

The Patient Advice System: A Technology Probe Study to Enable Peer Support in the Hospital

SHEFALI HALDAR, University of Washington, United States

YOOJUNG KIM, Seoul National University, South Korea

SONALI R. MISHRA, University of Washington, United States

ANDREA L. HARTZLER, University of Washington, United States

ARI H POLLACK, Seattle Children's Hospital, United States

WANDA PRATT, University of Washington, United States

Although peer support technologies are critical resources for patients managing health conditions, they do not address the needs of patients in the hospital (i.e., inpatients) or the unique design constraints of this healthcare setting. To examine how the design of these technologies can meet the needs of inpatients, we conducted a technology probe study with 30 pediatric and adult inpatients. We created the Patient Advice System (PAS) to enable peer support in the hospital setting, then studied how participants used and perceived it during their stay. Inpatients used the PAS to exchange emotional support and share peer advice on a range of topics (e.g., adjusting to the hospital, communicating with providers). They identified several benefits (e.g., fostered connections) and challenges (e.g., competing clinical priorities) with using the PAS in the real-world context of their hospital stay. Based on our findings, we discuss three design opportunities—highlighting local expertise, designing for dynamic engagement, and providing alternative modes of peer support—for future peer support technologies to empower inpatients and overcome the difficulties they face within the hospital.

CCS Concepts: • **Human-centered computing** → **Empirical studies in collaborative and social computing**; • **Applied computing** → **Consumer health**.

Additional Key Words and Phrases: peer support, social support, hospital, technology probe, patient engagement

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1 INTRODUCTION

Over 36.5 million people are admitted to the hospital as patients each year in the United States [2], a setting that is universally recognized as one of the most disempowering and complex within the entire healthcare system [14]. Hospital patients (i.e., **inpatients**) and the family members or friends who care for them (i.e., caregivers) face persistent challenges, including serious illness that requires constant monitoring, exposure to preventable medical errors, adverse effects of physical

Authors' addresses: Shefali Haldar, University of Washington, United States, shaldar@uw.edu; Yoojung Kim, Seoul National University, South Korea, tendtoyj@snu.ac.kr; Sonali R. Mishra, University of Washington, United States, srmishra@uw.edu; Andrea L. Hartzler, University of Washington, United States, andrea@uw.edu; Ari H Pollack, Seattle Children's Hospital, United States, apollack@uw.edu; Wanda Pratt, University of Washington, United States, wpratt@uw.edu.

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isolation, financial burdens of treatment, and emotional stress due to the uncertainty of their health condition.

The expertise of **peers**, or individuals with similar health and hospital experiences, could assist inpatients and caregivers in overcoming many of these challenges. This assistance—also known as **peer support**—is defined as the informational, emotional, and instrumental help that patients exchange to manage their health conditions [13]. Peer support has distinct value from the clinical support received from healthcare providers [34]. Patients who participate in peer support programs consistently demonstrate increased self-efficacy, knowledge, self-management, and improved health outcomes [10, 15, 21]. Given these benefits, peer support has been leveraged in many health contexts, such as diabetes [82], cancer [17], and mental health [46, 60]. Technologies to facilitate peer support take on many forms, including mobile applications, social media, and online health communities. These tools allow patients who manage health conditions in non-hospital settings to experience the positive outcomes and benefits of peer support, regardless of their physical distance and demographic differences [23, 55, 62].

However, inpatients have several peer support needs—including a desire to share information about hospital resources, strategies for communicating with providers, and preventing medical errors—that are not met by existing technologies [28, 29]. Although there are some peer support programs offered to inpatients in the hospital, they largely occur face-to-face, or participation is siloed for those with shared diagnoses and procedures [49, 79, 86]. Such programs can be difficult to access for inpatients who are low-mobility or are under contact precautions [1, 24]. Beyond understanding inpatients' needs for peer support, few studies have explored the real-world use of technologies that enable peer support in hospital settings. We know little about how inpatients use and experience technologies to exchange peer support during their hospital stay, and how the design of such technologies can better address their peer support needs.

To address this knowledge gap, we sought to **answer two research questions: (1) How do inpatients use a technology to interact with each other and exchange peer support? (2) What are inpatients' perceptions and experiences of using the technology probe during their hospital stay?** To answer these questions, we used the technology probe method [39]. **The purpose of this method is to deploy a technological artifact (i.e., probe) in a real-world context, study end-users' use and perception of the probe, and identify new design opportunities.**

To examine how inpatients use and perceive a peer support technology in the real-world context of their hospital stay, as well as uncover design opportunities for future such technologies, we created a technology probe—called the Patient Advice System (PAS)—that allows inpatients to connect and exchange advice with other inpatients at their same hospital during their stay. To capture the breadth and diversity of hospital experiences, we deployed separate instances of the probe with 30 inpatients at a pediatric and an adult hospital.

In this paper, we provide answers to our research questions and make the following contributions to the CSCW community:

- Empirical evidence of inpatients' use of the technology probe, including their usage patterns, social interactions, and types of advice shared with each other.
- A detailed understanding of inpatient perceptions and experiences of using the probe during their hospital stay.
- A discussion of novel design opportunities for future peer support technologies in the hospital setting.

These contributions help CSCW and HCI researchers create technologies that provide inpatients with access to important peer support, so they can navigate their challenges of their hospital stay,

share advice with peers, assert their expertise to providers, and feel empowered in managing their health within this care setting.

2 RELATED WORK

2.1 Patient-Facing Technologies in Hospitals

Researchers in the CSCW, HCI, and Health Informatics fields have examined how technologies can help patients overcome the challenges they face in the hospital by improving communication with their care teams. Patient-facing information displays share critical updates to health information—including medication allergies, vital signs, and test results—so patients can be informed of changes to their care plan [85]. Mobile applications give inpatients timely explanations about why certain medications and tests are prescribed [67]. To ensure patients are informed and prepared for leaving the hospital, Virtual Nurse Agents communicate simple and clear explanations of discharge paperwork [7]. Furthermore, hospitals have implemented consult services that refer patients to technology resources that suit their specific informational and logistical needs [40]. Other technologies such as medication reconciliation tools [69] and bedside screensavers [19] help patients and providers work together to reduce dangerous safety incidents in the hospital.

Inpatient portals are another type of patient-facing technology that have been increasingly studied in hospital settings [75, 80]. These portals are designed so that inpatients and their caregivers can gain access to up-to-date care information, usually imported from the provider-facing Electronic Health Record (EHR) system. While most of the commercially available patient portals offer select features—such as messaging providers [77]—previous studies have discussed the need to improve their design for the hospital setting [83]. For example, allowing inpatients to view their providers' clinical notes [25], addressing information breakdowns [65], creating features for collaborative tracking and goal setting [30, 57], and guiding patients through the sense-making process [43] are important ways for these tools to support patients during their hospitalization.

