Patients as Safeguards: Understanding the Information Needs of Hospitalized Patients in Voicing Safety Concerns

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Structured Abstract:

Purpose: To improve inpatients' experience and safety by involving them as active participants in their care. In particular, we inform the design of technological systems and processes that support and encourage inpatients in preventing, responding to, and recovering from medical errors.

Scope: Medical errors cause significant mortality and morbidity each year. Yet, limited work explores the unique perspectives of patients or their carepartners. Over the course of our studies, we engaged 529 total participants—including patients and their carepartners as well as clinicians from Seattle Children's Hospital and Virginia Mason adult hospital—to help us understand patients' needs and support ideas for preventing medical errors.

Methods: We employed a variety of methods including observations, interviews, the Q-methodology, focus groups, participatory design, technology probes, and surveys to understand inpatients' needs and technology design requirements to meet those needs.

Results: We found that existing technology does not support patients in safeguarding their own hospital care. New technology needs to help inpatients and their carepartners in (1) transitioning from home to hospital, (2) adjusting schedules and receiving status updates, (3) understanding and remembering care, (4) asking questions and flagging problems, (5) collaborating with providers and carepartners, (6) connecting with other patients or carepartners to normalize speaking up about concerns and to learn from others' successes and failures, and (7) preparing for discharge and at-home care. Such new technologies have the potential to both improve patients' hospital experience as well as reduce medical errors.

Key Words: patient safety, co-design, health informatics

Purpose:

We sought to understand what support patients and their carepartners need to safeguard and improve their overall hospital care. The three aims for this project were to: (1) identify information that would increase patients' and their carepartners' situational awareness as well as enable them to recognize potential safety concerns, (2) identify opportunities to support inpatients and their carepartners in capturing and managing health information, concerns, questions, and customized care needs, (3) determine strategies to support active dialogue among patients, carepartners, and providers around safety-related concerns and the overall hospital care experience. The results from our project will inform the design of systems and processes that support patients in preventing, responding to, and recovering from undesirable events.

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Scope

Medical errors cause significant mortality and morbidity each year and is estimated to be the third leading cause of death in the United States. Although this problem has received national attention for many years, including efforts to encourage patients to speak up about errors, less work has actively involved patients in preventing, detecting, and recovering from these errors. Patients and their carepartners offer a distinctive perspective on the delivery of care that is rarely captured or used to improve their overall hospital experience. Moreover, patients and carepartners experience cognitive, interpersonal, and system-level challenges that can affect their awareness of potential problems and inhibit their ability to communicate their concerns. They need support to overcome those challenges to most effectively engage in and safeguard their care. In particular, enhancing patients' and carepartners' access to and engagement with meaningful information can help address communication challenges that are often the root cause of many adverse events.

Our work took place in two hospitals: Seattle Children's Hospital and Virginia Mason Hospital (an adult-only hospital in Seattle). Thus, our work included children as one of AHRQ's priority populations. Children have been particularly understudied as active participants either in their overall hospital experience or in safeguarding their care. We included children ages 7 and up because previous work has shown that age 7 is a good minimum age as that is the age at which children are able to self-reflect and articulate their thoughts clearly. That age is also when they begin the abstract reasoning phase that allows them to understand the concept of designing technologies.

Across all phases of our research we engaged 529 participants, 500 of whom were patients or their carepartners. We also included 29 clinicians as participants in our focus groups and interviews because they are key stakeholders for inpatient-facing technologies too. We had 242 patient or carepartner participants in our survey, 48 of whom were children 7-18 years of age. For our interviews, technology probes, observations, or participatory design sessions, we had 89 children as participants. Thus, we had substantial involvement from this AHRQ priority population.

Methods:

To accomplish our objectives, we employed a mixed methods approach through multiple studies. We used an experience-based design process that encompasses a set of methods and practices aimed at gaining insight into people's goals, needs, preferences, current limitations, and future opportunities to inform the design and development of interventions. We also used a participatory or co-design process with patients, carepartners, and clinicians to create three types of artifacts: (1) low-fidelity

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prototyping cards, (2) mid-fidelity prototypes for displaying health information, and (3) technology probes or software prototypes. The low-fidelity feature cards included simple mockups of potential features that could be deployed for inpatient-facing technologies. We generated the features based on both the interviews and participatory design sessions. These cards helped us prioritize the features that people wanted in their inpatient technology.

