

Exploring the Design of an Inpatient Peer Support Tool: Views of Adult Patients

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Abstract

Despite wide recognition of the value, expertise, and support that patient-peers provide in a variety of health contexts, mechanisms to design and enable peer support in the inpatient setting have not been sufficiently explored. To better understand the opportunities for an inpatient peer support tool, we surveyed 100 adult patients and caregivers, and conducted follow-up, semi-structured interviews with 15 adult patients. In this paper, we describe five key peer support needs that our adult patient participants expressed: (1) adjusting to the hospital environment, (2) understanding and normalizing medical care, (3) communicating with providers, (4) reporting and preventing medical errors, and (5) empowering peers. In addition, we identify privacy concerns, situational impairments, and communication mode as barriers to, and preferences for, interacting with peers. Based on our findings, we discuss intelligent peer matching and aggregating peer data as design recommendations for future inpatient peer support tools.

Introduction

Over the course of a hospital stay, patients and caregivers must adjust to a new environment, understand complex medical jargon, deal with information-rich yet inaccessible Electronic Health Records (EHRs), risk experiencing a medical error, and manage the uncertainty of the patient's health.^(1,2) Given that 35 million hospital admissions occur annually in the United States, these pervasive challenges affect many people at any given time.⁽³⁾

To overcome these challenges, researchers have studied the design of patient-facing systems to keep patients informed about their dynamic care information. For example, Wilcox et al. in a Wizard-of-Oz study created large information displays for patient rooms in the Emergency Department of a hospital.⁽⁴⁾ Other health informatics studies have employed high-fidelity digital solutions—such as tablet computers and mobile phones—for patients to view their medical information and communicate with their care team.^(5–10) These solutions increase a patient's access to their EHR data, but assume the patient is a passive recipient of information, rather than an active and engaged contributor.⁽¹¹⁾ Moreover, these systems do not account for other types of information and support that patients need, beyond what clinicians can provide.

Patient-peers complement the expertise of clinicians by providing instrumental, informational, and emotional support to patients and caregivers navigating their hospitalization.⁽¹²⁾ Indeed, those who participate in peer support programs demonstrate improved clinical outcomes and increased knowledge, self-efficacy, and empowerment in their care.^(13,14) Patients managing chronic conditions outside of the hospital have access to their peers through a variety of mobile applications, social media sites, and online health communities.^(15–17) The needs of patients in the hospital, however, are not accounted for in the design of these tools.⁽¹⁸⁾ In medical research, inpatient peer support programs typically take place in-person or over-the-phone, and are created to evaluate clinical outcomes (e.g., readmission rates, treatment adherence) rather than patient-centered outcomes.^(19,20)

The few Human-Computer Interaction (HCI) studies examining peer support in the hospital all take place in pediatric settings. For example, 3-D environments and shared narratives allowed chronically-ill children to interact with and relate to each other during hospitalization.^(21,22) Liu et al. studied how children use social media during long-term hospital stays to stay in touch with existing friends.⁽²³⁾ Our own previous work identified the informational and emotional support needs of pediatric patient-peers in the hospital.⁽¹⁸⁾ However, less is known about adult patient peer support needs, and what—if any—additional design considerations must be made for this population. In this paper, we address the knowledge gap by presenting findings from a survey and interviews with hospitalized adults. We describe the peer support needs of adult patients, explain how their needs compare to pediatric patients, and provide additional design recommendations for an inpatient tool to address these needs. Our contributions highlight peer support as a promising aspect of patient-facing technologies, and as a way to further engage individuals in their hospital care.

Methods

Previously, we examined the needs and design recommendations of a peer support tool for pediatric inpatients and their caregivers.⁽¹⁸⁾ To understand perspectives of adult patients on an inpatient peer support tool, we used a similar approach with adult patients at an urban tertiary care hospital in the United States. Our approach consisted of two studies: (1) a survey, and (2) semi-structured interviews, both of which were approved by our institution's and study site's Institutional Review Board. In the context of our studies, we define **peers** as people with similar health and hospital experiences.