Most inpatient-facing technologies are designed to optimize communication and collaboration between patients, their caregivers, and clinical care teams. Few technology-driven studies in this setting have recognized the role of peer support in helping to understand, normalize, and improve the hospital experience.

2.2 Peer and Social Support Technologies in Healthcare

In recognition of the critical role that peer support has in helping patients engage in their care [18], researchers have studied how technologies can enable patients to more easily find and benefit from this support. Web-based chat tools have offered real-time peer conversations for people managing their mental health [63]. Mobile applications have connected patients living with diabetes [12, 71]. Prior work has also leveraged mobile technologies so that social networks can help each other to reach physical activity, weight loss, and healthy eating goals [48, 74]. Virtual environments have further facilitated peer support for patients who are in-clinic and receiving dialysis, or recovering from organ transplants, to interact with each other through 3D games [5, 6].

In addition to web, mobile, and virtual technologies, social media and online health communities (OHCs) are some of the most frequently studied forms of peer support. Facebook groups that cover health-related topics are often identified by patients as a place where they can ask questions, share academic research about their health condition, and receive experiential advice [61, 89]. Similar online spaces have been used by individuals to maintain normalcy with friends when receiving treatment [52], and to seek out supportive social environments when experiencing depressive symptoms [3, 9]. Vlogger and commenter interactions on YouTube, as well as video-mediated peer support hosted on OHCs, allow patients to discuss chronic conditions and substance use disorders

[11, 37, 72]. Other OHCs that are dedicated to specific diagnoses and health experiences—such as menopause [47], pregnancy [26], cancer [22, 84, 88], diabetes [59], mental health [90], and rare disease [41, 53]—serve as important resources for patients to fulfill their informational, emotional, and instrumental peer support needs.

Peer and social support technologies in healthcare have demonstrable value, but they are typically designed for use in clinic or home settings rather than hospitals, and intended for patients managing chronic conditions instead of acute conditions.

2.3 Inpatient Peer Support Technologies

Prior work has demonstrated that inpatients have peer support needs that are unique to the hospital experience. For example, inpatients seek to exchange advice about adjusting to the unfamiliar hospital environment, intervening in medical errors, experiencing treatment and medication side effects, and cultivating relationships with their evolving clinical care team [28, 29].

Although existing technologies such as OHCs could be accessed by inpatients from within the hospital, content is not always centralized or specific to these inpatient peer support needs. These limitations impose cognitive burdens on inpatients as they search for relevant information online [29]. Peer support via social media such as Facebook do not account for the level of anonymity that inpatients desire when communicating with other hospitalized patients [28]. Using peer support technologies in the hospital setting also presents additional design considerations. For example, inpatients' fluctuating health status can affect their use of technologies during their hospital stay [58], and physical isolation can exacerbate the lack of social connectedness patients can feel with their friends, family, and environment [76].

While inpatient peer support technologies have demonstrable positive impacts on the hospital experience—such as increased appreciation for peers and improved emotional wellbeing [31]—we know less about how inpatients use and perceive such technologies in the real-world context of their hospital stay, and what additional design opportunities exist to better meet their unique peer support needs.

3 TECHNOLOGY PROBE: THE PATIENT ADVICE SYSTEM

To explore inpatients' use and perception of a peer support technology, we created a technology probe called the Patient Advice System (PAS). The PAS, shown in Figure 1, is a customized WordPress website that closely mirrors Reddit (www.reddit.com), a common web-based medium for online health communities. The PAS helps inpatients exchange and find relevant support in the form of "stories" (i.e., blog posts with comment threads). The PAS—as well as the tablet device through which it is used—operates within the constraints of the hospital environment (e.g., is unobtrusive during care events and compliant with sanitation protocols). We chose Reddit as a model for the PAS because it satisfied the following key design criteria for inpatient peer support technologies [28, 29]: its asynchronous nature minimizes inpatients' obligation to keep up with real-time conversations while managing their illness; the trending stories page and designated discussion categories help reduce inpatients' burden of finding popular or relevant information; the aggregated counts of upvotes, opt-in information sharing model, and creation of the user's own alias affords inpatients' their desired anonymity. In the following sections, we describe the key features of the PAS in more detail.

3.1 Supporting Privacy and Anonymity

When engaging with their peers in the hospital, inpatients have expressed the need to protect their privacy and anonymity [28]. Therefore, the PAS allowed end-users to create their own alias tied to their website activity. To begin using the PAS, a patient registers an account by entering their email

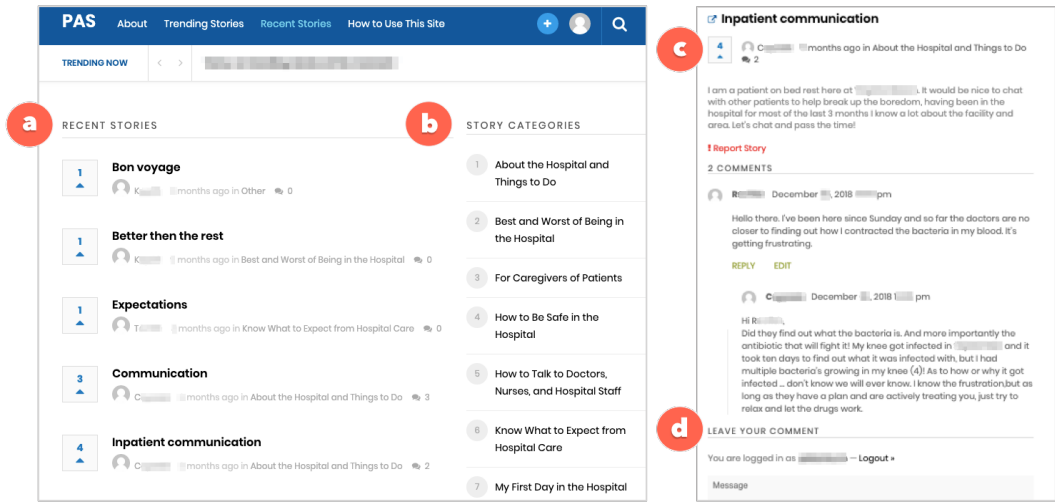


Fig. 1. Screenshots of the Patient Advice System (PAS) deployed at the adult hospital. Left: Home page where patients can a) view recently posted stories and b) browse story categories. Right: expanded story view, where patients can c) upvote and d) comment on the story. Note: images are cropped for space and sensitive information is obscured to protect privacy.

address and creating their username and password. This registration process is integrated directly with the WordPress registration form, ensuring the patient's self-created username is visible to peers, while their email is only seen by a research team member (acting as the site administrator) on the backend. Because the PAS was created for patients to voluntarily share their experiences and advice, the probe was compliant with United States health privacy laws (i.e., HIPAA) that give patients ownership and control over when and how to share their health information [36]. We also took measures such as restricting search engine indexing of the PAS to protect participants' privacy.

