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Understanding Patient and Caregiver Work to Support Health Care System Reliability and Quality

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Abstract

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Patients and their families face many challenges navigating and managing their care within hospitals and other healthcare environments. Outside of the stress and anxiety linked to a health crisis, patient and their families must also cope with significant information and communication challenges. The expansion of information generated by labs, tests, and specialist assessments creates greater complexity and gaps in care delivery and coordination than has existed in the past. With increased complexity, patients and families are exposed to risk of adverse care-related events that can negatively affect their health and well-being. Researchers have investigated these negative events and point to communication failure as one of the primary reasons for these occurrences. In this context, the field of Human-Computer Interaction provides useful frameworks and research methods to understand communication failures related to patient, family, and clinician interaction around health care data.

In this dissertation, I address the concept of patient participation in health care information management from a diverse range of care settings—hospitals, clinics, homes—and different medical scenarios including chronic, acute, and surgical cases. My research approach considers the design of systems through a

sociotechnical macroergonomic framework known for understanding the structures, processes, and outcomes of the work of health care professionals, patients, and families in regard to patient safety reporting. In addition, I employ different mixed methodologies to explore the information needs and artifacts within a clinical environment to support patient's awareness of their care.

In the first study, I consider the work that patients with chronic conditions perform outside of the clinic to reduce errors and ensure reliable self-care. In my second study, I explore the information workspace of patients and families in the hospital. In the third study, I demonstrate the use of Q methodology to elicit a diverse mix of attitudes of patients and caregivers regarding their communication needs in the hospital. In the final study, I explore the perspective of caregiver involvement in monitoring signs of delirium in the hospital.

The notion of increased patient participation in healthcare is a growing trend in the industry. However, as I review in the related literature below, researchers are just beginning to conduct studies that explain patient-centered needs as it relates to care quality from an informatics perspective. With this work, I provide a formative approach to addressing the care and communication challenges of healthcare from a patient perspective. This area of study can help medical systems to improve the overall patient experience and incorporate patient and family member contributions to clinical care information management.

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Chapter 1. Overview

Communication errors in healthcare are common, owing to a complex care environment and frequent patient handoffs between staff and facilities. A growing trend in the healthcare industry is to use a human factors and complex systems framework for understanding the problem and developing solution. Throughout this dissertation, I consider the design of systems and strategies for error management through a sociotechnical macro-ergonomic framework. In principle, a systems framework in healthcare focuses on the structures, processes, and outcomes of the work of health care professionals, patients, and families (Holden et al. 2013). Notable safety researchers such as James Reason use systems and ergonomics theory to dissect failures in complex systems and suggests both structural and human-based approaches to reduce errors. In particular, Reason emphasizes the role of human actors as proactive layers of defense against errors and a source of system resilience (Reason 2000). Through my dissertation work, I consider the value of patient and family-member engagement as an additional layer of defense in complex systems and to assert the patient role as a source of control in the system.

A major challenge to considering patients and families as proactive actors for error prevention is that outside of direct patient-provider interaction, health care systems typically limit input from patients to satisfaction surveys (Halpern et al. 2011). However, growing research suggests that a patient serves as a source of resilience by identifying gaps and concerns that can help a health care system adapt to changes in high-risk, complex situations (Cook et al. 2000). Researchers have shown that there is little overlap between doctors, nurses, and patients in what concerns they identify and suggests that the patient perspective can augment hospital awareness to safety and quality risks and enhance existing reporting mechanisms (Kaboli et al. 2010; Weissman et al. 2008).

In order to build on the research of patients as actors in error management, I focus on human-computer interactions (HCI) and evaluate information strategies and tools related to error detection and response. Related research has shown that the current patient experience is information poor within a hospital environment and few tools exist to support patients' awareness regarding activities related to their care (Wilcox et al. 2010; Skeels & Tan 2010). Using a mixed methods approach, I analyze patient and family contributions as engaged partners in healthcare systems, evaluate the information deficits that can inhibit patient and family involvement in their care, and consider the design of tools that can support greater patient and family member participation.

Research Aims

The purpose of this thesis is to better understand the role that patients and families members can play in order to mitigate and manage errors related to care management. In the following aims, I explore patient self-management strategies, information needs in the inpatient setting, and family member roles in patient monitoring and response. Using the findings from this research, I provide a formative approach to addressing the communication challenges and information needs associated with healthcare complexity from a patient-centered lens.

Aim 1. To identify the strategies employed by patients to enhance the reliability of their care management.

In this first aim, I seek to understand the factors and barriers that can affect consistency and reliability of self-care management for people with a chronic disease. For this research, I conducted a series of in-home visits and interviews with patients with chronic diseases. Using open-coding, qualitative analysis, I describe the challenges that patients experience with self-care management and introduce strategies and design considerations for improving reliability of their care.

Aim 2. To evaluate patient attitudes towards engagement around safety and information needs relating to the management of their care in the hospital.

For this aim, I used a mixed methods approach to identify information needs that affect the overall inpatient experience.

Aim 2.1. To characterize the interactions and information work of patients and families in a hospital setting. I conducted a survey of previously hospitalized patients and their family caregivers about their access to and management of information about the care provided. Through this work and a series of observations in a tertiary care hospital, I describe the information work and needs that patients experience while receiving care.

Aim 2.2. To evaluate patient attitudes to their situation awareness in the hospital. Through qualitative interviews with hospitalized patients, I explored (1) factors that influence patients' intentions and actions to communicate concerns, (2) methods that patients currently use to communicate, and (3) barriers to patient-provider communication. The interviews utilized Q-Methodology to assess the patients' self-efficacy, knowledge of their plan of care, and interactions with caregivers and hospital staff.

Aim 3. To identify design approaches to support patient and family discussions with providers about the plan of care and concerns about undesirable events.

Providing enhanced access to information can reduce the cognitive load for patients and improve common ground between the patient and their care team to identify and correct possible hazards and communication failures. Based on interviews with nursing staff, patients, and caregivers, I explore the communication breakdowns and challenges with episodes of delirium in the hospital. Based on these interviews and a set of participatory design sessions involving providers, nurses, patients, and caregivers, introduce design recommendations to improve caregiver awareness and involvement in delirium management.

Summary

Through this research, I contribute to a deep understanding of patient information needs that can inform future technology developments. The notion of an activated and involved patient has been discussed in the outpatient context for some time (Coleman et al. 2009; Greene & Hibbard 2011), but has received less attention in an inpatient context. With patient safety in a hospital environment, the patient is frequently thought of as a passive stakeholder while medical personnel are responsible for detecting and mitigating errors. However, patient engagement can be a valuable component of health care quality and safety improvement (Longtin et al. 2010).

As outlined in my research aims, I provide a formative approach to addressing the care and communication challenges of healthcare complexity from a patient perspective. This area of study can help medical systems to improve the overall patient experience and incorporate this valuable perspective into their patient management strategies. Empowering the patient and encouraging proactive dialogue between the patient and provider team around questions and concerns can support anticipatory behavior that increases overall system resilience (Patterson & Woods 2001).

Dissertation Overview

In this dissertation, I present findings from four studies: (1) a qualitative analysis of chronic disease patient strategies to reduce failures with self-management, (2) a set of observations and surveys used to describe the information workspace of patients and families in the hospital, (3) a mixed methods approach to understanding caregiver involvement in delirium detection and management, and (4) an evaluation of patient information needs in the hospital using Q methodology.

In chapter 2, **Background and Significance,** I review the current research of patient information needs, systems theory, and implications for undesirable events in US health care. Specifically, I review the idea of patient-centered undesirable events as distinguished from clinical-defined adverse events. Using theoretical models from Human Factors engineering and safety in complex systems, I provide a rationale for the value and importance of patient involvement in healthcare management. Supporting patient involvement can enhance system resilience as well as provide a complementary perspective on care that is rarely captured in a systematic way (Kaboli et al. 2010; Levtzion-Korach et al. 2010).

In chapter 3, **Engineering for reliability in at-home chronic disease management**, I consider the work that patients with chronic conditions perform outside of the clinic to reduce errors and ensure reliable self-care. I use in-home observations and interviews to explore the information needs and artifacts within the home environment to support patient's self-management and care coordination.

In chapter 4, **Patient information needs in the hospital environment**, I consider the information workspace of patients and families in the hospital. Based on an information needs survey and inpatient observations, I discuss the information gaps that patients experience and the challenges created by the physical environment that affect patient information management.

In chapter 5, **Q Method Exploration of Inpatient Information Exchange Priorities**, I demonstrate the use of Q methodology to elicit a diverse mix of attitudes of patients and caregivers regarding their communication needs in the hospital. My study explores a novel application of situation awareness as a framework to understand patient information needs in an inpatient setting.

In chapter 6, **Using Experience-Based Design to Understand the Patient and Caregiver Experience with Delirium**, I explore the perspective of caregiver involvement in monitoring signs of delirium in the hospital. Delirium events provide an informative view of information asymmetry between patients, families, and clinicians and opportunities to address this. Based on this study, I suggest concrete ways systems and tools can recognize regular participation from family caregivers in delirium detection and response.

In chapter 7, **Summary and Conclusion**, I summarize the contributions from this dissertation and present opportunities for continued research in the future.

Based on this work, I suggest three novel positions on the role of the patient in a hospital setting. First, patients and their family members offer a unique perspective on the delivery of care that is rarely captured. Second, providing tools that reduce the cognitive load of patients can not only enhance patient experiences but also improve their awareness of changes in the plan of care that can impact safety or well-being. Lastly, increasing patients' access to meaningful information provides a platform for more cross-checking dialogue between patients and their care team and helps address information and communication gaps that are often the root cause of many undesirable events (Cosby & Croskerry 2004). This work helps establish an early understanding of the way information tools focused on patients and family members can intersect with error prevention strategies.

Chapter 2. Background and Significance

Introduction

High quality care delivery is one of the primary benchmarks used by governments, private agencies, and patients to evaluate clinical settings and to ensure safe, excellent care services. The concept of high quality care has many definitions, but the Institute of Medicine (IOM) and Coulter's widely cited review of the topic refers to quality as timely, reliable, effective, and safe health care when the patient needs it; the provision of adequate information and support to patients and caregivers; being treated with empathy, dignity, and respect including incorporating patient preferences for treatment options and disease management (Coulter & Ellins 2006). An important component of this definition and an increasing trend in digital health is that the patient should play an active role in making decisions about her own care.

Since the publication of IOM's report, *Crossing the Quality Chasm*, quality in healthcare has received widespread attention from the media, research communication, and healthcare industry. Despite the focus on improving care services, medical errors are still widespread throughout the United States (Agency for Healthcare Research and Quality 2008). Based on an early 1990s Harvard study, the IOM suggested that as many as 98,000 people die in US hospitals every year due to preventable, avoidable errors (Kohn et al. 1999; Brennan et al. 1991; Leape et al. 1991). Other reports on the prevalence of errors in US health care reinforce the IOM's findings. Nuckols found that 9% of patients at two US hospitals had at least one reported incident that included medication errors, falls, and operative incidents. The medical reviewers believed that at least 59% of these incidents seemed preventable (Nuckols et al. 2007). A report from the Office of the Inspector

General calculated that 1 in 7 Medicare beneficiaries (13.5%) experienced an adverse medical event in 2008 (Levinson 2010).

The prevalence of breakdowns in care quality is notable, but it is important to note that this issue has been evaluated primarily from a clinical perspective using clinical definitions of errors. Throughout this dissertation and in the following review, I consider a patient-centric view of quality and the patient and caregiver role in care delivery. Ensuring high quality care is a complex problem and requires consideration from various perspectives. I review how deviations in care delivery are defined from clinical and patient perspectives, consider systems-level frameworks for evaluating health care quality, and provide rationale for patient engagement and participation in safety and quality of care activities.

The Influence of Patient Engagement on Care Quality

Increasingly, researchers have explored patient engagement as a means to improve the quality of care provided. Increased patient- and family-centric care reflects the shifting roles in modern healthcare of patients as active and informed stakeholders. Patient engagement or patient-centric care has many published meanings, but a widely cited definition refers to actions that "promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels" (Coulter 2012). Other reviews frame patient engagement as (1) a behavioral dimension in terms of what patients do, (2) a cognitive dimension in terms of what patients think and believe, and (3) an emotional dimension in terms of how patients feel about their health and their care (Barello et al. 2016). The belief is that patient engagement promotes greater personalization, access, commitment and therapeutic alliance and will lead to an improved healthcare experience (Higgins et al. 2017).

Empirical research on the impact of patient engagement is growing. Snyder's review of patient involvement argued that most existing research framed impact in terms of health outcomes, cost of care, and patient satisfaction (Snyder & Engström 2016). Studies of behavioral approaches to engagement such as increasing patient activation suggest that patient engagement can lead to better health outcomes and contribute to improvements in care quality and safety than patients who are disengaged and passive (Hibbard & Mahoney 2008; Greene & Hibbard 2011; Frosch & Elwyn 2011). In their systematic review, Coulter and Ellins argue engagement interventions are associated with patient behaviors including: patients' recall of information, knowledge about managing their conditions, the likelihood of patients reporting that a treatment path was appropriate for them, reports of patient-reported evaluation and satisfaction with their care, and overall use of health care resources (Coulter & Ellins 2006). The last behavior is notable in that engaged patients are more likely to adhere to a course of treatment and to participate in monitoring and prevention activities that are linked to lower cost and better outcomes.

Patient Perspectives on Adverse and Undesirable events

Deviations in health care quality can range across a spectrum of events that include serious medical harm to breakdowns in the patient experience. The research community in patient safety typically uses the term, **harm**, to broadly refer to medical care, preventable or not, that causes poor patient outcomes not related to the natural history of the disease (Govindan et al. 2010). While harm can encompass a broad array of adverse events, it excludes medical errors that did not injure the patient. When referring to errors in this proposal, I use the IOM's prior work to define an **error** as "the failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim" (Kohn et al. 1999). An **adverse event** indicates an unintended injury occurred due to a medical intervention and not due to the patients underlying condition. Not all errors cause an adverse event, but an error does indicate a failure of a plan in care. Additionally, the safety literature also considers **near miss events** that are described as potential adverse events identified before they cause harm to the patient. In most of the patient safety literature, authors describe preventable events such as adverse drug reactions, hospital-acquired infections, and operative-related complications using these classic definitions. Commonly agreed upon definitions of errors and adverse events are essential to surveillance methodologies that require reliable, repeatable, and accurate review of medical records and receipt of semi-structured incident reports from health care staff.

While most patients will agree with traditional health care definitions of error events, a patient's understanding of negative events may include other incidents that are detrimental to their care experience. Agoritsas and colleagues have promoted a patient-centric concept of **undesirable events** to describe "complications, problems, or unexpected or unpleasant situations" that were related to interpersonal, medication, or process problems (Agoritsas et al. 2005). More recently, researchers in the United Kingdom have conducted several surveys through which they describe an undesirable event as "an unintended or unexpected incident, which could have, or did lead to harm for the patient" (Davis, Sevdalis, Neale, et al. 2012). Outlined in Table 1, existing evidence suggests that patients conceptualize errors and unsafe acts more broadly than the classic medical definition of an adverse event. Patients conceptualizations include any act that results in physical, psychological, or financial harm, not just medically defined harm (Davis, Sevdalis, Neale, et al. 2012). Davis et al. categorizes many of these patient-centered concerns as medical complications, health care process problems, environmental related, and interpersonal and service related problems (Davis, Sevdalis, Neale, et al. 2012). Interpersonal problems are particularly important and not categorized within traditional definitions of safety concerns. Therefore, many patient concerns will relate to an adverse event, but not all adverse events capture patient-defined harm. Leveraging patient and caregiver knowledge of undesirable events can provide greater perspective and potentially new opportunities to tackle failures in care quality.

Table 1: Patient-centered undesirable events within a hospital. Modified from Davis RE, et al. 2012.

Category of concerns	**Typical undesirable events**
Medical Complications	• Sore arm or inflammation due to intravenous line drip • Hospital-acquired infection • Adverse drug reaction • Excessive bleeding, post-operative or catheter-related • ICU transfer due to complications while hospitalized • Pressure ulcers while in the hospital • Re-operated on urgently within 3 days of initial operation • Injury due to fall while in the hospital
Health Care Process Issues	• Medical records unavailable when needed • Pain management issues • Received wrong diagnosis • Given food/drink against instructions or contrary to diet • Fluids for IV drip not changed • Test not done when scheduled • Repeated/duplicate test (by mistake) • Wrong drug administration • Mistakenly mixed up with another patient during care • Test cancellation (due to a mistake) • Administered medication that causes known allergic reaction • Error in test result
Environmental	• Chaotic atmosphere due to sense of overcrowding • Concerns about cleanliness • Food service concerns
Interpersonal problems	• No explanation or guidance given around expected side effects of a medication or treatment • Lack of introductions or understanding of care team names and roles • Not informed of hospital procedures (e.g. meal times, locations of resources) • Not informed of expected course of care while hospitalized • Lack of information provided about post-discharge care and concerns • Poor interpersonal treatment by hospital staff • Lack of comfort in being able to ask questions to doctors and nurses

Research continues to support the notion that patients provide a distinct perspective on quality and safety events that is not captured through staff reports and medical record review. Weissman and colleagues looked at the overlap between adverse events reported by patients and by physician review of medical records and found that only 12% of the events reported were discovered through both mechanisms (Weissman et al. 2008). Friedman et al. also worked from classic definitions of adverse events and medical errors to compare post-discharge patient interviews with chart review and the hospital incident reporting system for events that occurred in an emergency department. None of the adverse events reported by patients appeared in the incident reporting system nor were they discovered by chart review (Friedman et al. 2008). In both studies, patients were likely to report on adverse drug events and pain or analgesia-related issues. A number of other studies over the past decade indicate that patients and family members in a hospital environment can identify adverse events affecting their care that are often overlooked by other surveillance methods (Weingart et al. 2005; Hasegawa et al. 2011).

Quality in Complex Systems

Conversations about ways to improve health care safety frequently turn to error-prevention strategies from other industries such as aviation and nuclear power. These industries have a long history of tackling complex and unpredictable hazards that can have serious consequences to human life and population health. Companies that have learned to maintain a high degree of safety in these domains are often referred to as high-reliability organizations (HROs). HROs are commonly known for their process simplification to remove defects and redundant practices to identify or manage failures (P. J. Pronovost et al. 2006; Carroll & Rudolph 2006). The health care industry has learned to adopt many of these HRO standardization practices, such as increasing use of checklists (Winters et al. 2009; P. Pronovost et al. 2006) and incorporating teach-back/repeat communication to team and patient-provider interactions (Kandula et al. 2011). HROs have pushed forward several system-level frameworks and concepts to understand and address quality from a holistic perspective.

For example, dialogue about safety has shifted over time in understanding agent causes and responsibility. In the past, organizations focused on individual accountability when dealing with safety events. The basis for healthcare liability insurance is a reflection of this view. However, it also represents a focus on what are easily controllable factors in a complex environment. When thinking about the forces behind an adverse event, it is easy to identify individual actions as at least a partial cause for the events that took place. Yet, numerous other parallel system level events do not get the same attention because they appear to be less controllable. When a plane crash occurs, few people blame gravity despite this force being the ultimate reason for why the plane plummeted to the ground. This factor lies on the extreme end of uncontrollable factors. But the aviation industry has accepted for quite some time that latent, unsafe conditions and not necessarily human errors can contribute to accidents occurring. As a result, this industry has implemented a number of strategies to standardize processes and limit the negative impact of complex environmental conditions on safety.

Health care researchers have more recently recognized a systems-based approach that focuses on organization-wide accountability. James Reason, one of the most well-cited researchers in high-reliability systems, argues that (1) errors in complex systems are to be expected and (2) proactive barriers and error management can improve system resilience (Reason 2000). Through his “Swiss-cheese model” for understanding system errors (Figure 1), he describes how a series of gaps in an existing system can align in such a way that an initial error (a “hazard”) can pass through subsequent barriers and lead to an adverse event (“loss”). Holden, Carayon, and colleagues extended this type of systems thinking with their human factors model, Systems Engineering Initiative for

Patient Safety (Holden et al. 2013). The latest version of this model discusses the importance of a person-centered approach to work systems that include organizations, tools & technology, people, tasks, and the internal and external environments where the work takes place. The work system helps to frame a complex series of interactions that produce care events with varying levels of quality and safety. Within this framework, I argue that the patient and family perspective should be evaluated as an additional and complementary proactive barrier to the hazards present in complex health systems.

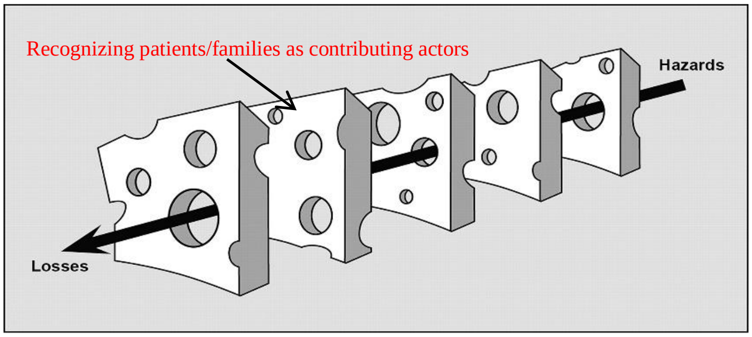

Figure 1: James Reason's Swiss Cheese Model of System Errors.
Each layer of swish cheese in this metaphor represents an actor, process, or other intervention designed to identify and flag an error. This thesis incorporates the model to consider the role of a patient and caregiver as another layer in a system designed to mitigate errors.

Human agents, in this case patients and family caregivers can take proactive roles in anticipating and adapting to potential failures that they observe over the course of a clinical visit (Nemeth et al. 2008). This type of flexibility to adapt to deviations in care reduces the potential for negative consequences from erroneous actions, surprise events, unanticipated variability and interactions in complex systems. In human factors research, resilience refers to how people avoid failures and adapt to changes in high-hazard, complex settings – an apt description of a hospital setting (Cook et al. 2000). In particular, resilience values behaviors which contribute to an entity’s ability to be flexible to new and unexpected demands (Jeffcott et al. 2009). In health care, the research community has placed increasingly attention to this concept in regards to communication before, during, and after clinical handoffs. For example, during handoffs, physicians and nurses will perform a systematic review of information being transferred and engage in cross-checking dialogue to confirm consistency in understanding of recent events and the overall plan of care (Patterson et al. 2004). The clinicians will frequently use anticipatory language such as “If-Then” statements to consider different plausible future possibilities. Structured points of resilience such as handoffs allow HROs to rely on human actors to handle errors that lack standardization.

This framing is equally applicable to the dynamic interactions that occur between patients and providers for medical decision-making and discussing plans of care. Therefore, it is important to understand the various levels of work that involve patients as actors in a clinical care environment. Holden and colleagues posit various levels to evaluate patient work in a care system (Holden et al. 2015). The patient work system includes multi-person communication and coordination processes, human-tool interactions, environment and cultural context, and considerations of person, task, and environmental barriers that can affect patient work. All these important variables should consider the patient and caregiver roles as active agents for affecting care quality and outcomes.