Mid-fidelity prototypes

To further explore inpatients' information needs, we conducted an iterative design process using Sketch[1] and Marvel[2] to create three different prototypes (Timeline, Goal, and Categorical) for a tablet-based inpatient portal. Each prototype emphasized one aspect of patients' values and needs based on the design guidelines from our previous low-fidelity prototype study. Based on the findings from this previous study, we also included a core set of features—contacting carepartners, messaging providers, and setting reminders—in all these prototypes.

The *Timeline* prototype (Figure 1a) emphasizes the need for patients to view timing and details of anticipated care events. It presents the patient's schedule for the day in the form of a timeline that allows people to click on any event and obtain more information about this event. For example, selecting the "Vitals Check" event shows a description of what will happen during this event, as well as the patient's most recent vital measures (e.g., temperature, heart rate, and blood pressure). Additionally, the name of the provider who is involved in the event is shared, as well as their documented notes. The last event listed on the patient's schedule is their projected discharge date.

The *Goal* prototype (Figure 1b) highlights the patient's and provider's goals along with the tasks that the patient must complete to meet each goal. For example, clicking on the "Recover from Surgery" goal reveals the details of the necessary tasks and care-related information (e.g., relevant medications, providers responsible for helping the patient complete the task). Above the goals and tasks section sits two dynamic sliding scales, each representing the patient's and provider's assessment of the patient's readiness to be discharged from the hospital. Within the prototype, the patient can change their sliding scale to communicate their perspective to the care team.

Finally, the *Categorical* prototype (Figure 1c) highlights categories of care information—such as medications, test results, and discharge details—and is most similar to current portal designs. Clicking on the "Dashboard" shows the care team's activity (e.g., when a

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provider shift change occurs) and most recent modifications to their care plan (e.g., when an order for a new medication is placed).

Figure 1. Midfidelity screenshots of Timeline (1a), Goal (1b), and Categorical (1c) prototypes.

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Technology Probes

We also designed and deployed the three technology probes—(1) an iPad app called Plan & Talk (see figure 2) which helps patients and their carepartners reflect on, track, and share their goals, (2) an iPhone app called Nuri (see figure 3) which audio records and semi-automatically transcribes and tags key concepts from patient-doctor interactions, and (3) the Patient Advice System (see figure 4) which provides a Reddit-like interface for helping inpatients exchange advice or support for one another. The in-hospital deployment of these probes were used to further our understanding of patients' and carepartners' needs and perspectives. We tracked the usage of these probes, but the primary insights came through observations of use and interviews with the patients and their carepartners after they used the probes.

Fig. 2. The interface of Plan & Talk application for the iPad. (A) About Me is where the patient can describe their information including name, age, preferences, and hobbies. (B) The Goals section is a space to display both the care team's and patient's high-level goals. (C) The Let's Plan page presents a timeline with three stages: When I'm in the hospital, When I go home, and Someday. The patient can create specific goals, assigning one of the six categories—medications, lab tests, drinking, eating, activities, and entertainment. (D) The Let's Talk page includes two sections called We Need to Talk About and Things Going Well. The patient can add topics to both sections by either adding a topic from scratch or marking a specific goal as Need to talk or Going well on the Let's Plan page.