3.2 Establishing Guidelines and Monitoring Content

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 [45]. To explicitly define the conduct and scope of the PAS community, we created an "About" page in the header navigation menu. This page provides the patient with information about the purpose of the PAS, reasons for the patient to contribute and interact with peers, directions for how to exchange peer support, and guidelines for what content is permitted. Participants were instructed that posts in violation of the guidelines would be deleted. A research team member regularly monitored patients' posts to ensure they met the guidelines.

3.3 Finding Stories

Structuring conversations of online communities can allow users to better achieve their goals of interacting with peers and highlighting conversations of interest could reduce the burden of finding relevant information [28, 45]. The homepage of the PAS (Figure 1, Left) shows **stories** from patients. Patients can sort these stories by what is trending (i.e., most popular) or by what is most recent (i.e., reverse chronological order). The homepage also contains a list of categories,

or topics, that can be clicked to browse and search for relevant stories. Most categories—such as “About the Hospital and Things to Do” and “How to be Safe in the Hospital”—were included in the PAS because prior work identified these topics as peer support needs for inpatients [28, 29]. Other categories (e.g., “My First Day in the Hospital”) were included to serve as icebreakers so inpatients could begin sharing stories and connecting with peers.

3.4 Reading and Interacting with Stories

Prior work found that inpatients’ did not want to feel obligated to engage with their peers at inopportune moments (e.g., when feeling unwell) during their hospital stay [29]. To reduce this obligation, we had users asynchronously engage with peers via reading, commenting, and voting on stories. In the PAS, clicking on a story reveals its expanded view, providing further information written by the patient who posted the story (Figure 1, Right). In this expanded view, inpatients can **upvote** stories to express agreement with the original poster or create nested **comments** to asynchronously respond to the story. Upvotes are displayed in aggregate to preserve anonymity of individual users. Stories with more upvotes appear higher on the “Trending Stories” page.

3.5 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 [45]. Aside from reading and interacting with stories from other PAS users, a patient can post their own story to share. Posting a story requires the patient to designate a title, or heading, for their story and provide more details (i.e., a description) regarding this story. When the story is ready to post, the patient can select its relevant category from a dropdown menu to increase the story’s visibility to the PAS community.

4 METHODS

We conducted a technology probe study with the PAS to understand inpatients’ use and perception of this technology during their hospital stay. We gathered data about how inpatients used the probe to interact with peers (i.e., other inpatients), and what benefits and challenges they experienced when using the PAS in the real-world context of their hospital stay. Our study took place at two sites: one pediatric and one adult hospital in a metropolitan area of the United States. Collectively, both hospitals manage a total of 800 beds and serve over 25,000 patients across a multi-state region.

4.1 Technology Probe Deployment

We pilot tested an initial version of the PAS with HCI experts to identify and resolve usability issues before deployment. We then created two separate instances of the PAS and installed them at two domain names, one for each hospital site. Due to the lack of existing centralized inpatient peer resources, and the need to ensure patients interacted with fellow inpatient peers, we pre-populated some content on each instance. This content was tailored for each study site. Members of the research team created content that included instructions on the type of information that could be shared in each story category, advice noted from related work with inpatients [28, 29], and—for convenience—links to each hospital’s respective maps, resources, and amenities.

We gave each participant an iPad to access the PAS via web browser during their hospital stay. Participants were only given the link to the PAS instance that corresponded to their hospital site. Based on recommendations from prior work [20], all iPads were connected to hospital Wi-Fi networks and fitted with nonporous cases so they could be cleaned according to sanitation protocols between uses.

4.2 Study Procedures

All procedures received ethical approval from the authors' and hospitals' Institutional Review Boards (IRBs). Patients were eligible for this study if they were at least 7 years old, were well enough to provide informed consent, were comfortable communicating in English, and if they had spent at least one night in the hospital during their current stay. We approached eligible patients across medical and surgical services of each hospital. A research team member and study-site coordinator were present during the approach to describe the study and handle consent procedures, respectively. Parental consent was required and obtained for all pediatric participants.

First, we conducted a semi-structured interview with the participant at their bedside in the hospital. The purpose of this interview was to establish rapport with the participant, learn about their health and hospital experience, and understand their expectations of engaging in peer support during their hospital stay. After the interview questions, we taught the participant how to use the PAS on their designated iPad, so they could familiarize themselves with its features and begin using the probe. This interview and instruction process lasted 30-60 minutes and was audio recorded.

Next, we told the participant to use the PAS at their discretion—however, whenever, and to whatever extent they wanted—during their hospital stay. We provided each participant with a print-out instruction packet for how to use the PAS and the research team's contact information so they could request additional help if needed. During this time, we collected usage data (e.g., timestamps and content of stories and comments). Occasionally, we checked in with the participant to answer questions, help them use the probe, and resolve technical issues. We also instructed caregivers, when present, how to use the probe so they could help the participant if necessary. Upon discharge, the participant returned the iPad to the research team.

Finally, we contacted the participant a minimum of 24 hours after their discharge from the hospital for a follow-up phone interview. The goal of this interview was to gather their thoughts and feedback on using the PAS during their hospital stay. These interviews typically lasted 15-40 minutes and were audio recorded.

4.3 Participant Characteristics

A total of 30 participants were recruited for this study: 15 pediatric patients (P1-P15) and 15 adult patients (A1-A15). Due to illness partway through their hospitalization, the caregivers of P04 and P14 became the primary users of the PAS in place of their child. Participants were divided by gender (15 females, 15 males) and hospital service (15 medical, 15 surgical). The mean age for pediatric participants was 13 years old ($SD=2.56$) and the mean age for adult patients was 55.8 years old ($SD=15.84$). All pediatric participants reported education levels as less than high school. Adult participants' education levels ranged from less than high school ($n=2$), high school graduate ($n=2$), some college ($n=5$), college graduate ($n=4$) and post-graduate ($n=2$). Twenty-four participants reported their ethnicity as White/Caucasian, two as Black/African American, three as Hispanic/Latinx, one as Asian, one as American Indian/Alaska Native, and one as "Other". At the pediatric site, the median length of stay was four days (range 2-16) and median usage period was three days (range 1-11). At the adult site, median length of stay was eight days (range 2-95) and median usage period was four days (range 1-85). Sixty percent of pediatric participants had prior experience as an inpatient in the hospital, compared to 93% of adult participants.

4.4 Data Analysis

Our study yielded two types of data: each participant's PAS usage data, and interview data collected during and after each participant's hospital stay.