Existing Approaches to Promote Patient Participation in Care Quality

Over the past two decades, several US organizations including the AHRQ, the Joint Commission (JCAHO), the Center for Medicare and Medicaid Services (CMS), and National Patient Safety Foundation (NPSF) have launched campaigns to encourage greater patient involvement in quality and safety. For example, JCAHO and CMS launched Speak Up, a campaign to encourage patients to take a more active role (The Joint Commission 2012a). The primary intent of this initiative was to distribute safety advisories that would inform patients and urge them to become more involved participants with their care team. In the UK, the National Health Service (NHS) developed a series of educational videos known as Participate Inform Notice Known (PINK) (Pinto et al. 2012; Davis, Nick Sevdalis, et al. 2011).

Within the research community, methods for soliciting patient feedback on errors or concerns with their care have focused mostly on post-discharge surveys conducted through in-person interviews (Davis, Nick Sevdalis, et al. 2011; Pinto et al. 2012), telephone follow-up calls (Weissman et al. 2008; Friedman et al. 2008), and mailings distributed within a year of the patient's hospitalization (Davis, Sevdalis, Neale, et al. 2012). Although these methods are easy to implement, the post-discharge surveys are prone to recall and social desirability bias. The surveys do not capture information from individuals that died while hospitalized or before contact from researcher teams. Few researched examples exist of hospital programs that actively survey patient perspectives of undesirable events in a near real-time manner. The most notable example in the grey literature is at Shadyside Medical Center in Pittsburgh. In 2005, the hospital established a protocol known as Condition H that allows patients or family members to directly initiate the equivalent of a rapid response call (Robert Wood Johnson Foundation 2011). For example, if a patient or family member notices a medical change or has some other concern that is not being adequately addressed by the assigned care team, the concerned individual can call the Condition H hotline and trigger a notification to a designated team of physicians, nurses, and patient relations coordinators. Although the overall use of the system was relatively low in the first two years (71 events reported), the hospital found that 41% of patient concerns related to pain management and medication issues. Moreover, based on a 2006 survey, UPMC Shadyside reported that 69 percent of the calls could have led to potentially harmful patient safety incidents (Josie King Foundation 2012).

At a national level, AHRQ has shown interest in the idea of providing a direct mechanism for patients and families to report medical errors. The agency is intending to launch a prototype Consumer Reporting System for Patient Safety (CRSPS) that will serve as a national consumer surveillance system (Clancy & Agency for Healthcare Research and Quality 2012). The prototype development aims to design and test a system for collecting information from patients about health care safety events following standard definitions and the AHRQ Common Formats. The system is based on a series of round table discussions with technical experts from consumer focus groups and patient advocacy organizations, along with interviews with hospital administrator stakeholders (Halpern et al. 2011). Importantly, the report driving this new system recommends a national-level collection system that exists separate from any single medical institution.

Many challenges with these existing approaches remain, however. Studies evaluating promotional materials showed that the majority of patients questioned the efficacy of the promotional materials in reducing errors, and some patients expressed skepticism that their own efforts would have an impact on safety (Davis, Nick Sevdalis, et al. 2011). Additionally, researchers have criticized these efforts for not involving patients in the development process, giving little direction to providers for how to include patients in safety-related conversations, and providing little practical instructions for patients to take action (Entwistle et al. 2005). The intent behind these initiatives is admirable, but the current campaigns do not appear to address the challenges patients face in engaging their providers about safety concerns.

Patient-centered Co-operative Work in the Hospital

In a complex system like a hospital environment, many of the people involved—patients, staff, family members, clinicians—perform work to organize care activities and manage unexpected changes in the patient's health or overall clinical care environment. Some of this work is visible and recognized through dedicated time and documentation. For example, a nurse will conduct a hand-off session with their incoming nurse colleague that typically involves routine, structured interactions with related documentation captured in an electronic medical record. Other work is often less visible. For example, that same nurse on an ad hoc basis might wander through a patient ward to visually evaluate the patients or inspect monitoring equipment. Similarly, a patient might spend time on mobility exercises to support their progress towards being able to leave the hospital and that work is visible during dedicated PT sessions, but less visible when done on their own over the course of the day. Star and Strauss label less visible work as **background work**: a type of work where "workers themselves are quite visible, yet the work they perform is invisible or relegated to a background of expectation" (Star & Strauss 1999). They define other important activities such as **articulation work** that serves to get things 'back on track' after unanticipated events that can frequently occur in the hospital (Star & Strauss 1999).

Background and articulation work provide a useful framing of activities that can be influential in how patients and families interact with their care. For example, Oudshoorn conducted research that suggested patient adoption and use of a cardiac telemonitoring device is heavily influenced by the invisible work performed by home-care nurses and physicians. The nurses in this study engaged in a lot of "inclusion work" to reassure and motivate patients that they could be independent users of this new technology (Oudshoorn 2008). There has been considerable ethnographic research to document and understand the invisible work performed by clinicians, but less so patients. Unruh and Pratt have identified extensive work performed by patients in ambulatory and home environments and found that despite the work being driven by clinical care concerns, such patient work is rarely acknowledged or supported by existing information systems and organizational processes (Unruh & Pratt 2008).

Another component to understand the background and coordination work that frequently takes place in a clinic environment are the tools and instruments used for communication with patients. The predominant non-verbal tool used to communicate with patients in a hospital is the whiteboard. There have been experiments to use whiteboards to communicate with patients about their stay as well as preliminary efforts to provide administration and test activity information in an emergency department environment (Wilcox et al. 2010; Sehgal et al. 2010). Marilyn Tan and colleagues found that whiteboards improved patient awareness of their care team and the goals for their care (Tan et al. 2013). Yet, many research questions remain of how best to convey care information of the course of a hospital stay and considerable difficulty in keeping the information up-to-date via this visual display tool.

A systematic review from Prey, et al. further highlights the value of technology to support patient engagement in an inpatient setting, but also acknowledges that this space is still in its infancy (Prey, Woollen, et al. 2014). There is growing use of digital tools as tablets and information resources such as patient portals to help patients and families access and capture information on demand. Greysen and colleagues have launched a study to further explore how increased access to electronic health records via tablet computers can influence patient engagement in the hospital (Ludwin & Greysen 2015). They found that patient reviewed medication information and leveraged a provider messaging system frequently when having access to a tablet-based tool. Patient-facing technologies in the inpatient environment can improve patient awareness and management of information about their care activities.

Patient Behaviors that Support Care Quality and Safety

Few national studies exist that explore issues as reported directly by patients. In 2004, Kaiser polled 2,012 adults to assess the public's perception around health care quality and how they use information for health care-related decision making. The survey results indicated that one in three Americans (34%) experienced or had a family member that experienced a preventable medical error. Among those individuals, 21% said the error caused "serious health consequences" such as death, long-term disability, or severe pain (Kaiser Family Foundation et al. 2004). These findings suggest that the public have significant concerns about the safety and quality of care in the US. The most widespread, standardized approach to measuring patient experiences is the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) Survey that the Centers for Medicare & Medicaid Services (CMS) has required of all hospitals since 2006. This post discharge survey captures patient responses to a set of Likert questions on nurse/doctor communication, responsiveness to staff of patient needs and pain management, and the cleanliness and quietness of the hospital (Centers for Medicare & Medicaid Services (CMS) 2013). Researchers' analysis of the survey findings suggests that patient satisfaction regarding their overall experience has some correlation with quality and outcomes (Jha et al. 2008; Manary et al. 2013). Yet the survey does not explicitly explore patient perceptions on safety, medical errors, and atypical events. Instead, it takes a hospital-centric view on capturing information on the overall pattern of care. Critically, a post-discharge survey like this obviously fails to capture the perceptions of patients that died as a result of an adverse event.

Various researchers have evaluated the ways in which to solicit patient and caregiver contributions to care quality. Based on a systematic review, Peat and colleagues developed a framework of analysis that defined three mechanisms through which patients could be involved: informing the management plan to ensure appropriate treatment, monitoring the treatment provided to ensure the care is given correctly and as planned, and finally informing systems improvement by providing feedback about care quality and being involved in care governance (Peat et al. 2010). Importantly, the review uses these “routes” for patient contribution to appraise interventions to promote patient engagement. Peat suggests that based on the particular route, an appraisal should: (1) evaluate the conditions necessary for patients to adopt behaviors and make an effective contribution, (2) question the support provided by the intervention to ensure that the necessary condition can be fulfilled, and (3) consider the potential negative effects of the intervention. Ward identified 13 papers published through August 2010 that sought to identify what patients can report, the settings that they participate in patient safety, and methods used to engage them (Ward & Armitage 2012). All of the studies reviewed did not explore spontaneous reporting from patients but instead actively solicited concerns through structured interviews or surveys. The authors also argued that there should be further research into how patient reporting can fit into existing governance and quality improvement efforts and a need to assess the impact of the recall period on the accuracy of information collected from patients.

Challenges with Patient Participation in Quality Improvement

How to systematically identify, report, and capture deviations in care quality is a significant challenge. Problems with recall, clinical knowledge, or other factors may bias or limit a patients’ ability to accurately report errors and related concerns. Patients are expectedly less likely to notice technical deficiencies in care and appropriateness of medical decisions and tests (Agoritsas et al. 2005).

In a review from Schwappach, et al., the authors focused on the theoretical underpinnings of patient engagement through an evaluation of 21 qualitative and quantitative studies published between 1995 and 2008. The articles that met the inclusion criteria explored patient attitudes and behaviors regarding patient safety and the impact of large educational campaigns on patient participation (Schwappach 2010). In their review, the authors framed their analysis using the Theory of Planned Behavior (Ajzen 1991), arguing that positive attitudes towards engagement predict a higher probability of actual participation in safety-related behavior. Based on this approach, the authors identified a gap between patient intentions and actual behavior depending on the nature of the actions (e.g. asking factual vs. challenging questions) and who the patient is interacting with (nurse vs. physician). In addition, higher self-efficacy, belief that a type of medical error is preventable, and patient perceptions that a particular behavior is effective significantly increased the likelihood that patients would engage in the behavior. Davis et al. put forth a conceptual framework of factors that include patient-related, illness-related, health care professional-related, health care setting-related, and task-related influences on patient engagement (Davis et al. 2007). The authors argue for greater research in assessing the impact, importance, and interaction among these factors in determining patient involvement. Doherty et al., conducted a similar analysis through a systematic review of 63 papers from 1999 to 2011 that evaluated relational and social factors affecting whether patients are willing and able to take actions to reduce the risk of medical error (Doherty & Stavropoulou 2012). Interestingly, the authors did not find an influence from factors relating to health literacy and health inequalities such as age, gender, and education.

Many of the reviews that seek to establish a framework of influences on patient participation in care quality behaviors identify social factors as a major category of influence. Problems with communication as a result of an interpersonal problem can have cascading effects on how patients and family members interact with their care team for the given episode of care and subsequent care. Although the exact mechanisms are still unclear, many of the patient-perceived issues with interpersonal relationships and the care environment surveyed by HCAHPS are associated with adverse health outcomes (Manary et al. 2013). Patients may have difficulties communicating their concerns due to a power imbalance in the traditional patient-provider relationship that typically favors the provider. Providers typically have greater expertise, decision-authority, and experience that establishes an “authority gradient” or power hierarchy, with physicians at the top. The concept of an authority gradient originates from the aviation industry where breakdowns in communication occurred due to perceptions of expertise and experience that deterred airline staff from challenging the decisions of the senior pilot in command (Cosby & Croskerry 2004). Consequently, these situations can lead to mishaps and accidents when team members fail to challenge an authority figure. With the publication of *To Err is* Human, the medical community started to acknowledge the existence of authority gradients between providers with different levels of experience (e.g. a resident communicating with an attending physician) and different roles (physicians versus nurses) (Kohn et al. 1999). However, this explicit concept has received less attention with patient-provider communication relating asking questions and raising concerns, despite widespread understanding of the power differential between the two stakeholders. Yet patients typically lack expert medical domain knowledge, are often hindered by their illness, and therefore encounter a steep authority gradient when communicating with their care team.

Due to the existence of this power gradient, the patient-provider relationship is an oft-cited influence on patient willingness to be active participants in their care (Alexander et al. 2012). Health care provider encouragement is instrumental in allaying patient concerns about negative repercussions to the staff or on their own care when they raise a concern (Doherty & Stavropoulou 2012; Davis, N Sevdalis, et al. 2011). Therefore physician, nurse, and other provider perspectives on patient involvement in care quality is crucial. A recent cross-sectional survey of physicians and nurses in a UK hospital showed an overall positive attitude towards patient involvement in safety (Davis, Sevdalis & Vincent 2012). Interestingly, when asked what types of safety-related behaviors they would engage in as a patient, the nurses and physicians responding to the survey were less willing to engage in challenging behaviors despite expressing support for them earlier in the survey.

Identifying the best mechanism through which patients' voices are captured is a challenge as well. The success of a reporting system depends on a number of factors including: (1) the level of difficulty for stakeholders to provide a report; (2) the feedback and response to demonstrate that a reporter's participation is both valued and worthwhile; (3) the confidentiality of the system and policies that mitigate fears of retribution for reporting concerns; (4) the quality of the information captured to support effective analysis, interpretation, and response (Johnson 2002). In regards to the latter point, researchers have observed a higher rate of reported incidents among studies with open-ended questionnaires versus structured reporting data models (King et al. 2010). In their review, King and colleagues argue that future systems need to balance the efficiency and reliability benefits of structured reporting with open-ended narratives that allow for patients to explain their experiences in their own words. This goal aligns with moving away from the strict definitions of an adverse event or medical error that do not adequately capture all of the problems that from the patient's perspective. The previously described undesirable events may be a more appropriate way to understand and respond to issues experienced during a hospitalization. Yet a flexible definition creates an inherent challenge with how to balance the strengths of structured data for system-level analytics versus the quality and ease of reporting with unstructured data.

On a generalized basis, patients, providers, and the public are supportive of active patient participation in error communication and prevention. The literature reviews also demonstrate that patients are able to be effective contributors improving patient safety. Open questions remain regarding the impact of and relationship among patient-, provider-, task-, and system-related factors on actual patient involvement. However, research approaches should also consider the limitations and possible negative consequences of different methods used to solicit patient reports. A sustained reporting process that includes patient concerns requires further evaluation of the tradeoffs between efficiency through standardized terminology with the sensitivity of open-ended capture of patient concerns.

Conclusion

Given the complexity of modern health care delivery, a multitude of reasons lead to the incidence of undesirable and adverse events. However, analyses of adverse events show that occurrences are dominated by communication failures and human factors, such as issues with staffing, skills, and fatigue (The Joint Commission 2012b, Leonard et al. 2004). There is widespread agreement that one component of the solution towards better quality care is enhancing patient engagement. The means to accomplish this goal is challenging, particularly in an inpatient setting. The research to-date suggests information gaps and interpersonal challenges are notable barriers to effective engagement. As noted by Prey and others, digital health has a potential role to address these barriers, but our understanding of patient-focused digital tools is still in its infancy in the hospital setting (Prey, Woollen, et al. 2014). We have a research opportunity in the hospital setting to inform the design of information technologies that empower patients and caregivers as participants in care delivery. To motivate the research in this dissertation, I argue that we need a greater understanding of the information needs and technology opportunities that can enable patients and caregivers to participate in the quality and safety of their care.

Chapter 3. Engineering for reliability in at-home chronic disease management

Abstract

Individuals with chronic conditions face challenges with maintaining lifelong adherence to self-management activities. Although reminders can help support the cognitive demands of managing daily and future health tasks, we understand little of how they fit into people's daily lives. Utilizing a maximum variation sampling method, we interviewed and compared the experiences of 20 older adults with diabetes and 19 mothers of children with asthma to understand reminder use for at-home chronic disease management. Based on our participants' experiences, we contend that many self-management failures should be viewed as systems failures, rather than individual failures and non-compliance. Furthermore, we identify key principles from reliability engineering that both explain current behavior and suggest strategies to improve patient reminder systems.

Introduction

People with chronic conditions, or those who care for others with chronic conditions, are expected to manage complex medical regimens. For many, the demands are monthly, weekly, or even daily. For example, patients with well-controlled hypertension, diabetes, and hyperlipidemia must perform more than 3,000 health-management activities a year to be adherent to recommended self-care guidelines(Steiner 2012). These activities include making changes to their diet, requesting medication refills, adhering to a medication regimen, monitoring critical health indicators (e.g. blood pressure), getting lab tests done, attending appointments, getting annual screenings and immunizations, and managing symptoms(Barlow et al. 2002). As a result of these challenges, many patients are not able to meet their goals for daily self-care activities successfully. In fact, half of individuals diagnosed with a chronic condition—such as asthma, hypertension, and diabetes—do not adequately adhere to their prescribed medication regimens(Sabaté 2003) and miss as many as 21-34% of their scheduled appointments(Finkelstein et al. 2013). These failures in chronic disease management can lead to adverse patient outcomes, increased care costs, and create challenges to the patient-provider relationship(Junod Perron et al. 2013; Schectman et al. 2008; Hussain-Gambles et al. 2004).

To support patients managing a chronic disease, health care systems increasingly send reminders for appointments and chronic and preventive care activities. Successful reminder systems can alert people to scheduled medical visits and screenings, improve adherence, and enhance communication between patients and their provider team (Vervloet et al. 2012; Szilagyi et al. 2000). Moreover, many patients already utilize personal reminder systems to remember everyday tasks. The following scenarios help illustrate how people incorporate explicit and implicit reminders into their daily routines:

Bob is a 60-year-old diabetic. His typical morning routine is to wake up, walk into his bathroom to take his medication that he keeps out on the counter, then have breakfast. As he walks into the kitchen, he sees his blood glucose meter sitting on the kitchen table and remembers that he needs to check and record his blood sugar. He then starts up his coffee machine, and glances at his wall calendar to see what is happening that week. While eating breakfast, he receives a call from his clinic reminding him about an appointment the next day. Later on, his wife, who is out of town, calls him to check-in. Realizing he forgot to check his blood sugar while making coffee, he walks back to the kitchen to get his glucose meter.

Cindy is a 34-year-old mother of a 9-year old child with persistent asthma. When she wakes up, she always glances at her smartphone's calendar to see her agenda for the day. She also takes a *minute to enter in a to-do list. Among other things, her son needs his allergy shot at the clinic and she needs to send off her sister's birthday package. Before heading out, Cindy notices and grabs her son's inhaler by the door to make sure it gets into his backpack for school that day. In the rush to get her son to school from the appointment, she forgets to stop by the post office. But on her way home later that day, Cindy passes a mailbox that reminds her to send off the package and she makes a turn to the nearest post office.*

These vignettes, based on activities and experiences described by our study participants, demonstrate how people rely on a variety of tools and subtle triggers to help remember to perform future actions. In the first scenario, Bob relies mostly on environmental cues that are part of his morning routine. However, his wife will frequently check-in with him, which serves as a backup in case he does forget to do something. In contrast, Cindy makes heavy use of her mobile phone to track what she needs to do for the day. She also makes deliberate use of visual cues like placing the inhaler by the door to make sure her son takes his inhaler. Yet, in both situations, the two people still experienced minor failures in achieving their intended tasks.

In this paper, we examine how individuals responsible for managing their own or others' chronic conditions integrate reminders and notification systems into their daily routines. By understanding these diverse individual experiences, we hope to gain insight into the optimal design characteristics for future patient reminder and support systems. We further contend that many self-care management failures may be accurately viewed as system failures, as opposed to failures of individuals (Steiner 2012). Our work highlights the complex ecosystem of interactions, tasks, and reminders between the clinic and home environment for a person managing a chronic illness. Finally, we apply key principles from reliability engineering to help explain participants' self-management behavior and offer suggestions for strategies to further improve patient reminder systems in the future.

Background and Related Work

This work draws on several divergent literatures: prospective memory as a basis for task planning and recall, clinical and personal reminder systems, and systems reliability engineering to frame patient self-care tasks and failures.

Prospective Memory as a Basis for Task Planning and Recall

Remembering to perform all the tasks expected for proper self-management requires effective recall of what has already happened and a continuous scan of what needs to happen in the near future. The process of remembering is frequently framed as either of two types: (1) retrospective memory that is concerned with the retrieval of past memories of people, events, and words, or (2) prospective memory that is concerned with remembering to perform a planned action or intention in the future (Kliegel et al. 2008). The latter process includes short-term intentions—such as daily intake of a medication—as well as delayed actions—such as going to an annual checkup appointment—that could occur weeks or months in the future. Outlined in Figure 2, the process for realizing a delayed intention begins with encoding the future action, retaining the intention, and then retrieving the intention at the appropriate time to complete the action. This can occur through either an explicit reminder system or through spontaneous retrieval. Actions such as remembering to take medication at breakfast often rely on spontaneous retrieval of the intention that is triggered through environmental and physiological cues linked to daily routines. However, intermittent actions further out in time often involve a more explicit signaling cue—such as creating an alarm on a phone—to retrieve and execute the action at the right time (Daniel & Einstein 2000). In the case of an individual managing a chronic condition, the capacity to reliably shape and direct future behavior is critical to successfully managing the disease. The role of both explicit and implicit reminder systems within this memory process is the focus of this paper.

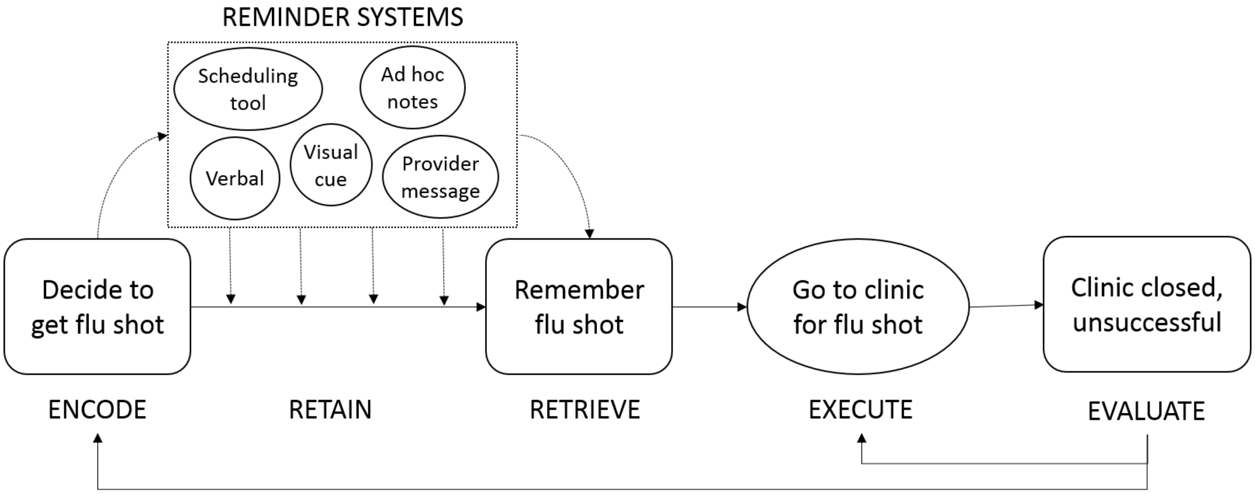

Figure 2: Model for establishing and realizing delayed intentions.
Adapted from Ellis, 1996 (Ellis 1996). When a person decides to get an annual flu shot (encoding), they need to maintain that intention over a delayed period (retention). At some point the person receives a signal to remember the flu shot (retrieval) and then goes to the clinic (execution). If successful (evaluation), the task is complete. Otherwise, the person attempts the activity again or re-plans the intention. In this model reminder systems provide a way for individuals to externalize the retention process as well as establish a way to cue retrieval of the delayed intention.