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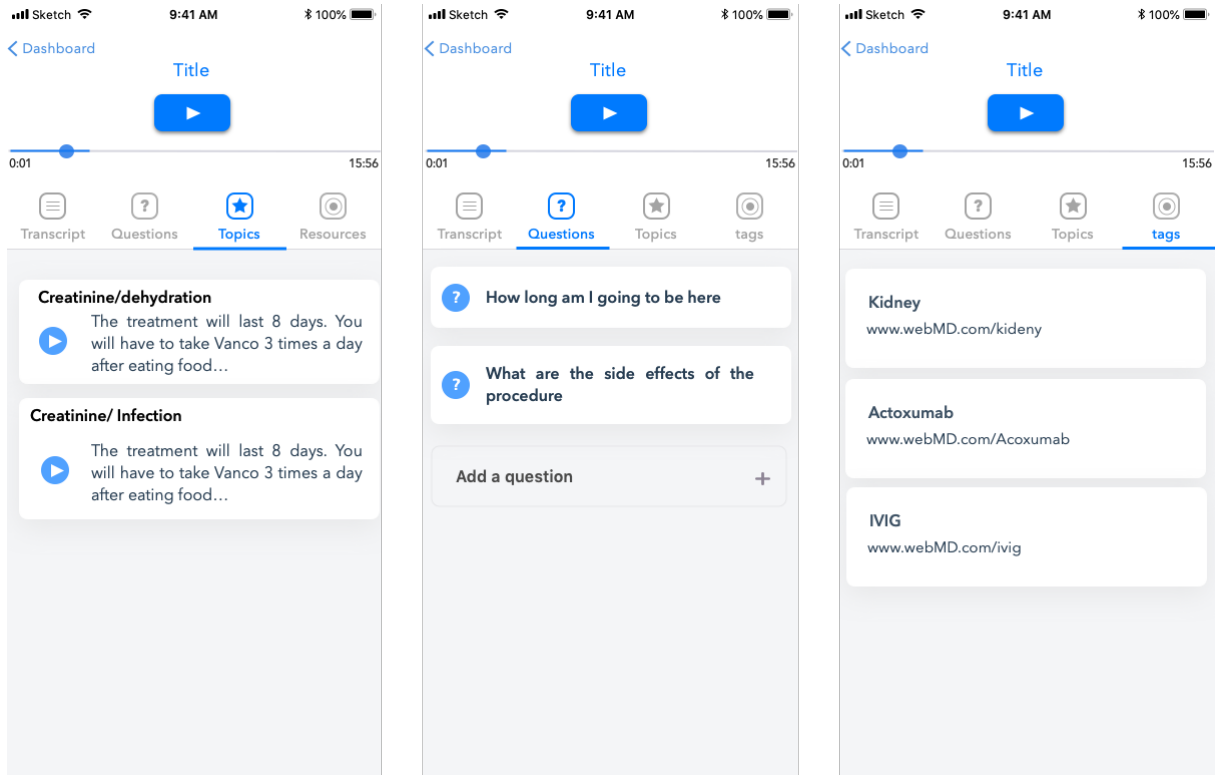
Figure 3. The NURI system showing the topics highlighted from the conversation, the questions that a patient has related to the conversation, and the tags for key concepts in the conversation.
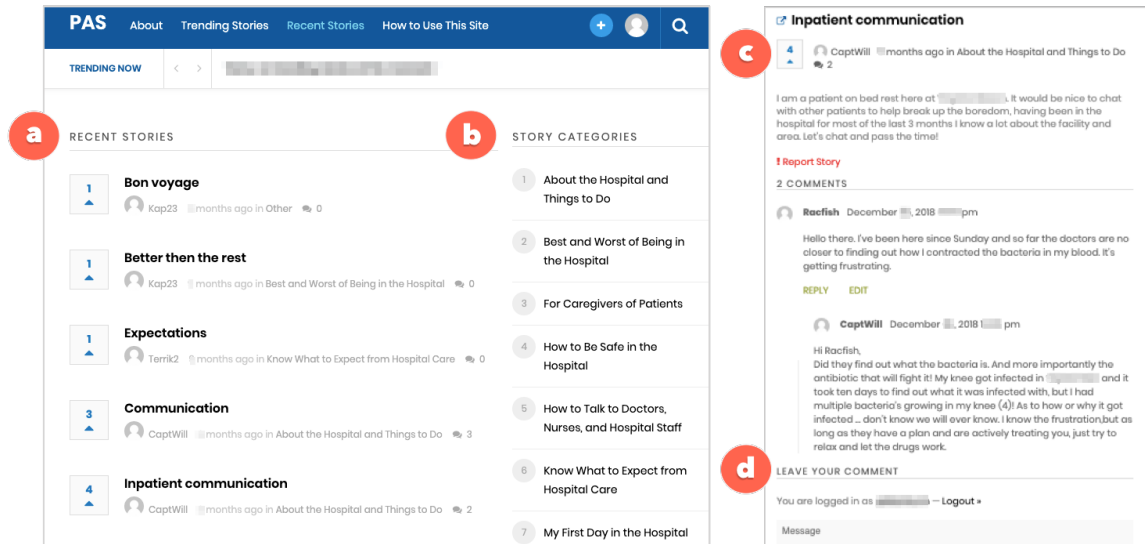
Figure 4. Screenshots of the Patient Advice System (PAS) deployed at the adult hospital. Left: Home page where patients can a) view recently posted stories and b) browse story categories. Right: expanded story view, where patients can c) upvote and d) comment on the story. Note: images are cropped for space and sensitive information is obscured to protect privacy.