To answer our first research question (How do inpatients use a technology to interact with each other and exchange peer support?), we first calculated descriptive statistics with the counts and timestamps of each participant's PAS **activity** (i.e., the total number of stories, comments, and upvotes associated with the participant). To compare participants' activity to each other, we normalized usage data by dividing the number of stories, comments, and upvotes they contributed by their **usage period** (i.e., number of days between their bedside interview in the hospital and their discharge, when they could have used the PAS). The research team then completed an initial affinity diagram process to identify patterns in participants' PAS activity and define groupings of user types. Because this initial process did not yield any clear patterns, we used k-means clustering to surface these patterns in participants' activity. We iteratively adjusted the K value to find the best fit by visual inspection (i.e., the sharpest elbow point [44]) with the optimal output being 6 clusters. Two research team members then used this k-means output to inform a second affinity diagram process. We examined participants in each cluster with their corresponding usage data, demographics, and relevant quotes from interviews. The research team members identified qualitative characteristics that were shared among distinct clusters (e.g., storytellers that received many upvotes vs. few upvotes) and refined these six clusters into five distinct user types.

Examining how participants used the PAS to interact with each other was an important component of our first research question. To visualize these interactions, we conducted a social network analysis. We used D3.js to produce a directed and weighted network diagram of participants' interaction patterns based on their story, comment, and upvote activity [64]. Each node in the diagram (Figure 4) represents one participant, while the size of the node represents the number of stories that participant posted. The edges, or thickness of the arrows, correspond to the number of times a participant commented on or upvoted another participant's story. The direction of the arrows indicates who the participant's comments and upvotes were directed toward. Nodes were weighted heavier than edges to account for additional effort involved in writing and posting a story. We also calculated degree centrality to determine each participant's popularity (the higher number of edges entering and exiting the node, the more "popular" the participant) using the NetworkX Python graph library (<https://networkx.github.io/>).

Characterizing the type of peer advice participants exchanged on the PAS was another key part of understanding how they used the probe during their hospital stay. We completed a deductive qualitative analysis of participants' stories and comments [56]. We used themes identified in prior research regarding the peer support needs of inpatients (e.g., understanding and normalizing care, exchanging emotional support) as an initial codebook [28, 29]. One research team member compiled the content from all participants' stories and comments, independently assigned themes to each instance, and discussed the process with other research team members until this analysis concluded.

Finally, to answer our second research question (What are inpatients' perceptions and experiences of using the PAS during their hospital stay), we qualitatively analyzed the transcribed audio recordings of their bedside and follow-up interviews. Three research team members conducted an inductive thematic analysis and met between several rounds of individual coding to discuss, reconcile, and converge codebooks [8]. Two of the three research team members then coded a shared subset of randomly selected transcripts and achieved consensus. These codes were then applied to the entire transcript dataset.

5 FINDINGS

We report the findings of our technology probe study in four sections. In section 5.1, we provide an overview of how participants used the technology probe during their hospital stay and define the 4 user types by which these participants were grouped. In section 5.2, we illustrate the results of our social network analysis and compare the network structures of both sites. In section 5.3, we

explain what types of advice inpatient-peers exchanged as uncovered by our deductive analysis. In section 5.4, we describe the results of our inductive analysis of interviews and share participants' experiences with using the PAS during their hospital stay.

5.1 Overview of Technology Probe Usage

Throughout the course of our study, participants across both sites posted a total of 19 stories, wrote 17 comments, and registered 34 upvotes. Pediatric participants averaged a total of 2.5 activities (SD=2.3) while adult participants averaged a total of 2.2 activities (SD=2.5) during their usage period. Overall the pediatric site had slightly more activity (37 total stories, comments, and upvotes) compared to the adult site (33 total stories, comments, and upvotes). One-third of participants engaged in multiple activities (e.g., posted stories *and* upvoted). Figure 2 shows the spread of participants' normalized activity at each site. Pediatric participants had a broad distribution of story and upvote activity whereas adult participants provided more comment activity.

Because the PAS emulated an online community, our k-means and affinity diagram processes found our participants could be grouped into five types of PAS users:

- **Storytellers** (n=11) used stories as their primary outlet on the PAS, and in many cases posted more than one story over the course of their hospital stay.
- **Commenters** (n=6) favored comments as their main communication method to discuss stories posted by peers or respond to research team prompts.
- **Upvoters** (n=6) almost exclusively used the upvote feature on the PAS to react to peers' stories. A subset (P05, P11, A08) were high-frequency upvoters, accounting for 53% of the total upvotes registered across both study sites.
- **Lurkers** (n=3) were participants who did not contribute stories, comments, or upvotes to the PAS, but indicated in their follow-up interviews that they periodically checked the probe and read the discussions during their hospital stay.
- **Nonusers** (n=4) were participants who had no activity on PAS during their hospital stay and, stated in their follow-up interviews, did not look at their peers' activity.

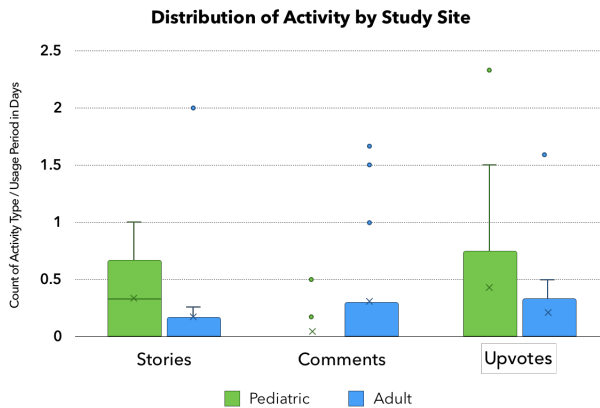


Fig. 2. Y axis is participants' normalized activity. Pediatric data are left plots and adult data are right plots.

Participants engaged in these roles and used the PAS at different points during their usage period (Figure 3). For example, several participants engaged almost immediately after receiving the probe without additional help or prompting from the research team (e.g., P08, A07). Some participants posted stories and comments early on, but soon halted this activity (e.g., P01, A14).

Others interacted with peers later in their usage period (e.g., P09, A13). A01 only used the probe at the end of their hospital stay, while A05 steadily engaged with the PAS throughout his usage period.

