm.

While the above examples describe existing solutions, the findings also suggest new opportunities for patient-facing technologies. For example, as patients and caregivers experience each stage of the model, they accrue knowledge and expertise about how to navigate UEs and harms. Throughout their experience, this information might never be shared outside of the patient-caregiver dyad and hospital staff but could be valuable for those who have not yet experienced UEs in the hospital. Research has demonstrated that support from patient-peers can help in making informed care decisions (Hartzler & Pratt, 2011; V. Lee, 2017). Patients have strong needs for—and sometimes actively seek out—this peer information during their hospitalization (Haldar et al., 2017; Haldar, Mishra, Khelifi, Pollack, & Pratt, 2018; Kaziunas et al., 2015). Future interventions could incorporate patient-peer support and examine its impact on patient and caregiver decisions to intervene in their safety.

When exploring opportunities for new interventions, the model can be used as a guide to scaffold the intervention based on the particular stage the patient or caregiver is experiencing during their hospital stay; or can be used to identify what element of the model should be targeted by the intervention. Such interventions could provide paths for patients and caregivers to 'reach in' early enough in their experience to positively influence the outcome, and help them engage in their safety on their own terms (O'Hara, Aase, & Waring, 2018).

Because the model is a representation of patient and caregiver experiences, several factors can shape this experience. For example, how providers choose to disclose the nature of UEs and harms can result in patients having different understandings and perceptions about the severity of these problems (Gallagher, Waterman, Ebers, Fraser, & Levinson, 2003; Hannawa, 2014; Mazor et al., 2013). Ambiguity in how safety terms (e.g., adverse events vs. medical errors vs. UEs) are defined

can cause challenges in recognizing and addressing these events (Vincent & Amalberti, 2015). Individuals also have varying thresholds for tolerating events, leading to further differences in what constitutes an event or harm (Sokol-Hessner, Folcarelli, & Sands, 2015). Finally, compensations made by patients, caregivers, and providers to avoid harm are not always apparent to others and influence their perspectives about those responsible for the harm (Vincent, Burnett, & Carthey, 2014). Refining the model to clearly illustrate the impacts of these factors on patients' and caregivers' experiences can unearth novel opportunities to be targeted by patient-centered interventions.

3.5 CONTRIBUTION

In this chapter, I presented a qualitative analysis of survey results to understand patient and caregiver experiences with UEs and harms. Based on this analysis, I developed a conceptual model that represents the shared experiences of over 200 participants. The model, consisting of four stages, reveals a great need for interventions that patients and caregivers can use to proactively prevent—rather than reactively report—the events and harms they experience. Future interventions must support patients and caregivers as equal partners in improving quality and safety. In the next chapter, I explore how patient-peers can serve as an intervention and resource to improve quality and safety.

4

EXPLORING NEEDS AND DESIGN RECOMMENDATIONS FOR INPATIENT PEER SUPPORT TECHNOLOGIES

Findings from the previous chapter revealed that there are upstream opportunities for interventions to improve patients' and caregivers' hospital experience and support them in preventing UEs. In this chapter, I explore peer support as one type of intervention that could improve the quality and safety of a patient's hospital stay. For the remainder of this dissertation, I define **peers** as people with similar health and hospital experiences.

As discussed in Chapter 2, patient involvement in safety and peer support are mutually influenced by factors such as self-efficacy, self-management, experiential knowledge, and relationships with other patients. Prior work has also demonstrated that patients see value in peer support to improve their safety, by helping them to fill knowledge gaps and recognize deviations in their care (Haldar, Mishra, Khelifi, Pollack, & Pratt, 2019).

Although technologies to facilitate peer support exist in many forms—such as SMS pairings, social media, online communities, mobile applications, and other dedicated tools—peer support interventions in the hospital typically consist of support groups and mentoring dyads that take place over the phone or in person (Parent & Fortin, 2000; Patterson et al., 2018; Wodinski et al., 2017). Despite the potential for technologies to enable peer support in the hospital, questions still remain about the nature of this peer support, how previously successful models of peer support might translate into the inpatient setting, and what unique design considerations must be made for hospitalized patients and caregivers.

In this chapter, I present data from a survey and interview study to determine what needs patients and caregivers have for peer support during their hospital stay, and what potential barriers exist to their using a peer support technology. Based on these findings, I describe a series of design recommendations for patient-peer support technologies in the hospital setting.

4.1 METHODS

4.1.1 Survey

As part of the survey instrument for the study mentioned in Chapter 3, one specific question was included that focused on the concept of peer support: *What advice would you give to others who might have had an [undesirable] event like [yours] in the hospital?* The purpose of this question was to understand the participants' knowledge gained through their hospital experience, and whether or not they were willing to share this knowledge with their peers. Because this question about peer support was incorporated into the survey instrument described in Chapter 3, the study procedures and recruitment strategies were the same as what was previously described.

4.1.2 Semi-Structured Interviews

In response to the survey question about peer support mentioned above, many participants wrote detailed advice for patients and caregivers. My initial review of this data revealed an opportunity to further explore the concept of inpatient peer support, beyond the specific topic of undesirable events in the survey. I conducted semi-structured interviews with inpatients and caregivers to (1) assess their interest in engaging with peers during their hospitalization, and (2) identify any unmet needs or design requirements that an inpatient peer support tool should accommodate (Appendix B).

To motivate the discussion during interviews, I created six feature cards that served as a design probe. Each paper-based card represented hypothetical features of an inpatient peer support tool (Figure 2). These cards contained statements that represented types of advice our survey participants provided, as well as specific features of a system (e.g., sharing advice with a peer, applying filters to find peers).

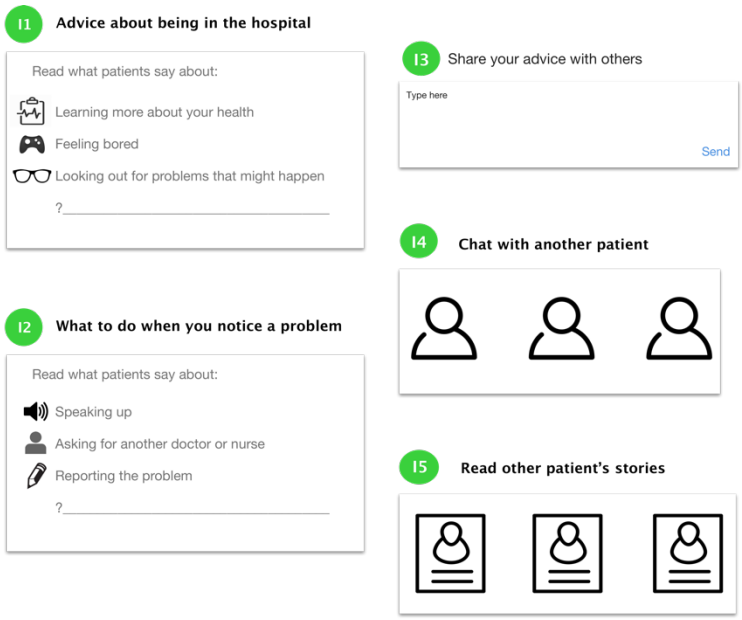

Figure 2. Examples of feature cards that were shown to participants during semi-structured interviews.

All interviews were conducted with patient and caregiver participants at their bedside during their hospitalization. In each interview, I would present the feature cards and explain their function. I would then ask the participant what they thought about the cards, how they envisioned using the cards, and what they did or did not value about the cards. For example, if patients said they were interested in chatting with another patient, I would follow up by asking why they were interested, and what they would want to chat with the other patient about. For their time, each participant was

compensated $25. Interviews lasted approximately 40 minutes, were audio recorded, and transcribed for analysis.

4.1.3 Data Analysis

I used an open coding approach to analyze both the responses to the survey question about peer support, and the semi-structured interview data (Strauss & Corbin, 1998). I did several rounds of coding to identify emerging themes in both data sets, which represented either a type of peer support need, or a barrier to using a peer support tool. During each round of coding I also used memoing to document observations, discrepancies, and new themes that were brought to the remainder of the research team for discussion, and subsequently incorporated into the codebook. The entire data set was then re-coded with the new codebook, and I compared the common and distinct themes between the survey and interview data sets.

4.2 PARTICIPANTS

Of the 246 responses to the survey instrument described in Chapter 3, 217 (88.2%) responses provided a written answer to the question, *What advice would you give to others who might have had an [undesirable] event like [yours] in the hospital?* The demographic characteristics of this subset of the survey respondents are summarized in Table 5.

Semi-structured interviews were conducted with a total of 30 participants across both hospital sites. Of these 30 participants, 12 were pediatric patients between the ages of 7-17, three people were caregivers of pediatric patients between the ages of 25-44, and the remainder consisted of 15 adult patients between the ages of 18-75. These 30 participants were equally distributed among gender (15 females and 15 males) as well as hospital service (16 medical patients, 14 surgical patients). Participants also identified as the following ethnicities: White/Caucasian (n=26),

Black/African American (n=1), Hispanic/Latinx (n=3), Native Hawaiian/Pacific Islander (n=1), and Asian American (n=1). Twenty-six of the 30 participants (86.7%) reported having prior experience with hospitalization, and each participant's length of stay at the time of the interview ranged from under 24 hours to over one week in the hospital.

	n (% total)		
	Pediatric Site	**Adult Site**	**Total**
Answered *"advice"* question	131 (60.4)	86 (39.6)	217 (88.2)
Patients	51 (23.5)	67 (30.9)	118 (54.4)
Caregivers	80 (36.9)	19 (8.8)	99 (45.7)
Gender Identity			
Female	98 (45.2)	47 (21.7)	145 (66.9)
Male	33 (15.2)	38 (17.5)	71 (32.7)
Other/No Answer	-	1 (0.46)	1 (0.46)
Age in years			
≤18	44 (20.3)	-	44 (20.3)
≥19	87 (40.1)	86 (39.6)	173 (79.7)
Education			
8th Grade	14 (6.5)	1 (0.46)	15 (6.96)
High School/GED	22 (10.1)	16 (7.4)	38 (17.5)
Some College	16 (7.4)	4 (1.8)	20 (9.2)
Two- or Four-Year Degree	39 (18.0)	30 (13.8)	69 (31.8)
Graduate/Professional	16 (7.4)	23 (10.6)	39 (18.0)
None/No Answer	22 (10.1)	2 (0.92)	24 (11.02)
Race/Ethnicity*			
White/Caucasian	98 (45.2)	68 (31.3)	166 (76.5)
Black/African American	8 (3.7)	4 (1.8)	12 (5.5)
Hispanic/Latin American	16 (7.4)	4 (1.8)	20 (9.2)
Asian	17 (7.8)	6 (2.8)	23 (10.6)
Native American/Pacific Islander	11 (5.1)	2 (0.92)	13 (6.02)
Other/No Answer	12 (5.5)	6 (2.8)	18 (8.3)

*Table 5. Demographic summary of survey respondents who answered the question, "What advice would you give to others who might have had an [undesirable] event like [yours] in the hospital?" *Participants could select more than one category.*

4.3 FINDINGS: INPATIENT PEER SUPPORT NEEDS

My analysis uncovered five specific peer support needs that patients and caregivers expressed: (1) adjusting to the hospital and managing downtime, (2) understanding and normalizing care, (3) learning about and communicating with providers, (4) preventing and reporting undesirable events, and (5) exchanging emotional support and empowering peers. In addition to peer support needs, I identified four potential barriers to using an inpatient peer support tool that emerged during the semi-structured interviews with participants: privacy concerns, situational impairments, type of content, and communication preferences.

Below, I describe each of these needs and barriers in detail, providing illustrative quotes and examples throughout. I use the following nomenclature when referring to participants: the first letter (S- or I-) indicates whether the participant was in the survey or interview study. The second letter (A or P) represents the participant's presence at the adult or pediatric hospital site. The third letter (P- or C-) symbolizes whether the participant was a patient or caregiver. The numbers that follow are unique identifiers for each participant.

4.3.1 Adjusting to the Hospital and Managing Downtime

A common theme among both survey and interview participants was the value of practical information from peers on adjusting to an unfamiliar hospital environment. Many survey responses included tips, such as when is the best time to order food from the hospital's cafeteria. Interview participants expressed interest in learning this type of information from peers. For example, I-AP-10 wanted advice from others about what hospital amenities she had access to, and what personal items she could have brought before her admission. Despite having gone through many overnight hospital stays as a chronically ill patient, I-AP-08 still thought the experiential knowledge of other

patients would have been useful to her. When asked what she wanted to know from other patients, she said:

> *"Well, things like clothing for instance. The first time I came [to the hospital] I didn't think about [wearing] buttoned shirts, so what I had on I kept on for the whole five days...so that's a tip that would be great to have on there...that would be useful because [the patient's] caregivers visiting them could bring them some clothes. So I think shared advice, I like it." (I-AP-08)*

Among pediatric patients, the theme of adjusting to the hospital was referred to in terms of knowing what hospital resources were available to them for managing the downtime they experienced when waiting for providers to visit their room, anticipating a procedure, or recovering from treatment. Pediatric survey and interview participants discussed advice on how to prevent boredom during these times. As I-PP-04 said, *"It's a hospital, it's not exactly Disney World."* One interview participant, I-PP-11, was interested in finding out this type of information from patients who have more hospital experience than herself: *"Maybe other kids have been here longer than me and I don't know all the places or where you can find things to do. And they could share advice about what to do in the hospital."*

Pediatric patients with previous hospital experience recommended taking advantage of existing resources such as renting books, movies, television shows, or board games to play with visiting friends and family. When I-PP-05 was asked about what he would want to talk with other patients about, he responded, *"Games and stuff. And like your cousins [could] play with you. And when you're bored, you can go - some people get iPad or VS [a gaming system]."* Alternatively, mental and physical exercises were mentioned by S-PP-137 as possible ways to avoid the monotony of a hospital visit: *"Try to keep your mind busy with productive things...walk as much as possible to feel like you are doing something helpful instead of watching tv or playing on a screen."*

Survey and pediatric participants across both hospital sites wanted peer support to learn the norms of the hospital and identify the resources available to them, in order to smoothly transition from home to the unfamiliar—and sometimes monotonous—hospital environment.

4.3.2 Understanding and Normalizing Care

Adult patient participants in both survey and interview studies emphasized the need to be an expert in the details of their hospital and health care. Survey participants frequently recommended that their peers be alert to every aspect of their hospital stay and be aware of potential medication side effects or discharge requirements. Others encouraged their peers to ask their care team to explain confusing medical jargon and the reasoning behind care decisions. While serving as a caregiver for his wife, S-AC-171 experienced many challenges in communicating with the care team about his wife's health. He recommended other patients be persistent when requesting information: *"Ask lots of questions, don't take medical gibberish for an answer - keep asking questions until you get an answer you understand and that makes sense in the context of the patient's health."*

Pediatric survey participants also repeatedly recommended that their peers ask questions and request follow up information from doctors and nurses. S-PP-94, a pediatric patient who had unexpected complications during a surgery and whose providers did not properly follow post-surgery instructions, wanted other patients to feel comfortable requesting information about procedures and complicated medical terminology: *"Don't be afraid to ask questions before, after, or during the procedure. If you don't understand the medical terms, ask them to explain it in layman terms. Learn more of the risks involved and the complications that can happen afterwards."* Another participant, S-PC-212, was a caregiver whose son experienced extreme discomfort due to an incorrectly inserted feeding tube, thought that knowledge from other patients

would have been useful in identifying the source of her son's distress. She recommended other caregivers ask for this information specifically: *"Ask more questions about the tools and side effects and what other patient feedback has been."*

Adult interview participants also viewed their peers as resources for assessing the normalcy of their medical care and reducing the uncertainty of their hospital experience. I-AP-05, through observations and casual conversations with patients on his hospital floor, gradually learned who might be undergoing chemotherapy treatments that were similar to his. Acquiring this knowledge helped him relate to other patients and increased his own awareness of the intricacies involved in his medical care. I-AP-12 wanted information from her peers to prepare for the high and low points of her own hospital stay. I-AP-15 was a complex care patient, recovering from a difficult spinal surgery. She wanted to find out if her recovery was normal by directly comparing her progress with others who had gone through the same procedures: *"This complex [surgery]...it would have been interesting to see how other people came through it and what they did. Especially when I was going through it, because I did very well, but I still wanted to see how the others compare, see what to expect ahead of time."*

Similarly, pediatric patient interview participants expressed interest in posing questions about procedures, treatments, and medications to patients who were currently going through or had already completed the process. I-PP-04 was a patient who wanted to ask others with her same diagnosis about surgeries they had to undergo, and the how well certain drugs worked. Another patient, I-PP-07, was waiting to undergo a transplant at the time of his interview. He also thought it was important to hear from other patients about their experiences firsthand: *"Like I'm going through a transplant. If there was another kid who was going through transplants, which there is, you could ask them 'okay, so how did it kind of feel like when you went through the transplant?'"* One pediatric caregiver was also interested in learning this type of information from other parents

of children with the same health condition, so her own daughter's health and symptom triggers could be normalized:

> *"If some parents can also share that okay, this many times in a year we have to visit because of this reason, and my kid is around this age, right? So this kind of information helps in coming up with a pattern and some kind of satisfaction that okay, this is what has happened with...most other folks, it's not only me who's having this problem. (I-PC-15)*

Participants across studies and hospital sites recognized the value of the experience and knowledge of peers when attempting to make sense of their medical care, as well as normalizing their experience and progress toward recovery.

4.3.3 Learning About and Communicating with Providers

Some of the survey and interview participants wanted to talk about their providers with their peers. Providers were a common topic of discussion among those who had a chronic or rare health condition and wanted to know more information about the doctors who specialize in their care. I-PP-04 said this when talking about advice she would want to read from other patients:

> *I-PP-04: You could also say advice about doctors.*
>
> *Interviewer: Like which doctor you have.*
>
> *I-PP-04: Yeah, this doctor was better for me, this doctor I switched out because this happened. Like this doctor seemed to really know what they were doing, this doctor's already seen what I have, has the most experience with what we have. So that would be good.*

For adult patient participants, exchanging advice with peers on how to communicate and collaborate effectively with their care team was critical for a successful hospital stay. Survey participants gave advice on this topic, suggesting that their peers find ways to get the attention of their providers, and to be familiar with their care team's chain of command, if questions or concerns needed to be raised to higher-level hospital staff. For those experiencing unsatisfactory communication with their care team, participants encouraged their peers to proactively notify providers of any care updates, to seek second or third opinions, get help from other third parties (e.g., legal advisors, patient-family advocates, social workers), and consider transferring hospitals altogether. This subject also emerged in the interview with I-AP-04, who said: *"If I was unhappy with the doctor or my diagnosis or maybe because it didn't come fast enough, then I changed doctors...I felt like I was in control...Maybe you can tell - somewhere, somehow, you could tell other patients that they could do this too."*

Similarly, many survey respondents shared advice for what to do when a patient's or caregiver's relationship with a provider is difficult. Through their own hospital experiences, participants described options available to a patient or caregiver that might not be commonly known. For example, S-PC-228 was a pediatric caregiver whose son received unsatisfactory care from a provider, which caused her to ask for a different doctor: *"When your child is in the hospital, ask to speak to a pediatrician immediately. I didn't know I had to request that, I assumed that since he was a child, we would of course speak to a Dr. for children."*

The quality of a patient or caregiver's relationship and communication with their providers can greatly affect their experience in the hospital. Advice on how to maintain this relationship, and tips for communicating with providers, was valuable for many participants to avoid conflicts and to receive the best care possible.