Clinic and Personal Reminder Systems to Support Recall

Reminders can be useful mechanisms to support the execution of delayed intentions described by prospective memory. James Reason describes the value of reminders in mitigating errors of omission that can lead to failures in planning and intention formation (encoding), intention storage (retention), action execution, and monitoring (Reason 2002). Research into reminders for health has typically evaluated clinic use of reminder systems. For example, health care organizations use postal mail or telephone calls to help prevent missed appointments and thereby reduce costs associated with disruptions to clinic workflow (Hashim et al. 2001). More recent articles have started to explore mobile phone-based strategies, such as text messaging and other types of electronic reminders (Vervloet et al. 2012; Gurol-Urganci et al. 2013). Vervloet's review of electronic reminder systems initiated by providers showed short-term effectiveness of these systems in supporting medication adherence but suggested more investigation of reminder content and timing (Vervloet et al. 2012). In a cross-sectional survey of patient preferences, Finkelstein et al. found that personalizing the delivery mechanism improved patients' responsiveness to reminders (Finkelstein et al. 2013). The research into clinic-initiated reminder systems indicates that they support improvements in patient adherence, are effective across diverse technologies, and are more likely to be successful through the personalization of message content based on patient preferences.

Outside of a clinic setting, individuals leverage a variety of tools for personal reminder systems. Grimes and Brush interviewed working parents and identified a number of challenges that they experienced in coordinating and interacting across their personal and professional schedules (Grimes & Brush 2008). In a separate study, Brush highlighted the value of triggers in the workplace that are created from a mixture of explicit self-reminder systems, tacit "breadcrumbs" from recent activities, or based solely on memory to recall specific tasks (Brush et al. 2007). However, there has been limited research into how these types of personal systems support patients' multiple chronic and preventive health care needs. For example, a review by Kapur et al. focused on the use of memory aids for neurological rehabilitation of individuals with severe memory impairments due to injury or a disorder (Kapur et al. 2004). While reminder systems are prevalent in a variety of contexts, there is an opportunity to explore how personal systems are used for chronic disease management, and importantly, how these tools integrate with clinic reminder activities and the home environment.

Systems Reliability Engineering to Understand Errors and Failures

Within this paper, we frame chronic disease management as a complex system of technical, organizational, economic, environmental, and human components that interact for a common purpose—the maintenance and coordination of an individual's health. This type of system highlights a growing trend in health care of utilizing human factors and ergonomics (HFE) concepts for designing patient-centered care. The National Research Council conducted a HFE evaluation of home health care that stressed systems engineering for designing technology interventions that facilitate interactions between the complex elements and tasks in the home environment (National Research Council 2011). Furthermore, Holden, Carayon, and colleagues introduced a popular framework for HFE thinking and reliability in health care with the Systems Engineering Initiative for Patient Safety (SEIPS) model (Holden et al. 2013). The latest version of this model discusses the importance of a person-centered approach to work systems that include organizations, tools & technology, people, tasks, and the internal and external environments where the work takes place. In the context of reminders, the activity of remembering and executing self-management tasks at home involves the interplay between the patient, clinic, home environment, and devices and tools used to coordinate and execute care activities.

Building on HFE concepts, we are concerned with the reliability of the system to support individuals' ability to use reminders to perform their care coordination tasks successfully. The principles of reliability science and engineering help to describe design strategies for mitigating and responding to failures in complex systems. Reliability refers to the probability that a system will meet its minimum performance requirements, without failure, for a given period of time (Zio 2009). Three activities in particular—engineered redundancy, diverse and independent design, and regular monitoring—can enhance the reliability of a system (International Atomic Energy Agency 2009).

Redundancy describes systems where duplicate processes or components are used to increase availability in case of a single point of failure. For example, many cars are designed with twin hydraulic brake circuits to ensure that the vehicle can still stop if one circuit fails. However, redundant systems do not increase reliability in situations where they are vulnerable to the same defect—referred to as common cause failure. To mitigate this vulnerability, engineers incorporate **diversity** into their design so that a system uses two or more different, independent techniques or processes for the same functional purpose (Littlewood & Strigini 2004). For example, when backing up a car, a driver can visually assess their environment with the car mirrors as well as listen to the beeping sounds produced by proximity sensors built into many modern vehicles. Finally, reliable systems can use **monitoring** to actively audit the system and mitigate the impact of a breakdown through early detection of failures. Modern automotive anti-lock systems actively monitor wheel deceleration and distance from other objects to adjust the brake speed and prevent uncontrolled skidding. Although researchers have used reliability engineering to frame inpatient safety (Luria et al. 2006), none have used this framework to examine patient adherence to chronic disease management activities.

Study Overview

We conducted a series of semi-structured, in-depth interviews with patients diagnosed with Type 2 diabetes (n = 20) and mothers of children receiving treatment for asthma (n = 19). The choice of the two populations maximized the variation in the perspectives and experiences of individuals managing a chronic disease. Our sampling of parents of children with asthma focused on mothers, rather than fathers, since women in this age group also have a large number of prevention and maintenance activities and are typically the primary health information managers within the household (Moen & Brennan 2005). The semi-structured interviews focused on reminder tools and systems that patients used for maintenance and care coordination activities such as appointment scheduling, medication adherence, and communication with their providers outside of the clinic. In addition to the interviews, the authors (LK, JE) toured the participants' homes in order to directly observe the systems and tools used in this context. This study was reviewed and approved by our institution's human subjects review board.

Sampling

We used purposeful sampling to identify participants that were representative of the general population in the Northwest United States based on gender, ethnicity, technology use (with recorded use of a patient portal as a proxy) and education. All participants were enrollees of an integrated healthcare delivery system that covers more than 300,000 members. Based on the sampling criteria, we contacted 586 individuals identified as either persons with diabetes or parents of a child with asthma. Of these, 402 could not be reached, refused to participate, or were lost to follow-up, and 118 were deemed ineligible based on follow-up screening. Of the remaining 66, we enrolled 39 participants, aged 27 to 88 (median=61). The diabetes cohort was older on average than the mothers of children with asthma and were less likely to use technology such as a patient portal for their health. Other details on our participant population are in Table 2. Each participant received a gratuity of $50 for completing the interview.

Table 2: Description of study participants.

	Diabetes		Asthma		Combined	
	N	%	N	%	N	%
Participants	20	100	19	100	39	100
Female	10	50	19	100	29	74
Race/Ethnicity						
White	10	50	9	47	19	49
Black	6	30	6	32	12	31
Asian	2	10	1	5	3	8
Hispanic	1	5	1	5	2	5
Mixed/Other	1	5	2	11	3	8
Technology Use						
Patient Portal User	13	65	18	95	31	79
Education						
High School or Less	12	60	5	26	17	44
More than High School	8	40	15	79	23	59

Analysis

The interviews lasted from 40 to 90 minutes. The audio recordings from each interview were transcribed and reviewed using Atlas.ti 7 and identified as “A##” and “D##” for the asthma and diabetes cohorts, respectively. To maintain confidentiality, we removed all information that could identify the patient from the transcripts. During the data collection process, the authors periodically reviewed transcripts to identify emerging themes and to assess topic saturation. Using an open coding technique and an affinity diagramming process (Martin & Hanington 2012), the authors clustered related terms and organized preliminary themes into higher-level categories. A subset of the authors then iterated on the codes through several rounds of transcript review to solidify the coding schema used for this article. One author used this schema to code each interview using Atlas.ti.

Results

Through this content analysis, we focused on two areas. First, we highlighted the reasons for failures in self-management routines as identified by participants during the interviews. Second, we characterized three strategies used by participants to improve the reliability of their reminder systems and overall management of their health. These strategies are summarized in Table 3.

Sources of Reminder Errors and Task Failures

Throughout the study, the participants provided examples of breakdowns in their self-management routines that included failures in memory, missed environmental signals, and failures in capturing tasks within a reminder system.

Memory failures were a common reason for failure as well as a rationale for using explicit reminder systems. Based on the prospective memory process in Figure 2, these types of errors can be described as retention and retrieval failures. For example, participants described how easy it was to forget because of their hectic schedules. A07 expresses the challenges representative of many busy mothers. *"If I don't have anything immediately reminding me of it, it's out of my head because I have so much going on. We have kids to pick up, drop off. We have cleaning house, I've got selling things, I've got to meet people." [A07]*. D02 and many elderly participants with diabetes described concerns with growing memory deficits as they aged. They expressed interest in updating their reminder systems as their memory started to become less reliable. Despite this interest, participants often relied on informal, tacit signals in the environment. For example, it was only after scheduling a separate appointment for herself that A08 remembered her child's annual well-child visit was overdue. Similarly, other participants remembered to go in for screenings and tests only after scheduling a visit for a separate health need. Reliance on environmental cues was particularly common for medication management. One participant described managing her child's inhaler by paying attention to when "*the propellant in it doesn't expel quite as well and so he doesn't feel like he's getting or receiving the medication as well and so he'll tell us that he needs a new one" [A11]*. Without having an explicit visual cue or timely notification from her child, she relies on trying to remember how much time has passed since the last refill. Tacit signals are dependent on the environmental cue occurring at the right time and place. If the person misses this signal, they can experience a retrieval failure.

In addition to missing cues from informal reminders, participants also described breakdowns with their reminder tools. In some situations the reminder was never captured and therefore never signaled the appropriate behavior. This type of encoding failure often occurs because individuals get distracted from capturing the task or do not have access to their reminder tool when they need it. One participant described how, "*I'll make an appointment and then start doing something else so I didn't write it down and just hope that I'll remember it." [A10]*. In this situation, A10 missed an appointment for her baby because the event did not get recorded into her phone and she did not get a reminder call. A14 used a system where she printed out calendars and captured appointments, bills, and other items. However, when she misplaced it, *"I was freaking out, because I had actually taken the time to write everything down—they had a trove of information on it. I couldn't find it and then I was like how the heck am I going to do this if I don't have a backup?" [A14]*. Her situation mirrored many of the participants where, because of a busy schedule, being away from home, or not having access to their normal reminder tool, they failed to set up or retrieve the cue from their system to perform the action in the future. Despite having systems that they often described as being fairly reliable, participants still experienced situations in which some aspect of their reminder process fell apart.

Table 3: Summary of reliability system design strategies used by participants to enhance self-care reminders.

Reliability Strategy	**Benefits**	**Drawbacks**
Redundancy: *Repeated reminders, back-up systems*	• Back-ups ensure availability of reminder for retrieval at the right time. • Repeated alerts enhance retention.	• Too many back-up systems can create unwanted noise and increase chance of being ignored.
Diversity: *Independent systems, different communication modes*	• Separate clinic and personal systems reduces reliance on single operator. • Multiple modalities improves availability of reminder for retrieval.	• Additional systems increase complexity and can create new opportunities for failure.
Monitoring: *Validating reminder capture, double-checking for errors*	• Improves retention through repeated exposure. • Increases likelihood of catching errors in the reminder system.	• Additional work required of system operators • Challenges with maintaining this behavior routinely.

Strategies for Redundancy in Reminder Systems

To compensate for these types of memory and organizational errors, participants employed a number of strategies to improve the reliability of remembering certain tasks for their care management. For example, participants integrated duplicative or redundant reminder systems in their homes to mitigate the chance that one reminder system might fail. In many cases, having redundancy was simply a backup. D04 used the calendar on her computer to manage most of her reminders. However, she purchased a smartphone because she recently got a virus on her computer and was concerned about its reliability in the future. Other individuals in the study described how having their spouse or children aware of their health management tasks served as a useful backup. They would regularly discuss upcoming events with the family member or ask them to check-in to make sure the participant took their medication. Even though it was rarely necessary, *“they're there if we do need them” [D08]*.

Participants expressed that having multiple, redundant systems helped to ensure that reminders get encoded. D02 maintained three calendars so that the intended task was captured regardless of where she was in the home. An added value of having multiple systems was that it helped to retain what she need to do. *“It’s like repetition. If you say something to me and say the same thing several times, it rings a bell and I remember it. I think that’s what the calendar does.” [D02]*. This system served as both a way to deal with memory deficits as well as ensure that upcoming events are always captured. A09 was worried that her husband would forget to pick up the kids and so “*I told him the night before, I told him the morning of, I sent him a text from work, I called him to make sure - don't forget.” [A09]*. While that many reminders were likely unnecessary, it reassured the participant and increased her spouse’s awareness.

Although redundant systems have advantages, they can be a burden as well. Providers are typically very proactive about letting a patient know of an upcoming appointment to reduce the impact of a missed appointment on their clinic workflow. Some participants expressed an interest in streamlining their different reminder systems—from both their providers as well as their personal reminder tools—to remove duplicative work and unnecessary reminders.

"My son, his dentist office annoys the heck out of me because they send reminders two months in advance and then send another one a month in advance and at that time they want you to click confirm on the appointment and then after you confirm it, they send another one a week in advance and then call you. It's overkill." [A09]

While repeated reminders increases the chance that the patient is aware of the appointment or task, it also creates more noise. The participants described many redundant reminders as unhelpful in situations where they already were aware of the appointment or task or it was not applicable to their needs. If they felt that it was an unnecessary reminder, they would simply ignore it. This situation is analogous to the alert fatigue that health care providers face with poorly designed EMR and other practice management systems.

Strategies for Diversity in Reminder Systems

The individuals in this study not only performed redundant work as a protection against failures, but also used a diverse set of reminder systems (Figure 3). Diversity provides greater protection against system failures that can affect even redundant systems. For example, a clinic that sends multiple appointment reminder notices in the mail will fail if the patient's address is incorrect. A phone that runs out of power will not be able to receive a text message about taking a medication.

Figure 3: Sample of personal reminder systems used by study participants.
From left to right: a whiteboard-style calendar; a sticky note wrapped around the strap of a handbag; pill bottles placed upside down to indicate they have been taken for the day.

Throughout the interviews, the study participants described an array of modalities used for communication and reminders about upcoming tasks.

All of the study participants emphasized the value of traditional reminders initiated by the provider such as paper mail, phone calls, and secure messaging within a patient portal. However, participants still used a number of additional, personal reminder systems that ranged from technology-centric approaches—such as a mobile phone—to informal mechanisms such as the placement of a pillbox on the kitchen table. A06 would get multiple text messages and phone calls from her dentist leading up to an appointment, but would still enter it into her phone right away. The major tenet of the diversity principle is to ensure independence in redundant systems and subsystems. Thus, by incorporating reminders from clinics as well as their own systems, patients add a layer of reliability—they are able to rely on the provider messages if their personal system fails or rely on their own system if they do not receive a reminder from their clinic. D01 described an incident where she had a scheduled phone consult with her doctor. She recorded the appointment in her personal planner. However, the clinic did not record the phone call information correctly, and the physician didn't call. D01 ended up having to call and remind the clinic about her phone appointment.

During the interviews, participants also explained how the mode of communication can have a meaningful impact. *"The phone call I think it's an accountability thing for me, if I actually physically speak to a person, it's easier for me to go okay, I need to write it down and remember it." [A03]*. Synchronous communication modalities, particularly where the patient is interacting with a health professional, make it difficult to ignore the reminder and ensure that the reminder reaches its intended audience. Conversely, other participants discussed how it was easy to overlook or disregard asynchronous, electronic messages like emails because they get overloaded with too many messages in that format. Paper notifications were often valued because they are more tangible and visible around the home. *"Well again, because I don't get a lot of paper notifications, it feels serious and this should be done." [A01]*

Diversity can enhance reliability, but it can also create a chaotic and complex experience as the patient tries to integrate multiple systems. Several of the participants, for example, owned multiple computing devices that each had a different, incompatible operating system. This creates barriers in syncing activities across the platforms and in some situations encouraged participants to rely on a paper method instead. Additionally, participants that received care from multiple physicians described challenges with getting phone calls from some clinics and paper mail or electronic notifications from others. The diversity of communication approaches made it challenging to reliably integrate the reminders into their personal systems.

Strategies for Monitoring Reminder Systems

Study participants incorporated a habit of active monitoring of their reminder systems as an additional method for addressing reminder failures. Monitoring provided a way to identify errors, validate their reminder systems, and involve their friends and family members in supporting self-management. First, routine monitoring helps to identify when failures in self-management occurred.

"I have to be more conscious about did I take my pills…Did I do that? Sometimes I'll actually get up and look to see whether I took my pills. It's kind of like turning your headlights off on your car, yeah, I took my pills but when I stop and think about it, I got to go check because I don't remember doing it." [D20]

Even if a participant forgets to do something like take a medication, the process of monitoring can lead the person to recognize the error and then be in a position to make changes for the future. Although a clinic can notify a patient when they miss an appointment or test, no feedback process informs patients when they forget activities at home. Having a system in place for monitoring can be helpful to evaluate one's behavior.

Second, active monitoring serves as a way of double-checking the reminder system and ensuring the right content is captured. The added benefit is that this helped participants retain what they needed to do in the future. Participants described deliberate efforts to consistently review and scan for future activities. *"I try to check the next couple days ahead, like I'm thinking today plus two or something so I'm aware what's coming." [A09]*. This participant also started involving her son this process by setting up a calendar in his room so he could cross off activities as they occurred. *"If I get an appointment, then I write it down...I go in [the patient website], because it shows upcoming appointments so then I'll print off the deal and go in there and check my calendar, so it's a backup type, so I got a system, my checks and balances." [D05]*. Redundant, diverse reminder systems are helpful in supporting this kind of auditing behavior by helping participants compare the content of a reminder from multiple sources.

Third, participants often shared the responsibility of monitoring activities across family members to help reduce the workload. This demonstrated a distributed process for auditing reminder systems and ensuring completion of self-care behaviors. Informal dialogue between spouses or between parent and child appeared to be a subtle but valuable mechanism for reviewing and validating upcoming appointments, medications, and tasks on a regular basis. A01 spoke about how she had transitioned from administering her child's inhaler directly to watching him do it himself. While this created other challenges around knowing if he took the inhaler correctly, A01 experience exemplified a transition in self-care responsibility common to many of the mothers of children with asthma.

Active monitoring does require additional work by participants and may be onerous when considering the activities already required for chronic disease management. Moreover, participants mentioned difficulties with making sure this type of monitoring is routine. A wall calendar with appointments listed is only useful as a reminder of upcoming events if the target audience makes the effort to review and validate the content. One participant assumed she had the correct information for an appointment on her wall calendar, but realized she had written the appointment on the wrong week after her husband walked by the calendar and pointed it out [D08]. Wall calendars contrast with systems like email and text messaging that will push information to the target based on a predefined event. However, sometimes these push systems actually discourage any active monitoring of a reminder system. *"I guess the hope is that it'll perform how I've asked it to, or that I've remembered to ask it to perform how I want it to." [A08]*. Another participant described how he messed up an appointment twice because he did not look back at his email about the appointment and his did not have his smartphone set properly to alert him [D16]. Becoming too dependent on the reminder system's capacity to create notifications can create a new avenue for failure.

Discussion

Forgetfulness, confusion, external distractors, fatigue and even a person's health condition can all lead to failures in self-management and perception of non-adherence. These types of errors, referred to as slips in human factors research, describe instances where an individual's intentions get waylaid en-route (Norman 2002). Although slips are often small failures, they are particularly relevant to breakdowns in the automatic, routine behavior that is at the heart of chronic disease management. Solely relying on memory or informal environmental cues may be adequate for a period of time, but if an individual does not retrieve the prospective action accurately or at the right time, no backup will ensure the activity happens. We observed participants adopting a variety of strategies—such as redundancy, diversity, and active monitoring behaviors—to improve the reliability of managing self-care responsibilities. Incorporating different systems, people, and modes of communication ensured multiple, repeated communication paths for reminders in the event of one system failing. Moreover, participants did not just rely on different tools and modalities, but continually audited these systems to ensure that they had the correct information and that activities were completed successfully.

The challenge is that incorporating redundancy and diversity across multiple, separate systems involves tradeoffs between reliability and complexity. Diversity inherently increases complexity, and the need for synchronization among multiple systems could create more opportunities for failure. Furthermore, as participants in this study described, there is a risk of noise fatigue when dealing with multiple reminders from multiple sources. Health care organizations need to be aware of the additional workload placed on patients at home and reduce complexity through more tailored communication and easier integration of clinic-based reminders with patient reminder systems. By evaluating chronic disease self-management through a systems lens, we argue that trying to fix breakdowns in self-management should focus on designing system-level changes that focus on the experience of patients.

Designing for Human Error

Importantly for systems-thinking, our study highlights the variety of ways that failures can occur in remembering to perform self-care management activities. Therefore, the design of reminder systems to support self-management should account for errors by making it easier to detect, evaluate, and respond to failures when they do occur. The concepts of redundancy, diversity, and monitoring represent system design concepts that, integrated with the prospective memory process (Figure 2), can inform approaches to the future design of reminder systems. In addition, well-established systems engineering methodologies and tools can support this design and evaluation process. For example, concurrent engineering and quality functional deployment (QFD) use methods similar to participatory design to explicitly capture all stakeholder needs in a complex system (Reid et al. 2005), including less visible needs—such as the personal reminder work of patients with chronic diseases. The SEIPS system model further reinforces the importance of design that incorporates the needs of patients and caregivers involved in chronic disease management work (Holden et al. 2013).

James Reason suggests that all reminders should meet certain universal criteria so that they are conspicuous at the right time, contiguous or available in time and space, provide the necessary context and content for the intended actions or tasks that need to be done (Reason 2002). While the patient reminder systems in this study incorporated many of these qualities and avoided errors in encoding, retention, and retrieval through redundant and diverse design, they often lacked a feedback loop to track if an activity was performed or to support evaluation of errors that may have occurred. An important aspect of high reliability systems is the practice of assessing failures in order to actively identify, correct, or mitigate the sources of failure in the future. Assessing variation in self-care management and if performance is within acceptable boundaries requires better tools and processes for capturing the metrics and data to calculate the variation. Information technology has the ability to support more robust monitoring and learning through different notification processes, passive data collection on behaviors/activity, and enhanced summary reports and real-time feedback. Participants across both cohorts leveraged mobile phones and other computing devices to support their self-management efforts. Increasingly, mobile phones link with ubiquitous sensing tools to support automated, detailed tracking of health metrics and performance around daily activities. These sensing tools can reduce patient work, integrate diverse metrics, provide feedback on progress towards achieving health goals, and identify deviations that are the result of errors or other failures. However, systems thinking and systems engineering principles should be considered in the design and the use of these tools so that they integrate in the wider context of strategies for more reliable self-care management.

Study Limitations

As with any qualitative study, our findings might not be fully representative of the populations under consideration. Despite making considerable effort to sample for a representative patient population, it is possible that our participants differ from other patients in terms of self-efficacy or their organization with managing their care. Because the diabetic population in this study encompassed a narrow demographic of mostly elderly, retired individuals, it is possible that we did not adequately capture a wide enough array of experiences and strategies for managing diabetes. However, we were able to contrast their experiences with those of young mothers taking care of their children with asthma. These mothers were often working and were more likely to use technology. Finally, the way that the participants used reminder systems in this study could reflect disease-specific needs of our two cohorts.