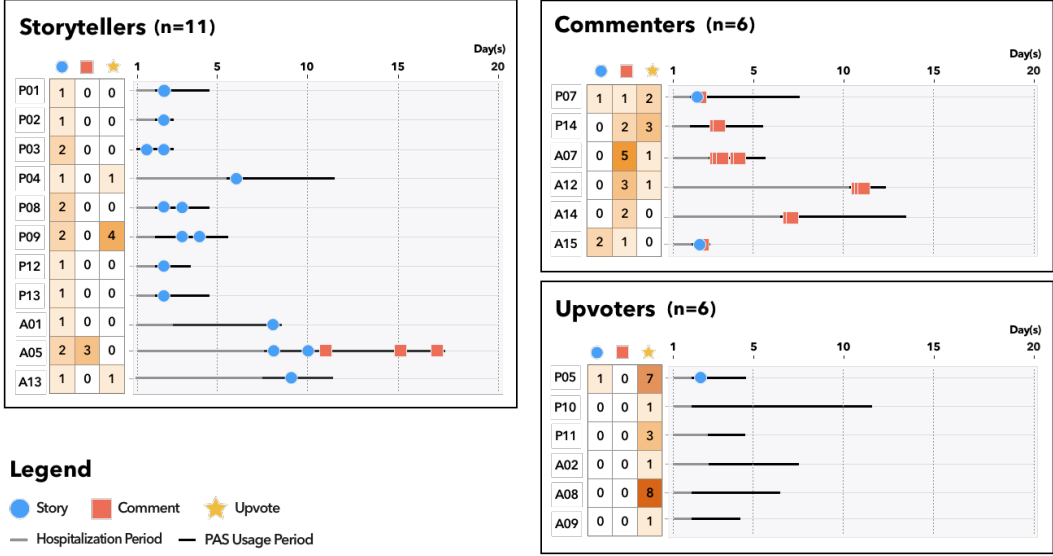


Fig. 3. Heatmap (left three columns) and timeseries (right) of the participants within each user type. Every row represents a participant. Inpatients enrolled and overlapped at different points, but we show timeseries data starting from their first day of hospital admission for ease of comparison. Notes: timestamps of upvotes were not captured, and therefore not included in the timeseries graphs; although P09 and A05 had more upvotes and comments than stories respectively, their normalized story activity was closer in similarity to other storytellers.

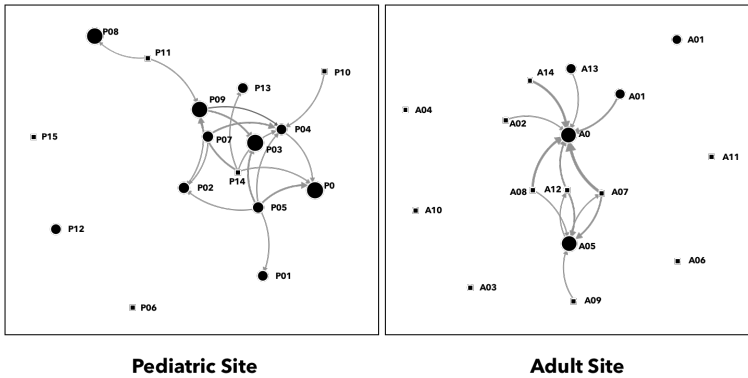


Fig. 4. Social network graphs of pediatric (left) and adult (right) peer interactions. **P0 and A0 are the research team's posts and prompts.** Small square nodes are participants that did not post stories. Larger circle nodes are participants who posted more stories. Thicker edges (lines/arrows) indicate more comments/upvotes.

5.2 Social Interactions of Inpatient Peers

Our social network analysis visualizes the inpatient-peer interactions that took place on the probe. We found slight differences in network structures between sites (Figure 4).

The pediatric site was more “social”, containing fewer isolates (i.e., participants who did not interact with peers via comments and upvotes) than the adult site. Excluding posts from the research team (P0 and A0), the pediatric site had more reciprocal interactions, with an even number of participants who both contributed and received comments or upvotes. In contrast, the adult site had more participants who contributed comments or upvotes than those who received them. Additionally, adult participants primarily interacted with each other by building upon posts from the research team (A0) rather than their peers’ stories.

5.3 Advice Exchanged with Inpatient Peers

Of the different types of activities that were available to participants via the PAS, stories and comments were the ways in which participants could exchange information with inpatient-peers. Here we describe the peer advice topics that participants discussed in their stories and comments, based on our deductive analysis using themes from prior work [28, 29]. All topics appeared at both sites, suggesting that the PAS met the peer support needs identified in prior work.

5.3.1 Adjusting to the Hospital and Managing Downtime. Adjusting to the hospital and managing downtime involves peer discussions about navigating the hospital, learning about available amenities, and making the transition from home to a new and unfamiliar inpatient environment. On the PAS, inpatient peers discussed the quality of their food service, creative recipes for nutritious snacks using ingredients from the cafeteria, and how comfortable they felt in their individual hospital rooms. To increase this level of comfort, P04’s caregiver posted a recommendation that others bring a blanket from home. 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 so dry and they recommended [the] concierge cart. Didn’t know they still did that but I got conditioner and could comb through my hair! Nice to feel human again!*”

5.3.2 Learning about Providers and Communication Strategies. Learning about providers and communication strategies involve peer conversations on how to work together and build relationships with their clinical care team. When referring to providers in their stories and comments, both pediatric and adult participants expressed favorable views of those caring for them during their stay. P02 shared, “*nurses have checked on me regularly and ask me questions on how I’m doing. I feel safe and like they are making 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 patients should find ways to “*give thanks*” to providers. Most stories and comments referring to providers were positive in nature, but A13 experienced challenges in communicating with her care team. She shared with peers: “*It would be nice if they had one point person to talk to the patient and summarizes the notes and question[s]. That way you... could get your questions answered...[and] the team can talk to more patients.*”

5.3.3 Understanding and Normalizing Care. Understanding and normalizing care is defined as peers discussing their experiences of receiving treatment in the hospital. Participants from both sites provided details and experiential information about their care in the hospital in their stories and comments, but most of these discussions were from pediatric patients. For example, P07 described to peers what kind of surgical procedure she was undergoing to both prepare for radiation and to

treat her cancer. P01 posted about the difficulty she faced when asking her providers for adequate pain medication. P03 also discussed the “uncomfortable” needles and his “dislike” of the pain he felt after surgery.

5.3.4 Preventing and Reporting Medical Errors. Preventing and reporting medical errors consist of peer advice about how to identify and intervene in errors that occur during their hospitalization. Two participants explicitly emphasized in stories and comments the importance of speaking up in the face of medical errors. A01 experienced several errors during her hospitalization and was driven to share advice with other participants via the PAS at the conclusion of her stay. She suggested they contact the charge nurse—a clinician whose role she was previously unaware of—to help resolve errors that might occur. P09 also encouraged her fellow peers to speak up when feeling “bad” to quickly fix the problem.

5.3.5 Exchanging Emotional Support and Empowerment. Finally, exchanging emotional support and empowerment involves peer discussions that empathize with each others’ hospital experiences and encouraging self-advocacy in their care. Pediatric and adult participants posted stories about their emotions surrounding their hospital stay. Participants described feeling nervous, stressed, and scared prior to their procedures, but reassured peers 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 at [adult hospital]. It would be nice to chat with other patients...let’s chat and pass the time!” In a second story, A05 explained to his peers that he wanted to meet other patients in similar situations because he felt it would be “therapeutic”.

5.4 Inpatient Experiences with Using the Technology Probe

Our interviews provided many insights into what benefits and challenges participants experienced when using the PAS during their hospital stay.