4.3.4 Preventing and Reporting Undesirable Events

Across the survey and interview studies at both hospital sites, participants discussed the value of exchanging information on how to prevent undesirable events that might happen during their hospital stay. For example, when asked about what type of support he would want from his peers, I-AP-01 said he wanted the ability to ask questions to patients about *"diagnosis stuff and future problems that might occur."* A pediatric patient, I-PP-07, explained why he found this type of information valuable: *"because that way you can know what's happening and any problems."* I-PP-12 also wanted other patients' guidance so he could consult with his doctors on how best to fix an issue. A third pediatric patient, I-PP-11, was interested in finding out what errors patients had experienced, so if she had a similar problem or noticed someone who needed medical help, she would know what to do.

Specific advice on how to avoid errors primarily came from survey participants, who offered strategies such as remaining alert, paying attention to the details of their care, independently documenting care activities, not being afraid to ask for help, keeping track of lab tests, and following up with their healthcare providers if needed. Others also emphasized double checking medication labels to help prevent drug-related errors such as giving a medication known to cause an allergic reaction, providing an incorrect dose, or administering the drug inappropriately.

In addition to preventing errors, many survey participants wrote advice about the importance of properly reporting errors that they encountered. S-PP-129 was mistakenly administered too much laughing gas before a procedure and discussed the importance of reporting events such as hers: *"Report what happened to you. I wonder all the time if the anesthesiologist has done this to other children, especially children younger than I am who had no way of knowing what was happening to them."*

A common recommendation for reporting errors was to notify everyone involved in the patient's care about the error as soon as possible. Others mentioned taking advantage of options to request a caregiver or patient-family advocate to mediate the situation, and to inform a state-level complaint agency, if necessary. S-AP-115 experienced anxiety and fear after being stranded overnight in her hospital room with mislabeled medications, insufficient nutrition, and an out-of-reach call button. After reporting the problem, she noticed a decrease in the quality of care she received, and an increase in personal conflicts with her care team. Based on her experience, she offered the following suggestion for her peers: *"Keep calm and explain your concerns to someone of a higher authority...you want to be specific and clear of what the incident was. Make it so you're not speaking from emotions, but from a more stable point of view."*

Due to the prevalence and danger of preventable undesirable events in the hospital setting, patients and caregivers were aware of the need for constant vigilance and prompt reporting. Participants wanted to exchange strategies with their peers on how to adopt a proactive—instead of reactive—attitude toward undesirable events.

4.3.5 Exchanging Emotional Support and Empowering Peers

Analysis of both interview and survey participants revealed the importance of emotional support during a hospital stay. In particular, pediatric patients discussed the idea of providing and receiving support from their peers through forming friendships, talking about their general health experiences, and offering encouragement. Connecting with others who were of the same age range, health condition, or hospital was frequently mentioned as an important aspect of communicating with peers. For many participants, this potential interaction was an opportunity to establish friendships and share mutual hospital experiences. One example was I-PP-09, who travelled from out of state to be treated at the hospital. She only knew of one other person in her home state with

her same diagnosis. She was excited at the prospect of talking with others like herself. S-PP-233 also expressed her interest and willingness to share information about her hospital experience with another patient like herself: *"I will just talk about my stay and learn about hers/his."* Another pediatric patient, I-PP-10, wanted to ask about others' health progress and hospital stay, in order to provide support to those who need someone to listen to them:

> *Interviewer: What kinds of things would you want to ask [other patients]?*
>
> *I-PP-10: How they're feeling and was it hard. And what they are going through.*

Beyond sharing information about hospital experiences, participants were compelled to offer comfort to others who are going through difficult times. I-PP-12, a patient diagnosed with epilepsy, offered support to other patients struggling to manage the resulting emotional impact of having this condition: *"I would say that it's okay to have epilepsy, even though you might feel like the odd one out, you could still be a perfect person in your own way."*

Adult and pediatric participants also revealed the importance of empowering peers during their hospital stay. Survey participants provided reassuring phrases such as *"listen to your body," "be patient," "don't be afraid," "trust your instincts," "stay strong,"* and *"be calm."* Others empathized with the emotional toll of a hospital stay and sought to encourage self-advocacy. For example, S-AP-289 was not given necessary medication and spent a night in the hospital in extreme pain. She had this advice for other patients: *"Put up more of a stink. Be an advocate of your own care. However, some of us are very shy and being in a hospital makes me feel vulnerable."* Similarly, S-PP-89 recognized the emotional and demoralizing impact of a stressful hospital visit: *"It's easy to feel unimportant to your doctors, especially when requests are not being acknowledged. Be your own best advocate."*

To help empower fellow patients and overcome feelings of vulnerability, survey participants from the adult hospital site suggested that peers *"speak up," "stand up for yourself,"* and *"be assertive"* when receiving inadequate care. Despite being placed under isolation protocols, I-AP-06 felt strongly about providing support to patients in need: *"if I can be an advocate for any of those people, I want to be."*

Survey and interview participants expressed a strong desire to offer and receive this emotional support. Forming such support—through strong connections, reassurance, and empowerment—has potential to help patients and caregivers manage the increased tension, anxiety and stress when the status of the patient's health is uncertain.

4.4 FINDINGS: BARRIERS TO INPATIENT PEER SUPPORT

The combination of survey and interview results provided a deeper understanding of the informational and emotional support peer support needs of hospitalized patients and caregivers. During the 30 semi-structured interviews with adult and pediatric patients, we also explored their perspectives about using an inpatient peer support system. Although most participants expressed some level of interest in such a system, they also brought up concerns and preferences that might hinder or prevent their use of the system: privacy concerns, situational impairments, type of content, and communication preferences.

4.4.1 Privacy Concerns

When discussing their perspectives on the idea of an inpatient peer support tool, some participants were reluctant to use such a tool because they wanted to maintain their personal privacy. These people described themselves as naturally reserved people and infrequent users of social media who preferred to focus on recovering and leaving the hospital rather than

communicating with their peers. Others drew parallels between hypothetical peer interactions and conversations with neighbors or acquaintances. They felt an obligation to be friendly towards others which—coupled with managing their illness in the hospital—was too burdensome. When asked about interacting with other patients like herself, I-AP-14 said the following: *"I guess I'm kind of hedging on that one because...you know, when you don't feel well and someone's visiting you, you feel like there's this expectation that you have to be cordial and talk to them. And if you don't feel good, you just don't want to do that."*

Two of the three pediatric caregivers who were interviewed (I-PC-14 and I-PC-15) had a similar sentiment and expressed unease about the ability for peers to identify them through virtual interactions. I-PC-14 described his hesitation to exchange information and communicate with peers: *"I mean, you run into people in the elevators grabbing coffee and if you feel like it you socialize, but if you don't, you just don't, right? Yeah, I would stay anonymous. Personally, I would."* Later in the same interview, however, I-PC-14 said he was more agreeable to anonymously engaging in content with other caregivers. I-PC-15 also positively responded to the idea of anonymous interactions, because she thought it would allow people to honestly disclose information about medications or treatments without the risk of being identified.

Some adult interview participants had concerns that using a system to connect with patient-peers would violate health privacy laws. These patients mistakenly thought that exchanging information with peers would result in legal liability, and this misperception of risk was a substantial barrier to accepting the idea of an inpatient peer support tool. I-AP-13 spoke about his perspective on this topic:

> *"I could see some potential liability with [seeing information from peers] because of the [health privacy] laws. I suppose if you had someone who was willing to share, and said 'I'm willing,' that would be different, but you have*

to be so careful these days...you can't give out other confidential information. So you'd want to check with the current interpretation of the [health privacy] laws." (I-AP-13)

The worries that these adult patient participants expressed about breaching these laws did not surface in the interviews with pediatric patients or caregivers but does suggest a pervasive misunderstanding of the regulation. This fear ultimately discouraged patients from the idea of engaging with their peers.

4.4.2 Situational Impairments

A patient in the hospital can experience several situational impairments—such as an uncertain health condition, continuous administration of medication, and recovery from treatment—that negatively influence the patient's ability to use technology (Sears, Lin, Jacko, & Xiao, 2003). Although this theme did not appear in conversations with pediatric patients, some adult interview participants explicitly mentioned situational impairments as barriers to using an inpatient peer support tool, despite wanting to engage with peers. For example, when asked about her opinion on chatting with other patients, I-AP-04 responded by describing the exhaustion she felt during her hospital stay: *"I'm not chatting with another patient. Actually, I'm tired. If I go through my shower and my meal and I listen to TV a little while, then I'm tired."*

In addition to fatigue, I-AP-09 mentioned having poor eyesight that made it difficult to read large amounts of text, and I-AP-08 was managing chemotherapy as well as symptoms from an autoimmune disease that caused reduced limb function. These situational impairments led adult patients to think they might not be able to interact with a technology that offers peer support and influenced their preference for how they wanted to interact with their peers.

4.4.3 Type of Content

Despite feeling nervous about reading potentially negative hospital experiences, most interview participants thought it was important to know this information. However, one pediatric patient preferred avoiding information from peers that might cause anxiety or sadness:

> *I-PP-01: I wouldn't want to see that.*
>
> *Interviewer: [...] How come?*
>
> *I-PP-01: I don't know. Some of them are pretty sad.*
>
> *Interviewer: You don't want to see the bad [stories]?*
>
> *I-PP-01: No.*

A few adult and pediatric patients thought that discussing details about their medical care was better suited for their providers, rather than their peers. For example, I-PP-04 already felt comfortable speaking up and asking her doctor questions, so advice from other patients on doing these activities was not useful to her. Another patient, I-PP-02, expressed her preference for discussing unexpected health problems with her providers and caregivers instead of her peers, *"because they would probably know what [the] symptoms could be or any treatment or medicine you're getting."*

4.4.4 Communication Preferences

In addition to the type of content, interview participants discussed what preferences they had for communicating with their peers. Several pediatric participants wanted to interact with one or more of their peers in real time, because it was thought to be a more personal, private, and effective method of communication. Although some patients struggled to articulate why this real-time

connection was important to them, it was particularly evident among patients who were interested in connecting with others experiencing similar health issues to share relevant information:

> *Interviewer: Would you want [communication] to be in real time?*
>
> *I-PP-12: Yes. [...]*
>
> *Interviewer: You'd be okay with [sharing your advice with others]?*
>
> *I-PP-12: Yes, because I think if I find something and others don't, I think it would be a good thing to put out there, so other people can read about it in case they didn't know what to do or what's going on.*
>
> *Interviewer: [...] Can I ask why it being in real time would be important to you?*
>
> *I-PP-12: Because, I think that in real time, it would be a lot better than any other time, because - I just don't know.*
>
> *Interviewer: You just like it better that way?*
>
> *I-PP-12: Yeah.*

Another pediatric patient, I-PP-02, was under isolation protocol, which prevented her from leaving her hospital room. Physical interactions with other patients were not an option. To overcome this challenge, she mentioned the use of existing video chat tools: *"Sometimes I can't come out of my room because I'm in isolation...maybe the other kid [and me] wouldn't be able to actually see each other physically, so you could Facetime or something like that."*

Patients such as I-AP-07 also wanted to chat with another patient in real-time, preferring to talk with a peer about personal interests like hobbies and careers, rather than *"medical business."*

This type of real-time personal conversation happened during I-AP-02's hospital stay and was thought to be a welcome distraction from a procedure. He and another patient were separated by a privacy curtain in the same post-operative room, and they began talking about sports teams they both enjoyed watching. When describing the experience, he said, *"We were comfortable. We never knew each other's name...I was talking to this curtain, and it was talking back."* Another participant, I-AP-08, had a similar in-person encounter with a patient on her same floor. Eventually, both patients learned they were on overlapping chemotherapy schedules and saw each other regularly during hospital visits. I-AP-08 recalled having both casual conversations and substantive support from their regular, face-to-face interactions:

> *"I've met one gentleman because we both have orange bags and so you know you're kind of probably a similar cancer...He's on a similar schedule to me, so we visit each other's rooms and have nice chats. [...] We talk about our scan results, we talk about how was our last week [at home] - how was the side effects, how was our fatigue. So making that connection is really - I think that's one of the best ideas[.]" (I-AP-08)*

In contrast, some participants explicitly mentioned their desire for asynchronous communication. I-PP-11 did not feel comfortable chatting with people she did not already know in person, and preferred reading information from other patients outside of a real-time environment. I-PC-15 expressed reluctance toward a live chat because it can be inconvenient when the patient needs attention: *"I think real-time chat would be difficult, being in hospital, because you don't know if your kid is upset or still recovering. If they had time and their kid is okay, then they can do real-time."*

For adult patients, situational impairments were a factor that led them to prefer asynchronous interactions, because it reduced the stress of keeping up with a real-time conversation. I-AP-09

said, *"sometimes I think when you're given chat sessions and video logs and stuff like that, that you get off topic real quick and this way...it's on my own time, when I want to do it, and I don't have to rely on someone else being there to answer my question."*

A few adult interview participants also preferred asynchronous interactions because of their familiarity with existing review websites and online health communities. I-AP-12 saw sharing advice with her peers as an opportunity to evaluate her experience, like a *"Yelp for the hospital"*. Others envisioned a forum-type resource, augmented with features that would allow them to search for relevant information from peers by age, diagnosis, symptoms, and procedures much more easily than existing tools. I-AP-15 described: *"You look online, but it's not - it'd be nice just to have [information from peers] all together instead of searching through massive information."*

4.5 DISCUSSION

The results described above build on related work investigating the role and design of health informatics systems in addressing the information needs of inpatients and their caregivers (Kaziunas, Hanauer, Ackerman, & Choi, 2016; Lee et al., 2018; Miller et al., 2016; Mishra et al., 2016; Pollack et al., 2016). These findings also demonstrate the diverse nature of patient expertise in the hospital environment, which is consistent with similar findings in clinic-based and at-home care settings (Civan & Pratt, 2007). Adult and pediatric participants across both survey and interview studies further revealed the need for new systems to help inpatients share their expertise and emotional support during an extremely vulnerable and stressful point in their health journey. Below, I detail three primary implications of these findings: intelligent peer matching, respecting privacy and anonymity, and accommodating a dynamic hospital stay. For each of these implications, I articulate design recommendations for future inpatient peer support technologies.

4.5.1 Intelligent Peer Matching

Many of the survey and interview participants strongly desired an open dialog with their peers. Indeed, for each emotional and informational need expressed by a participant, others in the study were willing to address that need and offered their expertise. The reaction to having such connections was especially strong for those who had shared personal attributes, such as comparable treatments, similar diagnoses, same age range, hobbies, and careers. I-AP-08 met someone on a similar chemotherapy schedule, with whom she regularly shared side effects and test results they had in common. I-AP-02 had a conversation about sports teams with another patient; I-PP-02 expressed her interest in connecting with other patients who also might be feeling lonely under strict isolation protocols.

Properly aligning the interests and common attributes of peers is critical when forming quality interactions and can be difficult to accomplish with existing tools. For example, Facebook[1] users must independently seek out individuals and groups related to their interests; the user may not know of or have access to a group, unless they receive an invitation from another group member. Online health communities such as PatientsLikeMe[2] are organized by chronic illness, so those who have similar experiences across diagnoses might be harder to identify.

Past Health Informatics and Human-Computer Interaction research has emphasized the value of matching peers who manage conditions such as diabetes, cancer, and rare diseases (Eschler & Pratt, 2017; Huh & Ackerman, 2012; MacLeod, Bastin, Liu, Siek, & Connelly, 2017). The findings presented above reveal the hospital as another health context where peer matching has value. Research on how to improve the process of peer matching is ongoing. For example, Hartzler et al. used profiles and posts extracted from online health communities to optimize peer and mentor

[1] https://facebook.com
[2] https://patientslikeme.com

recommendations (Hartzler et al., 2014, 2016). However, translating these techniques into the hospital environment poses a unique challenge. Much of the prior peer matching research focuses on sustaining longer-term connections (e.g., during a patient's chronic illness management), but inpatients have a much shorter window of time to create meaningful connections, as the average length of a hospital stay is approximately five days (*2015 CMS Statistics*, 2015). To overcome this challenge, I describe two design recommendations below: leverage the Electronic Health Record and incorporate personal profiles.

Leverage the Electronic Health Record

In conjunction with aforementioned peer matching solutions, an inpatient peer support system can leverage information directly from the Electronic Health Record (EHR) to successfully match individuals with each other. Age, diagnosis, medications, procedures, treatment plans, and current physical location in the hospital are all examples of information stored within the EHR. Thus, it would be possible to rapidly match individuals who are interested in connecting with their peers by identifying their similar characteristics across these dimensions. For example, I-PP-04 wanted to use a peer system that would help her find other patients of doctors who specialized in treating her rare condition, so she could speak to them in detail about the quality of care and differences in treatment protocols across providers. A system using information from the EHR could accomplish this by identifying groups of patients with the same diagnosis, healthcare provider, or hospital unit, who have also indicated an interest in connecting with peers. This would facilitate the exchange of expertise that I-PP-04 could use to further engage in her care.

Incorporate Personal Profiles

In addition to leveraging EHRs to enable rapid peer matching based on common medical traits, incorporating personal profile features could help match inpatients based on traits beyond those

contained in the medical record. This feature could be generated for those who want to be matched with their peers. Offering a space for patients to externalize and share information about themselves—such as their likes, dislikes, and personal medical history—has been explored as a solution for improved communication between patients, families, and providers during hospitalization (Miller, Pollack, & Pratt, 2016). If implemented, such a system could also enhance the agility and quality of peer matching in this context. Just before or after admission, individuals could create structured summaries of themselves. The patient could specify their health condition, level of hospital expertise, and informational or emotional support needs. They could also provide personal details, such as career experience or hobbies. Such a profile would give patients the opportunity to designate their preferred type of interaction: those who want in-person meetings with peers could indicate this preference and be matched with others who have similar interests. Patients like I-AP-06 and I-PP-02, who are under isolation protocol and unable to meet in-person, might indicate their desire to talk with someone in real-time from their hospital bed. Incorporating a profile-like feature that considers peer support needs of individual patients could help optimize the inpatient peer matching process. This solution also gives patients control over what personal information is shared, the parameters they want to base peer matches on, who they get matched with, and how they interact with peers.

4.5.2 Respecting Privacy and Anonymity

In general, people have varying opinions about privacy and anonymity, as well as a range of preferences for sharing their personal and health information. Although most of the interview participants expressed a need for peer information from multiple sources, some participants were reluctant to share their own information with others. Thus, a clear tension exists between wanting to exchange peer information and concerns about privacy. This conflict was most evident among adult interview participants: I-AP-14 thought maintaining her personal privacy would be difficult

if she engaged with a peer, and I-AP-13's cautious misinterpretation of health privacy laws affected his openness to the idea of an inpatient peer support tool.

The success of a peer support system within a hospital setting is dependent on supporting these preferences. Although existing tools like Facebook have the option for health-related groups to be closed or open to the public, there is currently no way for users to interact with these groups anonymously. To respect and support the privacy needs of inpatients when using a peer support system, I propose two design recommendations: offer opt-in information sharing models, and aggregate peer data.