Conclusion and Future Work

In summary, the experiences of our participants managing chronic disease at home highlights the diverse strategies they employ to manage their schedules and tasks. Moreover, even though many clinics and health systems have implemented reminder systems—such as follow-up phone calls—our study showed that patients must still do extensive work at home to integrate these reminders into their daily lives. These separate reminders enhance reliability through increased diversity, but also add to the overall complexity of the system. Participants often felt confident in relying on their memory for most routine needs, yet still valued redundant reminders as a backup to deal with any memory slips. We also note that in addition to formal systems—such as calendars—many participants in this study relied on subtle systems similar to what Donald Norman refers to as "knowledge in the world" (Norman 2002). These cues that are visible in the environment and trigger prospective memories are less visible but important to be aware of with evaluating reminders and support systems for chronic care management. Technologies that recognize and integrate with these tacit signals have the potential to provide more context-sensitive reminders.

Our findings also support evaluating failures in self-management from a systems perspective, rather than simply attributing a failure to individual's lack of responsibility. While non-adherence is a legitimate issue, our participants' experiences make it clear that some self-care failures are unintentional and can best be characterized as breakdowns in the interaction between people, machines, and environments within a system. To mitigate failures, many patients incorporated key characteristics from reliability science into their personal reminder systems—characteristics such as redundancy, diversity, and monitoring behaviors. We are not aware of other studies that have examined these strategies from a system reliability perspective. As future work seeks to support patients' ability to manage chronic conditions outside of the clinic, it will be important to design self-care and reminder tools that also capitalize on these reliability principles. Healthcare providers, systems, and designers should consider the use of engineering design, evaluation, and control methods to explore this subsystem of patient reminder work that is prevalent among individuals with chronic conditions. Greater understanding of how this patient work integrates with clinic workflows and programs can lead to more reliable care management and ideally improved outcomes.

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Chapter 4. Patient information needs in a hospital environment

Abstract

Despite growing access to outpatient medical records through patient portals, we understand little of how patients prioritize and manage information about their care in an inpatient context. Based on hospital observations and responses to an online questionnaire from previously hospitalized patients and caregivers, we describe information categories that patients and caregivers prioritize as important and challenging to access or manage while in the hospital. Based on our analysis, we found that patients and caregivers desired information—such as the plan of care and the schedule of activities—that is often unavailable through patient portals. Moreover, our study illuminates the various tools and approaches that patients and caregivers use to help monitor and improve their experience in the hospital. Based on our findings, we identify gaps in information needs not typically captured by a patient portal and suggest opportunities to enhance the patients' environment for managing information while in the hospital.

Introduction

Hospitals are complex, dynamic, and information rich environments, yet patients and family members experience many information challenges when they are in this environment. Most hospitals have large, diverse care teams that must coordinate rapidly changing health data among providers. In addition, the information about the patient changes fairly quickly and the source of information is fragmented across hospitalists, nurses, surgeons, and different specialist services. When providing that information to patients, clinicians convey much of that information verbally and often quite rapidly. Yet, research shows that patients forget almost immediately 40-80% of what was said during a medical consultation (Kessels 2003). Further compounding the issue, patients in the hospital are often severely ill, anxious, and stressed, which further decreases their ability to receive and process that information.

Although we know that providing outpatients with electronic information about their care can significantly improve their satisfaction with their care experience (Delbanco et al. 2012), we know little of patient and family information needs in an inpatient context. Moreover, new initiatives to expand the role of patient portals and the pervasive presence of smart phones, tablets, and other electronic devices suggest a future where patients and families will be able to leverage real-time access to their care information while in the hospital. To explore this information space, we conducted in-hospital observations of patient-provider communication and used an online questionnaire to collect details about the experiences of patients and families. We provide a summary of the difficulty that patients and their caregivers face in obtaining and managing information while they are in the hospital and highlight information needs that are not typically a part of ambulatory patient portals. Our analysis illuminates opportunities to transform the hospital environment into an information workspace that supports greater patient and family engagement.

Background

The hospital environment creates unique challenges for patients and caregivers who are trying to access, manage and understand information about their care. We review related work that either examined the needs of patients and families in the hospital or analyzed the provision of patient-centered electronic access to medical record data.

Prior research has shown that patients perform extensive work to manage their health in the clinic (Unruh et al. 2010) as well as throughout their everyday lives (Pratt et al. 2006; Moen & Brennan 2005; Klasnja et al. 2010). Although new technologies help these outpatients with their work, within the hospital, patient access to information about their care is traditionally limited to verbal dialogue and occasionally to standardized, printed materials. The predominant non-verbal tool used to communicate with patients is the whiteboard, which is often used to provide information such as nurse and provider names, family contact information, and occasionally discharge expectations. Nonetheless, Marilyn Tan and colleagues found that whiteboards improved patient awareness of their care team and the goals for their care (Tan et al. 2013). However, differences in use between different care providers and the difficulty in keeping the information up-to-date has constrained the effectiveness of whiteboards (Sehgal et al. 2010). Moreover, whiteboards are tools primarily managed by nurses and reflects a provider-managed view of determining what patients should know.

Skeels and Tan posited that technology could help patients learn about their health and care while filling the significant amount of idle time that they experience during their stay (Skeels & Tan 2010). Through inpatient interviews, the authors found that patients desired greater awareness of what was currently going on in relation to their care and more powerful and nuanced ways of communicating with their care team, families, and wider social network. In a pilot study by Weiland, et al., the authors demonstrated increased patient satisfaction and involvement in their care when cystic fibrosis patients were given a personalized schedule of their care (Weiland et al. 2003). Simply having enhanced information about the process of care delivery in the hospital improves the patient experience. A systematic review from Prey, et al. further highlights the value of technology to support patient engagement in an inpatient setting, but also acknowledges that this space is still in its infancy (Prey, Woollen, et al. 2014). Prey and colleagues also conducted a field study where hospitalized patients were given printed copies of their raw medical record data—lab results, physician progress and consult notes, radiology reports, medication administration records—and found that even if patients did not understand all of the technical terms, they felt more informed and were able to "fact check" some of the information (Prey, Restaino, et al. 2014). Patient-facing technologies in the inpatient environment can improve patient awareness and management of information about their care activities.

In an ambulatory and outpatient context, health systems increasingly give patients access to their medical information through patient portals. Although evidence of their impact is still lacking (Goldzweig Dr. et al. 2013), patient portals facilitate information exchange between patients and their providers and represent a larger movement to support patients in being more active participants in their care. The Open Notes project illustrates an enhanced approach to the traditional patient portal. Instead of providing a summary view of patient data and notes, Open Notes allows patients to have immediate access to the raw clinical notes created by providers as well as unfiltered access to imaging and laboratory data. In a pilot study of 19,000 patients across three institutions, most patients took time to log in and read their notes, and 99% indicated that they wanted to continue having access to their notes online (Walker et al. 2015). Increasingly, these types of tools show promise for supporting patients to identify medical record errors (Hanauer et al. 2014) and thereby mitigate possible safety risk, but their evaluation has centered primarily in environments outside the hospital.

Other researchers have sought to enhance access to information for hospitalized patients by migrating the patient portal concept to the inpatient environment (Pell et al. 2015). Although limited to the emergency room environment, Wilcox and colleagues proposed a patient-facing, electronic, in-room display that would facilitate within-visit information sharing, encourage post-visit sharing and archiving, and serve as a useful memory aid as well as reference of the care delivered (Wilcox et al. 2010). They further explored the value of providing information from the medical record to give patients insight into the background activities performed by health care staff that is normally invisible to the patient (Wilcox et al. 2011). The same research group used the findings from this study to pilot a mobile-based process of care summary (Pfeifer Vardoulakis et al. 2012). Researchers have also explored a tablet computer interface to either provide access to patient portal information or deliver educational content (Vawdrey et al. 2011; Greysen et al. 2014). They found that patient awareness of their medication administration helped the patients assess their overall progress and health status (Wilcox et al. 2012). Overall, this early work suggests that creating tools to provide automated summary information for patients is feasible and highly desired by patients and families.

As patient portals become pervasive, patients are more likely to have information about their health care available electronically, even while in the hospital. These related studies make a case for the role that technology can play in sharing care activities (1) to promote useful awareness among patients, (2) to support decision-making, and (3) to improve patient-provider communication. However, it is unclear that a traditional patient portal designed for long-term, ambulatory use will meet the needs of individuals in an inpatient environment. To understand the unique information needs in an inpatient setting, we explore the information work currently being done by patients and families while they are in the hospital.

Methods

We used two methods to explore the information needs of hospitalized patients: (1) observations of patient-provider interaction points conducted at two hospital facilities; and (2) an online questionnaire completed by patients previously hospitalized and by family members or other caregivers that took care of a hospitalized patient. This work was approved by the authors' institutional review board.

Observation Study

We conducted 118 hours of observations at a children's hospital (Site 1) and an adult tertiary care hospital facility (Site 2). The observations occurred at different interaction points with patients: physician and multi-disciplinary rounding, discharge, care conferences, physical and occupational therapy sessions, as well as ad hoc exchanges among patients and the nursing staff. The observation findings were primarily based on open field notes and sketches of the patients' environments. Our data reflects the perspective of care providers during their shift work, including hospitalist attending physicians, residents, specialist physicians, physical therapists, and direct nursing staff. In addition, we conducted in-room observations to observe communication and information flow from the patient's perspective. Overall, we observed communication interactions with more than 50 individual patients. The observation notes were analyzed for factors that promoted patient information access, barriers that inhibited patient interaction during a hospital stay, and types of information managed by healthcare providers, patients, and caregivers. Our research team met regularly to review observation findings in order to identify preliminary themes and evaluate the extent of coverage of patient-provider communication during inpatient care.

Online Questionnaire

We also created an online questionnaire that asked participants about a prior hospital experience. Participants were recruited using convenience and snowball sampling through postings on social media sites, mailing lists, and website announcements. The questionnaire included topics across three areas: (1) importance and difficulty of receiving different types of information in the hospital,

(2) approaches to managing information in the hospital, and (3) attitudes about care involvement and patient-provider communication. We received completed responses from 157 individuals from across the US and Canada who identified as being either a patient or a caregiver (e.g. family member) of a patient during a past hospitalization. We analyzed structured data from the questionnaire using descriptive summaries to identify general trends and patterns. Using an open coding technique and card sorting process (Martin & Hanington 2012), we evaluated free text responses for related concepts and themes.

Sample population

Of the 157 questionnaire responses, 61% were completed by former patients and the remaining 39% self-identified as a caregiver who supported a patient during his or her hospitalization For the caregiver group, approximately 33% identified as a spouse of the hospitalized patient, 21% were parents, 21% were adult children caring for a parent in the hospital, and the remaining 25% were relatives or friends. The majority of the participants were female (75%) and ranged in age from 18 to 79. Fifty-eight percent indicated they were between the ages of 40 and 59. Respondents predominantly identified as white or Caucasian (87%). In addition, the overall participant group tended to be more educated than the general public, with 58% indicating that they have achieved some level of post-graduate education.

Forty percent (n=63) of the respondents had experienced a hospitalization within 12 months from the time they submitted the questionnaire, 23% were in the hospital between 1 and 3 years ago, and another 19% within 3 to 5 years. The reasons for the hospital admission were diverse. Many described an acute injury, while others mentioned pregnancy and various surgical procedures. Moreover, 33% of the participants described a hospital stay that lasted more than 7 days, another 29% were in the hospital between 2 and 5 days, 18% for 5 to 7 days, and the remaining 19% were hospitalized for 1 day or less. The majority of caregivers (84%) visited the patient in the hospital daily.

Table 4: Participant Overview

	Patients	%	Caregivers	%	Combined	%
Total Participants (N)	96		61		157	
Female	70	73	48	79	118	75
18-29	24	25	7	11	31	20
30-39	15	16	12	20	27	17
40-49	19	20	12	20	31	20
50-59	26	27	18	30	44	28
60-69	9	9	11	18	20	13
70-79	3	3	1	2	4	3
80+	0	0	0	0	0	0
Less than high school	1	1	0	0	1	1
High school graduate	4	4	3	5	7	4
Some college	7	7	8	13	15	10
College graduate	33	34	10	16	43	27
Post graduate	51	53	40	66	91	58

Results

By triangulating findings from both our online questionnaire and in-hospital observations, we found that patients and caregivers performed extensive background work in order to manage their information needs. We begin with an overview of the patients room environment, characterized as an information workspace (Unruh et al. 2010). We follow these observations with an exploration of the patient’s experience receiving information based on provider workflow. By understanding the current state of information dissemination, we proceed to discuss the information gaps that patients and caregivers identified in the online questionnaire. This desired information motivates

Figure 4: A typical patient room at our study sites.
Patients were often distant from their devices such as smartphones and computers, papers with information about their medical condition were often stacked by the window, and the whiteboard was located across the room from the bed.

our final observations regarding patient and caregiver work in using different tools to track information about their health.

The information workspace of a patient room

The patient’s hospital room serves as the primary focal point for information transfer among patients, caregivers, and clinical care providers. Typically, the design of the hospital room focuses on aesthetics, space for visitors, accessibility needs, support for monitoring equipment in order to address issues like risk of falling, noise (Cabrera & Lee 2000), and general patient satisfaction (Harris et al. 2002). During our observations of patient, family, and care provider interactions in this environment, we found that different surfaces and spaces within the environment served as a means to organize, manage, and communicate care information. The design of the patient room in terms of how well the space supports information transfer is especially important considering the amount of idle time patients and caregivers experience while in the hospital.

Within the hospital rooms, patients have access to a variety of displays (Figure 4). The TVs have the ability to display educational content, but the content is standardized, rather than personalized to a patient's situation; thus, the devices are primarily used for entertainment. The whiteboards provide a pseudo-dynamic space for patients to receive personalized information. They often have a structured layout with defined content areas for provider names, diet orders, frequency of vitals, and family contact information. Occasionally, pre-printed posters were used to display structured pathways that outlined the recovery from common surgeries like knee joint replacement. Importantly, the pathway diagrams were actionable, goal-oriented displays to assist patients in understanding the steps required before they could leave the hospital. We also observed temporary pieces of information taped above a bed or near the whiteboard that displayed instructions for nurses about patient-specific issues, such as not drawing blood from a particular arm. The displays that we observed were visible to patients and provided awareness about their care team, discharge criteria, and general care activities; however, the clinical care team primarily managed them.

Although hospital rooms have a variety of displays and surfaces to convey information to patients, we also observed a number of challenges from the patient perspective. Factors such as the limited space within the room (especially in a double-room environment) and the position of display objects and other tools affected patients' ability to access and manage information. We observed that the surface most accessible to the patient—the mobile tray table—was often covered with food, liquid containers, and trash that accumulate over the course of the day. As a result, printed educational materials, notebooks, and the patients' devices were often pushed into stacks in the corners of the room. Others described challenges with information scattered throughout a room: *"Most of it I scrawled it on the back of some pamphlets that came out of a box of dressings because I didn't have any paper. They did have a whiteboard in my room so I could keep track of some of it there, but some of it was embarrassing and I didn't want it available to be read by anyone who walked in the room" (10466299)*. The whiteboard was rarely used by patients despite having a place for patient and family input. One caregiver described trying to use a whiteboard, *"only later did we find out that it was only for staff and not for our questions for the doctor" (10276700)*. In our observations, many whiteboards were out of date and the information displayed was limited—typically listing only the names of care providers.

From the patient and caregiver perspective, visibility and access to information within the patient room was a challenging experience overall. To some extent, the shift to electronic systems compounds this problem because the *"EMR eliminates ready review of what has been administered and when, etc. We learned to try and build good relationships with staff and were so happy when we had nursing staff that were kind, informative" (12878449)*. Rather than just review a paper medical chart at the bedside, the patient and their family had to develop a good relationship with their nurses in order to stay up-to-date on care activities. Ultimately, patient room design appeared to support provider information dissemination primarily and less so the patient's ability to utilize objects and surfaces in the room as a workspace for accessing and managing information for his or her particular needs.

Staying informed through verbal dialogue: provider-centered access to information

Not only are information displays in the patient environment designed for provider use primarily, but the way patients engage with information about their care is often through verbal dialogue driven by staff workflows such as rounding.

During rounding and other patient-provider interactions, we observed different challenges that can hinder patient and families ability to learn up-to-date information about their care. With the exception of using the call button, patients and caregivers often just have to wait around for a provider to stop by in order to obtain an update about their care. In rounding and handoffs, we observed that

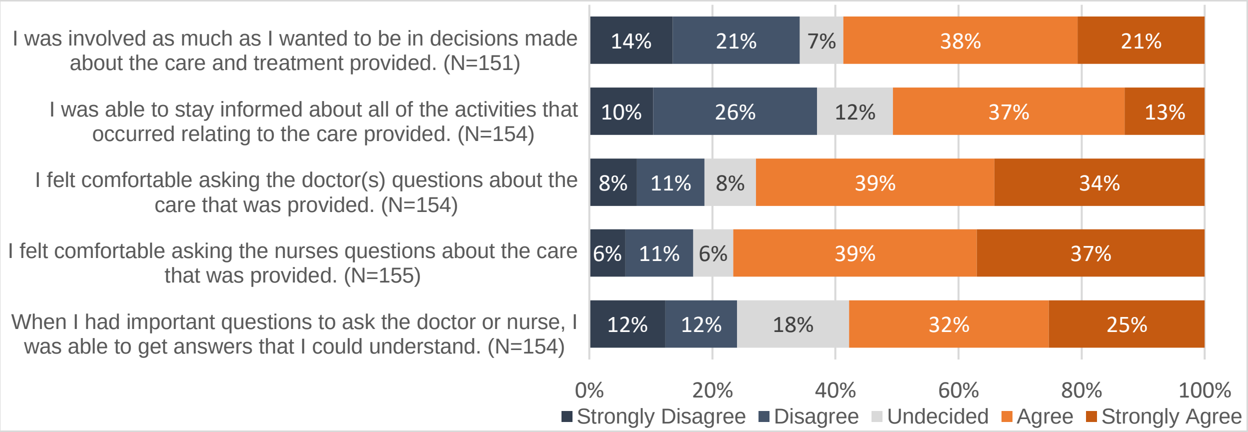


Figure 5: Patient and caregiver attitudes about their involvement and communication during a hospitalization. Respondents expressed greater disagreement with statements relating to their involvement and staying informed.

patients are often discussed in the third person as a resident explains their assessment and plan of care to the rest of the provider team. At our children's hospital (Site 1), the hospital had instituted large, multidisciplinary rounds where more than a dozen providers crowded at the patient's door and bedside. This creates a challenging environment for patients and caregivers to effectively communicate with their principal care team and can be intimidating to be involved in their care. As a result, participants in the online questionnaire were split in their level of agreement about their involvement in decision-making (Figure 5). Fifty-nine percent either agreed or strongly agreed, while 35% disagreed or strongly disagreed that they were as involved as they wanted to be. Relatedly, over a third (37%) of those surveyed disagreed with the statement, "I was able to stay informed about all of the activities that occurred relating to the care provided". These responses suggest that a large percentage of respondents experienced challenges in being involved and/or staying informed in their care.

We also observed providers employ strategies to mitigate some of the communication challenges and help to engage patients. While observing a patient being admitted at the children's hospital site, the admitting staff member finished talking to the parent, turned to the child patient, and told him she would need to know from him if he felt better or worse as they treat him. She told him he was a “full partner” in this. Moreover, physicians would utilize their mobile computers or print out materials to show radiology images at the bedside. In one example, a patient did not understand the reason why he was having difficulty swallowing and digesting food. The physician brought a computer with a large screen over to the bedside and showed the patient along with the patient’s family the latest CT scan. Not only the patient, but the patient’s entire family crowded around the physician and display and engaged in collaborative question and answer dialogue as the physician stepped through each image layer and explained his interpretation of the data. Patients and families experienced successful information exchange when their providers utilized electronic displays to collaborating explore the patients’ medical record data. Based on the experiences of patients in our questionnaire and during our observations, we found that effective tool use and collaborative dialogue related to data collection and analysis helped to address some of the communication challenges created by provider workflows.

Gaps in information needs: prioritization of workflow and care activity data

Traditionally, patients access to information in the hospital through verbal interactions with care providers and occasionally through standardized, printed content. We elicited a number of information needs prioritized by patients and observed patient-driven approaches to informal information exchange with peers in the hospital.

Respondents identified the top three most important pieces of information that they wanted to receive during their hospital stay as: (1) medications administered, (2) the expected next visit from a nurse or doctor, and (3) lab and imaging results (Figure 6). From the patient’s perspective, being able to access information on past medical history and at-home medications, was less important than the other items listed in the questionnaire. This result is in contrast to a care provider’s perspective on the importance of patient information for diagnoses and medication reconciliation.

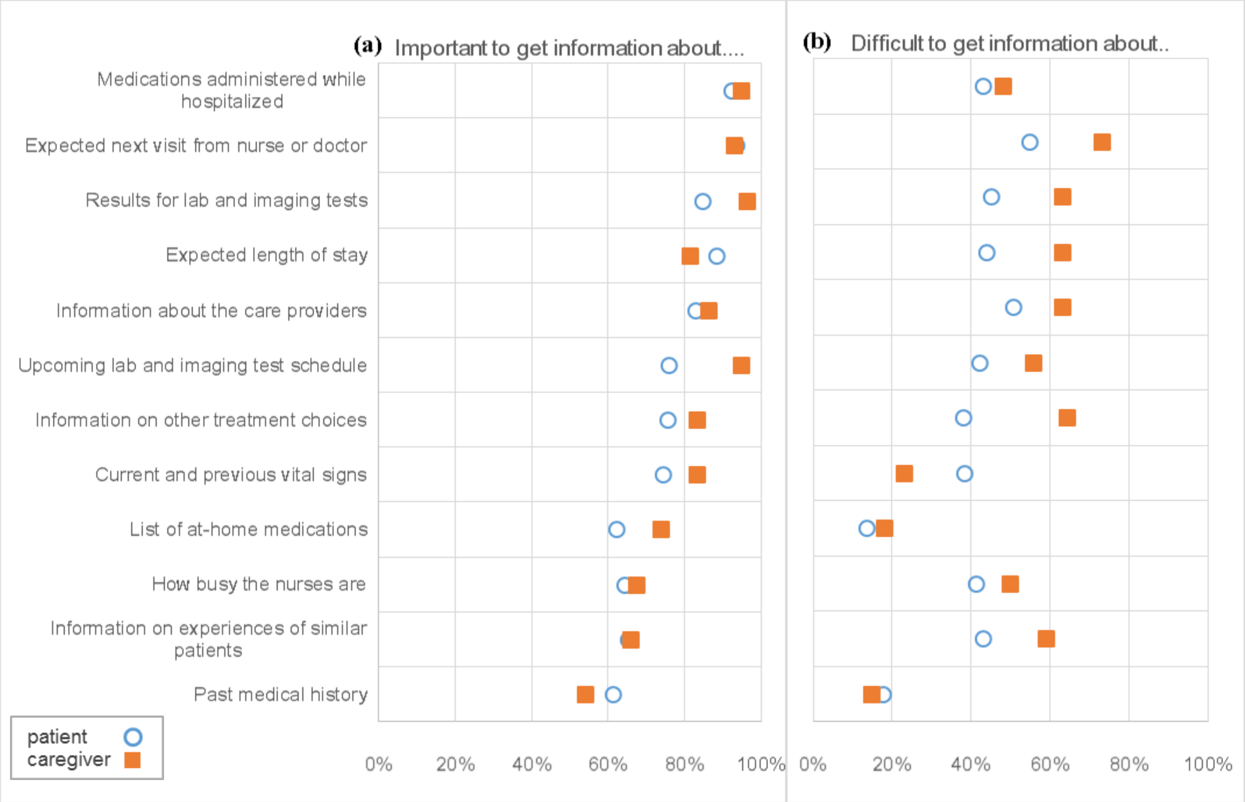


Figure 6: Patient/Caregiver Assessment of Different Types of Information.
Percentage of Caregivers (orange square) and Patients (blue circle) that evaluated accessing different types of information while in the hospital as "somewhat important" or " important", shown on the left (a) and "somewhat difficult" or "very difficult", shown on the right (b).