5.4.1 Fostered Peer Connections. Overall, participants reacted positively to the features that the PAS offered. Both pediatric and adult participants saw value in using the technology probe—by posting stories or comments—to share advice with peers during their hospital stay. After her time spent using the probe, P07 said, “I really like how you can share your experience and also have people to relate to on there.” Multiple participants agreed with this assessment, stating in their follow-up interviews that they enjoyed the opportunity to connect with others. A05 appreciated that the probe gave him “the ability to sit in bed and talk to somebody.” He later explained that—because the probe was web-based and allowed for anonymous engagement with peers—it was an “easier” way to share experiences, “especially with people that are going through similar issues.”

P09 also used the technology probe to share her advice with fellow pediatric patients. She referred to the probe as a chance to convey knowledge that would benefit her peers, “so that the next person wouldn’t make the same mistake.” In addition to posting stories, P09 frequently upvoted stories that other patients had posted. When asked about her reasons for doing so, she said, “I think some [stories] are just really good... the highest votes make other people want to look at it too, and if it was a great [story], maybe they would smile if they saw that one.”

Most participants described the features of the PAS as uncomplicated and “simple” to understand, navigate, and use. A subset of participants, however, described technical difficulties that they encountered. At the adult site, these difficulties often stemmed from a lack of familiarity with using an iPad device or interacting with web-based content. For example, A06 felt he “wasn’t savvy enough” to use the iPad device. His short hospital stay meant he “didn’t have enough time” to learn how to properly use the features of the probe, which hindered his desired engagement with peers.

Beyond the positive experiences and technical difficulties using the PAS, participants discussed ways to improve upon the asynchronous nature of the technology probe. Several pediatric patients—all of whom, notably, were receiving cancer treatment—thought a synchronous “chatroom” feature would be a useful way to cement their connections with others and “make friends”. P11 wanted a future version of the PAS to match peers based on cancer diagnosis, so they could more freely “ask them questions about their cancer or the same cancer that you have... and like how far you are with the chemo treatment.” P14’s caregiver discussed having some way to indicate which peers were in the hospital at the same time to connect or meet in person: “... it would be cool in the future if there were like a real time reference. So if you were posting and someone else was posting and you were both there at the same time, to somehow facilitate that connection... if users chose to say hey, I’m here and are there any other parents here too that want to connect [and] have coffee.” Offering such a feature was thought to help further strengthen relationships with peers.

5.4.2 Quality of Advice and Quantity of Engagement. Aside from the features of the PAS that connected patient-peers, participants spoke about the quality of the advice that peers shared with each other. In particular, participants recognized the probe as a good information resource that reflected a “wide variety of opinions” (P10). These opinions were deemed “helpful” and “useful” for patients to make informed decisions and to “ask more intelligent questions of their doctors and [nurses].” (A05). A few participants thought the PAS could be further improved by having more granular peer advice. They proposed adding information about “things to do if you’re hurting” (P09), “food and parking” (A15), and advice about health education classes that patients with specific diagnoses might take in the hospital (P12).

Other participants did not feel as though enough peer advice resonated with their personal experiences. A lack of relatable content—and in turn, lack of activity and responses from other patients—was mentioned by multiple adult patients as a factor that discouraged them from using the probe to the degree that they had initially intended. A09 stated in his follow-up interview, “There really wasn’t that much information on there. What little bit was on there didn’t really relate to me. [...] Maybe if there was people chatting on there, I might have said something, but I just didn’t. There was nobody talking on there, so I didn’t put anything in there.” This observed inactivity could be related to aspects of hospitalization (e.g., being busy with clinical treatments, avoiding physical and cognitive burdens), which we describe in more detail in the following sections.

5.4.3 Competition with Clinical Priorities. Although participants were interested in the prospect of engaging with their peers, the time spent using the PAS was sometimes in conflict with the time spent dealing with ongoing priorities related to their clinical care in the hospital. P08, for example, posted two stories about how she filled the downtime during surgical recovery. As her stay progressed, her providers visited her room more frequently and scheduled additional care events (e.g., physical therapy) to prepare her for discharge. Therefore, as P08’s hospital stay concluded, she was unable to contribute further to the technology probe. A11 described the difficulty of keeping up with a hectic schedule in the hospital and using the PAS. Regarding her lack of use, she said, “I was too busy with what was going on around me... concentrating on trying to get well.”

In addition to the “busyness” of the hospital (A11), some participants prioritized their relationships with providers and communications with family members or friends, rather than their inpatient peers. A14 was in critical care and maintained regular contact with individuals within her existing social circle about the status of her health. In her follow-up interview, she described: “You’re sick and you’re in the hospital and... you want to know what the experts have to say. [...] My communication was flowing with my family and my friends, and with my doctors and nurses and techs and that just felt like... where I needed to be.” For these participants, the technology probe was an additional

element of their hospital stay that diverted attention away from their relationships with providers and their healing process.

5.4.4 Cognitive and Physical Burdens. Participants described a number of cognitive and physical burdens that limited their ability to concentrate, hold the iPad, and type out their advice to share with other patients on the PAS. For example, A13—who shared her experience about challenges communicating with her care team—was receiving high doses of pain medication after surgery and had requested the help of a research team member to type out and post her story. When asked about her use of the PAS during the rest of her hospital visit, she replied: *“It’s difficult to use tools like that when you’re on pain medication.”* She went on to say that using *“electronic equipment... especially new technologies”* increased this burden while managing her health in the hospital. A07 mentioned similar challenges in his follow-up interview. Although he frequently commented on others’ stories, his high fevers and medication-induced fatigue restricted his desired level of engagement with the probe: *“There were times when I picked it up and set it back down again. I just didn’t want to deal with it. [...] When I was able to concentrate and I was already up in bed and I was already not feeling crummy, oh, I was on it until the battery went dead.”*

When pediatric patients experienced these challenges during their hospital stay, their caregivers (i.e., parents) helped them use the technology probe. In some cases, the patient verbally dictated stories or comments and the caregiver would type and post it on the patient’s behalf (e.g., P08, whose surgery restricted her arm movement). In P04’s and P14’s case, their caregiver independently used the PAS when the patient was not well enough to participate. P14 was undergoing his first round of chemotherapy after a new cancer diagnosis. His mother explained in their follow-up interview: *“I went on there a few times intermittently and made a couple of posts, just kind of investigated on my own. [P14] just didn’t have the energy or the focus... I was kind of encouraging him when he was feeling up to it, but that was not often.”* Thus, cognitive and physical burdens stemming from illness and treatment impacted inpatients’ ability to use the probe and connect with others.

6 DISCUSSION

Our technology probe study fulfilled its goal of examining how inpatients used and perceived a peer support technology in the real-world context of their hospital stay. We found that, regardless of whether participants were first-time or frequent hospital patients, they used the PAS in a variety of ways to connect with their peers and saw value in having access to the support that it offered.