Offer Opt-In Information Sharing Models

To be sensitive to individual preferences for sharing personal and potentially identifiable health information, an inpatient peer support system should use an opt-in model, rather than opt-out. Users must be properly informed about the risks of sharing their information with others, and safeguards for situations that result in potentially negative consequences should also be incorporated. Possible solutions can involve the system having different levels of anonymity, customizable user profiles, or icons to represent higher-level information such as health status or hospital service (e.g., surgery, oncology), so the user can selectively choose what information they are willing to share with others. Moreover, having flexible security settings—such as making specific personal information public or private—helps to accommodate the broad range of preferences that might also change over time, as patients and caregivers become more familiar with their peers.

Aggregate Peer Data

Another potential solution for mitigating important privacy concerns is to collect and display peer data in aggregate. Depending on the scalability of the system, the data could be sampled at

multiple levels: within the same hospital, similar geographic region, or among all patients with the same diagnosis. Individuals could choose to view or contribute to this data in several ways. For example, based on EHR or patient profile data, the system could tell a patient, "7 people like you are in the hospital today," or "10 patients spoke up to the nurse about their pain today." Users could also actively participate in the system by querying or polling their peers to get relevant information to their needs and questions. Other patients could choose to answer these queries, receive updates of responses, and use the data to generate their own questions for peers.

Providing this type of aggregated information could help to normalize the experiences of specific groups of patients and empower patients to recognize anomalies in their care. It would also allow for anonymous engagement with the tool, without requiring patients to share personal information directly with another individual. Moreover, a system that collects peer data with minimal effort would reduce cognitive and physical burdens for the patient, while still giving them the option to actively contribute to the tool and have access to the information they value. Incorporating such features would ultimately give patients the autonomy to decide if, when, and how they use peer data.

4.5.3 Accommodating the Dynamic Hospital Stay

The findings from survey and interview participants demonstrated a need for inpatient peer support systems to enable multiple levels of engagement. Participants such as I-PP-12 valued real-time interactions with their peers, while others such as I-PP-11 preferred to read content on their own time and interact with peers in an asynchronous manner.

The results also demonstrated a variety of peer support needs about the patient's health, the hospital, and emotional support. Facilitating this support while acknowledging these needs can change over the course of a hospital stay is also important. For example, a patient might need information from peers about what to expect before a procedure, or what potential errors they need

to watch for. After diagnosis or treatment, this patient might want to seek or share emotional support. During recovery, while the patient rests and waits for follow-up care, information about how to pass the time and hasten discharge might take precedence. We saw these changing needs among our study participants: I-PP-07 described wanting to know information and potential problems about his upcoming transplant, and S-PC-212 encouraged others to ask questions before undergoing a procedure. I-PP-12 was compelled to exchange emotional support after his epilepsy treatment. Following their surgical procedures, I-PP-11 and I-PP-04 wanted advice from peers about how to minimize boredom while they were confined to their hospital rooms.

Although research on cancer patients have also noted differing information needs over time (Eschler, Dehlawi, & Pratt, 2015), such dynamism is not typically considered by existing tools used for peer support. To enable these various levels of interaction and support needs, researchers have previously emphasized the importance of designing for passive and active involvement in a system (Maitland & Chalmers, 2011). Prior work has also explored the use of virtual spaces where patients can access a repository of advice organized by symptom, treatment, or common struggle (Civan, McDonald, Unruh, & Pratt, 2009; Webster et al., 2015). However, in reality, finding relevant and accurate information across many resources and at different points of the care process can be difficult for hospitalized patients, due to the cognitive and physical demands that are required. Patients and caregivers are not always capable of doing such burdensome work, due to medications or treatments (Morris & Karlson, 2011). In addition, mapping information solely by medical categories—such as symptoms—neglects the important dynamism during a hospital stay. To accommodate for this dynamism in the design of inpatient peer support systems, I suggest two design recommendations: provide multiple ways to access support and reduce the burden of finding relevant information.

Provide Multiple Modes of Information and Support

Providing synchronous features like text or video chat, coupled with a knowledge base to be accessed when convenient for the user, would be particularly beneficial for hospitalized patients and caregivers. Users in the hospital could have the option of connecting with other patients currently in the hospital or reading and contributing information to a knowledge base of patient and caregiver expertise. Individuals who were previously hospitalized and want to share their experiences could also add information by responding to queries, polls, or questionnaires after discharge. Allowing multiple modes of interaction could increase the peer resources available to current patients, while supporting individual preferences for engaging in the system.

Reduce Burdens of Finding Relevant Information

Adapting to peer support needs as they change over time and reducing the user burden for finding relevant support are other critical components of a peer support system in the hospital environment. One way to accomplish this adaptation is to have a user answer a series of prompts such as, "do you want to learn from others about your upcoming procedure?" or "do you feel like playing a game with someone?" Based on their responses, the user could be automatically referred to the appropriate resource for information or emotional support. EHR data about medications, diagnoses, or procedures could be another way to direct the individual to appropriate peer information. This may reduce the burden for patients and caregivers to search for information on their own, across thousands of existing platforms. Topics or people of interest to the user could also be featured prominently within a tool and support ease of navigation. A patient should be able to search, save, and organize information from their peers in a simple and efficient way. The type of content displayed could be adjusted based on their mood, health status, or current phase of their hospital stay. This capability would let individuals like I-PP-01, who only want to see positive

experiences from other similar patients, avoid finding negative patient stories and still participate in other aspects of the peer support system.

4.6 CONTRIBUTIONS

Through a survey question asking about advice one would share with their peers, and semi-structured interviews to determine what needs exist for peer support, I identified the needs and potential barriers that patients and caregivers have for using an inpatient peer support tool. Based on the results from both studies at the adult and pediatric hospital site, I proposed novel design recommendations for future inpatient peer support tools: (1) leverage the EHR, (2) incorporate personal profiles, (3) offer opt-in information sharing models, (4) aggregate peer data, (5) provide multiple modes of information and support, and (6) reduce burdens of finding relevant information. These recommendations aim to address the diverse informational and emotional support needs of patients. In an environment known to be intimidating and stressful, providing a mechanism for patients to exchange support with peers has the potential to increase self-efficacy, knowledge, and empowerment in all aspects of their care.

5

DESIGNING AND DEPLOYING AN INPATIENT PEER SUPPORT TECHNOLOGY PROBE

In Chapter 4, I described the peer support needs that inpatients and caregivers had during their hospital stay, as well as a series of design recommendations for inpatient-facing peer support technologies. I build upon this work and examine how patients in the hospital would use an inpatient peer support technology, and what impact this peer support could have on both a patients' perceptions of their hospital experience and the quality and safety of their care.

To answer these questions, I employed the technology probe method. The purpose of this Human-Computer Interaction method is to deploy a technological artifact (i.e., probe) in a real-world context, study and reflect on how it is used, and explore its impact on the user's perspectives and behaviors (Hutchinson et al., 2003). This method has previously been utilized in many other health contexts, such as prompting reflection for diabetes self-management (Mamykina, Mynatt, & Kaufman, 2006), monitoring home-based cardiac patients (Kjærup et al., 2018), optimizing surgical suite management (Rambourg, Gaspard-Boulinc, Conversy, & Garbey, 2018), and developing trauma resuscitation checklists (Kulp et al., 2017).

Following a similar methodological approach to these studies, I set out to understand the real-world use and impact of an inpatient peer support technology. In this chapter, I present my design rationale and process, describe the technology probe that I implemented (named the *Patient Advice System*), and summarize the steps I took to prepare for its deployment at the two hospital sites where this study took place. In the next chapter, Chapter 6, I explain my study design in more detail and present findings that answer the above research questions.

5.1 DESIGN RATIONALE AND PROCESS

My goals for an inpatient peer support technology probe were to (1) provide patients with a way to exchange information with their peers during their hospital stay, and (2) implement design recommendations that I identified in Chapter 4. In particular, the insights described in Chapter 4 suggested that despite valuing peer support during their hospitalization, patients anticipated several challenges in using an inpatient peer support technology. Patients were concerned about feeling obligated to engage with their peers when they did not feel well, saw difficulties in finding peer information relevant to their health experience, and wanted to protect their privacy and personal information. Therefore, I sought to design and build a technology probe that could facilitate asynchronous communication, so patients could engage with their peers without burdening their hospital care and health recovery. I also aimed to create a probe that would allow patients to reduce burdens of seeking out relevant advice from other hospitalized patients and minimize privacy concerns without compromising the value of engaging with other patients.

In addition to implementing these design recommendations from Chapter 4, the technology probe needed to be created and deployed within the constraints of the inpatient environment. For example, the probe had to be unobtrusive during patient-provider interactions, non-disruptive during care events, and function independently from the hospital's clinical systems to prevent data privacy and technical integration challenges. The probe also had to be suitable for mobile devices; patients needed to access the probe through iPads provided by the research study. Moreover, these iPads had to be compliant with hospital sanitation protocols.

With these design recommendations and constraints in mind, I, with the help of a colleague, Elena Agapie, ideated to identify key components of an inpatient peer support technology probe. We brainstormed several ideas, documented them on post-it notes, and created an affinity diagram

that organized these ideas across multiple dimensions, including: what type or form the technology probe should embody, what specific features the probe would have, what type of peer content would the probe be populated with, who would have access to the information within the probe (among the patient, caregiver, and clinical care team), and how patients would input their own information into the probe. The results of this ideation are shown in Figure 3.

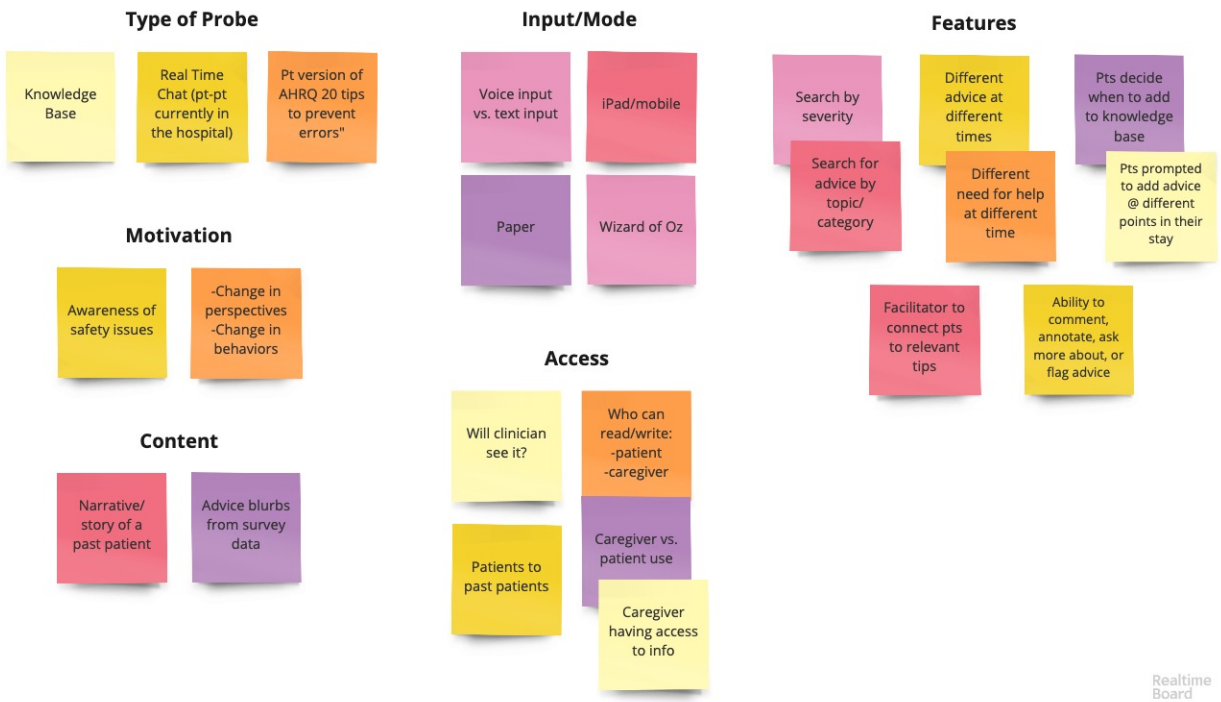

Figure 3. Recreation of the affinity diagram that resulted from an ideation session. The session generated specific ideas for designing and building an inpatient peer support technology probe. Ideas are grouped by the "type of probe", "motivation" for using the probe, "content" to offer within the probe, "input/mode" of this content, "access" of this content, and additional "features" that a probe might offer. "Pt" is used as shorthand to represent "patient". Figure was created using Realtime Board, an online collaboration tool.

This ideation produced a number of concrete design ideas, which allowed me to begin sketching potential technology probes. Early sketches involved a shared Google Docs file where patients could contribute their advice, and a Wizard-of-Oz system that would collect advice from patients via paper- or voice-input. However, the implementation required for these ideas required

resources that were unavailable or too complex to coordinate in a hospital setting. I then started to build higher-fidelity probes that could be easily implemented in the hospital environment and built upon existing infrastructure. One example probe I created was designed to push an online survey containing peer advice to a patient at various timepoints during their hospital stay, asking the patient for feedback about the relevance and usefulness of the advice (Figure 4a). Another example probe I created was a Slack workspace where individual channels were created for each potential topic of peer advice (e.g., #care-teams) derived from findings in Chapter 4 (Figure 4b). However, as each of these iterations were built, they presented new challenges and considerations—such as the potential to disrupt or interfere in hospital care, and how much training patients would need to use unfamiliar technologies—regarding the probe's design and implementation.

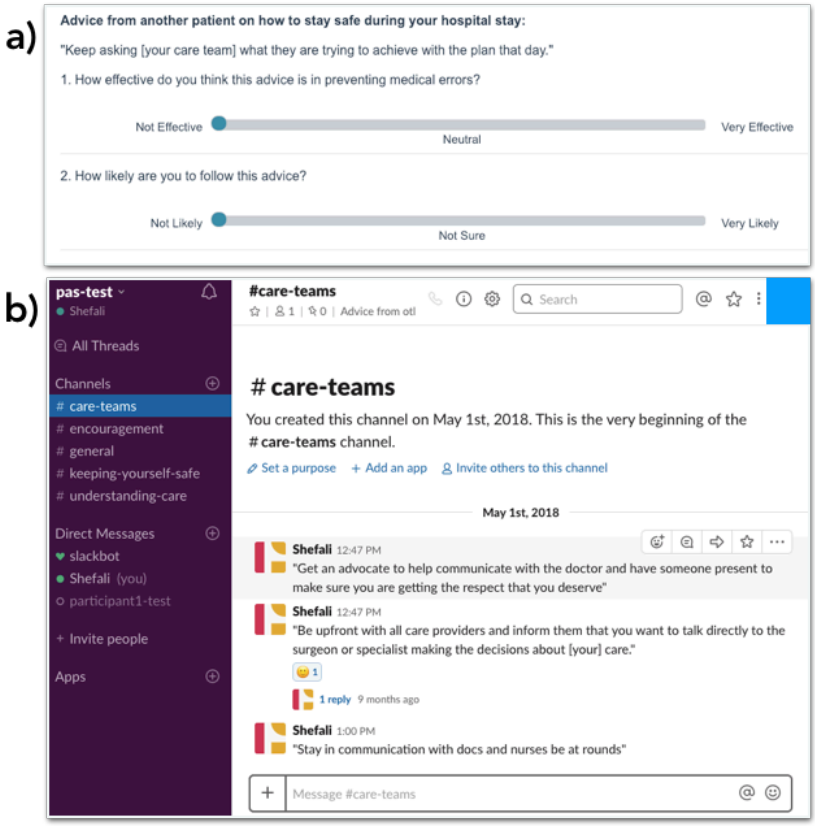

Figure 4. Examples of test probes that were created in early stages of design and development. a) a survey designed to be pushed to the patient at different points during their hospital stay. b) a Slack workspace designed to organize topics of conversation and facilitate rich interactions (e.g., emojis and response threads).

Therefore, after several iterations and test environments, I decided to create a probe that would be a WordPress website with functional similarities to Reddit[3], a web content repository and social media site. I chose this format because it could be created with an existing technological infrastructure and could be easily deployed within the constraints of the inpatient environment. Furthermore, the web-based medium allows the probe to be "lightweight", meaning it is (1) simple to build and implement, and (2) accessible via internet to the patient on any device and at any time throughout their hospital stay or after discharge.

5.2 THE PATIENT ADVICE SYSTEM

I built the technology probe (named the *Patient Advice System*) by installing the UpVote WordPress theme[4] at a designated domain name. The UpVote theme offers features for users—such as customizable profiles, posting of original content, commenting, and voting—that satisfy four of the six design recommendations identified in Chapter 4: incorporating personal profiles, offering an opt-in information sharing model, aggregating peer data, and reducing burdens of finding relevant information. Because the *Patient Advice System* closely mirrors the fundamental purpose and function of Reddit-based online health communities, I further customized the technology probe to fulfill applicable design guidelines from Kraut and Resnick on building online communities: establishing guidelines for use, and ensuring easy-to-use features for finding and sharing peer information (Kraut et al., 2011).

In the following sections, I share the key features of the *Patient Advice System*: supporting privacy and anonymity, establishing guidelines for use, finding stories, reading and interacting

[3] https://reddit.com
[4] https://themeforest.net/item/upvote-social-bookmarking-wordpress-theme/15542355

with stories, posting stories, and viewing user profiles. For each of these sections, I describe how the aforementioned design recommendations were incorporated into the probe.

5.2.1 Supporting Privacy and Anonymity

The process of creating a username allows users to have an alias tied to their website activity and gives user's control over their degree of anonymity. In the technology probe, a patient can register an account by providing their email address and creating their own username and password. The registration process is integrated directly with the WordPress registration form, ensuring the user's email is only viewable by myself, acting as the site administrator, on the website's backend.

5.2.2 Establishing Guidelines for Use

Establishing guidelines for using an online community can encourage users' altruistic engagement with peers, emphasize the importance of the user's contribution to the community, and establish what is "acceptable" content and behavior for engaging with peers (Kraut et al., 2011). An "About" page in the header navigation menu of the probe provides the user with information about the purpose of the *Patient Advice System*, reasons for the user to contribute to and interact with the probe, recommendations for specific ways in which to contribute to the probe, and guidelines for what content is permitted on the probe. This information is intended as a resource for patients that clearly defines the scope and conduct of the probe.

5.2.3 Finding Stories

Structuring the conversations of an online community allow users to more easily achieve their goals of interacting with peers and fulfill the purpose of the community's existence (Kraut et al.,

2011). Moreover, highlighting conversations of interest could reduce the burden of finding relevant information. The home page of the technology probe shows "stories", or posts, from other users (Figure 5). Users can sort these stories by what is "trending" (i.e., most popular) or by what is most "recent" (i.e., reverse chronological order). The home page also contains a list of "categories," or topics, which can be clicked to browse and search for relevant stories. I created most of these categories based on the peer support needs identified in Chapter 4 (e.g., "About the Hospital and Things to Do," "How to be Safe in the Hospital"). I provided three additional categories, two of which—"Best and Worst of Being in the Hospital" and "My First Day in the Hospital"—serve as icebreaker activities so patients can self-disclose their own story, and to highlight the community aspect of the probe. The third additional category, "Other," captures miscellaneous patient stories that do not align with the specified topics.