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Limitations

We recognize the limitations of this work. We sought input from participants at two hospital sites within one metropolitan area of the United States. Therefore, our findings might not be transferrable to other patient populations or geographic regions. Because study participation was voluntary, views of people who chose to participate might not reflect those who were not approached or decided against participation. When we were soliciting input based on the technology probes or prototypes, study team members who were involved in creating the prototypes also participated in interviews, and this overlap might have elicited more positive feedback than interviewers who were not involved in the prototype design or implementation. The novelty effect might have also influenced participant responses to the prototypes.

Results

Survey Results of Patient and Caregiver Perspectives on Undesirable Events

Based on our survey results, we demonstrated the breadth of quality and safety problems from the patient and caregiver perspective, and we discussed technology implications for inpatient safety interventions. Through our inductive coding process, we identified 29 distinct codes, of which 19 represented types of UEs, and 10 represented types of harms resulting from UEs; each survey response was coded with an average of 2.3 types of UEs and 1.8 harms. The 19 types of UEs fell into one of two major categories: clinical or non-clinical. The clinical events pertained to medical care that the patient received in the hospital (e.g., administration of medications, mistaken diagnoses, hospital acquired conditions). Non-clinical events encompassed other aspects of the hospital stay that—from the perspective of patients and carepartners—exacerbated their experiences with clinical events. Further analysis of non-clinical events revealed three subcategories: miscommunication, institutional barriers, and lack of respect. The 10 types of harms also consisted of two categories: physical and invisible (table 3). Physical harm refers to participant-reported harms that directly impacted the patient's health (e.g., pain, readmission). Invisible harm involves the personal impact of UEs, specifically: negative emotions and loss of trust, and additional burdens. We submitted these results to BMJ Quality and Safety where it is currently under review.

Results from our low-fidelity prototyping

In this part of our study, we investigated inpatient needs for tracking their health, and found that inpatients envision collaboratively tracking their health and care plan with their clinical team. We found their tracking process follows the stage-based model, but that collaborative tracking introduces new barriers to and requirements for successful tracking. We provided insights about designing collaborative tracking systems to help hospitalized patients manage their health and care,

reflections on how collaborative tracking extends the stage-based model of personal informatics, and suggestions for new research directions. With better tools for collaborative tracking, patients in the hospital will be able to keep track of their health and care, increasing the potential for improved health outcomes and medical error prevention. We applied the stage-based model to our findings to see if findings from other research in personal informatics can help us understand patients' needs in the hospital setting. Because the stage-based model held up well in this new context, we derive recommendations for supporting inpatients in collaborative tracking based on the personal informatics literature.

In addition, we analyzed how pediatric patients would like to communicate their needs. Our analysis revealed themes regarding attitudes and the potential use of emojis for pediatric patients, with eight out of twelve participants indicating interest in the use of emojis to facilitate communication with providers. Four participants responded very positively to the presented emoji "feature card", saying that they would use the emoji-based interface features as presented. Another four also reacted favorably but desired accompanying text from their providers to provide additional context about their health situation. The remaining four participants focused on other aspects of the low-fidelity prototype, without explicitly stating any strong feeling on emojis as a form of communication.

Results from our mid-fidelity prototypes

The results showed that patients used each display for different purposes. For example, the timeline prototype, displaying information in a calendar-like fashion, helped the hospitalized participants gain more control over their schedules and ensure a caregiver was present during medical rounds. Furthermore, the goal-oriented display helped pinpoint conflicting opinions between the patients and providers. The study findings suggested that hybridizing the presentation of medical information optimizes the information's usefulness at the bedside of patients. Pediatric and adult participants discussed our prototypes as meeting the following needs: forming active partnerships, navigating relationships and power dynamics with clinicians, understanding complexity of care, contextualizing health information, increasing efficiency of communication, and preventing lost information. Our findings show the importance of designing inpatient portals to support patients' agency, as well as their dynamic needs and preferences. By making such considerations in future inpatient portals, these technologies can begin to fulfill their potential of helping patients increase their engagement and improve their hospital experiences.