Overall, the respondents tended to rate information about care activities as most important. For example, information about the “expected next visit from a nurse or doctor”, was highly rated by participants and serves as a key communication point for patients to get an update on the plan of care. However, this information was also one of the most challenging pieces of information for clinicians to provide because it is difficult to anticipate. When asked about the difficulty in accessing information during hospital stays, more than 50% of survey participants stated that information on the expected next visit from the nurse or doctor, information about their care team, and information about patients that have experienced similar health situations were somewhat difficult or very difficult to access. As one caregiver participant described, *“We spent a lot of time sitting around waiting for the doctors. Then we would go to the bathroom or to get food, and come back* *and they would have been there without speaking with any of us. We would have to wait another day to ask our questions or share information or observations" (10264109).*

Even though it was not as important as knowing about care activities like the doctors next visit, 66% of patients and caregivers ranked getting information about the experiences of similar patients as either important or somewhat important. This was reinforced by observations of instances where patients engaged with their peers in informal, social interactions. For example, we observed one patient after her double-knee replacement surgery who was in the middle of a physical therapy (PT) session. These PT sessions often take place in a dedicated gym-like space where multiple patients and physical therapists are together working on rehabilitation exercises. In this case, the patient expressed a lot of uncertainty and doubt about her ability to climb a set of stairs as she started her session. However, she observed another patient completing the activity right before her and found out they both had the same type of surgery on the same day. Seeing another patient with a similar condition successfully perform the exercise, the patient appeared more confident at attempting the stair climb and succeeded in completing the activity. We also observed patients exchanging information while the patients walked around hallways in order to meet provider recommendations for mobility goals. Although these interactions were limited and not explicitly supported by clinicians, we observed patients providing social support and occasionally sharing information about their care experiences.

The patients and caregivers in our online questionnaire prioritized activity data—actions that have happened recently like medication administration, future plans related to scheduled tests and provider visits—when asked what information was most important. Patients also obtained valuable support through social interactions. These types of information needs indicate a desire for data about the background work of care providers and other patients.

Patient and caregiver information work

Throughout our observations and within the online questionnaire, patients and caregivers frequently demonstrated active work to manage information about the care provided. When we asked about information that they might track or manage while in the hospital (Figure 7), the respondents indicated that preparing questions for the care team was most important to them (90%). As one caregiver explained, despite having *"a robust care team…making sure we had a way to capture and communication our questions was essential" (10276700)*. However, their perspective on how challenging it is to keep track of questions was more mixed; 47% indicated that it was either somewhat or very difficult to track. Keeping track of changes in symptoms, another item rated as important, was the most challenging item across the two groups to manage (50%). Other items, such as bowel movements or visits from family and friends, were marked as easier to track, but were less important. Overall, the importance of the different information listed in Figure 7 suggests

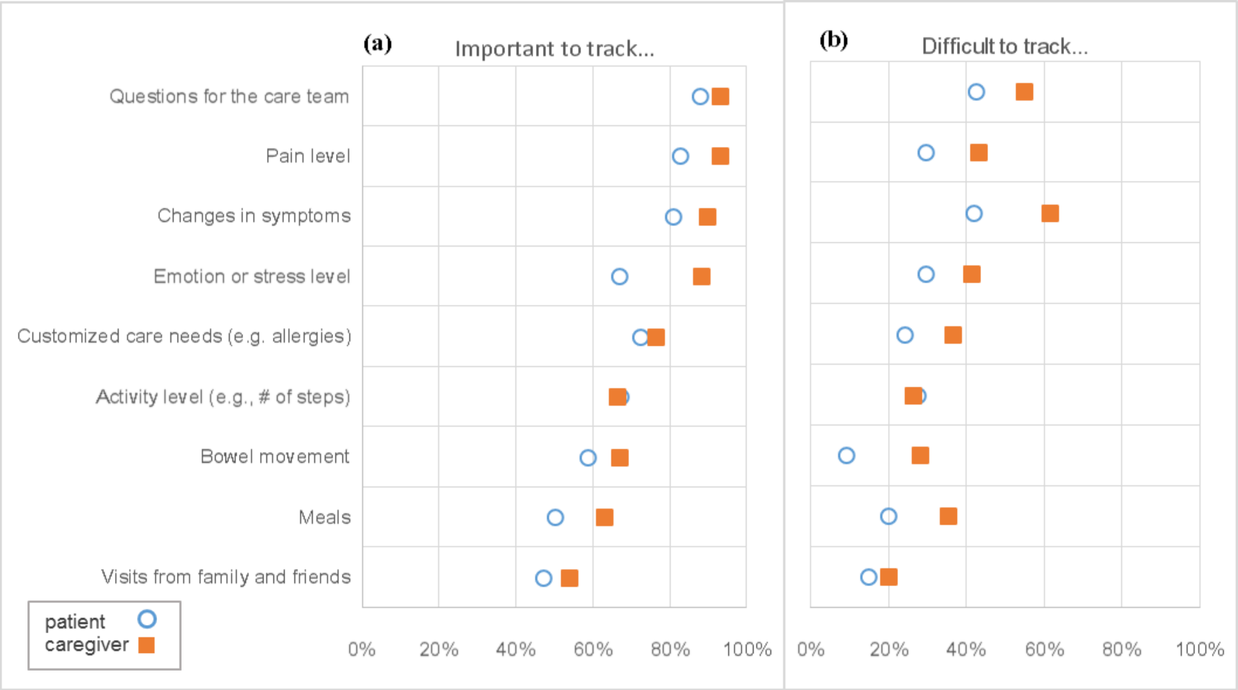


Figure 7: Patient/Caregiver Responses on Tracking Information While Hospitalized.
Percentage of Caregivers (orange square) and Patients (blue circle) that evaluated tracking different types of information while in the hospital as "somewhat important" or " important", shown on the left (a) and "somewhat difficult" or "very difficult on the right (b).

that patients and caregivers value the concept of actively tracking information about their health and care.

The participants listed a number of reasons and motivations for choosing to track information during their stay. The most cited reason was to help prepare and manage questions for the next visit from their physician or other health care provider. One participant prepared captured written notes, *“So we wouldn't forget our questions for the doctors, and so different members of the family could share information with each other or with the doctor or nurse when they arrived. We were never clear on when [the doctors and nurses] were coming by” (10264109).* Others cited monitoring care quality as a reason for tracking. For one questionnaire respondent, *“The main reason I kept track was because of an error during surgery. So I knew I needed to keep a log because I wouldn't remember all the events” (11740791).* Another caregiver explained how, *“We wrote down "ins and outs" (nutritional intake and output) ourselves and then gave to the nurse at end of shift”* because this *“significantly increased accuracy for us to track the info ourselves” (10260629).* Based on a prior event or because they believed their input was the most accurate source of data, patients and caregivers would actively record and share information with their care team.

The tools and methods used by patients and caregivers to track information about their health care varied widely. Of the respondents that stated they tracked information, almost half (49%) of these respondents used written notebooks or electronic data capture (often with a mobile phone) to document their care activities (Table 5). Some participants (18%) would keep track of things in the hospital through verbal interactions with their care team. These check-ins served as a way to reinforce what information needed to be remembered. For 5% of the respondents, they described relying on their caregivers to keep track of things for them.

Table 5: Methods and rationale for tracking in the hospital

Method (n=74)	%	Motivations and rationale for tracking
Written	49%	Being an active participant; Monitoring care quality; Being in the know; Improving communication with staff; Personal accounting; Concerns about safety; Coping with patient health challenges (e.g. cognitive state); Provider requested; Dealing with too many different events occurring
Memory	19%	Being an active participant; Monitoring care quality; Being in the know; Planning ahead; Being prepared for Q&A with staff; Sharing; Monitoring progress/recovery
Verbal	18%	Being an active participant; Monitoring care quality; Being in the know; Personal accounting; Provider requested tracking; Sharing; Post-hospital planning; Getting status updates
Electronic	14%	Being in the know; Personal accounting; Being prepared for Q&A with staff; Medication monitoring; Concerns about safety, Sharing
Caregiver	5%	Monitoring care quality; Concerns about safety; Coping with patient health challenges (e.g. cognitive state); Improving communication with staff; Pain management

However, a substantial number of participants relied on their memory to keep track of things (19%). During our observations, even though many patients had a smartphone or similar device available to them, few used these devices to manage information related to their care. They served primarily as entertainment or external communication devices. We noticed that many of these devices were placed on a surface out of reach from the bedside or piled under papers and other items accumulated during the stay. The children's hospital would actually provide patients with a tablet device during their stay, but even this was often pushed to corners of the room. Patients also had to cope with physical limitations because, *"with IVs in your arm and/or hand, it was difficult to write or type" (10269740)*. Patients and caregivers experienced difficulty using different tracking tools because of the unique constraints related to their health maintenance and the physical space of the patient rooms. The usability of the various tools also affected their ability to capture information for tracking purposes and manage information for communicating with their care team.

Discussion

Through our observations and questionnaire, we found that patients often experience an information-poor environment outside of conversations with their care team. Our data illuminates patient barriers in using their hospital room as an information workspace, the difficulties that they experience in obtaining information outside of provider workflows, and their desire for information not normally displayed in the EMR or through patient portals.

Patient rooms reflect a provider-centered information workspace, despite being equipped to convey information to the patient through electronic interfaces and physical wall displays like whiteboards. In our observations of whiteboard usage, we noticed incomplete and inconsistent content that further reinforced the difficulties that patients experience in obtaining up-to-date information. Despite these challenges, the whiteboards and other displays occasionally served as useful places for physicians to diagram procedures or use visuals to help explain the patient's condition and progress. The frequent presence of patient tools like smartphones and tablets suggest an opportunity to help patients organize all of the information collected over the course of a stay. Yet, these surfaces are frequently obscured by other objects or relegated to corners of the room away from the patient.

Within this physical environment, we found that the flow of communication is typically driven by provider workflows like rounding. Patients and caregivers experience communication challenges in this context because of the difficulty in being able to prepare for a visit that can occur at any moment. These interactions are also difficult because the information exchange is almost completely verbal and often time-constrained by the providers' rounding schedules. In some instances, we observed providers enhance their approach to patient engagement by using collaborative behavior and electronic displays to discuss medical record data alongside the patients and caregivers. Increasing the use of visual tools at the patient's bedside has the potential to enhance patient and caregiver participation in their care.

Finally, patients and caregivers expressed a variety of information and tracking needs related to their difficulty with managing their health information in the hospital. This extra patient and caregiver work was often motivated by concerns about care quality and wanting to stay informed when dealing with the care complexity of an inpatient environment. Accordingly, patients and caregivers indicated that information about their care team as being one of the most important and challenging pieces of information to manage. Our findings about tracking needs suggest that existing patient room displays and provider-driven information dissemination do not adequately support the patients' and caregivers' ability to use tools in their rooms and maintain awareness about their care activities. Moreover, the informal social interactions that we observed demonstrate that patients can obtain value through experiences of others. Reimagining the information workspace of a hospitalized patient should consider these needs and support opportunities for patient-driven care provider and peer interaction.

Addressing Information Needs

Providing enhanced access to information during a hospitalization can reduce the cognitive load for patients and improve common ground between the patient and their care team. The order that information is presented, modality, perceived importance, and health context can all have important impacts on the patient's likelihood of remembering information. Something like a printed or electronic summary of the plan of care—upcoming activities, discharge goals, provider visit times, and other items highlighted by our questionnaire participants—creates an opportunity for patients to process activities related to their care on their own time. They can then reassess situations with their care providers to ensure their expectations match with the documented plan of care.

Hospitals are increasingly migrating their outpatient portal into the hospital environment as one approach to addressing the problem of patient access to information about their care. This is a positive first step, but our observations and questionnaire data show that a traditional portal doesn't address most important information needs identified by participants, such as being able to know the plan of care and when to expect the next provider visit. The interest in information about care activities suggests that an inpatient-specific portal should reflect the dynamic nature of hospital care. There is an opportunity to capture the metadata contained within order sets and to explore approaches to communicating expectations for uncertain events like when the physician will be visiting the patient next. Leveraging the process of care data embedded in the electronic medical record provides an opportunity to reconsider the patient portal as a mechanism for maintaining awareness of changes and updates in a dynamic hospital environment.

Addressing Information Work

The patients and their caregivers that participated in our questionnaire developed various strategies for coping with the information communicated verbally in the hospital. Even though our respondents stated that they felt comfortable with asking their care providers questions and rated keeping track of questions as the most important activity that they could do, they also stated that keeping track of changes was one of the most challenging activities during their hospitalization experiences. This relates to our observation data showing that patients face barriers to using tracking tools. In part, this is due to constraints created by the physical environment. We often observed tracking tools such as smartphone devices, notebooks, and even pieces of paper were relegated to areas of the room distant from the patient's bedside. Even tools like tablets which are increasingly used to provide access to patient portals and health records were stored far away from the bedside. The only tool consistently at the patient's side was the call button which can alert a nurse or other provider if the patient has a question, but lacks the ability to track information.

Moreover, they often are able to track certain types of information about themselves more accurately than the care team that may not always be present in their room. The patient portal concept typically doesn't address tracking needs. In fact, patients and caregivers are using tools when they are available and cite the lack of resources as a major barrier to being able to manage the large amount of information and activity occurring during a hospitalization.

Limitations

Our qualitative, ethnographic approach to studying the patient experience in the hospital has several limitations. Our questionnaire sample is skewed towards a well-educated demographic. However, even within this population, a large percentage of both patients and caregivers experienced challenges with obtaining access to key information about their care. Ultimately, our questionnaire is not intended to be representative of a larger population, but instead provide a means to explore a broad range of patient and caregiver experiences across the US. Combining our questionnaire findings with observation data from two independent hospital environments also helped to validate our findings.

Conclusion

The triangulation of our online questionnaire with in-depth observations shows that inpatients face many information and communication challenges during their hospital stay. Analyzing the patient's room as an information workspace in the hospital illustrated challenges and opportunities for tools and displays that can enhance patient interaction with their care information. Moreover, when we consider the patient portal functionality that is typically used in an outpatient setting as a strategy to mitigate some of these challenges, we found that inpatients need additional support within the hospital context. Patients and caregivers highly desired yet found it quite challenging to obtain the patient's plan of care for each day. In addition, most patients wanted to track key aspects of their experience. Neither of these important functionalities are available in patient portals but often exist as metadata within the patient's medical record. Our work highlights these important needs and suggests new functionality that emerging inpatient information systems need to support. This type of new functionality has the potential to transform inpatient care by empowering these patients and caregivers with the information they need to have a satisfying care experience.

Chapter 5. Q Method Exploration of Inpatient Information Exchange Priorities

Abstract

Hospitalized patients and their family caregivers often face significant challenges maintaining situation awareness of their healthcare. There is scarce research that has explored the information needs of patients and families in this environment. Utilizing a purposeful sampling method, we used Q Methodology—a technique for quantifying subjective opinion—with 27 patients and 19 caregivers to understand attitudes towards receiving and managing information. Based on our patient participants' experiences, we found distinct views prioritizing immediacy, information modality, and empowerment. Caregiver participants emphasized the importance of information tracking. We leverage these views to discuss how different hospital strategies towards patient and family communication can meet the needs of these distinct groups.

Introduction

One of the greatest challenges in an inpatient environment for all stakeholders—patients, families, clinical staff—is maintaining an up-to-date and accurate awareness of the patient's current state and all the associated activities to care for the patient. Situation awareness (SA) is a term increasingly used to describe a person's understanding of their immediate environment and situation. It is "the perception of elements in the environment within a volume of time and space, the comprehension of their meaning, and the projection of their status in the near future" (Endsley 1995). Researchers have studied the notion of situation awareness in many cognitively demanding settings, including healthcare. For example, Gaba *et al.* introduced the concept of situation awareness in anesthesia as a way of assessing a clinician's skills for accurate decision-making and quality of clinical performance (Gaba et al. 1995). Gaba's model pioneered the use of simulation studies to show how situation awareness declines in emergency and non-routine events (Cooper et al. 2013).

The research into situation awareness in healthcare describes challenges to maintaining SA from a staff and provider perspective, but very little work has explored this concept from the patient and family perspective. To understand how patients prioritize and make sense of getting information while hospitalized, we conducted a set of interviews using Q Methodology, a systematic approach to quantifying subjective views that I describe in detail at the end of the background section, as well as observations with 27 hospitalized adult and pediatric patients. We found that a subset of both patients and caregivers aligned in terms of their association of empowerment with their information needs, but patients focused on a desire for understanding their immediate situation, while some caregivers emphasized the importance of tracking and capturing information about their care. Through this analysis of patient and caregiver attitudes, we identify important information needs for an inpatient setting.

Background

Within an inpatient environment, patients and their families or other caregivers face challenges with maintaining up-to-date awareness of the patients' status and plans of care. Stress, medication, and fatigue can affect how well patients and caregivers receive information, information exchange is often limited to in-person interactions based on clinician availability, and the dynamic nature of inpatient care requires staying up-to-date with fast-changing information. In order to develop the statements for the Q sorting process and to provide prompts during inpatient interviews, we explored the exchange of information among patients, caregivers, and providers in terms of: empowerment, information needs, understanding of health information, information management, inpatient doctor-patient communication, and perceptions of affiliation and relational attitudes.

Each of these concepts has an abundance of research, therefore we focused on key studies that explore the use of technology with patient information management, emphasizing inpatient care where applicable. We also review Q methodology as applied to understanding attitudes and beliefs with healthcare, information management, and human-computer interaction topics.

Patient-provider engagement and information sharing within an inpatient setting

Healthcare researchers have emphasized patient engagement and empowerment extensively, particularly since the Institute of Medicine formalized the concept of patient-centered care in *Crossing the Quality Chasm* (Institute of Medicine (IOM) 2001). The literature on this topic is extensive, so we focus specifically on inpatient engagement and technology. Prey et al. conducted a systematic review of the inpatient experience specifically and how different technological tools are being used to interact with patients (Prey, Woollen, et al. 2014). The authors found significant gaps in how well patient engagement has been studied to date in this setting and suggested opportunities for research into how electronic medical records and patient portals can further support patient engagement. They emphasized the need for design research to handle increasingly complex technologies such as decision support in order to improve patient adoption and usage (Prey, Woollen, et al. 2014).

Patient information needs in healthcare

Information needs and information management in healthcare are themes well-documented by the HCI and CSCW communities. For example, Skeels and Tan evaluated and identified opportunities for re-designing technical tools and care spaces to support information transfer (Skeels & Tan 2010). Kendall *et. al.* used a set of observations and interviews to evaluate the patient hospital room as an information workspace (Kendall et al. 2015). In a critical care environment, patients and families have limited cognitive resources to be able to process and manage. Research shows that patients may forget almost immediately 40-80% of what was said during a medical consultation (Kessels 2003). The order in which information is presented, modality, perceived importance, and health context can all have important impacts on the patient's likelihood of remembering information (Kessels 2003). The patient's understanding of medical terms and tests can affect their recall as well. These factors affect how information is taken in, how it is integrated with other knowledge, and how it is stored for later retrieval and use. The impact of illness, medications, stress, and often rapidly evolving healthcare situation contribute to the limited cognitive resources and suggests an opportunity to improve the design of how patients and families receive information.

Information Management

HCI investigators have begun to recognize how these needs affect information workflow and management in clinical settings. Prior work hints at various types of information that patients want to manage, capture, and communicate to the care team. For example, patients want confirmation that their self-reported health profiles, such as allergies, had propagated properly to their current clinical team (Wilcox et al. 2010; Wilcox et al. 2011) and contextual information about their treatment routine and individual preferences are properly transferred to a new clinic staff for the continuity of the care (Pratt et al. 2006). Without a mechanism for effectively capturing and sharing the information directly with patients and caregivers, these individuals must remember everything and be responsible for keeping their providers aware of their needs throughout shift changes and other transitions in care (Pratt et al. 2006). Prior work has shown that patients in a critically ill state often require substantial third party support in their information management (Unruh & Pratt 2008).

Contextual information, customized care needs, and collaboration are often not formally stored in the medical record and present an opportunity for further research and discovery.

Relationship and social perceptions in care delivery

Another component of the inpatient experience includes relational attitudes of the patients and how they perceive and interact with medical professionals and caregivers. Gitell and colleagues posit that high-performance work systems require coordination through "frequent, high quality communication supported by shared goals, shared knowledge, and mutual respect" (Gittell et al. 2010). In an inpatient context that often requires involvement of patients and families, it is important to consider the relationships and attitudes between patients, clinicians, and families. Different studies have explored the impact of the quality of the patient-provider relationship on patient healthcare utilization and outcomes. Gabay showed a significant improvement in patient trust in their provider based on increased levels of perceived control and communication that the patient experienced (Gabay 2015). Eton *et.al*. conducted research with chronic disease patients and found an association between high quality provider relationships and lower disease burden and greater use of preventative care services (Eton et al. 2017). Wachter and colleagues have explored provider continuity in the hospital context and the hospitalist influence on patient safety and quality improvement. The researchers explain that while a dedicated hospital specialty can add significant value to processes within the hospital, it also introduces new transitions between the hospital and primary care environment (Wachter & Goldman 2016). Timothy Bickmore has conducted several evaluations of enhancing the social experience of patients via a virtual agent, showing widespread acceptance, including older adults (Bickmore & Picard 2005; Bickmore et al. 2010; Bickmore et al. 2013). The use of a virtual agent in these studies demonstrates the potential for addressing potential gaps when clinical staff are not available for in-person interaction, including critical information handoff periods such as discharge and transfer (Jack et al. 2009). Relationships in the hospital are an important contributor to collaboration and task effectiveness in this setting and the results from researchers like Bickmore suggest that relationships may be supported via well-designed electronic tools.

The HCI research community has also explored patient social support as a valuable component of the overall relational experience in a clinic setting. Miller, et al. used observations and interviews with parent caregivers of pediatric patients to frame five key behaviors performed by the caregivers: companion, assistant, representative, navigator, and planner (Andrew D Miller, Mishra, et al. 2016). While caregivers will frequently adjust the way that they support the patient depending on the circumstances, these roles highlight the value of a third party acting in support of the patient in a critical care environment. Liu also explored the importance of technology for pediatric inpatients and found that technology-mediated social support helped to normalize the experience of being a patient as a child or adolescent (Liu et al. 2015). Skeels et al. have devoted several studies to the topic of social support for cancer patients (Skeels et al. 2010). They found that caregivers played a critical role in major care transition periods, as well as assisting with the cognitive challenges associated with cancer treatment, such as memory loss.