Users can further search for stories by "tags" generated by the users who posted stories. I installed and customized the Cool Tag Cloud WordPress plugin to display all existing tags in descending order from highest to lowest frequency. Higher frequency tags are displayed in a larger font to represent its common use on the website. As with topic categories, clicking on a tag reveals all stories associated with that tag.

Figure 5. A screenshot of the Patient Advice System's home page, captured after deployment concluded at the pediatric hospital site.

5.2.4 Reading and Interacting with Stories

Reading, commenting, and voting on stories are ways to asynchronously engage with patient-peer content, and reduce the burden of a patient feeling obligated to interact with their peers at inopportune moments (e.g., when feeling unwell) during their hospital stay. Within the technology probe, clicking on a story reveals its expanded view, providing further information written by the user who posted the story (Figure 6). In this expanded view, users have the option of commenting on posted stories. The comment box appears in the expanded view of the story and allows for

nested comment threads. In addition, users can "upvote" stories to demonstrate agreement with, or encouragement towards, the user who posted the story. These votes are displayed in aggregate to preserve the anonymity of patients while still conveying positive sentiment towards their peers.

The expanded view offers users another option to report the story if they believe it does not comply with the established guidelines for posting content. Clicking "Report Story" generates an email report that is sent to the site administrator, who then decides upon taking further action (e.g., removing the story or contacting the original user who posted it). Although I continuously monitored the content posted on the probe, this feature offers patients—and parents of pediatric patients—a way to participate in this monitoring process.

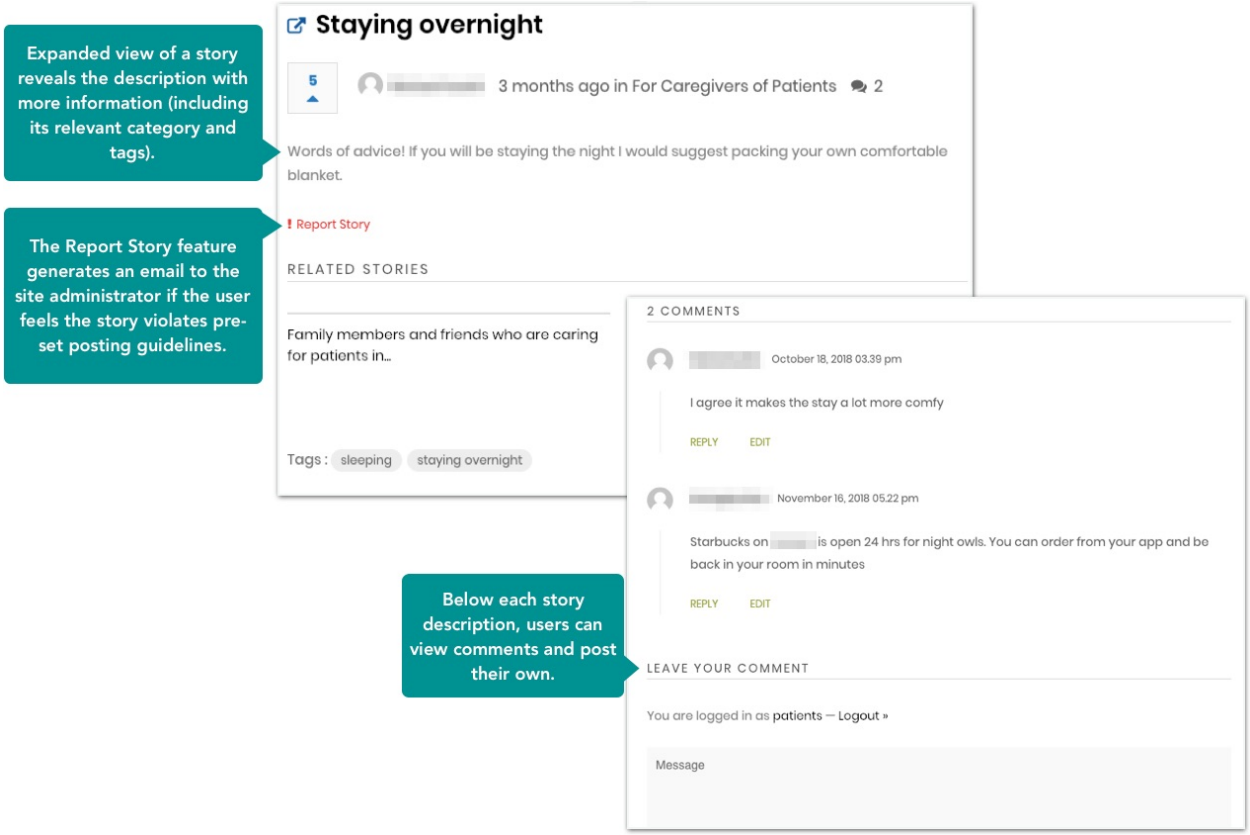

Figure 6. Expanded view of a story posted on the Patient Advice System's pediatric deployment, showing more details under the story title, comment threads, and the option to report a story.

5.2.5 Posting Stories

Features of online communities that allow for easy sharing of content between peers can help increase the visibility of, and engagement with, this content (Kraut et al., 2011). Aside from reading and interacting with stories from other users, a user can post their own story to share (Figure 7). The process of posting a story requires users to designate a "title" or heading for their story and provide more information in the "description" box of their story. When posting a story, users select a relevant topic category from a dropdown menu and can create optional tags that they type in the "add tags" field, to increase the visibility of their story.

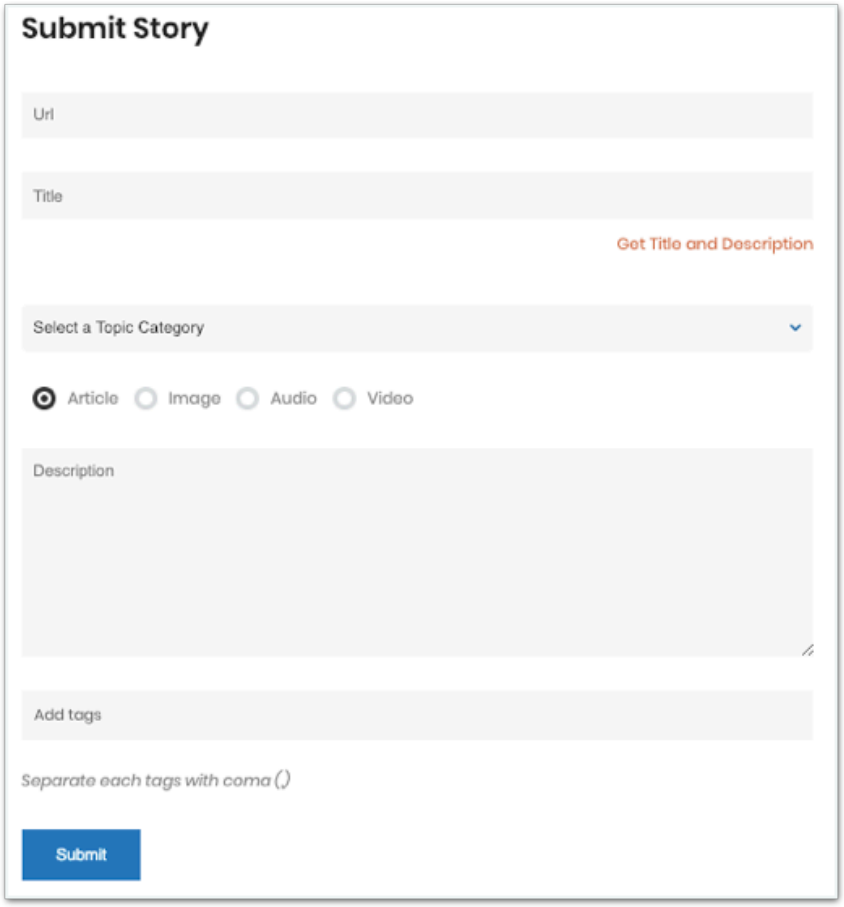

Figure 7. The "Submit Story" page that patients fill out in order to post their story to the Patient Advice System.

5.2.6 Viewing User Profiles

Every registered user of the probe has a profile or "dashboard" that displays a count of their individual posts, comments, and votes. Such profile pages give users a common point of reference with which to initiate introductions and conversations. User profiles are also a useful resource for observing how individual patients were actively engaging with the system during its deployment, if at all.

5.3 PREPARING FOR DEPLOYMENT

5.3.1 Pre-Populating Content and Creating Instances for Each Site

In addition to including the features above, I pre-populated three types of content within the probe: "Admin" posts that gave instructions or prompts for what type of information patients could share in topic categories, "Advice from a Past Patient" posts which consisted of advice that patients and caregivers shared through the survey study described in Chapter 4, and "Outside Resources" posts that shared information such as hospital amenities, and patient-safety tips from government or nonprofit organizations. My decision to pre-populate this content was twofold: (1) to provide some value for early users of the probe, and (2) encourage early users to engage with the probe and bootstrap its content for later users.

A preliminary version of the technology probe underwent testing with Human-Computer Interaction researchers and target end users to identify and resolve usability issues before deployment. I installed the probe at two domain names, one for each study site. I added the pre-populated content, tailored for each study site's probe (e.g., advice from past pediatric patients was posted in the version of the *Patient Advice System* to be deployed at the pediatric site). Patients were only given the link to the probe that corresponded to their designated hospital site.

5.3.2 Device Configuration and Management

To scale the probe's deployment across both pediatric and adult hospital study sites, I configured a total of 8 research study-owned iPads that participants could use to access the probe during their hospital stay, adapting recommendations from prior work (Dykes et al., 2015). All iPads were protected with LifeProof[5] cases to ensure durability, and device passcodes were disabled for ease of use. Because the plan was to enroll both pediatric and adult patients, the iPads were set to prevent access to adult content and App Store downloads. At the pediatric site, I connected the iPads using a private network that did not require user-specific login credentials. An equivalent network did not exist at the adult site, so the study coordinator used their personal credentials to connect each device to that site's private network. After establishing a steady internet connection, I tested the probe's function via installed Safari and Google Chrome web browsers.

I created labels to place on the back of every iPad, which included a unique number serving as the iPad's "name" in the device settings. The number was used to track which participant was loaned which iPad and if it had been returned within a participant enrollment spreadsheet. All iPads were registered on Find My iPad to identify their location if necessary. Per recommendations from the adult site's nursing staff, I informed nurses when their patient was lent an iPad, allowing nurses to monitor the device's location as needed. To further reduce the likelihood of theft or loss, I did not provide participants with chargers for their iPads.

The iPad labels also contained names and contact information of research team members, and instructions for return. At the pediatric site, I instructed participants to drop off the iPad at the Unit Coordinator (UC) desk located on each floor. At the adult site, centrally-located nursing stations on every floor served as device drop-off and pick-up points. After participants returned their iPad

[5] https://lifeproof.com

at discharge, UC and nursing staff at their respective sites contacted the study coordinators for retrieval. Upon pick-up, I sanitized the device according to hospital protocols. Between use, iPads and their chargers were stored in locked cabinets within card-access offices at each hospital site.

5.4 CONTRIBUTION

In this chapter, I summarized the design and key components of the *Patient Advice System*, and the steps I took to deploy devices containing this technology probe in two distinct inpatient settings. The initial ideation and testing part of the design process allowed me to "fail early", or generate several ideas, then build, test, and iterate on them before arriving at a solution that was most suitable for my research questions and study populations. By following the design process, I was able to create a technology probe that not only addressed most of the design recommendations that I discuss in Chapter 4, but also operated within the resource and environmental constraints of the hospital setting. In the following chapter, I present the methods and findings of my technology probe study to examine the use and impact of the *Patient Advice System* on patients' hospital experiences, as well as the quality and safety of their care.

6

EXAMINING THE USE AND IMPACT OF AN INPATIENT PEER SUPPORT TECHNOLOGY PROBE

In this chapter, I continue to answer the research questions raised in Chapter 5: how do patients in the hospital use an inpatient peer support technology, and what impact might this peer support have on a patient's perceptions of their hospital experience and quality and safety of their care? After building the *Patient Advice System*, I deployed it at both pediatric and adult hospital sites. In the following sections, I describe the study design, participants' usage patterns, content shared on the probe, and the many ways in which the probe influenced their hospital stay.

6.1 METHODS

As mentioned in Chapter 5, a key component of the technology probe method is the opportunity for both end-users and researchers to understand and reflect on the usage of the probe. Therefore, I designed a multi-stage study (Figure 8) with three data collection phases: a bedside interview and onboarding process (i.e., short tutorial on how to use the probe) with patients, their use of the *Patient Advice System* during the remainder of their hospital stay, and a follow-up phone interview (Appendix C).

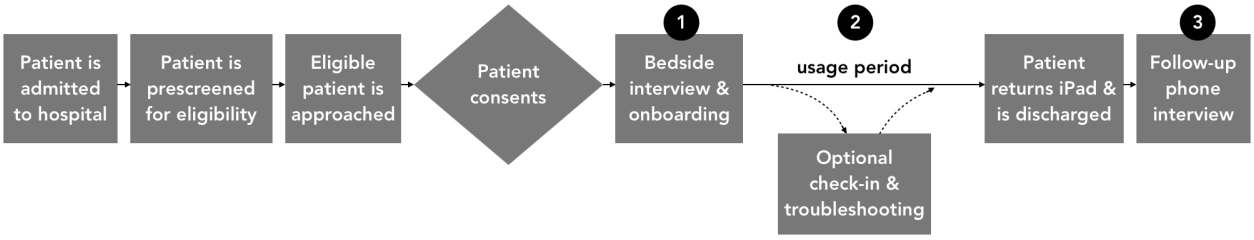

Figure 8. Technology probe study design to understand the use and impact of the Patient Advice System with numeric labels indicating the three phases of data collection.

6.1.1 Bedside Interview and Onboarding Process

The purpose of the first phase of data collection was to establish a connection with the patient, learn about their health situation and experience in the hospital so far, and understand their thoughts on exchanging information or advice with other patient-peers in the hospital. To gather this information, I conducted semi-structured interviews with pediatric and adult patient participants at their bedside during their hospital visit. During this interview, I asked the participant questions such as, "How is your hospital stay going so far?*"* and "What are your thoughts on getting advice from other patients in the hospital?" Each interview lasted approximately 30 minutes and was audio recorded.

Another purpose of this first connection with the patient was to teach them how to use the technology probe. At the conclusion of their bedside interview, I introduced the participant to the *Patient Advice System* on the iPad designated for their use. I then had the participant complete an onboarding process to set up their account for the probe and familiarize themselves with its features. To conclude this process, I offered participants the opportunity to post a story for patient-peers in the probe. This "learning by doing" approach was intended to help patients build up their confidence in using the probe, especially if they were unfamiliar with the technology, or if their treatment affected their cognitive ability to exclusively listen to my description of the instructions. This step also was intended to scaffold the probe's content and acclimate the participant to its

social nature. In addition to a digital instruction manual linked within the probe (in the form of a view-only Google Docs file), I gave participants a paper printout of this manual that they could follow while using the probe, if needed. The combined interview and onboarding process lasted between 30-60 minutes.

6.1.2 Usage Period and Optional Check-In

After completing the bedside interview and onboarding phase of the study, all participants were given an iPad and the probe to use at their discretion for the remainder of their hospital stay, until they were discharged from the hospital. One pediatric participant elected to use their personal smartphone, instead of an iPad, to access the probe. If I observed the participant's uncertainty about using the probe, or if the participant requested additional help, I checked in within 1-2 days after the onboarding process to answer their questions, resolve technical issues, or help them use the probe. Upon discharge, the patient was instructed to return the iPad to either the Unit Coordinator's desk (at the pediatric site) or nursing station (at the adult site).

6.1.3 Follow-up Phone Interview

After the patient had been discharged from the hospital for at least 24 hours, I contacted them to conduct a follow-up interview over the phone. The purpose of this interview was to learn about the remainder of the patient's hospital experience since the bedside interview and discuss their thoughts about using the *Patient Advice System*. I asked whether the probe changed their experience or perspective about their hospital visit and about exchanging advice with their peers, as well as what ideas they had for future iterations of the probe. These phone interviews were typically 15-40 minutes in length.

6.1.4 Data Analysis

This study produced two data sources for analysis. The first data source was the technology probe itself, encompassing the participants' activity on the probe (e.g., number of stories, comments, votes, page views), and the content of the stories and comments they contributed to the probe. I worked closely with a colleague, Yoojung Kim, to conduct quantitative analyses of this data. To compare participants' activity throughout their usage periods, we calculated descriptive statistics using the counts and timestamps of participant activities on the probe. To determine the tone and valence of the emotions expressed by participants on the probe, we did a sentiment analysis of stories and comments using IBM Watson's Natural Language Understanding[6], a text analysis tool. Finally, I conducted a qualitative analysis of participants' stories and comments to understand what peer support topics were exchanged within the probe. Using the peer support needs I identified in Chapter 4 as a codebook, I deductively assigned the applicable codes to each story and comment.

The second data source consisted of the bedside and follow-up phone interviews. All interviews were audio recorded and transcribed for qualitative analysis in Atlas.ti[7] (version 8.21). I led an inductive, open-coding analysis with the involvement of two other colleagues, Sonali Mishra and Elena Agapie (Strauss & Corbin, 1998). To identify themes relevant to the study's research questions, we did two rounds of independent coding on a randomly selected participant's transcripts. We met between each round to discuss emerging themes, resolve discrepancies, converge our list of codes, and formulate a codebook. After this process, Sonali Mishra and I tested the codebook on a set of transcripts from another randomly selected participant and achieved consensus. The entire data set was then analyzed using this codebook.

[6] https://www.ibm.com/watson/services/natural-language-understanding/
[7] https://atlasti.com/

	Pediatric Site	Adult Site
Total Participants	15	15
Gender Identity		
Female	8	7
Male	7	8
Age in years		
Mean (SD)	13 (2.56)	55.8 (15.84)
7-12	6	0
13-17	9	0
18-24	0	0
25-44	0	3
45-64	0	6
65+	0	6
Education		
Less than High School	15	2
High School Graduate	0	2
Some College	0	5
College Graduate	0	4
Post Graduate	0	2
Race/Ethnicity*		
White/Caucasian	13	11
Black/African American	2	0
Hispanic/Latin American	2	1
Asian	0	1
American Indian/Alaska Native	0	1
Other	0	1
Hospital Service		
Medical	10	7
Surgical	5	8
Length of Stay		
Mean (SD)	5.13 (3.74)	14.4 (22.79)
Median (min-max)	4 (2-16)	8 (2-95)
Length of technology probe usage period		
Mean (SD)	3.7 (2.69)	8.9 (15.98)
Median (min-max)	3 (1-11)	4 (1-65)
Been a patient in the hospital before		
Yes	9	14
No	5	1
Unsure	1	0

Table 6. Summary of participant demographics for the technology probe study.
*Unless otherwise indicated, all numbers indicate n. *Participants could select more than one category.*

6.2 PARTICIPANTS

A total of 30 participants were enrolled in this study: 15 pediatric patients and 15 adult patients. Table 7 above summarizes the participant demographics for this study.

6.3 RESULTS: TECHNOLOGY PROBE USE AND CONTENT

In the following sections, I summarize the results from my analysis of the technology probe data. This data includes the participants' activities (i.e., stories, comments, tags, and votes), and the nature of the content that was contributed to the probe. References to specific participants are accompanied by identifiers P# (for pediatric participants) and A# (for adult participants). Quotations of stories and comments that were posted to the technology probe are paraphrased to protect participants' privacy and anonymity.