Results from the Plan & Talk System

We found opportunities for and challenges in using Plan & Talk for the inpatients' goal management, communication with the care team, and self-expression. By incorporating our findings and considerations for complex contexts surrounding hospitalized youth, we provide four design guidelines: (1) infuse new technologies into old infrastructure, (2) highlight the phases of care, (3) connect medical goals to personal life goals, and (4)

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provide multiple profiles to resolve intra-family tensions. This study highlights the importance of supporting pediatric patients and their carepartners in reflecting on and communicating their goals with the clinical care team. Our hope is that future tools, built upon insights from Plan & Talk, will provide youth with the right tools to make their voices heard and improve their overall care in the critical hospital setting.

Results from NURI

We found that the patients highly valued having technology at their side to help them overcome their communication challenges, particularly in remembering what was said and its significance within the context of other aspects of their conversation. We described the ways patients used NURI to help them play an active role in their care by sharing information more effectively, collaborating more efficiently with their care team, and planning their care. Furthermore, the participants reported that NURI helped them to recall and understand their medical conversation. However, we identified potential risks from of having NURI at the bedside of hospitalized patients. While patients did not report any personal worries, clinicians worried that NURI could lead to malpractice lawsuits. In conclusion, NURI delivered enormous support to help patients manage their hospital conversations with clinicians. Further work should be done to improve clinicians' acceptance of NURI.

Results from the Patient Advice System (PAS)

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 noted factors, like fostered peer connections and competing clinical priorities, that helped and hindered inpatients' use of the PAS during their hospital stay. We identified three new design opportunities: (1) highlighting local expertise, (2) designing for dynamic engagement, and (3) providing low-burden forms 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.

Conclusions

Overall, our studies revealed a population of patients and their carepartners who are deeply invested in engaging with their care. However, different aspects of the clinician-patient relationship either promoted or inhibited participants' desire to engage in their safety. This influence occurred even with safety behaviors that did not obviously deviate from the traditional patient role and was exhibited by both patient and carepartner participants. Patients' willingness to perform safety-related behaviors is influenced by their relationship with their clinicians. Our findings shed light on how different aspects of the clinician-patient relationship motivate or discourage patients from engaging with their safety. We identified how patient-facing technologies could support the

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motivational aspects of this relationship while mitigating the inhibiting influence of other aspects of the clinician-patient relationship. We suggest that designing patient-facing technology to facilitate non-confrontational communication with clinicians could frame safety behaviors as collaborative acts that would encourage safety engagement. In addition, we found that existing technology does not support patients in safeguarding their own hospital care. New technology needs to help inpatients and their carepartners in (1) transitioning from home to hospital, (2) adjusting schedules and receiving status updates, (3) understanding and remembering care, (4) asking questions and flagging problems, (5) collaborating with providers and carepartners, (6) connecting with other patients or carepartners to normalize speaking up about concerns and to learn from others' successes and failures, and (7) preparing for discharge and at-home care. Such new technologies have the potential to both improve patients' hospital experience as well as reduce medical errors. These approaches could help patients to engage with their safety and prevent unnecessary harm in the hospital.

List of Publications:

1. Haldar S, Khelifi M, Mishra SR, Apodaca C, Beneteau E, Pollack AH, Pratt W. Designing Inpatient Portals to Support Patient Agency and Dynamic Hospital Experiences AMIA Annu Symp Proc. 2020 (in press)
2. Haldar S, Kim Y, Mishra SR, Hartzler A, Pollack AH, Pratt W. The Patient Advice System: A Technology Probe Study to Enable Peer Support in the Hospital. Proc. ACM Hum.-Comput. Interact., Vol. 4, No. CSCW2, Article 112. Publication date: October 2020, 23 pages. https://doi.org/10.1145/3415183 (in press)
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