Patient attitudes towards engagement around patient safety

The different approaches to studying patient concerns have shown an interest and willingness on the part of patients to participate in patient safety improvement. In a telephone survey of 2,078 patients recently discharged from several Midwest hospitals, Waterman and colleagues found that more than 91% of respondents agreed that patients could help prevent errors (Waterman et al. 2006). The patients in the study reported being comfortable with information-seeking questions such as asking about a medication's purpose but much less comfortable with challenging questions such as asking if a health care provider washed his or her hands. In a systematic review patient willingness to engage in safety, Doherty et al. identified four broad influencers on patient engagement: the patient's illness, individual cognitive characteristics, the patient-provider relationship, and organizational factors. The fear of being perceived as a "difficult" patient and the asymmetrical power dynamic that is typically dominated by the physician are significant barriers to greater patient participation in this area (Doherty & Stavropoulou 2012). This correlates with known enablers for reporting of safety concerns – anonymity, regular and timely feedback, and the existence of a safety climate – regardless of the person's role in the health care environment (Frey & Schwappach 2010). Other research has added patient-specific characteristics (e.g. demographics, socio-economic status) and task requirements (such as challenging a provider's behavior) as additional parameters that influence a patient's decision to participate in safety (Davis et al. 2007).

Q Methodology to Systematically Assess Attitudes and Preferences

In order to delineate the various attitudes and opinions of patients and caregivers across the topics mentioned above—such as information management—researchers have employed different methods to organize qualitative attitudes. Many of the studies cited employ a mixture of surveys, observations, and interviews to provide insights into novel topics. Q methodology is one technique for quantifying subjective opinions that has two major components – a set of statements about a topic, and a grid for ranking those statements in the shape of a normal distribution (Brown 1993). Researchers are increasingly leveraging Q methodology in HCI research. Katie O'Leary and colleagues used Q method to capture design thinking beliefs and reactions to HCI tools (O'Leary et al. 2013). Her work shows the value of this method for HCI design purposes in order to describe in a structured way the tradeoffs and attitudes individuals have about health technology (O'Leary, Eschler, et al. 2015). While applying this method in a chronic disease population, O’Leary and colleagues showed how common attitudes towards health and technology supersede typical demographic segmentations like gender, age, and ethnicity (O’Leary, Vizer, et al. 2015).

With very little research exploring patient’s perspective on information delivery and communication in a hospital setting, there is an opportunity to explore patient information needs while hospitalized. Once these attitudes and beliefs have been identified, hospitals and researchers can develop frameworks to improve the design of a tools and programs that provide patients and families with information about their care.

Study Design

Using a mixed methods approach, we partnered with patient and caregivers to complete a card sorting process, two interviews, and field observations with each participant. This approach enabled our research team to capture both structured and unstructured opinions from the study participants, as well as to capture observations of the care environment from the patient and caregiver perspective. Below we review the detailed methodology employed used to conduct the study, the process for selecting the Q set of statements, the study population sample, and our data analysis approach.

The Q Set

For the Q sorting process, we created an initial set of 89 statements that described different attitudes related to interacting with information and people in the hospital environment. We developed the statements using prior literature on patient-provider communication, patient information needs, situation awareness, and based on data from a prior survey of patients and caregivers (Kendall et al. 2015). The survey is discussed in more detail in Chapter 4. The previously stated background work provided guidance in developing the final categories and statements listed in Table 6.

Using an affinity diagraming process (Martin & Hanington 2012), the research team organized the statements into 5 categories including communication preferences, empowerment, information management, information needs, and relationships. Based on a series of pilots with both children and adults, and an iterative internal review process, we narrowed the original Q set of 89 statements down to 34 statements (Table 6). We tested phrasing for consistency across statements in order to reduce alternative interpretations. In line with published recommendations (Watts & Stenner 2005), we capped the number of Q statements at 34 to reduce the sorting burden placed on sick patients and to make the exercise more accessible to a pediatric population. Table 6 shows statements for the patient Q set. Caregiver statements were almost identical, except for adjustments to the pronoun where appropriate. For example, the patient statement #4, "It's important to know when I can leave the hospital" was changed to "It's important to know when the patient can leave the hospital" for the caregiver Q set.

Table 6: Q Statement by Category

Category	#	Statement
Engagement and Empowerment	6	It's important to speak up to doctors and nurses when I have a question
	17	It's important that I be an active participant in my healthcare
	30	I prefer to leave decisions about my medical care up to my doctor
	31	I only want to know what my doctors think is important
	34	It's important that my doctors and nurses understand what is most important to me
Information needs	2	It's important to know what will happen with my care today
	3	It's important to know why each medication is given to me
	4	It's important to know when I can leave the hospital
	5	It's important to know the cost of being in the hospital
	7	It's important to know about different options for how to treat my illness
	8	It's important to know how to get help if I am worried or need information
	9	It's important that I know what I will need to do for my health after leaving the hospital

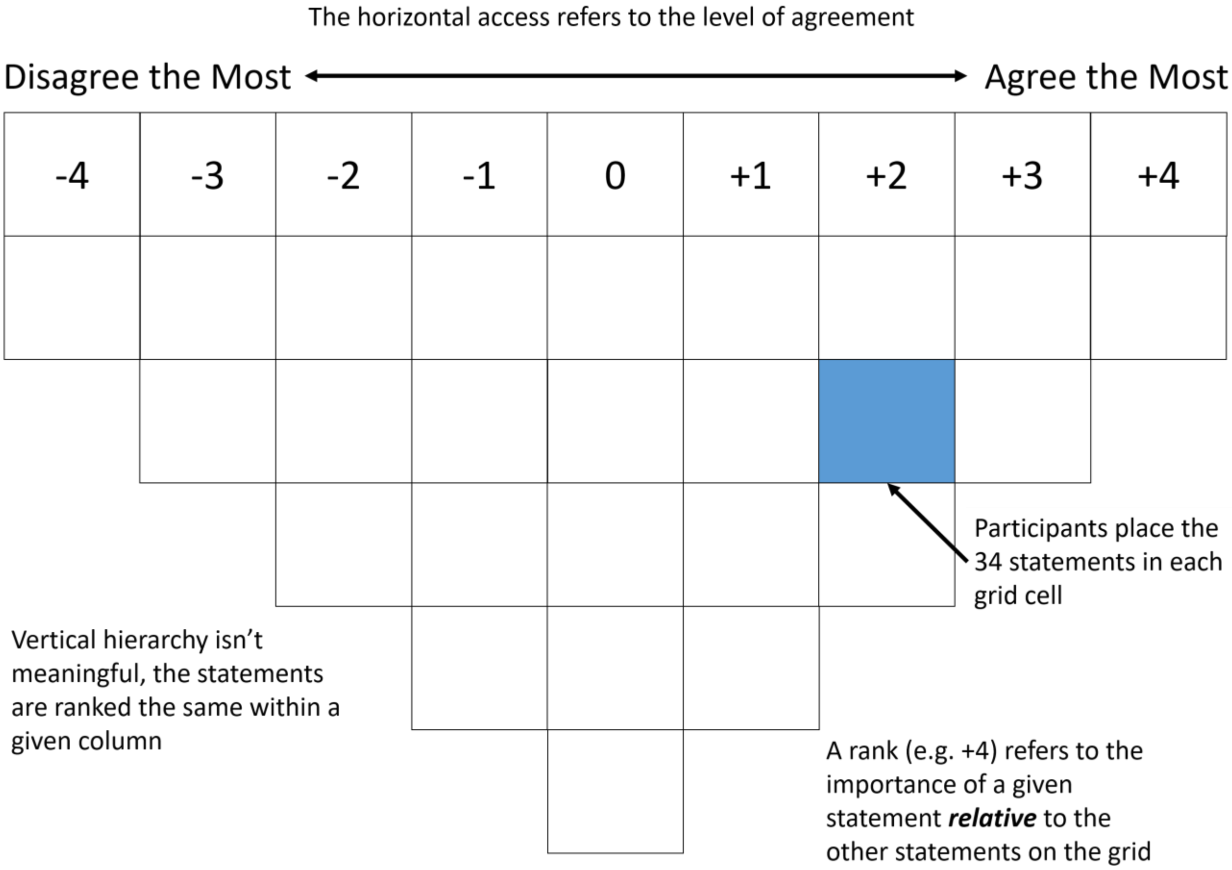
	10	It's important to know when I will see my doctor next
	13	It's important to know what to ask my doctors or nurses
	15	It's important to know how serious my illness is
	18	It's important that I keep track of things by writing them down so that I remember them
	25	It's important to know what kinds of safety errors can happen with patients in my situation
	29	It's important to know what activities are okay based on my current condition
	32	It's important to get information at a time when I can focus
	33	It's important that I understand my doctors' reasoning when they give a recommendation
Information Management	19	It's important that someone else helps me keep track of things
	20	I like to keep track of things by just paying attention and remembering
	24	It's important to get information in a way that's easy to share with others
Communication preferences	1	It's important to know the names and responsibilities of my doctors, nurses, and other health care providers
	6	It's important to speak up to doctors and nurses when I have a question
	11	It's important to get information in a way that I can understand
	16	It's important that I get information about how my health condition is changing over time
	21	It's important that my doctors and nurses listen to me
	22	It's important to know how my doctors and nurses are communicating with each other when there are shift changes
	23	It's important that I know right away when there is a change of plan for my care
	28	It's important that the hospital respects my need for privacy
	32	It's important to get information at a time when I can focus
Relationships and norms	12	It's important that I am not a bother to my doctors and nurses
	14	It's important to feel like my doctors have time to answer my questions
	26	It's important that my doctors and nurses agree with my decisions for my care
	27	It's important that I have a positive relationship with my doctors and nurses

Methodology

At our two study sites—an adult tertiary care hospital and a pediatric hospital—our team reviewed the inpatient census each day and used purposeful sampling to identify eligible participants. The final study sample is described in further detail below, but the purposeful sampling was broadly based on age, gender, regional demographics, and a determination on whether the primary purpose of a patient’s stay was for medical and surgical reasons. We used regional population demographics for hospitalized patients to set targets for race and age, and sought equal representation of gender and medical vs surgical causes for hospitalization. A dedicated research study coordinator approached each patient and their families to evaluate ability and interest to participate. We excluded non-English speaking participants and any participants that the hospital floor staff determined were too sick to participate in a conversation. After obtaining informed consent, the study coordinator conducted a brief verbal questionnaire to collect demographics and information about the current hospital stay.

At the start of the first interview, our team employed Q methodology to structure the data collection conducted with the patient as well their primary caregiver, when available. The methodology requires participants to rank order a set of statements *relative* to one another using a grid similar to the one shown in Figure 8. We first opened the interview with a set of preliminary questions that

Figure 8: A sample Q sorting grid that participants use to place their statements relative to one another. Ranks help capture the relative importance of different opinions.



sought to understand the patient's hospitalization prior to the Q sorting exercise. We then asked participants to read through a Q set of 34 statements and place them into a grid based on how much they agree or disagree with the statement relative to all the other statements. The process for creating these Q statements is described in greater detail below. After completing the sorting activity, the investigators probed the participant to explain his or her reasoning for the placement of statements and general opinion about the statements.

Following the Q sort, participants were asked to complete two interviews, one in the hospital and one over the phone within 7 days of discharge. The investigators also conducted an in-room observation within the hospital following the first interview session with a study participant. The in-room observations complemented a set of observations conducted from the staff perspective during critical moments of information transfer between patients and their providers, such as nursing bedside hand-offs, care conferences, interdisciplinary rounding, and at discharge. The interview protocol included topics such as patient routines during the course of their stay, communication with staff, families, and friends, and use of technology while hospitalized. All methods were reviewed and approved by the IRB.

Sample

We employed a purposeful sampling method to recruit 27 patients and 19 caregivers. Patients were selected from a daily inpatient census based on whether the patient was primarily a surgical or medical patient, based on fitness to participate, and ensuring a representative demographic distribution. Eligible patients had to have been in the hospital for at least 24 hours, speak English, and be able to participate in a conversation about their immediate care. Patients that were disoriented to person, place or time or were not recommended by the attending staff were excluded. For our pediatric cohort, eligible participants were at least 7 years old and required parental consent. Caregivers included family members and friends of patients who actively observed or participated in the hospitalized patient's care.

Table 7: Study population sample

		Adult Patients	Child Patients	Caregivers	Total
Total N		**14**	**13**	**19**	**44**
Gender					
	Male	7	6	2	15
	Female	7	7	15	29
Ethnicity					
	Hispanic or Latino	0	3	3	6
	American Indian/Alaska Native	0	1	1	2
	Asian	2	2	1	5
	Native Hawaiian/Pacific Islander	0	0	1	1
	Black/African American	4	2	1	7
	White/Caucasian	8	10	12	30
Education					
	Less than high school	1	13	0	14
	high school graduate	2	0	2	4
	Some college	6	0	5	11
	College graduate	4	0	8	12
	Post graduate	1	0	2	3
	Unspecified	0	0	0	0
Age					
	7-12	0	3	0	3
	13-17	0	7	0	7
	18-29	2	0	1	3
	30-39	2	0	7	9
	40-49	2	0	6	8
	50-59	4	0	3	7
	60-69	2	0	0	2
	70-79	2	0	0	2
	Unspecified	0	2	2	4

We also sampled basic details about the participants past healthcare experiences and use of technology. Thirty-eight of the 44 participants (86%) reported having used a smartphone. Twenty of the patient participants and 13 of the caregivers (45% and 30% respectively) reported having a prior hospitalization. All but one of the patient participants had already been in the hospital for at least 1-3 days with nine of the participants (20%) having spent at least one week in the hospital.

Analysis

The primary goal for analyzing Q data is to identify a set of factors that describe an intrinsically coherent representation of what an individual associated with what that factor believes about the topic. We analyzed the Q sorts collected from our study participants using the freely-available PQ method software (Schmolck 2017). We separated the sorts created by caregivers from those created by patients to analyze each groups' views on inpatient information needs independently. The software provides a detailed statistical summary of correlations between each sort and the statements within each sort. We then used principal component analysis on the software-produced correlation matrix to identify unique "factors" where participants' Q sorts clustered together. A factor is essentially an amalgamation of similar Q sorts into a single, gestalt configuration. Factors are defined by a selection of persons who unambiguously load highly on the factor. After obtaining the factors from the principal component analysis, we then used varimax rotation to maximize the likelihood that each individual sort tended to be associated with just one factor (McKeown & Thomas 2013). For the purposes of this analysis, we chose the factors based on the principle of Eigenvalues Greater Than Unity (Watts & Stenner 2005). The eigenvalues refer to how well a given factor characters the study sample. In both the patient and caregiver Q sorts, the analysis produced four factors. In each sample, the top three factors greatly exceeded or were very close to an eigenvalue of one, while the remaining fourth factor was below 0.20 and had an explanatory variance of one percent. Even though there is not an objective number of factors that should always emerge from a Q analysis, prior research suggests 2 to 4 factors is typical (Watts & Stenner 2005; Brown 1993).

As part of the Q analysis, we calculated for each statement a normalized weighted average statement score that reflects a statement's relative position within an overall distribution of gathered scores (in this case, how much each factor grouping agrees with a statement). Typically, statements with a z-score larger than 1 or smaller than -1 are referred to as characterizing for that factor. The z-score is calculated as a mathematical expression of the distance between a particular absolute score and the mean average score of the measured sample, expressed proportionately in terms of standard deviations.

Interviews were audio recorded and then transcribed for qualitative analysis following the interviews. Codes were grounded in the original statement categories, with additional codes developed based on emergent themes identified during the content analysis. All study methods were reviewed and approved by a university IRB as well as an IRB at each site location.

Results

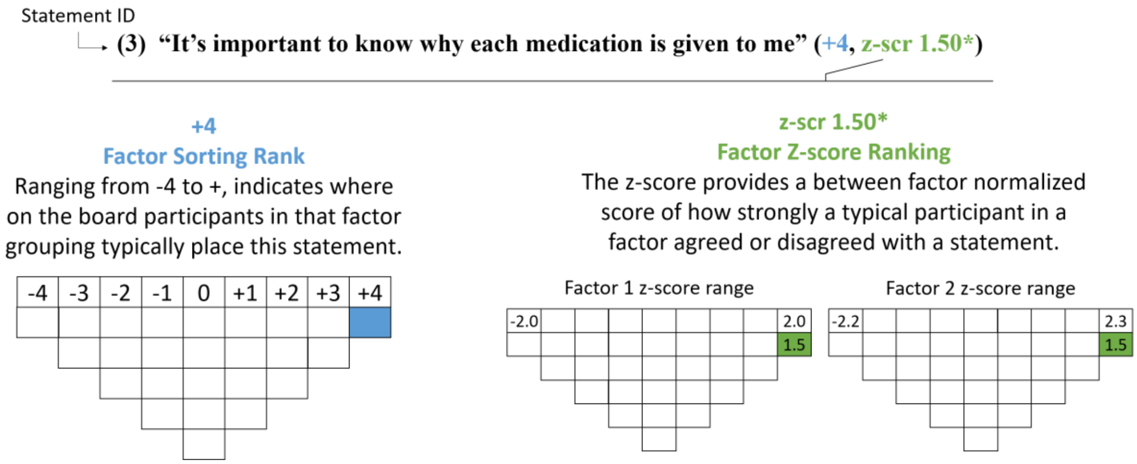
Of the original 28 patient participants, 2 were not able to complete the Q sorting process (one of whom dropped out of the study due to earlier than expected discharge). We found that 22 of the remaining 26 patient participants and 16 out of 19 caregiver participants each sorted into three factor groups. Four patient participants were excluded from the final analysis—2 did not have significant associations and 2 other participants sorted across multiple factors. Three caregiver participants sorted across more than one factor and were excluded. In our patient group, the final group of factors account for 43% of the variance. In our caregiver cohort, the final group of factors account for 59% of the variance (Table 8). In the patient group, the participant q-sorts were relatively evenly split across the three groupings (9, 6, 7 patients, respectively). In contrast, most of the caregiver participants loaded into the first factor oriented around tracking.

Table 8: Patient Factors

	Explained Variance	n	Female	Medical	Surgical
Patient Factors					
Factor 1: Immediacy	19%	9	56%	67%	33%
Factor 2: Information modality	11%	6	50%	33%	67%
Factor 3: Patient Empowerment	14%	7	43%	57%	43%
Caregiver Factors					
Factor 1: Tracking	28%	10	80%	50%	63%
Factor 2: Caregiver Empowerment	18%	3	100%	33%	67%
Factor 3: Patient Safety	13%	3	67%	67%	50%

Each factor has a subset of distinguishing statements out of the total set of 34 statements. In the factor summaries presented below, a distinguishing statement is followed by its relative ranking on the grid (+4 to -4) for that factor group and a z-score value that indicates the level of agreement (positive) to disagreement (negative) relative to the sample average score. The grid ranking (+4 to -4) is a useful comparison within a single factor group indicating the most important statements at +4 and least important at -4, while the z-scores are particularly useful for comparing the same statement's normalized ranking across all three factor groups. For example, in Factor 1 statement 8 is presented as, "It's important to know how to get help if I am worried or need information" (+3, z-scr 1.35*). The value of +3, means that people in the Factor 1 group typically valued this statement in the 2nd from the most important tier of the sorting grid. The z-score of 1.35 is a normalized statement ranking for the factor group and has an asterisk to indicate that it is statistically significant at $p<0.05$. In this case, the participants from the other factors ranked statement 8 with a z-score of 0.29 and -0.26, while Factor 1 had a score of 1.35. This scoring suggests that people in Factor 1 think statement 8 is more important than people in the other groups. Additional explanation is provided in Figure 9.

Figure 9: Example of how factor ranking and score ranking are reported in this study.



Ranging from -4 to +, indicates where on the board participants in that factor grouping typically place this statement.

The z-score provides a between factor normalized score of how strongly a typical participant in a factor agreed or disagreed with a statement.

Patient Q Results

Patients sorted into three factor groups that conveyed three attitudes towards managing and receiving information in the hospital. The factors had an even distribution among hospital sites, gender, and type of service (medical vs. surgical). All patient participants strongly disagreed with statement #30, "I prefer to leave decisions about my medical care up to my doctor". These patients expressed general agreement with statements about wanting to know what will happen with their care for the day (#2), the importance of speaking up when they have a question (#6), and feeling like their doctors and nurses listen to them (#21). However, key differences emerged regarding how the participants prioritized types of information, relationships, and information modality. The first group, named Immediacy, focused on the importance of information that was recent or can change frequently. The second group, named Information Modality, prioritized statements that emphasized how information is communicated. The final group, Patient Empowerment, stressed the importance of feeling ownership over their care and empowered to make choices as an essential part of their hospital experience. Adult patient quotations are indicated by an “A” and pediatric quotations by a “Y”, followed by a number (e.g. A02).

Factor 1: Immediacy

The first factor grouping was characterized by an emphasis on information that described the patient’s current status and immediate situation. Based on the q-analysis, Factor 1 was associated with 8 distinguishing statements, summarized in Figure 10.

Participants loading on this factor had strong agreement with statements on wanting to know how serious the patient’s current situation is (#8/#15) and wanting to be informed about changes that occurred while in the hospital (#16). Many patients spoke specifically about changes in their medications. As one of the participants explains, “*knowledge is power and [knowing] what medications*

Figure 10: Distinguishing statements for Factor 1 loading from patient interviews and Q analysis.
The statements emphasize the importance of understanding the immediate situation. Each statement is followed by a sorted ranking from + 4 to -4 and a z score indicating normalized level of agreement relative to the group average, ranging from 2.26 to -2.19.

Items Ranked Higher in Factor 1 Array than Other Factors (sorted by greatest agreement)

(3) “It’s important to know why each medication is given to me” (+4, z-scr 1.50*)

(15) “It’s important to know how serious my illness is” (+4, z-scr 2.02*)

(8) “It’s important to know how to get help if I am worried or need information” (+3, z-scr 1.35*)

(12) “It’s important that I am not a bother to my doctors and nurses (-1, z-scr -0.41**)

Items Ranked Lower in Factor 1 Array than Other Factors (sorted by greatest disagreement)

(22) “It's important to know how my doctors and nurses are communicating with each at shift changes” (-3, z-scr -1.51**)

(20) “I like to keep track of things by just paying attention and remembering (-3, z-scr -1.26*)

(1) “It’s important to know the names and responsibilities of my doctors, nurses, and other health care providers” (-2, z-scr -0.86**)

(14) “It’s important to feel like my doctors have time to answer my questions (-1, z-scr -0.58**)

All statements listed have significant loading with this factor: (*) denotes p<0.05; (**) denotes p<0.01

I'm taking and for what condition and is this a medication that's just temporary related to this condition that I have or is this one of my regular medications that I take for a different condition?" (A06). This patient, A06, articulated the importance of this statement because of concerns about allergic reactions and a desire to have a collaborative relationship with their care team. Not being informed about this kind of information can increase this group's levels of anxiety. *"When I'm really, really worried, I get really stressed out and no one helps me, and I overstress and I get just - but when someone helps me, I stop stressing because I get random times of stress and it's not very fun. It makes all my muscles tense up and hurt." (Y05).*

Wanting to receive frequent updates from the care team and be informed about the immediate situation aligns with Factor 1's emphasis on having positive relationships with the nurses and doctors providing care. This group emphasized the importance of not being a bother (#12) more so than the other factors. In one respect, they don't care as much about feeling like they have time with their clinicians (#14), but they do want to make sure that their voice is heard when they do interact with their clinical care team (#3). *"If you're still confused [and] nobody can help now, you worry. So you need something, like ask doctor what I have to do to keep my body continue to working" (A14).*

However, people in the immediacy factor were the least concerned among the different factors with knowing the names and responsibilities of their care team (#1/#22). One patient explained, "*I don't have to know what they're talking about. All I care is the doctor or nurse come to see me, that's it. They know what they're doing about me. When they change their shift, I don't need to know. They have the chart, they have the data. It's not important to me" (A14).* The patients associated with this factor appeared to be less concerned with hospital staff responsibilities and coordination activities, but instead focused on events that directly impacted their health like medications.