Survey

As part of a larger effort to understand inpatients' perspectives, we developed a web-based survey instrument to ask patients and caregivers about their experience with undesirable events in the hospital.⁽²⁴⁾ We defined an **undesirable event** as (1) a small or big concern, (2) something that was unpleasant or caused harm, and (3) could have been avoided. For this part of the study, we included one optional, free-text question that dealt with the topic of peer support: *What advice would you give to others who might have had an [undesirable] event like yours in the hospital?*

Research team members approached patients and caregivers in-person during their hospital stay, to describe the study and determine eligibility and interest in participation. Individuals were recruited across medical and surgical services. Patients and caregivers were considered eligible for participation if they could read and write in English, were well enough to provide informed consent, and had experienced an undesirable event during their current—or a past—hospital visit. Those who were eligible and volunteered to participate were administered the survey on an iPad.

Semi-Structured Interviews

In response to our survey question above, many participants wrote detailed advice for patients and caregivers. Our initial review of this data revealed an opportunity to further explore the concept of inpatient peer support, beyond the topic of undesirable events from the survey. Thus, we conducted semi-structured interviews with patients 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. To motivate the discussion in our semi-structured interviews, we created six “feature cards” of hypothetical aspects of an inpatient peer support tool. Cards contained statements representing the types of advice our survey participants provided, and depicted potential features of a system, such as sharing advice with a peer, or applying filters to find peers (figure 1).

Interviews were conducted with adult patients during their hospitalization. One research team member, serving as lead interviewer, presented the feature cards and described their function to the participant. The interviewer would then ask the participant what they thought about the cards, and to explain the reasoning behind their thoughts. A second research team member was present in every interview to record notes and ask follow-up questions. All participants were compensated \$25. Each interview lasted approximately 40 minutes, was audio recorded, and transcribed.

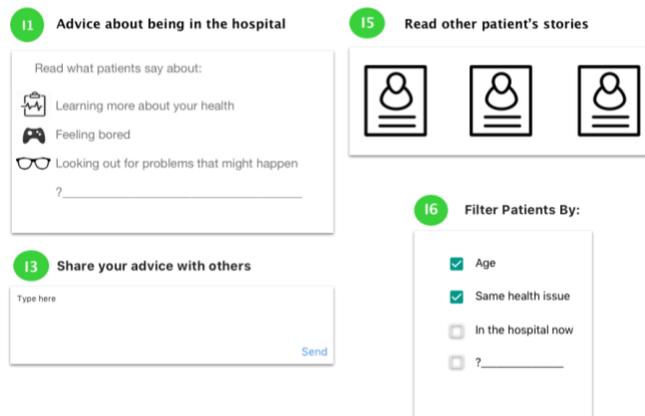


Figure 1. Examples of the cards we showed to interview participants, depicting various features of a hypothetical inpatient peer support tool.

Data Analysis

Following both deductive and inductive processes,⁽²⁵⁾ we analyzed the responses regarding advice our survey participants would share with others, and our semi-structured interview data. For the deductive process, we used our previous findings in the pediatric inpatient setting as an initial codebook to analyze the data from adult patients. Each code represented either a type of peer support need, or a preference for interacting with peers.⁽¹⁸⁾ As these codes were applied to the data set, a research team member used memoing to document observations, discrepancies, and emergent themes, which were brought back to the research team for discussion. For the inductive process, the new themes were incorporated into the codebook, and the data set was re-coded. The research team member then compared both adult and pediatric survey and interview data sets to identify their common and distinct themes.

Participants

We received 100 survey responses from adult patients and caregivers of adult patients. Out of these 100 participants, 86 provided an answer to our optional survey question, *What advice would you give to others who might have had an [undesirable] event like yours in the hospital?* (response rate: 86%). We conducted our follow-up, semi-structured interviews until we reached thematic saturation with 15 adult patients. All interview participants had prior experiences with hospitalization. All participant demographics are summarized in table 1.

Results: Peer Support Needs

Our analysis revealed five key peer support needs of adult inpatients: (1) adjusting to the hospital environment, (2) understanding and normalizing medical care, (3) communicating with providers, (4) preventing and reporting medical errors, and (5) empowering peers. Below, we describe each peer support need in detail and provide quotes from participants. Quotes from survey participants are designated with an S-#, while interview participants are referred to as I-#. In each section, we explain how these results are similar to—or different from—our previous findings from pediatric patients.

Adjusting to the Hospital Environment

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 information from peers. For example, I-10 wanted advice from others about what hospital amenities she had access to, and what personal items she should have brought before admission. Despite having gone through many overnight hospital stays as a chronically ill patient, I-08 still thought the experiential knowledge of other patients would have been useful for 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-08)

This finding among adult patients contrasted with that from our prior studies with pediatric patients. Although pediatric patients wanted to know about the resources available to them in the hospital, they had more specific interest in toys, games, books, or movies that might be available in order to combat the long periods of boredom they experienced in the hospital. Our adult patient participants, on the other hand, were interested in peer support to learn the norms of the hospital, to identify the resources available to them, and to understand how to smoothly transition from the familiarity of home to the unfamiliar hospital environment.