6.3.1 Summary of Participant Activity

The overall usage period of this study—from when the first participant was enrolled to when the last participant was discharged—lasted for 7 weeks at the pediatric site and 10.3 weeks at the adult site. Throughout this time period, participants at both sites posted a total of 19 stories, 17 comments, 4 tags, and 34 votes. Pediatric participants averaged a total of 2.7 activities, while adult participants averaged a total of 2.2 activities. Figure 9 presents these four different activities by hospital sites. Pediatric participants contributed more stories than comments, votes or tags. In contrast, adult participants contributed more comments than stories, votes, or tags.

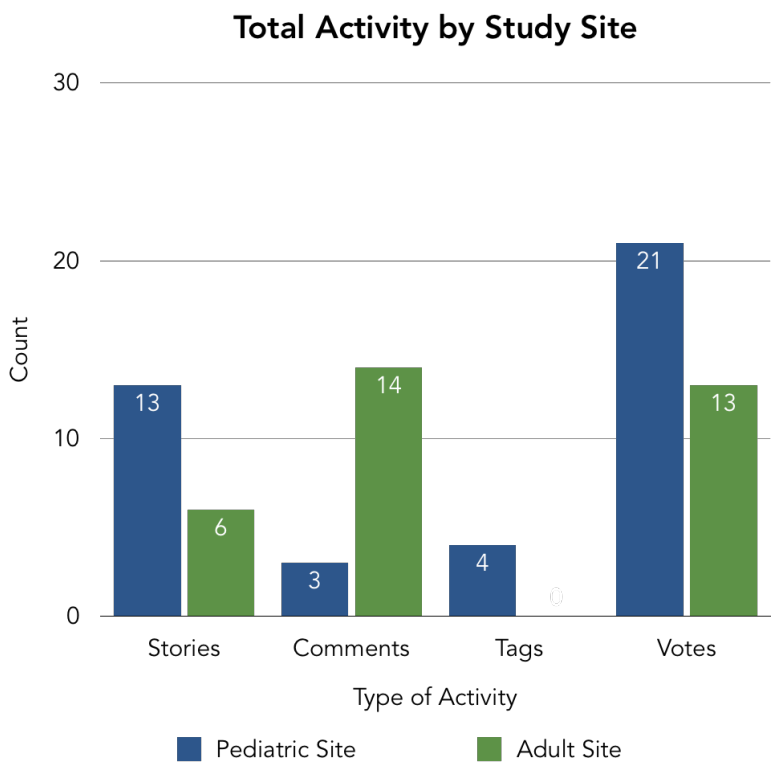

Figure 9. Total stories, comments, tags, and votes contributed by participants to the pediatric and adult technology probes.

Tables 8 and 9 provide a further breakdown of each individual participant's activity on the inpatient peer support technology probe, followed by a figure showing a normalized comparison of this activity. Overall, the pediatric site registered more activity than the adult site. Across both study sites, a total of 6 participants exclusively posted stories, 1 participant exclusively commented on stories, 5 participants exclusively voted on stories, and 11 participants did some combination of two or three types of activities. The remaining users (2 pediatric participants and 5 adult participants) had no recorded activity on the probe. None of the 30 participants at either site engaged in all 4 possible activities (i.e., did not contribute stories, comments, tags, *and* votes).

Pediatric Participant	Usage Period (in days)	Technology Probe Activity				
		Stories	Comments	Tags	Votes	Total Activity
P01	3	1	0	0	0	1
P02	1	1	0	0	0	1
P03	2	2	0	0	0	2
P04	11	1	0	2	1	4
P05	3	1	0	0	7	8
P06	2	0	0	0	0	0
P07	6	1	1	0	2	4
P08	3	2	0	0	0	2
P09	3	2	0	1	4	7
P10	8	0	0	0	1	1
P11	2	0	0	0	3	3
P12	2	1	0	1	0	2
P13	3	1	0	0	0	1
P14	4	0	2	0	3	5
P15	2	0	0	0	0	0
Total Activity	**-**	**13**	**3**	**4**	**21**	**41**

Table 7. Usage periods and total activity of pediatric participants.

Adult Participant	Usage Period (in days)	Technology Probe Activity				
		Stories	Comments	Tags	Votes	Total Activity
A01	6	1	0	0	0	1
A02	5	0	0	0	1	1
A03	16	0	0	0	0	0
A04	2	0	0	0	0	0
A05	10	2	3	0	0	5
A06	2	0	0	0	0	0
A07	3	0	5	0	1	6
A08	5	0	0	0	8	8
A09	3	0	0	0	1	1
A10	65	0	0	0	0	0
A11	3	0	0	0	0	0
A12	2	0	3	0	1	4
A13	4	1	0	0	1	2
A14	7	0	2	0	0	2
A15	1	2	1	0	0	3
Total Activity	**-**	**6**	**14**	**0**	**13**	**33**

Table 8. Usage periods and total activity of adult participants.

To compare individual participants' activity to each other, I normalized the data by dividing the total number of stories, comments, tags, and votes that each participant contributed to the probe by that participant's usage period (i.e., number of days they were enrolled in the study and could have used the probe before returning it at discharge). Figure 10 visualizes this normalized data of the different types of activities each participant engaged in.

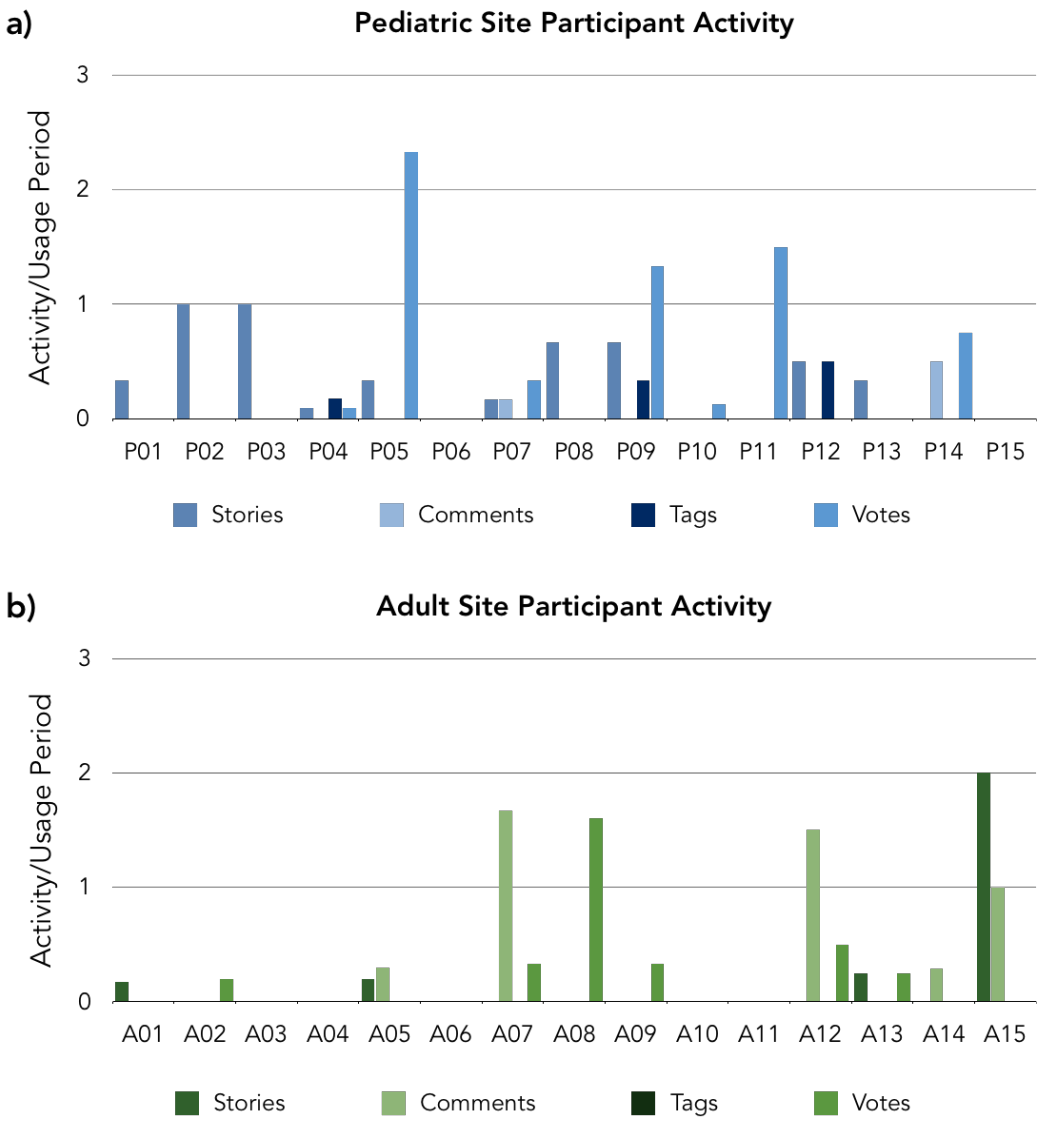

Figure 10. Participant activity by a) pediatric site and b) adult site. The Y axis represents a normalized unit to compare participants to each other, dividing the number of stories, comments, tags and votes of each participant by their usage period (in days).

To understand the variability of participants' activity, I plotted the normalized numbers of each type of activity for all participants and generated a box-and-whisker plot, shown in Figure 11. The plot reveals a wider distribution of story and vote activity among pediatric patients, while some outliers are observed at the adult site. These outliers are indicative of A15's multiple stories and A08's frequent voting, relative to other participants in the data sample. Regarding comment activities, a lack of box plot for the pediatric site confirms the presence of fewer comments at this site. At the adult site, there exist greater outliers and more variability of comment activity. Additionally, greater outliers are observed for tag activity at the pediatric site, although there was less overall utilization of this feature at both sites.

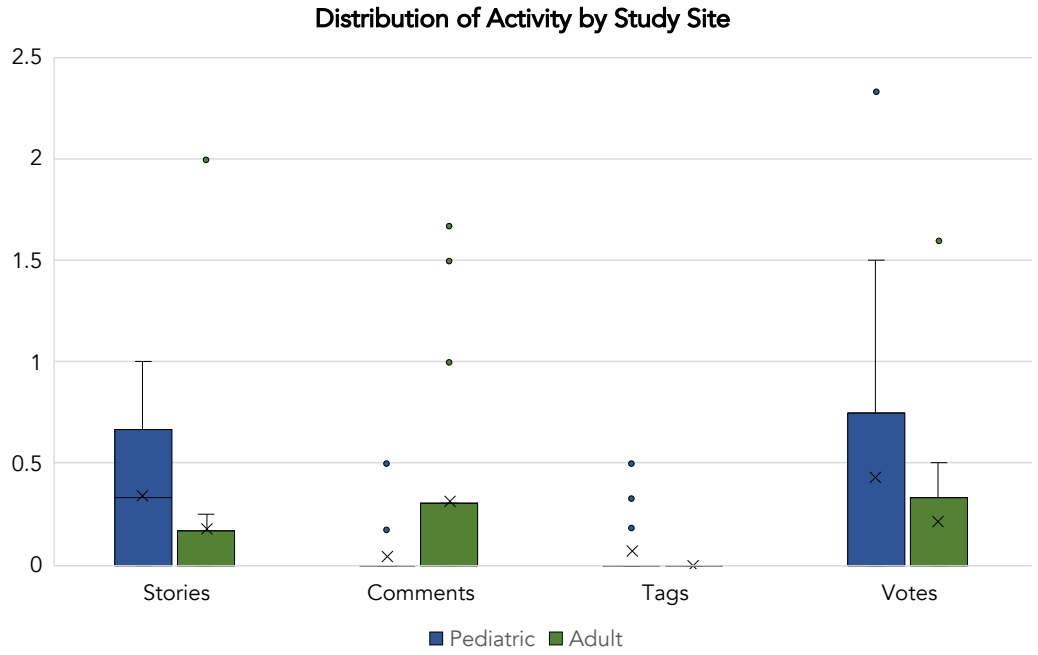

Figure 11. Box-and-Whisker plot showing the distribution of individual participants' activity, using the normalized measure of the number of stories, comments, tags, and votes divided by the usage period (in days). Means are marked by an "x".

6.3.2 Content Shared with Peers

Of the different types of activities (stories, comments, tags, and votes) that were available to participants through the probe, stories and comments were the ways in which participants could share information with patient-peers. Thirteen of the 30 participants involved in this study (11 pediatric patients and 7 adult patients) posted stories or comments to share their perspectives and advice with peers via the technology probe. As mentioned in the previous section, these 13 participants authored a total of 19 stories and 17 comments. Excluding story "titles", the average length of stories that participants contributed to the technology probe was 65.6 words at the pediatric site and 105.75 words at the adult site. The average length of comments that participants posted in response to their peers' stories was 22 words at the pediatric site, and 89.6 words at the adult site. In the following subsections, I describe the nature of the peer support shared through these stories and comments.

Peer Support Needs in Stories and Comments

Through a deductive analysis, I determined whether the peer support needs that I describe in Chapter 4 were mentioned by participants in their real-world use of the probe. The results of my deductive analysis—where I coded all 13 participants' stories and comments using the previously mentioned peer support needs—are shown in Figure 12.

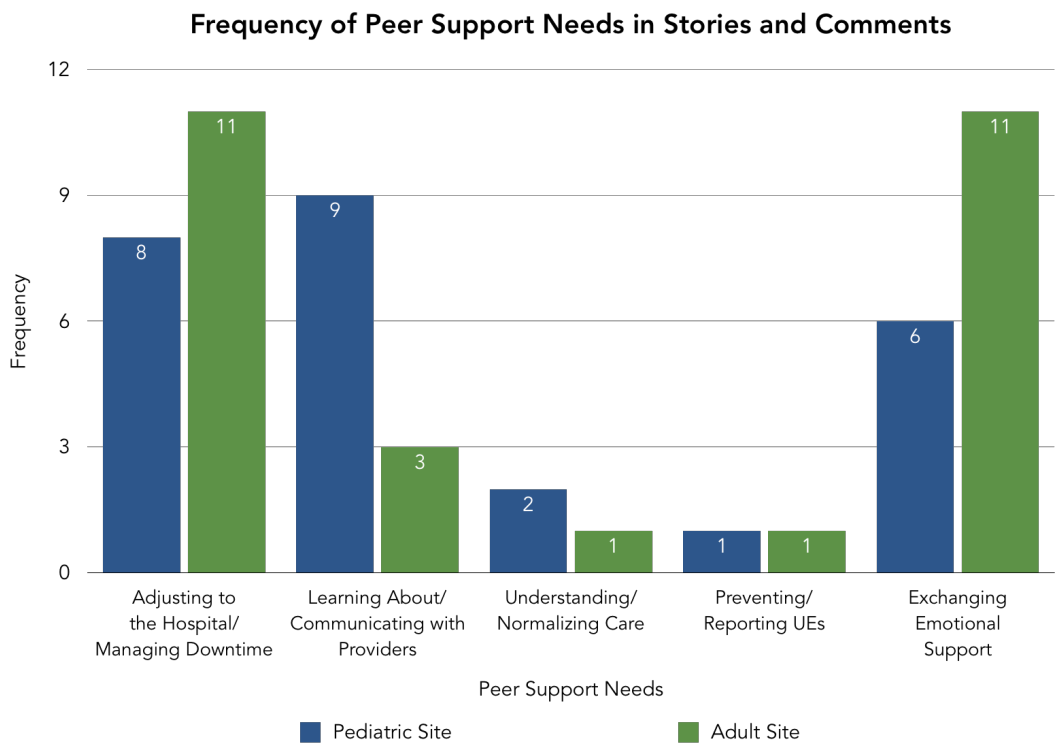

Figure 12. Frequency, or number of times, each peer support need was coded in participants' stories and comments.

All themes appeared at least once at each hospital site. Overall, information pertaining to adjusting to the hospital and exchanging emotional support were more prevalent at the adult site, whereas information about providers and understanding hospital care were more prevalent at the pediatric site. These themes manifested in the following ways:

Adjusting to the Hospital and Managing Downtime. Adult and pediatric participants shared information with their peers about hospital amenities, including the good quality of the food service, recipes for creative and nutritious snacks using ingredients from the cafeteria, proximity of coffee shops within the building, and the comfortable nature of their individual hospital rooms. To increase this level of comfort, P04's caregiver posted a recommendation for other patients: *"if you are staying the night in the hospital, pack your own comfy blanket."* Another participant, P08, described her experience of painting with

an art therapist to pass the time during her post-surgery recovery. Adult participants also shared practical tips for their peers, such as ensuring their cell phone was charged to keep friends and family updated about their condition. On the topic of personal comfort and hygiene, A12 posted, *"I told the nurses my hair was really dry and they recommended the concierge cart. I didn't know they still did that but I got conditioner and could brush my hair! Nice to feel human again!"*

Learning About and Communicating with Providers. When referring to providers, both pediatric and adult participants expressed their favorable views of those caring for them during their stay. P02 shared that his *"nurses check on me regularly and ask how I'm doing. I feel safe, and they make sure I'm doing ok."* Others mentioned that when asking questions, their providers were responsive, supportive, and good communicators. To recognize this work, P09 suggested to other patients: *"we should give thanks to nurses because of everything they do. They care for us and some give us food and I appreciate that."* Although most stories and comments referring to providers were agreeable in nature, A13 experienced challenges in communicating with her care team. She wanted peers to know: *"it would be nice to have one point person to whom you could ask questions and summarize notes, instead of multiple teams visiting you. Then you might get your questions answered and the teams could talk to more patients."*

Understanding and Normalizing Care. Participants from both sites provided some details and experiential information about their care in the hospital. For example, P07 shared the surgical procedure she was undergoing to prepare for radiation to treat her cancer diagnosis. P03 discussed the *"uncomfortable"* needles and pain he experienced after

surgery. P01 informed other patients about the difficulty of managing her pain: *"if you're in a lot of pain like me the providers need to jump over many hurdles to get you good painkillers."*

Preventing and Reporting Undesirable Events (UEs). The two participants who discussed this topic emphasized the importance of speaking up when a problem occurs, or when the patient feels *"bad"* (P09). A01 experienced multiple UEs during her hospitalization and posted this advice: *"if you don't think you're getting the care you need, ask for the charge nurse as recourse. If you aren't getting enough medication for pain relief, ask for more."*

Exchanging Emotional Support and Empowering Peers. Pediatric and adult participants posted stories and comments about their emotions surrounding their hospital stay. Patients described feeling *"nervous," "stressed,"* and *"scared"* prior to their procedures, but reassured peers that they felt *"safe"* and that *"nothing bad happened"* because they were *"in good hands"*. A05 posted two stories that expressed his interest in connecting with other patients during his visit. His first story stated, *"I am a patient on bed rest here…let's chat and pass the time!"* In his second follow-up story, he explained: *"Patients discussing information about their care is a fantastic idea…just being able to talk with others who are in the same or similar situation is sort of therapeutic and a great way to meet new people."*

Sentiment of Stories and Comments

In addition to the above qualitative analysis, I examined the overall sentiment, or emotional tone, of the content that participants contributed to the technology probe. A text analysis using the IBM Watson NLU tool produced a sentiment score for each story and comment that was posted by a participant. This score, ranging from -1 to 1, represents both the type and magnitude of the sentiment expressed. For example, a score approaching 1 indicates a very positive sentiment (e.g., "my doctor is great" = 0.97), while a score approaching -1 indicates a very negative sentiment (e.g., "I hate needles" = -0.96). It is important to note that a negative sentiment score does not necessarily indicate a complaint by a participant. Rather, it provides a quantitative measure with which to understand the overall tone of the story or comment.