Factor 2: Information modality

The second factor grouping was characterized by an emphasis on the way information is communicated, grounded in a concern about patient safety. Based on the Q-analysis, Factor 2 was associated with 8 distinguishing statements, summarized in Figure 11.

Participants in the information modality factor were very concerned with staying informed about hospital operations (#3/#22) and how information is communicated (#11). Factor 2 patients critiqued a lot of the traditional approaches to communicating information. Standard handouts were difficult for one participant: *"Well, because I know I'm a visual person, like you can't just like give me a bunch of handouts and tell me to read them and that I'll get it? I'm a visual person, you have*

Figure 11: Distinguishing statements for Factor 2 loading from patient interviews and Q analysis.
The statements emphasize the importance of understanding the immediate situation. Each statement is followed by a sorted ranking from + 4 to -4 and a z score indicating normalized level of agreement relative to the group average, ranging from 2.26 to -2.19.

Items Ranked Higher in Factor 2 Array than Other Factors

(3) "It's important to know why each medication is given to me" (+4, z-scr 2.26**)

(11) "It's important to get information in a way that I can understand" (+4, z-scr 1.47**)

(26) "It's important that my doctors and nurses agree with my decisions for my care" (+3, z-scr 1.18**)

(25) "It's important to know what kinds of safety errors can happen with patients in my situation" (+3, z-scr 1.12*)

(22) "It's important to know how my doctors and nurses are communicating with each other when there are shift changes" (+2, z-scr 0.72**)

Items Ranked Lower in Factor 2 Array than Other Factors

(28) "It's important that the hospital respects my need for privacy" (-3, z-scr -1.08*)

(7) "It's important to know about different options for how to treat my illness" (-2, z-scr -0.64**)

(15) "It's important to know how serious my illness is" (-1, z-scr -0.42**)

All statements listed have significant loading with this factor: (*) denotes p<0.05; (**) denotes p<0.01

to like – well, in this case, you kind of have to like show me when you're talking to me" (A02). Some participants mentioned that getting information as pictures or video, or being able to talk through the handout with a clinician would make the information easier to understand.

Although this group was also concerned with frequent everyday activities like medication administration, it was grounded in concerns about safety (statement #25). Compared to the other groups, Factor 2 had the strongest agreement with this statement (+3, z-scr 1.12*)**.** This attitude towards around safety was strongly associated with having caregivers involved as recipients of information. For the patient, it was a challenge "t*o focus, yeah. Luckily [my caregiver] was here… I know that tomorrow when he comes to pick me up and I go home, then they'll give us all that stuff and I want to make sure that he's here in plenty of time so when they're explaining it to both of us, we're both hearing it. I might not be hearing it as clearly, but he'll be there to hear it too." (A08, #25).* Participants in this factor emphasized the importance of having physicians and nurses agree with the patient's decisions (#26).

Compared to other groups, participants associated with Factor 2 disagreed the most that cost concerns and respecting privacy are important. In contrast to Factor 1, patient participants in this group were less concerned about the seriousness of their medical situation.

Factor 3: Patient Empowerment

Participants associated with the third factor agreed with statements that highlighted the importance of being an active, engaged patient—categorized as emphasizing “patient empowerment”. People in this group placed greater emphasis on the longer-term trajectory of their care and their personal responsibility for managing their health. Based on the Q-analysis, Factor 3 was associated with 9 distinguishing statements, summarized in Figure 12.

All patient participants in the study seemed to express some level of autonomy and self-determination about their car. For example, all 3 patient factor groupings disagreed with statement #30, “I prefer to leave decisions about my medical care up to my doctor”. However, patients associated with Factor 3 placed statement #17, “It’s important that I be an active participant in my healthcare”,

Figure 12: Distinguishing statements for Factor 3 loading from patient interviews and Q analysis.
The statements emphasize the importance of understanding the immediate situation. Each statement is followed by a sorted ranking from + 4 to -4 and a z score indicating normalized level of agreement relative to the group average, ranging from 2.26 to -2.19.

Items Ranked Higher in Factor 3 Array than Other Factors (sorted by greatest agreement)

(15) “It’s important to know how serious my illness is” (+4, z-scr 1.97**)

(17) “It’s important that I be an active participant in my healthcare” (+4, z-scr 1.75**)

(9) “It’s important that I know what I will need to do for my health after leaving the hospital” (+3, z-scr 1.51**)

(33) “It's important that I understand my doctors' reasoning when they give a recommendation” (+3, z-scr 1.08)

(4) “It’s important to know when I can leave the hospital” (+1, z-scr 0.63**)

Items Ranked Lower in Factor 3 Array than Other Factors (sorted by greatest disagreement)

(12) “It’s important that I am not a bother to my doctors and nurses” (-4, z-scr -1.63)

(25) “It's important to know what kinds of safety errors can happen with patients in my situation” (-3, z-scr -1.32**)

(13) “It’s important to know what to ask my doctors or nurses” (-2, z-scr -0.69*)

(11) “It’s important to get information in a way that I can understand” (0, z-scr -0.15**)

All statements listed have significant loading with this factor: (*) denotes $p<0.05$; (**) denotes $p<0.01$

as one of the highest ranked items in their sorting grid compared to participants in the other factor groupings. *"I'm a control freak, I like to be in control so it's important that I am, if not totally in control, a participant…when you're otherwise young and healthy, you really want to be an active participant so that you understand the consequences later on, because you expect to be living the consequences later on." (A05)*. Participants in Factor 3 scored this statement at +1.75 (z-score), compared to 0.60 and 0 in Factors 1 and 2, respectively.

The focus on active engagement appears to be linked to other statements around the importance of future responsibilities like knowing what to do after leaving the hospital (#9). Similar to Factor 1 (Immediacy), the Factor 3 participants want to know how serious their illness is (#15, z-score 1.97). However, they focus primarily on how this impacts the future and when they can leave the hospital (#4, z-score 0.63). *"I don't want to know if it's worsening, but I want to know how serious it is so I can do stuff myself to help." (Y12)*. Factor 3 still agreed with, but placed less emphasis on statements relating to more immediate concerns, like "what will happen with my care today" (#2) and "it's important to know why each medication is given to me" (#3).

Like Factor 1 (Immediacy), people in this factor believe that having a positive relationship with their clinical care team is important (#27, z-score 0.98) and rank highly that "it's important to feel like my doctors have time to answer my questions" (statement #14, z-score 0.94). Factor 3 patients interpret the relationship slightly differently, however, and do not care about being a bother (#12, z-score -1.63) when trying to get answers. Interesting, people in Factor 3 are the least concerned out of the patient factor groupings with the way information is communicated (#11) and do not focus their questions around concerns with possible safety errors (#25). Factor 3 rated this statement on safety concerns the lowest out of the factor groupings, with a z-score of -1.32 compared to 0.59 and 1.12 for Factors 1 and 2, respectively.

Caregiver Q Results

During our inpatient visits, we collected 19 complete Q sorts from interviews with caregivers. All pediatric patients had caregivers frequently present, but far fewer adult patients in this study had such active caregivers. Thus, our sample includes 16 caregivers of pediatric patients and 3 caregivers of adult patients. In contrast to the patient Q sort process, this caregiver group had a greater consensus in attitudes—both agreement and disagreement—about the statements in the sorting grid. This meant that there were fewer statements that varied between each factor grouping for the caregiver cohort. Some of the topics that caregivers commonly agreed with each other included (1) giving importance to having information that's easy to share with others (#24), and (2) saying that having someone else help keep track of things is important (#19). However, caregivers across factors said that feeling like the doctors had time to answer their questions (#14) and knowing about different treatment options (#7) were important. Caregivers loaded in 3 primary factor groupings, linked to themes of “Tracking”, “Caregiver Empowerment”, and “Patient Safety” for Factors 1, 2, and 3, respectively. The majority of caregiver participant q-sorts loaded into the Factor 1 group focused on tracking. However, those participants in factor 2, for example, had very high loadings within that factor, suggesting a highly independent group of opinions relating to information needs in the hospital. The caregivers ranked each statement on the sorting grid from +4 to -4, with normalized z-score values ranging from +2.1 to -2.15. The normalized z-score values provide a baseline comparison for the strength of attitudes scored by a given factor grouping. In this case, statements with z-scores closer to 2.1 or -2.15 represent the most strongly held attitudes by caregiver participants. Each quotation is labeled “A” for adult patient, “Y” for young pediatric patients, or “C” for caregiver, followed by the participant number (e.g. C08).

Factor 1: Tracking

The caregivers in Factor 1 (F1) represented the largest sample of participants. This group is uniquely different from the other groups based on how these caregivers rated the importance of capturing information in order to keep track of activities (statement #18). Compared to Factors 2 and 3, the caregivers in Factor 1 expressed greater agreement with statements around the importance of information management. There were six distinguishing statements for this group, summarized in Figure 13.

The importance of tracking is supported by the fact that F1 participants strongly disagreed with just relying on memory (#20, z-score -1.37). One caregiver explained how they used a variety of strategies to keep track of their daughter's care. "*They gave us a notepad when we were welcomed in. I wrote things down like that, I also put things in my phone and then also calling and letting someone else know pretty immediately is also a way to help*" (C14). Other participants mentioned using the hospital room whiteboard during the inpatient stay and maintaining a binder to collect and track information over multiple clinical visits. Whiteboards were frequently used to capture

Figure 13: Caregiver distinguishing statements for Factor 1 loading from the caregiver interviews and Q analysis.
Each statement is followed by a sorted ranking from + 4 to -4 and a z-score indicating normalized level of agreement relative to the group average, ranging from 2.1 to -2.15.

Items Ranked Higher in Factor 1 Array than Other Factors (sorted by greatest agreement)

(15) "It's important to know how serious the patient's illness is" (+4, z-scr 1.41)

(27) "It's important that I have a positive relationship with the doctors and nurses" (+2, z-scr 0.93**)

(18) "It's important that I keep track of things by writing them down so that I remember them" (+0, z-scr -0.15**)

Items Ranked Lower in Factor 1 Array than Other Factors (sorted by greatest disagreement)

(5) "It's important to know the cost of being in the hospital" (-4, z-scr -2.15)

(20) "I like to keep track of things by just paying attention and remembering" (-3, z-scr -1.37)

(4) "It's important to know when the patient can leave the hospital" (-2, z-scr -1.09)

All statements listed have significant loading with this factor: (*) denotes p<0.05; (**) denotes p<0.01

questions or to make notes about physical therapy goals and progress. Caregivers in F1 seem to care about how serious the patient's condition is (#15, z-score 1.41), having medications explained to them (#3, z-score 1.29), and knowing different treatment options (#7, z-score 1.14). These caregivers believe that “it’s important to feel like our doctors have time to answer my questions (#14, z-score 1.17) and disagree with only wanting to know what the doctor things is important (#31, -1.62). This F1 group focused on tracking appeared to care less about cost compared to participants in other factors. When presented with statement #5, “it’s important to know the cost of being in the hospital”, the caregivers in F1 disagreed the most with this statement compared to any other statement on the grid (q sort value -4), with a normalized z-score of -2.15.

Compared to participants in Factor 2 (Caregiver Empowerment), the Factor 1 caregivers placed greater importance on knowing the seriousness of the patient’s health condition (#15) and less importance on the notion of being an active participant in the patient’s care (#17). Factor 1 caregivers differed from the group in Factor 3 (Patient Safety) in that the F1 participants placed less importance on patient safety (#25) and strongly disagreed with leaving medical decisions solely up to the patient’s doctor (#30). Overall, Caregivers in Factor 1 placed importance on performing an assistant type of role for the patient.

Factor 2: Caregiver Empowerment

The caregivers associated with Factor 2 (F2) place the greatest importance on the idea of being an active participant (#17) compared to the other groupings. There were eight distinguishing statements for this group, summarized in Figure 14.

Factor 2 caregivers ranked statement #17, “It’s important that I be an active participant in the patient's healthcare” as the most important statement in the entire Q set (+4, z-score 2.10). This attitude correlates with other statements such as the importance that doctors and nurses listen to the caregiver (#21, z-score 1.69). This group disagreed the most with the statement about leaving decision-making solely up to the clinicians (#30, z-score -1.90). In fact, one caregiver in this factor group summarized this sentiment very clearly. “*I'm very active in her care, so I really don't prefer to leave any of it all the way up to the doctor. Her doctor, specific doctor who we don't get to see*

Figure 14: Caregiver distinguishing statements for Factor 2 loading from the caregiver interviews and Q analysis. Each statement is followed by a sorted ranking from + 4 to -4 and a z-score indicating normalized level of agreement relative to the group average, ranging from 2.1 to -2.15.

Items Ranked Higher in Factor 2 Array than Other Factors (sorted by greatest agreement)

(17) “It’s important that I be an active participant in the patient's healthcare” (+4, z-scr 2.10**)

(21) “It’s important that the doctors and nurses listen to me” (+4, z-scr 1.69)

(6) “It’s important to speak up to doctors and nurses when I have a question” (+3, z-scr 1.58*)

(1) “It’s important to know the names and responsibilities of our doctors, nurses, and other health care providers” (+2, z-scr 0.63**)

Items Ranked Lower in Factor 2 Array than Other Factors (sorted by greatest disagreement)

(12) “It’s important that I am not a bother to the doctors and nurses” (-4, z-scr -2.10*)

(30) “I prefer to leave decisions about the patient's medical care up to the doctor” (-4, z-scr -1.90*)

(15) “It’s important to know how serious the patient's illness is” (+0, z-scr 0.02**)

(3) “It’s important to know why each medication is given to the patient” (+1, z-scr 0.32**)

All statements listed have significant loading with this factor: (*) denotes p<0.05; (**) denotes p<0.01

all the time because he's not on call, but always asks me my opinion first because he knows that I read up on the disease” (C03).

This is a group that embodies a typical feeling of wanting share in any decision-making. How the caregiver relates with the clinical care team seems particularly important for this group. The caregivers in F2 place a lot of importance on knowing the names and responsibilities of the doctors and nurses (#1). Moreover, F2 participants seemed to not care about being a bother to their care team (#12, z-score -2.10). This group places high importance on having a voice with doctors and nurses when the caregiver has a question (#6, z-score 1.58).

Compared to Factor 1 (Tracking), the participants in F2 were relatively neutral in their attitudes about information management. They strongly disagreed with, “It’s important that I keep track of things by writing them down so that I remember them” (#18, z-score -1.68) or about getting support from others in tracking things (#19, z-score -0.96). In contrast to F2’s emphasis on empowerment and engagement, Factor 3 (Patient Safety), focused more on ceding ownership of care to doctors and nurses.

The attitudes revealed in the statements selected by Factor 2 suggest a strong "representative" role on behalf of the patient. F2 is also less concerned than the other factors with collecting information, but instead wants to be very involved with the clinical care team.

Factor 3: Patient Safety

Caregivers in Factor 3 uniquely appear to emphasize concerns about safety (#25), but feel neutral or disagree with the importance of the patient’s information management relative to other aspects of the patients’ care. There were six distinguishing statements for this group, summarized in Figure 15.

One of the most representative statements for Factor 3 was, “It’s important to know what kinds of safety errors can happen with patients in our situation” (#25, z-score 1.01). F3 also agreed the most with the ideas that it's important to understand the doctor's reasoning (#33, z-score 1.53) and getting information about how the patient’s situation is changing over time (#16, z-score 1.48). While the other factors also agreed with statement #16, in the context of the other statements associated with F3, the caregivers in this group exhibit an attitude aligned with a “monitoring” type of role. While receiving status updates is important (#16, #23), the caregivers in this factor are not really concerned with any issue of getting information at a time when they can focus (#32, -1.74).

The caregivers in Factor 3 appears to be more neutral regarding their role relative to clinicians (#30, #31). These caregivers ranked statement #21, “it’s important that doctors and nurses listen to me” lower than the other factor groupings. However, Factor 3 participants did score highly statement #33, “that I understand the doctors' reasoning when they give a recommendation” (#33, z-score 1.53). Factor 3 placed less importance on being an active participant compared to Factor 2 (z-score 0.84 versus 2.10 for F2). F3 also was associated with a more neutral attitude about being

Figure 15: Caregiver distinguishing statements for Factor 3 loading from the caregiver interviews and Q analysis. Each statement is followed by a sorted ranking from + 4 to -4 and a z-score indicating normalized level of agreement relative to the group average, ranging from 2.1 to -2.15.

Items Ranked Higher in Factor 3 Array than Other Factors (sorted by greatest agreement)

(25) “It’s important to know what kinds of safety errors can happen with patients in our situation” (+2, z-scr 1.01**)

(30) “I prefer to leave decisions about the patient's medical care up to the doctor” (+0, z-scr 0.08**)

(31) “I only want to know what the doctors think is important” (-1, z-scr -0.48**)

Items Ranked Lower in Factor 3 Array than Other Factors (sorted by greatest disagreement)

(32) “It’s important to get information at a time when I can focus” (-4, z-scr -1.74**)

(21) “It’s important that the doctors and nurses listen to me” (-2, z-scr -0.71**)

(34) “It’s important that the doctors and nurses understand what is most important to me” (-1, z-scr -0.43**)

All statements listed have significant loading with this factor: (*) denotes p<0.05; (**) denotes p<0.01

a bother to clinicians compared to Factor 2's disagreement with this statement. In contrast to F1, F3 is less likely to care about writing things down (#18, z-score -1.48) or having information in a way that's easy to share with others (#24, z-score -1.83). The Factor 3 caregivers ranked the latter statement the lowest across all statements and compared to other factor groups.

Overall, caregivers in Factor 3 have concerns about safety and being informed of changes in the patient's health status or plan of care, but appears to hold attitudes leaning in favor of placing more control with clinicians. This group emphasized understanding the reasoning behind clinician's recommendations and getting status updates on medication administration and changes to the plan of care.

Discussion: Implications for inpatient communication

Through our interviews of caregivers and patients using Q Methodology, we identified discreet attitudes within these groups about how individuals engage with care information in an inpatient environment. Within the patient cohort, we observed group alignment around information elements that referred to near-term or immediate events, preferences around how the information is communicated, and how information facilities greater patient empowerment. Many caregivers emphasized the importance of information tracking. However, a subset of caregivers also focused on how information can empower caregiver involvement, and how information can help to monitor for patient safety.

One notable finding with this analysis is the diversity of participants within each factor grouping. Even though participants in this study represented very different age groups and care settings and diverse health care scenarios, the results of the Q analysis show alignment in attitudes about information needs in a clinical setting that do not group together along traditional demographics. For example, in the patient Q sort groupings, there was almost equal representation of adults and pediatric patients in each factor grouping. This equal representation also applied to both the type of inpatient care environment, with equal representation from both medical and surgical patients in each group. Pediatric and adult hospital environments can vary in culture, environment, and health care needs. Yet we found similar attitudes and priorities across these settings.

The Q analysis results did show interesting similarities and differences when comparing patients and caregivers. Both cohorts included factor groupings around themes of “empowerment” and “patient safety”. However, patients expressed empowerment in terms of their own independent responsibility and decision-making for their care. The caregivers in Factor 2 emphasized empowerment in terms of a representative role on behalf of a potentially seriously ill patient. In contrast to patients, caregivers uniquely focused on the importance of information management in terms of tracking. The Factor 1 caregiver Q sort expressed an attitude aligned with the "assistant" kind of role for a patient's care. The final caregiver group focused on patient safety did not focus on being an active decision-maker for the patient, but instead remaining in the loop to monitor activity as it occurred. The caregiver attitudes in Factors 1 and 2 linked to assistant and representation in the Q analysis are also reflected in the roles identified in Miller *et. al.*’s work (Andrew D Miller, Mishra, et al. 2016). However, the small cluster of caregivers in Factor 3 suggests an additional monitoring type of role that is separate from the roles identified by Miller and colleagues.

The various factor groupings suggest notable implications for strategies and design of patient-centered communication tools in the hospital. Almost all participants ranked privacy as an unimportant topic relative to other information and relational statements in the Q set. The patients in Factor 2 grouping focused on information modality clearly implies the importance of providing diverse communication paths to facilitate patient needs. Verbal communication with clinicians worked for some patients, but others expressed a need for more visual forms of communicating instructions and education about their medical situation.

Most caregivers expressed an interest in being able to track and monitor information. However, few caregivers prioritized the importance of being able to share information. The caregivers in Factor 3 also focused on the issue of patient safety in terms of frequent status updates and monitoring, but not in terms of advocacy or control over the patient's care. Information in this context seemed to be about providing reassurance and awareness. Factor 2 caregivers, meanwhile, emphasized information elements that emphasized decision-making control. This emphasis suggests an opportunity to design information tools that empower caregivers to express their preferences and capture their questions.

Limitations

Q methodology provides a means for quantifying subjective views and attitudes around a set of topics. However, like other qualitative methods, this study relies on a small sample of hospitalized patients and their caregivers. Our participants spoke English primarily, which can lead to vary different information needs than patients who experience language barriers. In most cases, we interacted with patients in non-critical care environments and therefore sampled potentially less acute conditions that can impact the patients' information needs and communication experiences. We used purposeful sampling to increase the diversity of our study population but the sample of individuals from these two hospital locations may not be representative of the broader population. At the time of the study, the two institutions had limited technology in place for patients to be able to access their medical record information. Patient experiences may differ as patient portals become more ubiquitous. These two institutions are also academic and tertiary care centers that will likely have a different patient population than a county hospital, for example. In addition, the caregiver population in this study is mostly represented by recruitment from our pediatric population site. This result is primarily due to a higher involvement of caregivers in pediatric facilities, but also could lead to a sample of attitudes specific to a pediatric care environment and population. Some literature suggests having a greater number of Q statements. However, due to the acute state of many participants and the needs to work with a pediatric population, we intentionally limited the statement set to 34 statements. These statements provide a representative corpus of topics and issues related to information needs and communication in the hospital environment while also remaining a management amount for this study population to be able to complete while in severely ill state. Finally, the attitudes and preferences captured by the Q sort reflect a particular moment in time. It is possible that patients and caregivers might shift their ranking preferences over the course of the hospital stay, or the views could be anchored around a specific time period in the hospitalization episode. The alignment of views across different care settings and medical scenarios validates the attitudes to a certain extent, but it's possible that individual participants in this study could shift between factor groupings over time.

Conclusion

This study demonstrated clear nuanced attitudes of how patients and caregivers prioritize information and communication preferences in a hospital setting. We solicited views in diverse care environments. Notably, the inclusion of pediatric patients and their caregivers represents a poorly understand patient population in the context of information needs. Using Q method, we found that the attitudes on information needs do not necessarily align across traditional demographic or medical segmentations. We created a quantitative understanding of how different individuals converge on similar attitudes and preferences in this complex care setting.