	Survey Participants (%)	Interview Participants (%)
Patients	67 (77.9)	15 (100.0)
Caregivers	19 (22.1)	-
Gender		
Female	47 (54.7)	7 (46.7)
Male	38 (44.2)	8 (53.3)
Other/No Answer	1 (1.2)	-
Age in Years		
18-24	1 (1.2)	2 (13.3)
25-44	14 (16.3)	2 (13.3)
45-64	41 (47.7)	5 (33.3)
65+	30 (34.9)	6 (40.0)
Education		
Less than High School	-	1 (6.7)
High School/GED	15 (17.4)	2 (13.3)
Some College	16 (18.6)	4 (26.7)
2 or 4 Year Degree	30 (34.9)	5 (33.3)
Graduate or Professional	23 (26.7)	3 (20.0)
Other/No Answer	2 (2.3)	-
Race/Ethnicity*		
White/Caucasian	68 (79.1)	15 (100.0)
Black/African American	4 (4.7)	-
Hispanic/Latinx	4 (4.7)	-
Asian	6 (7.0)	-
Native American	2 (2.3)	-
Other/No Answer	6 (7.0)	-
Hospital Service		
Medical	49 (57.0)	7 (46.7)
Surgical	37 (43.0)	8 (53.3)
Length of Stay**		
Less than 1 day	-	2 (13.3)
1-7 days	58 (67.4)	10 (66.7)
More than 7 days	26 (30.3)	3 (20.0)
Unknown/Unsure	2 (2.3)	-

Table 1. Summary of participant demographics. *Participant could select more than one category. **For survey participants, LOS was at the time of the undesirable event they reported through our survey.

Understanding and Normalizing Medical Care

Adult patient participants in our survey and interview studies emphasized the need to be an expert in the details regarding 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 and discharge requirements. Others encouraged their peers to ask the care team to explain confusing medical jargon and the reasoning behind care decisions. While serving as a caregiver for his wife, S-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.” (S-171)

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-05, through observations and casual conversations with other 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-12 wanted information from her peers to prepare for the high and low points of her own hospital stay. I-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.” (I-15)

Similar to our observation with pediatric patients, adult patients—in addition to knowledge from providers—valued the experience and knowledge of peers when attempting to make sense of their medical care. Finding commonalities in other patients was also valuable in helping adult patients normalize their hospital experience and progress toward recovery.

Communicating with Providers

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, in case 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, and consider transferring hospitals altogether. This subject also emerged in our interview with I-04:

“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.” (I-04)

In terms of receiving this type of advice, one interview participant (I-09) mentioned his interest in seeing recommendations from his peers about specific providers with whom he should work. Overall, participants expressed a greater interest in sharing, rather than learning, communication strategies to use with providers. However, consistent with our results from pediatric patients, adult patients viewed this information as important for staying informed and involved in their hospital care.

Preventing and Reporting Medical Errors

Across our survey and interview studies, adult patient participants discussed approaches for preventing medical errors that might happen during their hospital stay. For example, when asked about what type of support he would want from peers, I-01 said he wanted the ability to ask people questions about *“diagnosis stuff and future problems that might occur”*. Survey participants expressed ways to meet this need by instructing peers to alert providers to allergies or sensitivities, to confirm that all care team members have thoroughly reviewed the patient's chart, to independently document care activities, to insist on going home only when the patient feels ready, and to ask for help when needed without hesitating.

In addition to preventing errors, many survey participants wrote advice on how to properly report errors they encountered. A common recommendation was for patients 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 advocate to mediate the situation, to report the error directly to hospital staff, and inform a state-level complaint agency if necessary. S-115 was a patient who 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 frequent 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." (S-115)

Similar to our findings with pediatric patients, adult patients wanted strategies from their peers on how to adopt a proactive—instead of reactive—attitude toward medical errors.