The average sentiment score was calculated for stories and comments posted on each study site's technology probe. Figure 13 shows the number of stories and comments at each site that expressed either a positive (score > 0) or negative (score < 0) sentiment. Across both hospital sites, a greater number of stories and comments reflected a positive, rather than negative, sentiment.

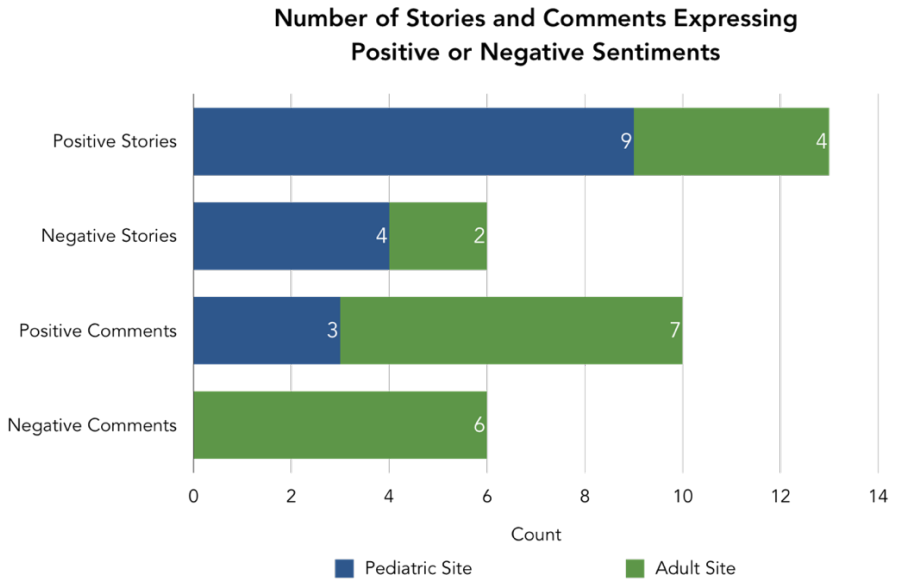

Figure 13. Total number of stories and comments at each site that received a positive or negative sentiment score.

Figure 14 displays the average sentiment scores of the individual participants who contributed stories and comments to their respective technology probes. Nine of 11 pediatric participants (81.8%), and 4 of 7 (57.1%) adult participants, had stories and comments that yielded positive average sentiment scores. These findings suggest that, although there is some variation among individual participants, the content that they shared with patient-peers generally reflected positive suggestions, experiences, and expressions of support.

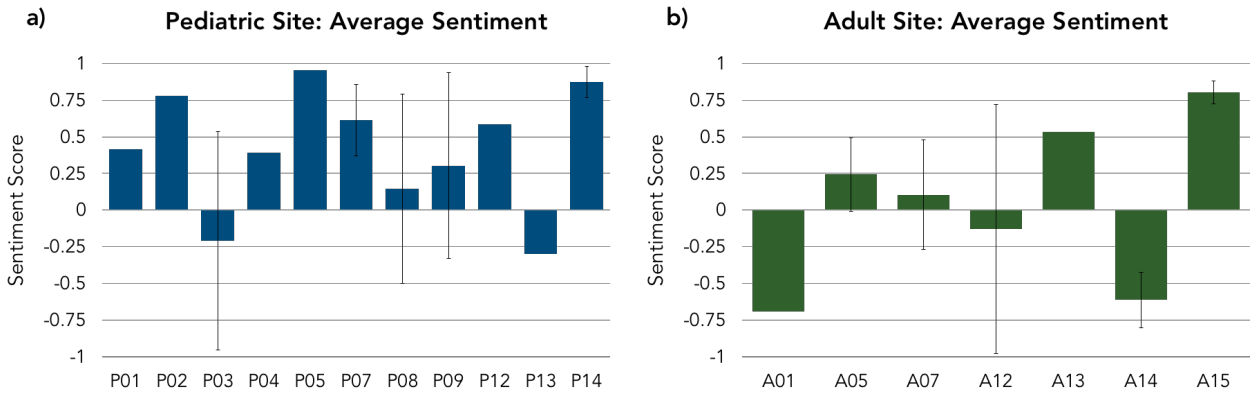

Figure 14. Average sentiment scores of participants' stories and comments at the a) pediatric and b) adult sites. Positive and negative error bars represent the Standard Error of the Mean (SEM) for each participant.

6.4 RESULTS: IMPACT OF INPATIENT PEER SUPPORT

In addition to understanding how participants used the technology probe and the nature of the peer support they exchanged with each other, the bedside and follow-up phone interviews with all 30 participants provided insights into how this peer support impacted their hospitalization. In the following sections, I describe the four ways in which participants' perspectives, actions, and hospital experiences were impacted: (1) increased awareness and value of peer networks, (2) increased appreciation of providers and the hospital, (3) improved quality and safety, and (4) improved emotional wellbeing.

6.4.1 Increased Awareness and Value of Peer Networks

Outside of the peer support offered through the technology probe, a few participants mentioned that they already had existing networks of patient-peers with whom they were comfortable exchanging advice. For example, P02, P10, A04, A05, and A14 all referred to immediate family members and friends with whom they discussed their shared health or hospital experiences. Additionally, A11 had previously participated in a cancer navigation program to learn survivors' stories. For most of these participants, having tangible, real-life connections also meant they favorably viewed the exchange of advice with other hospitalized patients via the technology probe.

However, some participants did not have these existing peer resources, and were unaware of people in their life who had been to the hospital before or had experienced their health condition. Despite these participants having an interest in making connections with other patients, few opportunities presented themselves during their hospital stay. P07 was an early adolescent pediatric cancer patient who wanted to become friends with, but had not yet met, other patients on her floor. By attending an in-hospital class about learning to manage her new diabetes diagnosis, P06 saw another patient in the class with her. She observed both of their parents *"laughing and stuff"* but did not interact with the other patient directly.

After using the technology probe, participants described how it helped them feel more connected to the other patients in the hospital. Given that the nature of A15's procedure restricted her ability to leave her bed and walk around her floor, the probe increased her cognizance of the patients around her, as well as their experiences. She explained:

> *"I liked a lot of things about [the probe]. I thought it was pretty useful. Before the [study participation] came up, I had been talking to myself about I wonder what other people are in here for and how they're doing. Some*

people are up walking around, I'm just stuck in this bed. So it was interesting to see what other people were doing." (A15).

In contrast, A02 was a participant who initially viewed peer support as a helpful resource and was inspired by an earlier exchange of advice she had with her hospital roommate. Later in her stay, however, she was transferred to a single room where she experienced multiple UEs regarding her care and discharge process. Although she did not engage with the technology probe after the introductory onboarding process, she described her frustration with these UEs and her awareness that other patients might also be enduring such problems: *"I'm just feeling like if it happened to me, it probably happened to other people too…it felt like there was no real investment in me. I don't know about the other patients."*

Aside from an increased awareness, participants described how their use of the technology probe allowed them to learn from the expertise of their peers. Although some patients such as A06 and A11 preferred to know information that was specific to their health condition, other patients saw value in receiving unique insights about the hospital from a broader peer community. P15 described her thoughts on how patients who were less familiar with the hospital environment could benefit from having access to peer information: *"I think it would just be helpful for like other people who are new to being in the hospital and they don't really understand yet or they don't know what to do, that kind of thing."* Another patient, A07, at first expressed some reluctance at receiving advice from peers, stating that he didn't know if he *"would really take too much heed."* His use of the technology probe, however, changed his opinion on this advice and how he thought about his care: *"…It's informative. It lets you know how other people feel and then I would say oh, [another patient] thinks this? I don't know if I think that way, you know?"*

Those who had considerable expertise as hospitalized patients also saw value in sharing their expertise with other patients through the technology probe. A12 thought it was important to *"make*

people aware" of lesser known amenities that the hospital offered. A05 expressed a similar opinion about the importance of sharing his knowledge with others: *"I think there's a lot that patients have in common, common feelings from what tastes good in the cafeteria to important medical things. I think by sharing that, other people can…learn from somebody else's experience."*

Some patients expressed their perceived value of peer support in terms of how it compared to the support from their health care providers. A few patients maintained the opinion that their providers were the best resource for care- and condition-specific health information, whereas patient-peers were the preferred resource for personal, experiential information on *"how to be a patient"*. When asked about the comparison between advice received from providers versus peers, P09 likened her experience using the technology probe to *"school, but at the hospital"* where her peers were analogous to her classmates and nurses had the role of giving *"the advice a teacher would give"*. Another participant, P11, sometimes preferred the information from his peers because it was more helpful and easier to understand than the information from his care team. He explained: *"sometimes you understand [other patients] more, because the big words that the doctors are using…if we're talking about [my] medicine, sometimes I don't always know what they're talking about."*

The stories that patients shared via the technology probe helped participants view their peers as a new source of support. The knowledge from peers not only broadened their perspectives about their care, but also complemented the information they received from providers involved in their care.

6.4.2 Increased Appreciation of Providers and the Hospital

Participants discussed how the information and interactions they shared with each other through the technology probe affected their perceptions of their care team. P10 described how

reading stories from other patients changed her attitude toward her care team members as people. A frequent hospital visitor with a *"tricky"* health case, and an expert in managing her condition, P10 was *"fed up"* with her providers' uncertainty and miscommunications surrounding her treatment. Her initial belief that advice from peers and providers were similar shifted after using the technology probe. She said, *"I just liked seeing [the] wide variety of opinions…it's nice…because not everyone's body is the same and not one is going to be exactly the same…I think some doctors struggle with the fact that not everyone's going to be by the book and that kind of thing."* In recognizing this struggle among her care team, P10 thought the technology probe helped her understand their approach to decision-making: *"my surgeons are doing as much as they can with what they have. It was a gentle reminder that yeah, it sucks, but it's life."*

In addition to their perceptions of providers, participants discussed how the technology probe impacted their thoughts about the hospital at which they were receiving care. P14 and his caregiver used the technology probe during the hospital visit where he was receiving his first round of chemotherapy. With such a new diagnosis and treatment plan, P14's caregiver explained how the probe not only served as a resource to help process all the new information they received, but was also indicative of the hospital as an institution that cared about supporting their family:

> *"I mean, there are external groups online and so forth, support groups, but…I kind of felt like this particular website, knowing that the hospital is investing resources in the families' experience, the patients' experience, and helping to connect people to other people in the same environment, I think it made me feel just a little more cared for…just that one extra step that okay, this hospital…really is invested in my family, not just my son and his clinical care and his emotional care. It's like our whole family is being*

wrapped and supported and here is another avenue…that we can help families be supported through this horrible awful time." (P14's caregiver)

Being exposed to a broad range of opinions and ideas within the technology probe allowed participants to gain a deeper understanding of their providers on an individual level, and an appreciation for the support their hospital could provide at an institutional level.

6.4.3 Improved Quality and Safety

Aside from the value of learning from peers' general hospital experiences, a number of participants articulated how the technology probe served as a resource for patients to be aware of and avoid potential problems in their care. A09 was a patient who was in the hospital to correct a mistake that was made in his previous surgery. He wanted more information from peers about both the positive and negative experiences in the hospital: *"if it's just positive [experiences] all the time and nobody knows if there's anything wrong happening – I'm not sure everybody has a positive experience in [the hospital]."*

A01 was another patient who experienced multiple UEs over the course of her hospital stay, including a missed dose of pain medication. Her original impression of exchanging advice with peers was that it was *"like gossip pretty much to me. That's like let's bitch to each other about what's going on."* Later in her stay, she discovered the role and power of her charge nurse in improving these UEs. She shared this advice via the technology probe and explained why she was compelled to do so: *"If people knew that was available, it would resolve a lot of issues by the end of the day. You wouldn't have to go through what I went through…you shouldn't have to ask for a charge nurse. Ideally, you're in a hospital, they should be taking care of you."*

A15 also expressed a desire to share this type of advice with her peers. A botched surgery caused her to change hospitals and seek out a new provider to help resolve the long-term

consequences of this surgery. During her follow-up interview after her discharge from the hospital, she described wanting to continue using the technology probe to instill confidence in her peers about the importance of getting second opinions for major care decisions:

> *Interviewer: Can you tell me what kind of advice you'd like to give?*
>
> *A15: I think everything's important. Knowing you can ask for a second opinion…even when I had thought that maybe I should get a second opinion, I didn't know how…I trusted that the doctors knew more than I knew, and that I was going to be just fine. But I should have followed my gut instinct. […] I could have avoided all of this.*

A small subset of participants translated the knowledge they received from peers into action by following the peer advice posted within the technology probe; they described the positive results of implementing this advice. After reading advice from P04's caregiver—recommending patients to have a comfortable blanket in the hospital—P09 and P11 both asked their families to bring these personal effects from their homes, which increased the *"comfort and warmth"* of their hospital stay. A08 had never been to the hospital before and was on a rigid intravenous (IV) fluid schedule during his stay. His preliminary thoughts about support from patient-peers was that it might only be useful if it came from those who experienced his similar condition. However, after noticing a care coordination issue where his IV was not refilled in a timely manner, A08 used the advice from the technology probe to speak up about the issue to his care team:

> *"There was another [thread]…related to engaging more with the nursing staff and being proactive with reminding them about steps. […] I didn't directly confront them or anything, but I did tell them that the machine is beeping a lot and maybe they could keep one or two of those [refill] bags ready so they don't have to go off looking for them when they start*

beeping…the last 36 hours [of my stay] they did have one or two bags always on the table. So whenever the thing started beeping, one of them ran in and switched it out." (A08)

In using the technology probe, participants recognized—and in some cases, fulfilled—the potential for peer support to benefit others and improve the overall quality and safety of their hospital stay.

6.4.4 Improved Emotional Wellbeing

Finally, participants described how using the technology probe impacted their emotional wellbeing over the course of their hospital stay. For example, participants such as P03, P15, and A07 thought the technology probe was another way to pass the time that made their hospitalization more enjoyable and entertaining. P08 felt *"happy"* after reading a *"funny"* post on the technology probe. P09 said that the technology probe was fun to use because *"it really made me smile to think that other patients were also smiling…"*

Others cited the interactions with peers as satisfying a need to connect and feel supported by patients with shared experiences. These participants valued the information within the technology probe as helping them relate to other patients who might be going through similar struggles, within and beyond their specific health condition. Moreover, this peer support was viewed as a source of reassurance that helped individual patients manage the negative emotions surrounding their hospital stay. P05 described how *"scared"* he felt upon his admission due to the risk of having to undergo surgery. Although the surgery was ultimately avoided, P05 still felt the impact of the technology probe: *"it did change my hospital stay. I wasn't as nervous because it told me."* Another pediatric patient, P07, also explained how the technology probe helped to address feelings of isolation during her hospital stay: *"It made me feel a little better about being in that*

situation...because I felt like I wasn't alone and I could relate to people." When asked what her thoughts were on sharing her own advice with other patients, P07 responded: *"I thought it might help other kids with what they're going through…kind of sharing that the first time isn't as scary as you would think."*

Participants used the technology probe as a space to alleviate the negative emotions—such as fear, worry, and anxiety—that surrounded their hospital stay. Sharing their individual experiences and expressing sympathy toward each other sometimes helped patients convert these negative emotions into more positive thoughts.

6.5 DISCUSSION

In this study, I examined how an inpatient peer support technology probe was used by pediatric and adult patients, as well as what impact it had on these patients during their hospital stay. Participants contributed many stories, comments, tags, and votes to the technology probe. They used the probe to exchange support about multiple aspects of their hospitalization, including how to adjust to the new environment and how to report and prevent UEs. In addition, the probe impacted participants in several positive ways, such as increasing their appreciation for peers and providers, and improving quality, safety, and their emotional wellbeing. Building off of my prior work in Chapter 4 that identified a need for peer support among patients in the hospital (Haldar et al., 2017, 2018), the findings described in this chapter—obtained at two independent hospital sites and produced by two distinct patient populations—demonstrate that the inpatient peer support technology probe I created does address this need and has a positive impact on the quality, safety, and experience of their hospital stay.

Not only did the participants who engaged with the technology probe come from both medical and surgical services of the hospital, but they also represented a variety of clinical backgrounds.

Participants ranged from having no prior experience as a patient, were in the early, mid, and late stages of managing a chronic condition (e.g., cancer, diabetes), or were self-described experts and advocates in managing their hospital care. In contrast, most prior work on digital peer support technologies tend to be customized for those who share health conditions. For example, mobile applications have been created for patients managing diabetes and weight loss (Chen, Chen, Randriambelonoro, Geissbuhler, & Pu, 2017; Rotheram-Borus et al., 2012), and dedicated online community spaces exist for those living with cancer (Demjén, 2016; Eschler et al., 2015). Studies investigating face-to-face peer support programs within the hospital also enable this support among patients experiencing similar treatments and trajectories for recovery, such as burn victims (Patterson et al., 2018). Yet, participants in my technology probe study saw value and learned from those who were not strictly from their same health condition. Although P04 was in the hospital for epilepsy treatment, the advice his caregiver shared about bringing a comfortable blanket resonated with P11, a cancer patient. For these participants, the shared experience of being in the hospital was sufficient to yield the benefits of peer support.

Interestingly, participants reported benefits from having access to the stories and comments within the technology probe, even if they did not contribute a substantial amount of their own content to the system. Examples of this were P10 and P15, who might be classified as "lurkers" on the technology probe. Neither participant posted original stories or comments to the system but described in their interviews how reading and following the advice from other patients helped them feel more understanding towards their providers and more connected to their peers, respectively. This finding supports prior suggestions that despite their lack of active engagement with the system, "lurkers" still receive benefits from this level of participation in online communities (Han, Hou, Kim, & Gustafson, 2014; Mo & Coulson, 2010).

A subset of participants who did post stories and comments shared tips with each other about what actions they could take to independently improve their hospital experience, care quality, and safety. In addition to making personal requests from the hospital's concierge cart (A12), patients encouraged their peers to speak up to providers if they noticed something wrong about their health (P09) and to contact their charge nurse to resolve severe UEs (A01). Although most of the stories did not deal specifically with UEs, peer advice on other topics, such as adjusting to the hospital, were implemented by patients to better their experience and care. A08 was an example of someone who used peer advice about communicating with providers to successfully speak up about a coordination problem in his care. Although researchers have previously involved patients in their safety via real-time reporting tools (Collins, Couture, Smith, et al., 2018), medication reconciliation tools (Prey et al., 2018), inpatient portals (Woollen et al., 2016), and shared inpatient clinical notes (Grossman et al., 2017), findings from this technology probe study indicate that inpatient peer support—regarding various aspects of a hospital stay—also helps patients proactively engage in the quality and safety of their care.