Participants used the PAS to exchange advice with each other on a range of topics, such as adjusting to the resources and amenities of the hospital, communicating with their providers, and preventing medical errors that might occur in their care. While concerns about peers sharing health-related advice are well documented [73], our data supports prior work demonstrating that the descriptive and experiential support from patient-peers complements the prescriptive clinical support from providers [34].

Our interviews revealed participants’ positive experiences with using the PAS during their hospital stay. Posting and commenting on stories helped foster peer connections and allowed inpatients to share valuable advice, despite being physically isolated from each other within their respective hospitals. Although several participants found PAS simple to use, other participants also pointed out some challenges (e.g., competing clinical priorities, cognitive and physical burdens) that they encountered when using the PAS.

These challenges might partly be due to two key characteristics of the PAS community. First, peers are connected based on their shared experience of a place (i.e., receiving treatment in a hospital). Second, peers transition through this shared place at a high rate, with average lengths of hospital stays being 4-5 days [2]. Online communities connect people based on shared places

(e.g., Nextdoor, a social network for individuals within local neighborhoods), and past research has examined transience in online communities over the course of months and years [54]. Here we study a place-based community with high rates of member turnover. Such characteristics (i.e., shared place and frequent transience) could further influence community members' desire to adopt certain roles. For example, a user might choose not to ask a question to the community if they are unsure whether peers are in the shared place at the same time to respond. We saw some indications of this in our analyses. Participants adopted user types corresponding to past findings in larger OHCs (e.g., Storytellers analogous to Story Sharers, Commenters analogous to Informational or Emotional Support Providers [87]), but inpatients tended to share emotional and experiential support more often than informational support on the PAS. Participants like P14's caregiver expressed the need to know which peers were transitioning through the shared place at the same time in order to engage with them. Our study is a first step towards understanding a variety of distinct roles in this type of community, and others defined by similar characteristics (e.g., Meetup groups) should investigate how shared place and frequent transience might influence members' motivation to adopt certain roles when participating in these communities.

The initial goal of our study was to uncover design opportunities for inpatient peer support. Our findings, however, suggest new design opportunities that can sustain meaningful and continuous engagement with peers both during and after their hospital stay. Below, we discuss these design opportunities—highlighting local expertise (6.1), designing for dynamic engagement (6.2), and providing alternative modes of peer support (6.3)—in more detail.

6.1 Highlighting Local Expertise

To design our inpatient peer support technology probe, we adapted recommendations for critical mass (e.g., having a “trending stories” page to surface active conversation threads [45]). Our participants' responses to these features uncovered important questions about what scale and granularity of peer support is valuable within the hospital. For example, patients such as A09 struggled to find content that resonated with their personal experience. Overcoming such struggles would require a larger community of users across multiple hospitals to achieve critical mass, but could result in a loss of institution-specific peer expertise that P12 and A15 thought was important. Indeed, a lack of this specific experiential information is a barrier to inpatients seeking peer support about their hospitalization from established online health communities (OHCs) [29].

Researchers could consider ways to emphasize local peer expertise in the design of future inpatient peer support technologies. Prior work used a collectivistic approach (i.e., for the benefit of others, instead of oneself) for end-users to document and share their experiential knowledge about healthy eating behaviors with individuals in their neighborhood [66]. In this vein, future inpatient peer support technologies could be framed as a “collective”, or small-scale local community, where inpatients can exchange their institution-specific knowledge to benefit peers at that location or health network.

Given that the social interactions among pediatric patients (e.g., independent and story-driven) was distinct from the interactions among adult patients (e.g., prompted by research team posts and comment-driven), “collectives” of inpatient peers can be designed to scaffold these different and population-specific ways of engaging with peers. For example, during or after their hospital stay, adult patient peers could answer simple prompts from the system about their experiences with building amenities, parking locations, and hospital events organized for patients. To address participants' needs for granular and institution-specific peer support, other mediums—such as images or videos—could visually share how inpatients manage their life in their local hospital (e.g., how they contact their providers for help, where to find the cafeteria, what they learn in patient education classes). This system could be further integrated with external sites such as

Yelp or Google Maps for peers to recommend nearby resources (e.g., hotels, grocery stores) that inpatients and their caregivers can use before, during, or after their hospital visit. Such emphasis on localized peer support can provide deeper insights for inpatients that they are unable to receive from larger scale OHCs. These deeper and collective-specific insights could lend further validity to the community and strengthen bonds among peers.

6.2 Designing for Dynamic Engagement

In addition to the local scale of an inpatient peer support community, our findings showed how the dynamism of participants' hospital stays impacted their desired engagement with peers. Although patients such as P08, A11, and A14 valued support from fellow patients, the constant monitoring of their uncertain health condition meant that their fluctuating schedule of care events, and communication with providers, took precedence over using the PAS to interact with peers during certain periods of their hospital stay. Aside from dynamic treatment needs, hospitals have high turnover rates of patients being admitted and discharged [2]. Without a technology to coordinate and facilitate support, peers with overlapping hospital stays might only have the opportunity to meet through chance encounters in shared hospital spaces, if at all [42, 51].

Our participants' use of the PAS throughout their dynamic hospital experiences—by leveraging different features of the probe (e.g., stories, upvotes, lurking) to engage with peers and glean support—connects to past CSCW research on how individuals can transition through OHCs or other social communities for purposes that can evolve over time [27, 54]. In considering the shorter-term nature of the inpatient setting, the hospital also can be thought of as a transitional space, where inpatients have a continuously evolving health status, expertise in understanding their health, and physical presence during their average 4–5 days the hospital. Prior work has discussed adapting peer support needs based on a person's dynamic health status [22], but our study uncovered the need to design appropriate “on-ramps” and “off-ramps” for users to engage or disengage with peers during these transitional states.

During the shift from hospital to clinic- or home-based treatment, inpatients must gather knowledge and develop skills to self-manage their health before discharge [68]. As they experience this transition from constant clinical monitoring to self-management during their stay, future inpatient peer support technologies could provide on-ramps in the form of support groups or paired “buddies” to connect inpatients who are taking the same educational classes about their condition in the hospital. This shared experience with another patient could allow individuals such as P12—who was taking a class about his new diabetes diagnosis at the time of our study—to continue interacting with other patients in the class after it concluded and to share self-management advice after leaving the hospital. Alternatively, a peer mentoring approach could be implemented [35], where an experienced patient who has been discharged from the hospital can be remotely connected with a newly admitted patient. In line with the helper therapy principle [70], patients who are preparing to leave the hospital could then in turn become a peer mentor and share advice for future inpatients. Peer mentors could maintain access to the system and share their experience after leaving the hospital. This approach would allow peer mentors to continue contributing or enhancing their local expertise after discharge (section 6.1), would help inpatients currently in the hospital to anticipate their trajectory of care and gather practical insights about their post-discharge transition, and could yield a growing network of rich mentor and mentee connections.