Empowering Peers

Finally, our analysis revealed the importance of emotional support for empowering peers during their hospital stay. Survey participants provided encouragement to patients through reassuring phrases such as: *"listen to your body"*, *"be patient"*, *"don't be afraid"*, and *"trust your instincts"*. Others empathized with the emotional toll of a hospital stay. For example, S-289 was never 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." (S-289)

To help peers overcome these feelings of vulnerability, other survey participants encouraged peers to *"speak up"*, *"stand up for yourself"*, and *"be assertive"* when receiving inadequate care. Despite being placed under isolation protocols I-06 felt strongly about providing this support to patients in need: *"if I can be an advocate for any of those people, I want to be."*

Although survey and interview participants expressed a strong desire to offer this emotional support, only one adult interview participant (I-08) specifically expressed her desire to receive this support and bond with others going through similar experiences. This result differed from our previous study's findings, where most pediatric patients expressed interest in both offering and receiving emotional support with peers.

Results: Barriers to Use and Interaction Preferences

In addition to the peer support needs described above, the adult patients we interviewed expressed potential barriers and interaction preferences that might hinder or prevent their use of an inpatient peer support tool: (1) privacy concerns, (2) situational impairments, and (3) communication mode.

Privacy Concerns

During our discussions with interview participants about using an inpatient peer support tool, a few patients were reluctant to consider using the tool due to their desire to maintain their personal privacy. These individuals described themselves as naturally reserved people and infrequent users of social media. Similar to a subset of our findings from with pediatric patients, a few adult patients thought conversations about medical care were better suited for providers, rather than a patient-peer. Some participants preferred to focus on recovering and leaving the hospital as soon as possible, instead of communicating with peers. Other patients 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, a participant 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." (I-14)

Interview participants also had concerns that using a system to connect with patient-peers would violate HIPAA⁺. Certain 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-13 spoke about his perspective:

“I could see some potential liability with [seeing information from peers] because of the HIPAA laws. I suppose if you had somebody 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 HIPAA laws.” (I-13)

The many worries that our adult patient interview participants expressed about breaching HIPAA did not surface in our former studies with pediatric patients, but does suggest a pervasive misunderstanding of the regulation. This fear ultimately discouraged adult patients from engaging with their peers.

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.⁽²⁶⁾ Although this theme did not appear in our findings from pediatric patients, some of our adult patient 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-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.” (I-04)

In addition to fatigue, I-09 mentioned having poor eyesight that made it difficult to read large amounts of text; I-08 was managing chemotherapy as well as symptoms from an autoimmune disease that caused reduced limb function. These situational impairments caused 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.

Communication Mode

Our adult patient interview participants had distinct preferences for various communication modes: synchronous vs. asynchronous, and online vs. in-person interactions. Related to the previous theme of situational impairments, accessibility was a factor that led interview participants to largely favor asynchronous interactions, because it reduced the stress of keeping up with a real-time conversation:

“[S]ometimes 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.” (I-09)

Participants also preferred asynchronous interactions because of their familiarity with existing review websites and online health communities. I-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 relevant information from peers by age, diagnosis, symptoms, and procedures much more easily than existing tools: “*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.*” (I-15)

Although most adult patient participants preferred asynchronous communication, a few participants were interested in the potential to have synchronous conversations with peers. I-07 wanted to chat with another patient in real-time, although he preferred to talk about personal interests like hobbies and careers, rather than “*medical business*”. This type of real-time personal conversation actually happened during I-02’s hospital stay, and was thought to be a welcome

⁺ Health Insurance Portability and Accountability Act (HIPAA): a United States law that limits a provider’s ability to disclose a patient’s personal health information without permission, and establishes a patient’s right to own and share their personal health information in all forms (e.g., electronic, paper, oral).

distraction from his 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-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-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-08)

The balance between asynchronous and synchronous communication with peers also emerged in our findings with pediatric patients. Pediatric patients tended to favor synchronous, online communication (e.g., real-time chat, FaceTime), while their parents favored asynchronous methods of communication. Similar to the parents of pediatric patients, adult patients broadly preferred asynchronous interactions with peers. However, some adult patients mentioned the possibility of—and expressed interest in—a tool to facilitate in-person peer interactions. This particular finding was not present in our pediatric study population.

In summary, our adult patient participants expressed their concerns about privacy and the potential difficulties of using an inpatient peer support tool. They also revealed reasons for their inclinations toward asynchronous, real-time, or face-to-face communication based on situational factors.