Throughout this study, multiple patients requested that the technology probe remain functional and accessible to them after their completion of study procedures, suggesting a desire for a more permanent system within the hospital that facilitates peer support. However, strategies for implementing such a system into the existing clinical and hospital workflows remains an open question. Past literature has documented a history of concerns that non-patient stakeholders (i.e., health care providers, administrators, and executives) have voiced—including privacy of health information, patients' abilities to comprehend complex medical information, and evolving roles of clinicians—when inpatient-facing technologies are introduced into the hospital setting (Collins et al., 2016; Wilcox et al., 2010). Providers have also expressed concerns about the accuracy and quality of information shared between patient-peers online (Tan & Goonawardene, 2017).

Yet, previous research on peer support technologies (specifically, online health communities) shows that these concerns are largely unfounded. For example, less than 0.5% of posts within an online breast cancer community were found to contain inaccurate or misleading clinical information, many of which were noticed by other patients within the community and promptly corrected (Esquivel, Meric-Bernstam, & Bernstam, 2006). When a medical question is posed by a patient, their patient-peers will encourage them to seek a health care provider, rather than self-diagnose or self-treat (Huh, 2015). Moreover, patients will seek feedback from their providers about the information they obtain from online health communities (Rupert et al., 2014). In this technology probe study, participants did not share specific recommendations for their peers regarding medical treatment. Topics of conversation instead focused on normalizing their individual experiences, exchanging emotional support, and offering suggestions for how to improve the comfort and quality of their hospital stay.

Implementing an inpatient peer support system could introduce additional concerns about patient-peers sharing complaints about specific providers, especially when UEs occur. However, this was not observed within the technology probe. Stories and comments that received a negative sentiment score often dealt with negative aspects, or dislikes, about the hospital stay (e.g., feeling pain after surgery) rather than targeted complaints toward providers or hospitals. Participants who did experience UEs chose to share actionable advice with their peers on how to avoid similar problems (e.g., by speaking up and requesting a charge nurse), and did not mention providers by name. These observations might in part be due to establishing guidelines for use that define what is "acceptable" behavior (described in Chapter 5) and emphasizing these guidelines during the onboarding process with participants. Nonetheless, the nature of the advice shared within the technology probe conveyed an overall positive emotional valence and led to many positive impacts for patients.

6.6 CONTRIBUTION

In this chapter, I examined how patients used a peer support technology probe during their hospital stay. I found that the advice they exchanged with each other met the peer support needs expressed in Chapter 4 and expressed an overall positive sentiment. I also described the many positive impacts that this peer support technology probe had on participants by increasing their awareness and value of peer networks, increasing their appreciation of their providers, improving quality and safety, and improving their emotional wellbeing. I demonstrate that the positive impacts of peer support can be experienced by patients regardless of their individual health conditions and levels of engagement with the technology probe. Furthermore, I provide evidence that peer support helps patients take proactive steps to improve the quality, safety, and overall experience of their hospital stay.

7

CONCLUSION

In this concluding chapter, I review my findings and describe how I fulfilled each of the dissertation aims that were introduced in Chapter 1. I then provide a summary of my contributions, discuss the limitations of my studies, and point to opportunities for future research. Finally, I share a concluding statement.

7.1 FULFILLMENT OF DISSERTATION AIMS

The findings presented in this dissertation address the following aims:

Aim 1: Understand Patient and Caregiver Experiences with Undesirable Events (UEs). I surveyed over 200 pediatric and adult patients and caregivers, asking open-ended questions about the UEs they experienced during their hospitalizations (Chapter 3). A qualitative analysis of their responses to these questions revealed the complexities of hospital safety from their perspective. In addition to the well-known clinical issues that arise during care, participants identified a range of non-clinical UEs (e.g., lack of information, burdensome policies, comfort of the hospital environment). These quality and safety issues are often overlooked by—and are unreported to—hospital staff. In many cases, participants experienced clinical and non-clinical UEs that exacerbated each other. Additionally, participants reported a series of invisible harms (e.g., negative emotions, loss of trust, life burdens) that were a consequence of UEs. These findings served as the foundation for a conceptual model of patient and caregiver experiences

with UEs. The conceptual model showed that patients and caregivers require interventions to support them much earlier in their experience to proactively intervene in UEs, rather than reactively report these events. Moreover, the knowledge and expertise that patients and caregivers accrue from their experiences could help their patient-peers successfully navigate UEs and avoid harms.

Aim 2: Explore Needs and Design Recommendations for Inpatient Peer Support Technologies. I integrated results from the aforementioned survey study with a follow-up interview study with 30 patients and caregivers to explore peer support as one type of intervention that could improve the quality and safety of a patient's hospitalization (Chapter 4). I found that patients and caregivers expressed the need to exchange advice with each other about a variety of topics regarding the quality, safety, and experience of the hospital. These topics included how to adjust to the hospital and manage downtime during their recovery, understanding and normalizing the care they were receiving, learning about their providers and how to communicate with them, strategies for preventing and reporting undesirable events, and the desire to share emotional support with peers. In considering technology as the medium through which this peer support could be enabled, participants spoke about their anticipated barriers (e.g., privacy concerns, situational impairments) to using such a technology during their hospital stay. Based on these needs and barriers, I developed a series of design recommendations for inpatient peer support technologies, consisting of intelligent peer matching, respecting privacy and anonymity, and accommodating a dynamic hospital stay.

Aim 3: Examine the Design, Use, and Impact of an Inpatient Peer Support Technology. To examine inpatient peer support in a real-world context, I implemented a subset of my

previously identified design recommendations and built the *Patient Advice System*, a Reddit-style website that allows end-users to post original stories, participate in comment threads, and upvote the stories of other end-users (Chapter 5). The design and development of this system carefully accounted for the constraints of the hospital environment (e.g., non-disruptive and unobtrusive during care-related events). I then deployed this system and, using the technology probe method, studied its use and impact in the hospital (Chapter 6). Through bedside and follow-up interviews with 30 pediatric and adult patients, I discovered that 76.6% (23/30) patients engaged with the *Patient Advice System* in some way (i.e., contributed stories, comments, or votes). The stories and comments that patients exchanged with each other expressed an overall positive sentiment and aligned with the peer support needs that I uncovered in Chapter 4. Furthermore, participants described a multitude of positive impacts that the *Patient Advice System* had on the quality, safety, and overall experience of their hospitalization. Patients explained how the exchange of peer support during their hospital stay increased their awareness of patient-peers around them, increased their appreciation for their providers and their hospital, drove them to take actions to improve their quality and safety, and improved their emotional wellbeing.

7.2 SUMMARY OF KEY CONTRIBUTIONS

In fulfilling the three dissertation aims above, I make several contributions to the fields of Personal Health Informatics, Human-Computer Interaction, and Patient Safety. My contributions to the Personal Health Informatics field are as follows:

1. A rich understanding of the needs that patients and caregivers have for informational and experiential support from their peers, and the barriers they face to obtaining this support (Chapter 4).

2. The *Patient Advice System* as a patient-facing technology that provides the informational and experiential support of their peers, and that can be deployed, used, and scaled within complex clinical settings (Chapter 5).
3. Evidence of the benefits that patients experience when using the *Patient Advice System* and interacting with their peers during their hospital stay (Chapter 6).

When considering this dissertation from a Human-Computer Interaction lens, I make the following contributions:

1. Design recommendations that provide guidance on how inpatient peer support technologies can best meet the needs of patients and overcome barriers they face in receiving the benefits of peer support during their hospital stay (Chapter 4).
2. The *Patient Advice System* as a working technological artifact that aligns with a subset of my specified design recommendations for inpatient peer support technologies, and that incorporates design recommendations for online communities (Chapter 5).
3. Empirical data about how patients used the various features of the *Patient Advice System* to exchange advice and interact with their peers (Chapter 6).

Finally, my contributions to the domain of Patient Safety consist of:

1. An understanding and conceptualization of patient and caregiver perspectives on the UEs they experience during their hospital stay, their resulting harms, and new opportunities for patient-centered safety interventions (Chapter 3).
2. The *Patient Advice System* as a novel patient-centered intervention that patients can use to obtain advice peer advice about improving quality and safety during their hospital stay (Chapter 5).

3. Evidence that patients experience many positive impacts from using the *Patient Advice System*, and that this peer support improves aspects of the quality and safety of their hospital stay (Chapter 6).

7.3 LIMITATIONS AND FUTURE WORK

While this dissertation adds new knowledge about the opportunities, needs, and impact of inpatient peer support technologies within the context of patient safety, I acknowledge some limitations to the studies described in this dissertation. These studies were conducted at two hospitals in the Pacific Northwest region of the United States and represent a somewhat homogeneous demographic and geographic population. Self-selection bias may exist in the survey study (Chapter 3), as patients and caregivers were not compensated for their participation. Because safety was emphasized in the survey study, the advice patients shared with peers via the survey (Chapter 4) may also be influenced by this topic. In addition, the results from the technology probe study were generated by participants using the *Patient Advice System* (Chapter 5), a system that encapsulates only a subset of the design recommendations I identify in Chapter 4. The novelty effect might have a partial role in the levels of activity on the *Patient Advice System* that were observed in the technology probe study (Chapter 6). My decision to not provide iPad chargers to participants as a way to reduce the likelihood of device loss might also have affected their levels of use (Chapters 5 and 6). Due to the nature of study participation, patients and caregivers in all three studies might be considered highly engaged in their health care and hospital safety, more so than the broader patient population.

Despite these limitations, the findings presented in this dissertation reveal several new avenues for future research in the fields of Personal Health Informatics (PHI), Human-Computer Interaction (HCI), and Patient Safety.

7.3.1 Opportunities for PHI and HCI

As shown by my technology probe study, patients experienced several benefits from using an inpatient peer support technology that closely resembled an online forum such as Reddit. An important next step will be to determine if these benefits hold true or differ based on the medium through which inpatient peer support is offered. Future work can implement other design recommendations I identified as a result of my survey and interview studies—such as the leveraging of Electronic Health Records (EHRs) to match peers based on shared characteristics and facilitating real-time chats between patients—to make this determination. Past research has explored the construction of 3D environments and raised the idea of collaborative gaming systems that patient-peers can use to interact with each other while receiving care (Bers, Chau, Satoh, & Beals, 2007; Liu, Inkpen, & Pratt, 2015). As these novel voice and visual interfaces (e.g., conversational agents; augmented and virtual reality) become increasingly common in health care, future research could explore how such technologies could enable collaboration and support between patient-peers to reduce their physical isolation from each other.

Another avenue for future work in the PHI and HCI spaces is investigating the feasibility of offering inpatient peer support technologies as a separate, standalone system versus as a feature within other inpatient-facing technologies (i.e., inpatient portals). However, pursuing this investigation can lead to several ethical questions. For example, if the technology were to function as an independent system, what entity is responsible for maintaining the privacy of its data and quality of its content? If patient-peer support was incorporated as a feature within a hospital's larger technological ecosystem, should the hospital or EHR vendor have access to the information that patient-peers exchange with each other? Does the ownership of the system by a hospital or EHR vendor change the nature of the support that is exchanged between patients? Answering these

questions will be essential to the success and trust of an inpatient peer support system. Although I observed an overall positive tone of the peer support exchanged within the technology probe, more work is needed to determine if this positivity is maintained when this type of system is scaled to larger patient populations and hospital systems.

7.3.2 Implications for Patient Safety

A common thread among my studies was the desire for participants to exchange some level of peer support pertaining to the quality and safety of their care. Although these participants' conceptualization of quality and safety was found to be quite broad in comparison to the perspectives of health care providers, they shared advice on an equally broad range of these topics, including what they thought could be improved about their hospital stay, with their peers. One opportunity for future research in this area is to explore how peer support—and technologies that enable this support—might help patients "triage" their questions and concerns for providers and make decisions about reporting the UEs they experience. As a new source of information about UEs and the overall hospital experience, additional work could examine what affect inpatient peer support systems have on the influx of quality and safety data that health care organizations are currently managing, as they attempt to reconcile multiple data sources and construct complete pictures of quality and safety problems (O'Hara & Lawton, 2016; Shojania, 2010).

7.4 CONCLUSION

Over the course of this dissertation, I have demonstrated the opportunities and value of peer support for patients during their hospital stay, and that inpatient peer support technologies have positive impacts on the quality, safety, and overall hospital experiences of patients. As a patient-centered safety intervention, inpatient peer support technologies still have a great deal of

unrealized potential to help patients in identifying, preventing, reporting, and coping with the effects of UEs and harms.

The three studies that I present in this dissertation are rooted in the recognition of patients and caregivers as equal stakeholders in improving the quality and safety of their hospital care. Acknowledging their points of view yielded previously unidentified opportunities for patient safety interventions, and previously unaddressed needs for patient-peer support. Exchanging advice with other patients enhanced their peers' hospital stay. Moreover, the value and benefits of inpatient peer support transcended the patient's specific diagnosis and hospital service, asserting that expertise can be shared—and knowledge can be gained—within and beyond health condition-specific silos.

The hospital is universally recognized as one of the most unsafe and disempowering clinical settings for a patient. However, patient-peers have a role in equipping patients with important information and support to mitigate safety concerns, and in empowering patients during their hospital stay. Technologies that enable peer support can maximize these benefits across patient populations to elevate them as equal partners in the quality and safety of their health care.

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APPENDICES

APPENDIX A: SURVEY INSTRUMENT

University of Washington: Patient and Caregiver Experience Survey

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Logic: Show/hide trigger exists.

Based on your current age, please choose one of the following:*

( ) I am 18 years or older

( ) I am 14 to 17 years old

( ) I am 7 to 13 years old

Hospital

( ) [redacted – pediatric hospital]

( ) [redacted – adult hospital]

Medical Service:

_____

Logic: Hidden unless: Question "Based on your current age, please choose one of the following:" is one of the following answers ("I am 18 years or older")

About: The goal of this survey is to better understand your perspective on a current or previous hospital visit, including undesirable events you may have experienced as a patient or caregiver. This survey is part of a larger research study at the University of Washington called *Patients as Safeguards*, funded by the United States Agency for Healthcare Quality and Research (AHRQ). The goal of this study is to understand the types of information patients and caregivers need during a hospital stay in order to help detect, prevent, and recover from hospital errors. We hope to use this knowledge to improve future hospital experiences.

Eligibility: In order to take this survey, you must be at least 7 years old. You must also have been a patient or caregiver of someone who was hospitalized overnight.

Participation, Confidentiality, and Risks: Your participation in this survey is completely voluntary, and you may decline participation or stop answering questions at any time, without consequence. By submitting your responses, you are agreeing to participate in this study. Your responses will be anonymous and will not be shared with your healthcare providers, and therefore will not impact your current or future care in any way. We do not require you to provide any personal information. Demographics such as gender, age, and race will only be collected for data analysis and reporting. We do not anticipate any risks to your privacy, but by asking you to recall potentially significant health events related to a hospital visit, you may feel anxious or stressed.

Length: Based on your responses to each question, this survey will take about 15 minutes to complete.

Contact Information: If you have further questions about this survey or the *Patients as Safeguards* project, please email us at [research team email address].

Logic: Hidden unless: Question "Based on your current age, please choose one of the following:" is one of the following answers ("I am 14 to 17 years old")

About: The goal of this survey is to better understand your past or current hospital experience, especially times where you felt worried, when you experienced something unpleasant or harmful, or something you think could have been avoided, as either a patient or caregiver. This survey is part of a larger research study at the University of Washington called *Patients as Safeguards*, funded by the United States Agency for Healthcare Quality and Research (AHRQ). The goal of this study is to understand the types of information patients and caregivers need during a hospital stay in order to help detect, prevent, and recover from hospital errors. We hope to use this knowledge to improve future hospital experiences.

Eligibility: In order to take this survey, you must be at least 7 years old. You must also have been a patient or caregiver of someone who was hospitalized overnight.

Participation, Confidentiality, and Risks: Your participation in this survey is completely voluntary. You can decide not to take the survey or stop taking the survey at any time. By submitting your responses, you are agreeing to participate in this research study. Your responses will be anonymous and will not be shared with your healthcare providers, and will not impact your current or future hospital care in any way. You do not need to provide any personal information. Demographics such as gender, age, and race will only be used for data analysis and reporting. We do not anticipate any risks to your privacy, but by asking you to remember potentially significant health events related to a hospital visit, you may feel worried or stressed.

Length: Based on your responses to each question, this survey will take about 15 minutes to complete.

Contact Information: If you have any more questions about this survey or the *Patients as Safeguards* project, please email us at [research team email address].

Logic: Hidden unless: Question "Based on your current age, please choose one of the following:" is one of the following answers ("I am 7 to 13 years old")

Information for Parents and Guardians

About: The goal of this survey is to better understand your and your child's perspective on a current or previous hospital visit, including undesirable events you may have experienced as a patient or caregiver. This survey is part of a larger research study at the University of Washington called *Patients as Safeguards*, funded by the United States Agency for Healthcare Quality and Research (AHRQ). The goal of this study is to understand the types of information patients and caregivers need during a hospital stay in order to help detect, prevent, and recover from hospital errors. We hope to use this knowledge to improve future hospital experiences.

As a parent, you have the option of letting your child take this survey on their own, or helping your child fill out their answers.

Eligibility: In order to take this survey, both you and your child must be at least 7 years old, and must also have been a patient or caregiver of someone who was hospitalized overnight.

Participation, Confidentiality, and Risks: Both your and your child's participation in this survey is completely voluntary, and you both may decline to participate or stop answering questions at any time, without consequence. By checking the box below, and letting your child submit their answers, you are agreeing to let your child participate in this study. The responses will be anonymous and will not be shared with your child's healthcare providers, and therefore will not impact your child's current or future hospital care in any way. We do not require you or your child to provide any personal information. Demographics such as gender, age, and race will only be collected for data analysis and reporting. We do not anticipate any risks to your or your child's privacy, but by asking your child to recall potentially significant health events related to a hospital visit, you or your child may feel anxious or stressed.

Length: Based on your responses to each question, this survey will take about 15 minutes to complete.

Contact Information: If you have further questions about this survey or the *Patients as Safeguards* project, please email us at [research team email address].

Logic: Hidden unless: Question "Based on your current age, please choose one of the following:" is one of the following answers ("I am 7 to 13 years old")

Study participation:*

[ ] I have read and understood the above information and agree to let my child participate in this study.

Logic: Hidden unless: Question "Based on your current age, please choose one of the following:" is one of the following answers ("I am 7 to 13 years old")

Information for the Participant

What is a research study? Research studies help us learn new things. We can test new ideas, ask questions, and try to find the answer.

Why are we doing this research? We are trying to find out more about times in the hospital where you felt worried, you didn't want something to happen, or you think something could have been stopped.

What do you need to know? You can decide if you want to take part in this research. You can say 'yes' or 'no' at any time. No one will be upset if you say 'no'. If you say 'yes', you can say 'no' later. We want you to feel comfortable and get good care no matter what you decide.

What would happen if I join this research? If you decide to be a part of our research study, we will ask you to answer some questions about your time in the hospital. You can ask for help from your parent or guardian to fill out your answers, and can take as much time as you need.

How long will this take? Depending on your answers, it will take about 15 minutes to finish all the questions.

Could bad things happen if I join this research? The questions we ask may make you feel worried or uncomfortable. Some questions might be hard to answer. You can ask for help or stop answering questions at any time.

Could this research help me? This research will not help you directly. We do hope to learn something from this research and help other kids who are in the hospital.