When inpatients need to prioritize their clinical needs and disengage with peers (e.g., A14), future technologies could provide off-ramps in the form of inpatients setting “away messages” to indicate their presence in the hospital or change their communication preferences (e.g., from storyteller to lurker). Additionally, a system could support inpatients “bookmarking” peer advice to save for later reference.

In considering the short time frame and unpredictable nature of a hospital stay, a system could be integrated with the inpatient's Electronic Health Record to activate these on- and off-ramps in a timely manner, surrounding events such as a procedure, medication delivery, or discharge from the hospital. Before such an event, this system could notify the inpatient of peer relevant advice from their "buddy" or prompt them to ask questions about their experience. After the event, the system could send the inpatient encouraging messages or tailor their information and communication preferences to reduce their cognitive and physical burdens of engaging with peers. Incorporating these dynamic approaches can help inpatients receive timely, valuable, and tailored support during their dynamic hospital stay.

6.3 Providing Alternative Modes of Peer Support

Our study uncovered the cognitive and physical burdens that patients such as A13, A07, and P14 encountered when using the PAS, due to the treatment they received in the hospital. Although we saw some caregivers assist pediatric patients with using the PAS, both pediatric and adult participants cited these burdens as impeding their desired level of firsthand engagement with peers. This finding supports related work recognizing such burdens (i.e., situational impairments) as important considerations when designing patient-facing technologies for the hospital setting [30, 58]. To accommodate for situational impairments, we designed the PAS to be asynchronous, so patients could post stories without the burden of keeping up with real-time conversations with peers. Yet, patients like P11, P13, and P14's caregiver expressed their desire to participate in synchronous interactions.

Future inpatient peer support technologies should strike a balance between offering asynchronous and synchronous peer interactions while also mitigating situational impairments. Examples of technologies that could achieve this balance are collaborative gaming platforms [52] and 3D environments [33] which have been found to help patients connect with new and existing social networks during treatment. Another emerging example in the HCI literature is the use of virtual and mixed reality (VR/MR) systems for patients [50, 78]. VR/MR systems have been increasingly used in the hospital setting to assist inpatients with a variety of challenges, including maintaining their social connections with friends and family at home [4]. These systems could provide peers with a shared virtual space to "meet" and connect with each other in the way that they choose, without some challenges (e.g., typing) of using tablet-based technologies in the hospital. Such systems would remove some of the burdens that our participants experienced with the PAS, but designers and researchers must be sensitive to other barriers that could be introduced. For example, VR/MR systems might present a higher risk to anonymity, or require relatively high technology literacy that would prevent a subset of inpatients from accessing valuable peer support. Inpatients who want to focus on their clinical priorities should also have the right to not participate in a peer support system. To handle these potential barriers, future alternative modes of peer support systems could allow inpatients to opt-in to using the system, or enable increasingly complex ways to engage with their peers, depending on their desired level of participation and synchronicity. Although we saw pediatric and adult participants readily engage with peers that they did not otherwise personally know through the anonymous, text-based PAS, future research must examine whether this level of engagement holds true with alternative forms of peer support.

7 TRADEOFFS, LIMITATIONS, AND FUTURE WORK

Our study revealed important insights into the design and use of inpatient peer support technologies. Because we were creating a mechanism to enable peer support in hospital settings, we made the decision to include some content from the research team on the PAS (e.g., icebreaker prompts, predefined story categories) as a way to bootstrap engagement and provide value for preliminary

end-users [45]. This approach might have influenced how participants used the probe and what advice they exchanged with each other, but it worked well for encouraging early participants to contribute their own content to which peers could add. We observed this success with adult participants, who primarily used comment threads of the research team's posts to share support with each other.

Relative to traditional OHC studies, our sample size of 30 participants might be considered smaller in scale and not reflective of other inpatient populations. A consequence of our scale was the difficulty in reaching critical mass. Some participants cited a perceived lack of peer engagement as a barrier to engaging further with the PAS. Despite the limited number of stories and comments that were shared on the PAS, the activity we observed is similar to prior work measuring patients' technology use in hospital settings (e.g., [25]). Moreover, our participant interviews suggest that value can still be gained from this limited peer activity. Although a subset of participants did not interact with peers beyond upvoting or lurking, prior work has shown that those who lurk can still benefit from having access to the information exchanged between active users of peer support technologies [32, 81]. However, we recognize our small data sample may have influenced use of the PAS and types of advice exchanged, and may not reflect findings of a larger data or participant sample. In addition, the novelty effect and social desirability bias might influence our results, as participants might have been more willing to use the new technology, or might have expressed more positive opinions knowing that the research team who enrolled them in the study also created the technology [16]. Future research could explore the use of inpatient peer support technologies among a larger number of end-users. Specifically, exploring the relationships between their disease severity, complexity of their hospital stay, and usage patterns could be useful in tailoring the aforementioned design opportunities for subsets of the inpatient population. Our findings also suggest the importance of investigating whether caregivers have unique needs and uses for a peer support technology as they care for their patient in the hospital. Examining whether inpatients and caregivers adopt multiple user roles, and whether these roles change over time, could inform how future systems can adapt to meet these users' needs.

We worked closely with clinical partners throughout our study development and PAS deployment. Yet we chose not to include providers as end-users or study participants. The reason behind this decision was twofold: (1) Because the PAS was a patient-facing probe, the scope of our study was to examine the PAS in the context of the *patients'* hospital experiences; (2) By scoping the use of the PAS to patients—and caregivers, when applicable—we thought it important to ensure that end-users were comfortable exchanging support with true *peers* (i.e., fellow inpatients). Although prior studies have explored the benefits of involving providers in OHCs [38], future work could examine how their involvement could impact inpatient-peer support, considering known unbalanced patient-provider power dynamics [14]. For providers and hospitals, peer support data has value in identifying opportunities for quality improvement, and more work is needed to explore issues of conflict escalation, privacy, control, and ownership that inpatients might have with the information they exchange with peers, especially during negative hospital experiences.

8 CONCLUSION

We present a technology probe study we conducted to explore inpatients' use and perception of the PAS, an in-hospital peer support technology probe. We found that participants adopted different user roles—including storytellers, commenters, and upvoters—on the PAS. Pediatric and adult participants formed distinct social interaction patterns based on their use of commenting and upvoting features. These participants exchanged informational and emotional support on a range of topics, such as adjusting to the hospital, understanding their care, and preventing and reporting medical errors. Furthermore, we describe factors, like fostered peer connections and competing

clinical priorities, that helped and hindered inpatients' use of the PAS during their hospital stay. We discuss three novel design opportunities: (1) highlighting local expertise, (2) designing for dynamic engagement, and (3) providing alternative modes of peer support. These insights provide guidance for future inpatient peer support technologies to increase inpatients' knowledge, self-efficacy, and empowerment during their hospital stay.

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