Discussion

Our results build on related work investigating the role of health informatics systems in addressing the information needs of inpatients and their caregivers.^(1,27–30) Our findings also demonstrate the diverse nature of patient expertise in the hospital environment, which is consistent with similar findings in clinic-based or at-home care settings.⁽³¹⁾ The adult patients who participated in our studies revealed the need for new systems to help inpatients share their expertise and empower each other during an extremely vulnerable and stressful point in their health journey.^(32,33) Although we uncovered many similar peer support needs in adult and pediatric populations, we also highlight new themes that emerged among adults, including concerns about HIPAA and situational impairments, and interest in a peer support tool to facilitate in-person connections. Based on these themes, we discuss two novel design recommendations: (1) intelligent peer matching, and (2) aggregating peer information.

Intelligent Peer Matching

For each informational or emotional support need expressed by a participant, others in our survey and interview studies had a desire to address that need, and offered their expertise. Additionally, connecting peers based on shared personal attributes—including similar health condition, age, careers, and interests—was a strong theme among adult interview participants. I-08 met someone on a similar chemotherapy schedule and regularly discussed the side effects and test results the two patients had in common; I-07 wanted to limit peer conversations to hobbies and careers; I-02 had an engaging conversation with another patient about their favorite sports team.

HCI research has emphasized the value of matching patients who manage conditions such as diabetes, cancer, and rare diseases.^(34–36) Our findings illustrate the hospital as another health context where peer matching has value. Although inpatients have a variety of diagnoses and are admitted under different services, good quality matches could be established between patients who share personal attributes, have similar emotional support needs, or whose information needs and expertise align. Strategies for matching peers in online communities and patient portals have been suggested and tested.^(37,38) However, translating these techniques into the hospital environment poses a unique challenge. Much of the peer matching research focuses on sustaining long-term connections (e.g., during a patient’s chronic illness management). For a hospitalized patient, the window of time to create a meaningful connection is much shorter, as the average length of a hospital stay is approximately 5 days.⁽³⁹⁾

To overcome this challenge, we previously discussed leveraging EHRs to enable rapid peer matching, based on treatments or medications received, and physical location in the hospital.⁽¹⁸⁾ We propose extending this method with an opt-in patient-profile feature, generated for those who want to be matched with 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.⁽⁴⁰⁾ If implemented, such a system could also enhance the agility and quality of peer matching in this context. Just before or after hospital admission, individuals could opt-in to create a structured summary 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-06, 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 could also mitigate important privacy concerns by giving 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.

Aggregating Peer Data

Our adult patient interview participants expressed a need for peer information from multiple sources. For example, I-15 wanted to know if her progress was “normal” compared to someone like themselves. By observing the many patients on his floor, I-05 learned who might have a similar cancer or chemotherapy. Yet, a clear tension exists between the desire to exchange peer information, and concerns about privacy. The conflict was evident among several participants: I-14 thought maintaining personal privacy would be difficult if she engaged with a peer, and I-13’s cautious misinterpretation of HIPAA affected his openness to the idea of an inpatient peer support tool.

One way to address these barriers 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 ask questions and get relevant information to their needs. 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 kind of aggregated information could help normalize the experiences of specific groups of patients, and empower patients to recognize anomalies in their care. It would also allow for anonymous engagement in the tool, without requiring patients to share personal information directly with another individual. Moreover, a system that collects aggregate peer data with minimal effort would reduce cognitive and physical burdens for the patient, while still giving them the option to actively engage in the tool, and have access to the information they value. Incorporating these features would ultimately give patients the autonomy to decide if, when, and how they use peer data.

Limitations and Future Work

Our findings and suggestions point to additional opportunities for inpatients to receive individualized peer support. However, we acknowledge some limitations to our approach. First, our survey study was designed to solicit participants’ experiences with hospital safety, a natural focus for many of those who offered peer advice. Second, our adult patient interview participants represent a homogenous population with regards to ethnicity and previous hospital experience. Third, our studies were conducted at an urban hospital in the United States, and might not reflect the perspectives of patients in other geographic areas. Finally, self-selection bias might have affected our results, as survey participants were not compensated and interview participants might be considered extremely engaged in their care. Future studies can maximize diversity across several dimensions (e.g., ethnicity, geography) to validate the findings presented in this paper, and consider the views of other stakeholders—such as providers and hospital administrators—on the adoption of an inpatient peer support system.

Conclusion

In this paper, we describe a survey study and semi-structured interviews to explore the design of an inpatient peer support tool. Our findings reveal adult patient needs, potential barriers, and interaction preferences for using a peer support tool during their hospital stay. Based on our results, we propose two novel design recommendations for future inpatient peer support tools: (1) intelligent peer matching, and (2) aggregating peer data. 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 hospital care.

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