Is there anything else? If you want to be in this research study, please check the box below. When you check the box and finish all the questions, it means that you understand the information on this page and that you want to take part in this research.

Logic: Hidden unless: Question "Based on your current age, please choose one of the following:" is one of the following answers ("I am 7 to 13 years old")

Study participation:*

[ ] I understand the information on this page and I want to take part in this research.

What is an "undesirable event"?

An undesirable event:

- **was either a small or big concern**
- **may have been unpleasant or caused harm**
- **could have been avoided**

What is a "caregiver"?

A caregiver is a family member or friend who helps the patient during their hospital stay. Some of this help may include:

- **spending time with the patient in the hospital**
- **driving the patient to or from the hospital**
- **helping to make decisions related to the patient's health during their hospital stay**

Logic: Show/hide trigger exists.

1) Were you a patient or a caregiver at the time of this event? *

( ) Patient

( ) Caregiver

What is an "undesirable event"?

An undesirable event:

- **was either a small or big concern**
- **may have been unpleasant or caused harm**
- **could have been avoided**

What is a "caregiver"?

A caregiver is a family member or friend who helps the patient during their hospital stay. Some of this help may include:

- **spending time with the patient in the hospital**

- **driving the patient to or from the hospital**
- **helping to make decisions related to the patient's health during their hospital stay**

3) When did this undesirable event happen?

( ) Less than 1 month ago

( ) 1 to 3 months ago

( ) 4 to 5 months ago

( ) 6 to 11 months ago

( ) 1 to 2 years ago

( ) More than 2 years ago

( ) I don't know

Logic: Hidden unless: #1 Question "Were you a patient or a caregiver at the time of this event? " is one of the following answers ("Patient")

4) How long was your hospital stay at the time of this event?

( ) 1 to 2 days

( ) 3 to 4 days

( ) 5 to 7 days

( ) 8 to 14 days

( ) More than 14 days

( ) I don't know

Logic: Hidden unless: #1 Question "Were you a patient or a caregiver at the time of this event? " is one of the following answers ("Caregiver")

5) How long was the patient's hospital stay at the time of this event?

( ) 1 to 2 days

( ) 3 to 4 days

( ) 5 to 7 days

( ) 8 to 14 days

( ) More than 14 days

( ) I don't know

6) Was this a planned hospital stay?

( ) Yes

( ) No

Logic: Hidden unless: #1 Question "Were you a patient or a caregiver at the time of this event? " is one of the following answers ("Patient")

7) Did you have a caregiver during this hospital stay?

( ) Yes

( ) No

( ) I don't know

Logic: Hidden unless: #1 Question "Were you a patient or a caregiver at the time of this event? " is one of the following answers ("Caregiver")

8) How old was the patient at the time of the hospital stay?

( ) Less than 1 year old

( ) 1 to 6 years old

( ) 7 to 13 years old

( ) 14 to 18 years old

( ) 19 to 24 years old

( ) 25 to 34 years old

( ) 35 to 44 years old

( ) 45 to 54 years old

( ) 55 to 64 years old

( ) 65 to 74 years old

( ) 75 years or older

( ) I don't know

Logic: Hidden unless: (#1 Question "Were you a patient or a caregiver at the time of this event? " is one of the following answers ("Patient") AND #7 Question "Did you have a caregiver during this hospital stay? " is one of the following answers ("Yes"))

9) How involved was your caregiver in making decisions about your hospital care?

( ) Extremely involved

( ) Very involved

( ) Somewhat involved

( ) Slightly involved

( ) Not involved

Logic: Hidden unless: #1 Question "Were you a patient or a caregiver at the time of this event? " is one of the following answers ("Caregiver")

10) How involved were you in making decisions about the patient's hospital care?

( ) Extremely involved

( ) Very involved

( ) Somewhat involved

( ) Slightly involved

( ) Not involved

11) Did you report this event to anyone? Please check all that apply.

[ ] The doctor or nurse

[ ] Family or friends

[ ] Other - write in: _____

[ ] I did not report this event

12) Please tell us more about this undesirable event:

_____

_____

_____

_____

---

13) In your opinion, what caused this event?

_____

_____

_____

_____

14) What was the outcome of this event?

_____

_____

_____

_____

15) In your opinion, what could have kept this event from happening?

_____

_____

_____

_____

---

16) How would you describe the possible or real harm of this event?

( ) Extremely harmful

( ) Very harmful

( ) Somewhat harmful

( ) Slightly harmful

( ) Not harmful

Logic: Show/hide trigger exists. Hidden unless: #1 Question "Were you a patient or a caregiver at the time of this event? " is one of the following answers ("Patient")

17) In your opinion, what information would have helped you during this event? Please check all that apply.

It would have helped to know:

[ ] Who was in my room or why they were there

[ ] Who to contact for help or questions

[ ] When the doctor or nurse was coming into my room

[ ] When I was scheduled for a test or procedure

[ ] Information about my medicines

[ ] More about my tests and procedures

[ ] More about my treatment plan

[ ] More about what medical terms mean

[ ] Hospital resources I could access during my stay

[ ] Things I could do to get better while in the hospital

[ ] When I would be discharged

[ ] What to do after discharge

[ ] Other - write in: _____

[ ] None of the above

Logic: Show/hide trigger exists. Hidden unless: #1 Question "Were you a patient or a caregiver at the time of this event? " is one of the following answers ("Caregiver")

18) In your opinion, what information would have helped you during this event? Please check all that apply.

It would have helped to know:

[ ] Who was in our room or why they were there

[ ] Who to contact for help or questions

[ ] When the doctor or nurse was coming into our room

[ ] When the patient was scheduled for a test or procedure

[ ] Information about the patient's medicines

[ ] More about the patient's tests and procedures

[ ] More about the patient's treatment plan

[ ] More about what medical terms mean

[ ] Hospital resources we could access during our stay

[ ] Things we could do to help the patient get better while in the hospital

[ ] When the patient would be discharged

[ ] What to do after discharge

[ ] Other - write in: _____

[ ] None of the above

Logic: Hidden unless: #17 Question "In your opinion, what information would have helped you during this event? Please check all that apply.

It would have helped to know:" is one of the following answers ("Who was in my room or why they were there","Who to contact for help or questions","When the doctor or nurse was coming into my room","When I was scheduled for a test or procedure","Information about my medicines","More about my tests and procedures","More about what medical terms mean","Hospital resources I could access during my stay","Things I could do to get better while in the hospital","When I would be discharged","What to do after discharge","Other - write in")

Piping: Piped From Question 17. (In your opinion, what information would have helped you during this event? Please check all that apply.

It would have helped to know:)

How would you want this information given to you? Please check all that apply.

Paper Handout	**Audio/ Video**	**Written on the patient whiteboard**	**When talking with doctors and nurses**	**Text message**	**Email**	**Mobile App**	**Patient Portal**	**Other electronic form**

			during rounds					

Logic: Hidden unless: #18 Question "In your opinion, what information would have helped you during this event? Please check all that apply.

It would have helped to know:" is one of the following answers ("Who was in our room or why they were there","Who to contact for help or questions","When the doctor or nurse was coming into our room","When the patient was scheduled for a test or procedure","Information about the patient's medicines","More about the patient's tests and procedures","More about what medical terms mean","Hospital resources we could access during our stay","Things we could do to help the patient get better while in the hospital","When the patient would be discharged","What to do after discharge","Other - write in")

Piping: Piped From Question 18. (In your opinion, what information would have helped you during this event? Please check all that apply.

It would have helped to know:)

How would you want this information given to you? Please check all that apply.

Paper Handout	**Audio/ Video**	**Written on the patient whiteboard**	**When talking with doctors and nurses during rounds**	**Text message**	**Email**	**Mobile App**	**Patient Portal**	**Other electronic form**

---

19) What advice would you give to others who might have had an event like this in the hospital?

_____

_____

_____

_____

The next few questions are about your general hospital experience.

20) The hospital is responsible for a patient's care during their hospital stay. Who else should share the responsibility for each of the items listed below?

	Patient	**Caregiver**	**Both**	**Neither**
Making sure the patient understands the diagnosis	( )	( )	( )	( )
Making sure the patient understands the treatment	( )	( )	( )	( )
Finding out about different treatment options	( )	( )	( )	( )
Explaining the treatment and diagnosis to others, such as family and friends	( )	( )	( )	( )
Knowing reasons for taking medicines	( )	( )	( )	( )
Remembering when to take medicines	( )	( )	( )	( )

Remembering the right dose for each medicine	( )	( )	( )	( )
Keeping track of what happens during the hospital stay	( )	( )	( )	( )
Speaking up when something is wrong	( )	( )	( )	( )
Knowing what to do after leaving the hospital	( )	( )	( )	( )
Keeping a current version of the patient's medical history	( )	( )	( )	( )

Logic: Show/hide trigger exists.

21) Which of these resources do you use when you have a health-related question? Please check all that apply.

[ ] Social media such as Facebook, Reddit, or Twitter

[ ] Online health communities or support groups such as PatientsLikeMe or QuitNet

[ ] Health information websites such as WebMD or Medline Plus

[ ] Hospital or organization websites such as American Heart Association

[ ] Magazine or newspaper articles

[ ] Newsletters or books

[ ] Television or radio programs

[ ] Emergency hotlines

[ ] Research papers or scientific journals

[ ] Blog posts

[ ] People with similar health issues

[ ] Medical professionals

[ ] Family or friends

[ ] Other - write in: _____

[ ] None of the above

Logic: Hidden unless: #21 Question "Which of these resources do you use when you have a health-related question? Please check all that apply. " is one of the following answers ("Social media such as Facebook, Reddit, or Twitter","Online health communities or support groups such as PatientsLikeMe or QuitNet","Health information websites such as WebMD or Medline Plus","Hospital or organization websites such as American Heart Association","Magazine or newspaper articles","Newsletters or books","Television or radio programs","Emergency hotlines","Research papers or scientific journals","Blog posts","People with similar health issues","Medical professionals","Family or friends","Other - write in")

Piping: Piped From Question 21. (Which of these resources do you use when you have a health-related question? Please check all that apply.)

Do you use these resources inside the hospital, outside the hospital, or both?

	Inside the hospital	**Outside the hospital**	**Both inside and outside the hospital**

DEMOGRAPHICS

22) How many overnight hospital stays have you had in the last 5 years?

( ) 1 to 3
( ) 4 to 6
( ) 7 to 9
( ) 10 or more

23) Did you use a smartphone (such as iPhone, Android), tablet (such as an iPad), or laptop device during your most recent hospital stay?

( ) Yes
( ) No

24) What is your gender?

( ) Male
( ) Female
( ) Other - write in: _____
( ) I prefer not to answer

Logic: Show/hide trigger exists.

25) What is your age?

( ) 7 to 13 years old
( ) 14 to 18 years old
( ) 19 to 24 years old
( ) 25 to 34 years old
( ) 35 to 44 years old
( ) 45 to 54 years old
( ) 55 to 64 years old
( ) 65 to 74 years old
( ) 75 years or older
( ) I prefer not to answer

Logic: Hidden unless: #25 Question "What is your age? " is one of the following answers ("19 to 24 years old","25 to 34 years old","35 to 44 years old","45 to 54 years old","55 to 64 years old","65 to 74 years old","75 years or older","I prefer not to answer")

26) Do you work in the healthcare field?

( ) Yes

( ) No

27) What is the highest level of education you have completed?

( ) 8th grade or equivalent

( ) High school, GED, or equivalent

( ) Some college

( ) Associate's or 2 year degree

( ) 4 year college degree

( ) Graduate or professional degree

( ) None of the above

( ) I prefer not to answer

28) Is English your first language?

( ) Yes

( ) No

( ) I prefer not to answer

29) Are you of Hispanic or Latino/a origin or descent?

( ) Yes, Hispanic or Latino/a

( ) No, not Hispanic or Latino/a

( ) I prefer not to answer

30) What is your race? Please check all that apply.

[ ] White or Caucasian
[ ] Black or African American
[ ] Asian
[ ] Native American or American Indian
[ ] Pacific Islander
[ ] Other - write in: _____
[ ] I prefer not to answer

31) How did you hear about this survey?

[ ] A member of the research team
[ ] Email
[ ] Social media
[ ] Other - write in: _____

OPTIONAL QUESTIONS

Optional: If you have anything else you'd like to tell us, please write it here:
_____
_____
_____
_____

Validation: email format expected

The University of Washington's *Patients as Safeguards* project is funded by the United States Agency for Healthcare Research and Quality (AHRQ). The goal of this project is to understand the type of information support that patients and their caregivers need in order to help prevent, detect, and recover from hospital errors or undesirable events that may lead to these errors.

Optional: if you would like to receive updates about the *Patients as Safeguards* project, please write your email address here:

_____

THANK YOU!

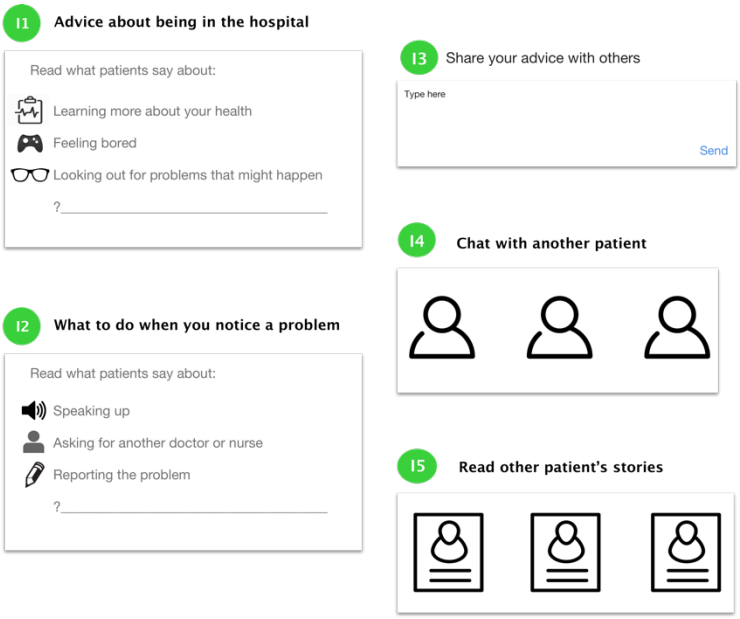
Your answers have been submitted. Thank you for taking our survey.

If you have more questions about this survey, or the *Patients as Safeguards* project, please contact us at [research team email address].

Take this survey again if you would like to talk about another undesirable event.

APPENDIX B: INTERVIEW AND FEATURE CARD STUDY PROTOCOL

Note: the below protocol was developed with members of the *Patients as Safeguards* research group. This interview study was conducted as part of a larger *Patients as Safeguards* study to examine the design of inpatient-facing technologies. The green dots paired with each card represent the peer support "theme" they encompass and differentiate them from other "themed" cards (e.g., patient-doctor communication) that were shown to participants in this study. The letter-and-number code within the green dots was a reference schema used for interpreting sections of the participants' interview transcripts when they discussed or mentioned specific cards.



PRELIMINARY QUESTIONS

- How are you feeling?
- What brings you to the hospital today?
- How is your hospital stay going so far?

INTRODUCE FEATURE CARD ACTIVITY

We're working on building an iPad app that will help give patients like you more information about their care in the hospital. We are looking to get your input on what types of things you might want to see in this kind of app. We are going to show you these many cards we have—each card represents a feature that might be included in the app—and we will ask about your thoughts and feedback about each of these cards.

FOLLOW UP QUESTIONS TO ASK WHILE GOING THROUGH THE CARDS

- Can you talk about why that card is/is not important to you?
- What information, other than what's on the card, would you want to see? Why?
- How would this card have/have not been useful to you during your current hospital stay?

APPENDIX C: TECHNOLOGY PROBE STUDY PROTOCOL

PRE-TECH PROBE INTERVIEW (AT BEDSIDE)

What brings you to the hospital today? How is your stay going so far?

What is a day in the hospital like for you?

What have you talked to your doctors and nurses about during your hospital stay?

How easy or hard is it to ask the doctors and nurses for things? Why or why not?

Have you talked to your doctors and nurses about personal preferences you have for your hospital stay?

What kinds of questions have you been asking the doctors and nurses during your stay?

What parts of your hospital stay have been good? Why?

What parts of your hospital stay do you think could be better or improved? Why?

Have you experienced any problems during your hospital stay so far? Anything that you didn't want to happen?

What kinds of things have you done, or wish you could do, to make your hospital stay better?

In general, what does it mean for you to be safe in the hospital?

What are some things you do, or wish you could do, to keep yourself safe in the hospital?

Have you ever gotten advice from other people about being in the hospital?

- Can you give me examples of advice other people have given you?
- What are your thoughts on getting this advice from your doctors and nurses?
- What are your thoughts on getting this advice from other patients?
- What are your thoughts on sharing advice with other patients?

INTRODUCE TECH PROBE/ONBOARDING (AT BEDSIDE)

- If participant is using our iPad: connect iPad to hospital Wi-Fi

- Walk through User Manual

- Ask participant to:
    - Create account
    - Write a post
    - Know how to comment on another story
    - Know how to vote on another story
    - See stories tagged as "outside resources"

- If participant is using their own device: bookmark the PAS on their home screen

- Give participant user manual for later reference

- Remind participant that:
    - Other participants in the study are the only people who know this URL and will be using the tool
    - We are not asking for, and they should not provide, identifying information like their hospital room number, etc.
    - We are keeping an eye on the site and will delete any posts that are disrespectful or contain identifying information. They can always flag a story to bring our attention to it too.
    - We are keeping the website up and running for the entire study. They will still be able to see it, and use it if they want to, after they go home.

- Research team: remember to disable participant's view of the WordPress dashboard upon login

Participant's Email Used to Register: _____

Participant's User Name: _____

(If applicable: PAS iPad # given to participant): _____

When/how to follow up: _____

POST-TECH PROBE INTERVIEW (OVER THE PHONE AFTER DISCHARGE)

How did the rest of your hospital stay go?

- What things are you doing at home as part of your recovery?
- Follow up appointments with doctors? Long-term life changes due to care?
- Any remaining questions or concerns that you have about your care?
    - How are you planning to bring these up with your providers?
- Was there anything that you thought could have been better about the rest of your stay?
- Was it easy or hard to get info/updates about your care during the rest of your stay? Why/Why not?
- (ask about other details mentioned in Interview 1 - unanswered questions/concerns etc.)

I want to hear your thoughts about the website we gave you.

- When was the last time you looked at/used the website?
- What were some things you liked about it?
- What were some things you didn't like about it?
- What did you think about seeing information from other patients?
- What information from other patients was most interesting/useful to you? Why?
- If applicable: What did you think about sharing your thoughts/advice with other patients?
    - What value do you see in sharing your thoughts with other patients?
- What things would you add or change to make the website better?
- Did the website/info from other patients change how you felt or thought about your stay? Why/Why not?
- Did you use any of the advice from other patients during your hospital stay? Why/why not? Example?

Now that you're home, what are your thoughts on being safe in the hospital?

- Did you feel protected against things like medical errors/mistakes in your care? Why/Why not?

If you were to go back to the hospital, what would you do differently, if anything? Why?

Was there anything about this entire process (talking to you in the hospital, setting you up on the website, leaving the iPad with you for the rest of your stay) that could have been better?

Do you have any other thoughts or feedback before we wrap up?

For your time today, you'll be emailed a $25 Target gift card. (confirm email)