The interviews, in contrast, serve as mechanism to develop a deeper, qualitative interpretation of patient and family members' perspectives on communication needs while hospitalized, their willingness to engage their providers with questions, and their opinions about the role that technology can play in a hospitalization experience. These needs help to define areas of opportunity for future patient-centered communication platforms. For some individuals, tools that improve dialogue between patients and providers have the potential to improve how well patients and caregivers can anticipate post-hospital decision-making needs. Patients have diverse preferences in what types of information they want to know and how they receive information. Some may prefer to be less involved while other may desire tools that increase their involvement. Digital tools have the capacity to enhance personalization of care delivery, enable more proactive 2-way collaboration, and empower caregivers to track information about the patient to engage the clinical care team in asynchronous ways. Ultimately, the interviews in this study pointed to a consistent, strong desire for changing the flow of information in the hospital to enable patients and caregivers to have access to key data about their care when they need or desire it.

Chapter 6. Using Experience-Based Design to Understand the Patient and Caregiver Experience with Delirium

Abstract

We sought to understand patient and caregiver experiences with episodes of delirium in the hospital and develop novel approaches to enhance patient and caregiver involvement. We interviewed 30 patients, caregivers, and hospital staff and surveyed an additional 135 individuals about their experiences with delirium. Through our analysis of conversations with study participants, we found that caregivers: (1) often serve as early detectors of delirium; (2) help patients re-orient during episodes of delirium; (3) lack adequate preparation or training to be actively involved in delirium detection and response; and (4) can create challenges to delirium management and response. In addition, through a set of co-design sessions with key stakeholders, we developed tools and processes designed to enhance caregiver education about delirium and facilitate their involvement in detecting and responding to signs of delirium. Our work increases understanding of the caregiver perspective and role in episodes of delirium as well as describes strategies to support increased caregiver involvement in the hospital.

Introduction

Delirium is an acute state of confusion and cognitive impairment associated with increased risk of morbidity and mortality that affects more than 20% of hospitalized patients (Morandi & Jackson 2011). It is often poorly diagnosed and recognized by hospital staff (El Hussein et al. 2015). Delayed diagnosis can lead to longer hospital stays, additional health complications and can contribute to cognitive and functional decline. Also, patients with delirium have a 2.19 times increased relative risk of death (Salluh et al. 2015). The reasons for delayed diagnosis are diverse, but include staff challenges in recognizing changes from a patient's cognitive baseline state, communication barriers with patients and family caregivers, and inconsistent use of assessment tools (Lawlor & Bush 2014). Importantly, delirium is a potentially preventable clinical syndrome and therefore is increasingly recognized as an important indicator of patient safety and health care quality. Many of the components associated with delirium prevention—physiological monitoring, medication assessment, and care coordination—are also important elements of enhancing patient safety in a hospital setting (Reston & Schoelles 2013).

Considering that delirium identification requires detecting a change from a patient's baseline state, health system interventions are increasingly recognizing the role of family caregivers—persons that often have the most comprehensive perspective on a patient's baseline cognitive state. Yet family involvement with delirium management and care is a novel and undeveloped approach. Overall, no delirium study has fully utilized the expertise that family members can offer clinicians, including caregivers' knowledge of the patient in question (Halloway 2014). Leveraging caregiver expertise in a hospital setting is an emergent topic and offers a complementary approach to delirium recognition and management. To understand patient and caregiver involvement in delirium, we conducted a series of interviews and group workshop sessions and found that:

- Caregivers often act as an important source of surveillance for delirium symptoms
- A lack of support and coordination of caregiver involvement can create unnecessary barriers and stress on both patients and staff
- Patients, caregivers, and staff identified tools to support greater caregiver involvement as part of the patient's care team

Background

The diagnostic and care coordination challenges related to delirium highlight the providers' lack complete awareness of a patient's baseline cognitive state or the capacity to identify changes from baseline. This awareness gap points to the potential value in understanding the experiences and work conducted by patients and families in coping with this issue. We examine existing approaches to involving families and caregivers in addressing delirium, our current understanding of the emotional and psychological impact of delirium, and how research and practice management has conceptualized patient and family involvement within an inpatient setting.

Approaches to involving patients and family in delirium

Research into involving families around the issue of delirium has primarily focused on staff-led screening, education, and bedside interventions (Halloway 2014). Yet, the information that family members and close caregivers have about a patient's previous mental state and their observations of changes in mental status are invaluable for timely and accurate recognition of potential delirium. A systematic review by Finucane and colleagues found that studies of caregivers linked to delirium focused on three areas: (1) caregiver experience particularly related to stress, (2) the caregiver role in detection and symptom monitoring, and (3) caregiver support with information needs and intervention methods (Finucane et al. 2016).

Based on the widely used Confusion Assessment Method (CAM) screening instrument, the Family Confusion Assessment Method (FAM-CAM), was developed by Inouye, Steis, and colleagues to screen for delirium by interviewing family caregivers of the patient (Steis et al. 2012). The authors' study suggests that structured capture of family caregivers' observations provides signal comparable to a trained interviewer for delirium detection. Engaging the family caregiver in alerting health care professionals about a change in mental status has the potential to increase the likelihood of earlier identification of delirium.

As an alternative approach, Massachusetts General piloted the Fam-HELP program, a multicomponent family intervention for delirium prevention. This program targeted specific actions that family caregivers could perform including: (1) helping orient patients through memory cues such as a clock or family photos; (2) engaging the patient in cognition stimulating activities such as current events or past memories; (3) ensuring the patient has accessories available such as eyeglasses and hearing aids; and (4) conversing with the patient with a focus on re-orientation to his or her immediate circumstances (Rosenbloom-Brunton et al. 2010; Rosenbloom & Fick 2014). As part of the program, families and caregivers were tasked with managing a standardized Family Caregiver Tracking Form to document interventions completed each day, with any reasons for non-completion. This approach emphasized partnership between healthcare providers and family caregivers and focused on explicit actions and tracking mechanisms to be owned by the family caregivers.

However, most efforts to engage patients and families in delirium detection and management primarily emphasized increasing education and enhancing knowledge about delirium. Greaves and colleagues interviewed caregivers of patients with cancer and found that the caregivers desired information from healthcare practitioners about the potential for delirium given before a delirium episode occurred (Greaves et al. 2008). Keyser and colleagues used the “Knowledge to Action” process to educate families of older adults about delirium and found that most participants were able to recall information related to risk factors and signs of delirium (Keyser et al. 2012). In another study, participating families were responsible for implementing the advice in a booklet provided by hospital staff and asked to use the suggestions to individualize the content of their interactions to the unique needs of the patient (Black et al. 2011).

Previous qualitative studies on delirium

Despite the potential value of family involvement in delirium detection and management, this issue is often psychologically and emotionally traumatic for patients, families, caregivers, and nursing staff (O'Malley et al. 2008). Prior studies have examined significant increases in level of distress reported by family members when the patient experiences an episode of delirium (Bruera et al. 2009; Morita et al. 2004). Nursing staff similarly face distress when dealing with an aggressive behavior change among patients experiencing delirium. Beyond increased stress, delirium episodes can lead to a greater emotional toll on all of the stakeholders involved.

In a review of qualitative studies on the experiences of nurses and patients experiencing delirium, Bélanger and Ducharme found that while both groups had a strong emotional response to these episodes, they differed in their response strategies and behaviors. Nurses leveraged standardized procedures to complete specific goals and achieve certain symptom targets despite feelings of stress and discomfort (Bélanger & Ducharme 2011). The authors' review also suggested that when nurses actively recognize the patients' experience of delirium episodes it can improve the therapeutic process and help with recovering from the trauma associated with these experiences. Caregivers and patients, conversely, do not have explicit care strategies and were more focused on dealing with the lived experience of distress, often leading to feelings of isolation. Bélanger suggests that the standardized delirium management procedures performed by nurses should proactively incorporate involvement of patients and families to create a more collaborative response to these types of episodes. This idea of acknowledging the patients' emotional experience is important considering that other research has identified gaps in the quality of care practice, including: limited psychological and emotional support of patients during a delirium episode, variation in staff attitudes and ownership of responsibilities for management delirium episodes (Teodorczuk et al. 2013). With limited strategies for responding to a delirium experience, patients can have a stressful and negative care experience.

Overall, limited research describes patients' experiences with delirium from the caregiver perspective. Thus, we have an opportunity to further explore family members' perceptions, experiences, and involvement in relation to patients' delirium particularly as it relates to information needs and management (Greaves et al. 2008).

Conceptualizing patient and family member involvement with patients' care

Recognizing the role of a family member or other caregiver with managing delirium is not inherently new — when a patient is cognitively impaired, physicians and nurses will consult and communicate with the family members about the current state of care. However, few formalized representations exist of the work that patients, family members, and caregivers perform in an adult hospital setting. Often in a complex system like a hospital environment, many of the people involved—patients, staff, family members, clinicians—conduct activities and perform work that are less visible to others. Star and Strauss label this work as background work: a type of invisible work where "workers themselves are quite visible, yet the work they perform is invisible or relegated to a background of expectation" (Star & Strauss 1999). Unruh and Pratt have identified extensive invisible work performed by patients in ambulatory and home environments and found that despite the work being driven by clinical care concerns, such patient work is rarely acknowledged or supported by existing information systems and organizational processes (Unruh & Pratt 2008). In relation to delirium, the lack of formal recognition of caregiver work misses an opportunity to enhance delirium management and leverage strategies that can reduce the burden placed on caregivers in these situations.

Recently, researchers have started to experiment with formalizing patient and caregiver involvement in care. AHRQ's established communication training program, known as TeamSTEPPS, provides evidence-based strategies to improve clinical team communication and collaboration (King et al. 2008). The program has refined tools like SBAR, Check-Back, Two-Challenge Rule, CUS, and Briefs, Huddles and Debriefs as ways to improve safety and reliability and help reduce the communication breakdowns in healthcare. The researchers extended the communication program in a pilot to include patients as part of a care team (US AHRQ 2014). The AHRQ pilot involves a short curriculum to enhance patient/family member knowledge and train them to support participation in a labor & delivery care. Although constrained to a non-emergent health episode, the program showed improvement in family members' perceptions of partnership.

Within the field of human-computer interaction, Hayes et al helped define early research in how parent caregivers leverage tools and identify information needs related to managing their children's health (Hayes et al. 2014). In her research, Hayes explains that caregivers face challenges with their role definitions and highlight a greater need for technology to support their daily background work. Pollack, et al conducted an analysis of caregiver information needs in pediatric settings. Pollack's work highlights the types of challenges parents can face getting information while in the hospital and suggests design opportunities for improved sharing, particularly with the clinical care team (Miller, Pollack, et al. 2016). Miller et al also defined a framework that specifies the roles that caregivers often perform on behalf of patients (A.D. Miller, Mishra, et al. 2016). Caregivers provide companionship, assistance, serve as a patient representative or support planning activities. The roles are not persistent, as caregivers will frequently shift the way they support the patient depending on the circumstances. Kendall and colleagues conducted a series of surveys and observations to describe the information needs of adult patients and caregivers (Kendall et al. 2015). One notable finding was how the design of hospital rooms poorly supported patient and caregiver use of the rooms as an information workspace. The researchers observed situations where caregivers would coopt surfaces like whiteboards for their own tracking purposes.

Many of these studies exploring the patient, family, and caregiver experiences with delirium suggest wide-ranging opportunities to make improvements to the way that these stakeholders participate in a highly emotional and challenging information environment. Tools like FAM-CAM increasingly recognize the value of a patient and family member perspective on delirium detection and management. Evidence that suggests with early detection, multicomponent interventions are effective in preventing incidence of delirium (Martinez et al. 2014). However, patient, caregiver, and staff experiences around this issue are still poorly understood. In this study, we seek to more formally recognize the work and role of family caregivers as a component of delirium management and response.

Methodology

Our analysis is based on cases of delirium at a tertiary care institution in the Pacific Northwest. Using an experience-based design methodology (Bate & Robert 2006), we employed a mixed-methods process of observations, interviews, and questionnaires to explore the experiences of patients with delirium from multiple perspectives within the hospital environment. Finally, through a set of co-design sessions with key stakeholders, we designed tools and processes to enhance caregivers' education about delirium and facilitate their involvement in detecting and responding to signs of delirium. This research was reviewed and approved by the hospital's IRB where this study was conducted.

Observations: We completed 16 hours of observations of hospital units with known high prevalence of delirium, such as wards dedicated to managing patients with sepsis. The researchers observed nursing staff conduct rounds, collected field notes from general unit observations, as well as observed patient-clinician discussions about delirium risk. Six staff and researchers conducted the observations.

Interviews: The authors conducted 16 staff interviews, 10 patient interviews and 4 caregiver interviews. Staff were recruited through flyers and email outreach to nurse and physician units where delirium had been diagnosed within the hospital. Patients were recruited based on a random sample of patients with a delirium diagnosis and hospital admission during the previous 12 months. The research team sent out 450 mailings inviting the previously hospitalized patients to participate in interviews. We also invited the primary caregiver (e.g. spouse or other family member) of interested patient participants to take part in the interviews. We conducted additional recruitment within an established patient & family partner program managed by the hospital.

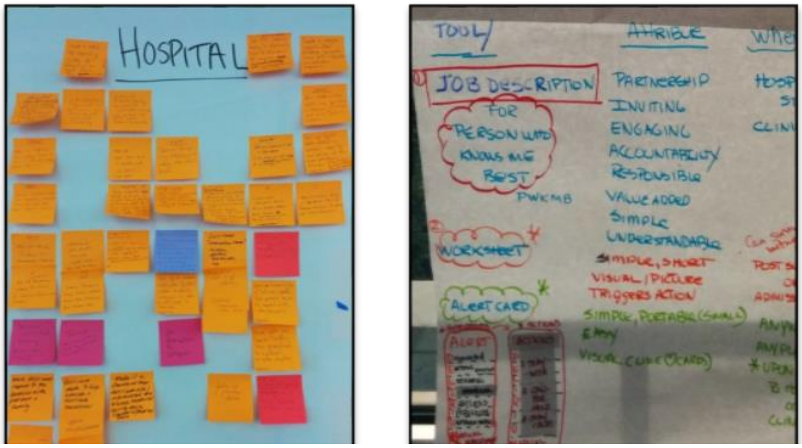
Questionnaires: Between October 2014 and February 2015, we gathered questionnaires from 61 staff, 34 patients and 41 caregiver respondents. Using discharge records for the tertiary care hospital, we sampled all patient households with known delirium from the 2014 calendar year and sent two questionnaires designated for the patient and a family member or other caregiver who was with them during their time of delirium. We designed the questionnaire topics based on insights and themes gained in observations and interviews. Hospital staff completed a similar questionnaire exploring their attitudes around delirium management that was distributed through nursing and unit floor managers throughout the hospital.

Participatory Co-design Sessions: In addition, we invited patients, family members, and hospital staff to partake in two participatory co-design sessions set four weeks apart. Participatory design (PD) is a user-centered design approach that in contrast to other design methodologies, asks users to influence the design process directly (Muller & Kuhn 1993). The PD process included three stages of design research: (1) initial exploration of work through analysis of users, tasks, and context—session 1; (2) discovery and definition processes through interactive design—session 2, and (3) iterative prototyping—post-sessions. The aim of these sessions was to develop a set of prototype tools and processes to address challenges with episodes of delirium from the patient and caregiver perspective. The first session included a series of open-ended brainstorming and discussions about experiences with delirium, affinity diagraming, and initial design ideas for tools and processes to enhance patient and family member experiences. After the first session, the research team met to review session notes and ideas collected and focused the set of topics to inform session 2. Session 2 included a subset of patients, staff, and family members from session 1 who developed initial design mock-ups for tools and resources for patients and families Figure 15.

Analysis

We sent audio recordings from the interviews to a third-party for transcription. The research team then coded the transcripts using an iterative process. We developed emergent themes using a grounded theory approach through axial and open coding and affinity diagrams (Strauss & Corbin 1998). The team regularly met to evaluate data saturation when interview themes no longer presented new theories. Based on affinity diagraming (Figure 16), the research team developed consensus on six themes that emerged from interviews: (1) information flow, (2) emerging from delirium, (3) impact of care environment, (4) staff attitude and behavior, (5) caregivers' reaction and involvement to episodes, (6) post-hospital experiences.

Figure 16: Affinity Diagramming
In the co-design workshop, researchers and participants used an affinity diagramming process to identify and categorize common themes. The research team separately used an iterative process to continue to refine the themes into key categories.



Results

Our team used a mixed methods approach of interviews, observations, and surveys to triangulate on common themes voiced by participants. We found that participants shared a number of concerns and strategies for how delirium was managed during their experiences in the hospital. Participants highlighted feeling poorly prepared for dealing with a delirium episode, experiencing the anxiety around the psychological impact of delirium, and dealing with communication breakdowns that are particular to a delirium episode. Participants also discussed strategies that helped improve timely identification and management of delirium in the hospital.

“Feeling left in the dark”: patient and family information needs and engagement

All our participants—patients, caregivers, and staff—emphasized the challenges with delirium episodes throughout the interviews and questionnaires. Patients and caregivers described feeling unprepared and lacked awareness about delirium until the patient actually experiences an episode. This lack of understanding and preparation contributes to: (1) increased communication barriers between the caregivers and hospital staff, and (2) a potentially missed opportunity for caregivers to be involved in the early detection of the patient’s delirium.

Reflecting on their delirium experience, one participant described how challenging this experience was for his family: *"What kind of frustrated my caregivers was that they had no idea what delirium was [sic]" (P02).* They described how the word "delirium" was never used, which made it difficult to have discussions about what was happening.

Table 9: Staff, Patient, and Caregiver agreement or disagreement on feeling informed about current care situation.

Patients/Families: *I was able to stay informed about all of the care and treatment activities that occurred.*

	Patients		**Caregivers**	
Strongly Agree	3	19%	12	36%
Agree	9	71%	16	48%
Disagree	5	5%	3	9%
Strongly Disagree	0	5%	2	6%
Neither	3	10%	1	3%

Patients/Families: *I was given the right amount of information about the events, care, and treatment activities that occurred relating to the delirium experience.*
Staff: *The current educational materials that we use meet the needs of patients, families, or other caregivers.*

	Caregivers		**Patients**		**Staff**	
Strongly Agree	9	31%	3	17%	5	14%
Agree	12	41%	6	33%	24	65%
Disagree	5	17%	7	39%	8	22%
Strongly Disagree	3	10%	2	11%	0	0%
Neither	6	21%	0	0%	0	0%

One caregiver described the busy environment as an inhibiting factor for her ability to engage around the delirium issue. She mentioned how, "*It just would have been helpful if I would have had somebody take me aside, sit in a room, kind of go over it with me away from my husband because I was with him all the time…I was always asking questions and everybody was busy*" (P23). In the survey, another stated how the "*nurses were busy with hallway computers, never [giving] a feeling that they were aware of patient as individual. No effort to either explain or work* *with me during the daily 8 hours I was present*" (F09). Staff also described how they faced challenges with finding time with patients and caregivers to walk through delirium as a risk. For example, caregivers are not always available and many other topics around the patient's health are often a greater priority. During observations, we noticed that patients were often provided with a packet about delirium, but that this information was one of many documents that ended up getting stacked in a pile by the patients' bedside, usually unread.

Table 10: Staff, Patient, and Caregiver agreement or disagreement on care participation.

Patient/Families: *I was involved as much as I wanted to be in decisions made about the care and treatment provided*.
Staff: *Family members or other caregivers are adequately involved in detecting and managing delirium.*

	Caregivers		**Patients**		**Staff**	
Strongly Agree	12	36%	4	27%	5	9%
Agree	15	45%	8	53%	24	44%
Disagree	5	15%	2	13%	13	24%
Strongly Disagree	1	3%	1	7%	0	0%
Neither	1	3%	7	47%	13	24%

Patients/Families: *I felt confident in speaking up to doctors and nurses when I had a question or concern.*
Staff: *Family members and caregivers feel comfortable speaking up about their questions and concerns relating to delirium.*

	Caregivers		**Patients**		**Caregivers**	
Strongly Agree	15	43%	4	19%	5	12%
Agree	17	49%	15	71%	28	65%
Disagree	2	6%	1	5%	10	23%
Strongly Disagree	1	3%	1	5%	0	0%
Neither	1	3%	2	10%	0	0%

In the questionnaire, there was general agreement among staff, patients, and caregivers that patient and families are involved in delirium management. However, staff strongly felt like caregivers were not sufficiently involved (Table 10) and 23% disagreed that family members felt comfortable raising questions. One nurse practitioner explained "*It feels like patient families don't feel comfortable coming to the provider freely or that they need to ask permission*" (S06). It's possible that even though family members felt positively in the questionnaire about their involvement, they were not aware of the desire from staff for greater engagement. One caregiver mentioned that "*I think I was more reactive than proactive, and if you know what's happening then you can work with it as a team instead of why are you doing this or why is he laying in all his poop, that kind of thing*" (P16). The way information is communicated and the design of the hospital environment could indirectly put caregivers into a passive mode of interaction.

"It's not going to happen to me": communication challenges with delirium

Even though in most case caregivers are perceived as having a positive role and influence in delirium detection and response, we also heard from numerous stakeholders that patient and caregiver involvement could create challenges with delirium management. Being told about delirium can increase stress. Caregivers might not be present at critical times or they might inadvertently create barriers to staff interventions and increase patient anxiety.

Nursing staff mentioned that one challenge with involving family is that they are not reliably present at the moment when you need them. One participant noted, "*the family member can be kind of a beacon that things are somewhat normal—and so delirium can be very challenging to manage without family*" (S19). Overall, staff reported positive experiences when caregivers were consistently present. When caregivers are not present during a delirium episode, staff shared feelings of stress and frustration.

Families can also be disruptive at critical times when proper delirium management requires that the patients have a quiet, low stimulus environment. In one of our staff interviews, a technician mentioned an experience where a caregiver *"was ripping off the restraints when she came into the room and being very hostile to us as the staff because, again, that was kind of emotions [sic] that had other grounds, so it wasn't as much the patient as, like, the family member that sticks in my memory and mind"* (S10). In many cases, disruptions caused by families were not intentional. For example, "s*omething to watch for is that big families can hamper sleep cycles, especially during evening and night time visits*" (S06). Thus, the desire for families to be present and provide support to the patient can also inhibit delirium management.

Not all participants felt the need to be informed about delirium. As one patient participant noted, "*I kind of have mixed emotions about this, preparing the patient philosophically, psychologically with a warning that this might happen*" (P11). This participant indicated that being more informed could contribute to stress. A nurse supported this, explaining that "*some people want to know everything and other people just want a little bit at a time, but being sensitive to that I think is important*" (S###). Other participants framed this idea around a belief that delirium was a concern for others, not them: "*in my mind I said no, it's not going to happen to me. I don't do things like that*" (P20). The mixed attitudes around whether to inform patients about delirium could be in part due to the way the information was communicated. In most cases, patients and families are given a packet of information and a brief overview of what delirium is. However, one participant mentioned that "*It would have been much more helpful to have somebody verbally sit down rather than just handing me a pamphlet*" (P16).

"I wondered if he would come back to normal': the lasting emotional impact of delirium

Because delirium is associated with sudden behavioral changes, participants described feeling great anxiety and distress relating to their experiences with delirium. Through a questionnaire, participants described feeling angry, depressed, hopeless, disrespected, afraid, and resentful in relation to their experiences. Some patients described feeling guilty because they were not able to control their behavior during an episode and had no recollection of what they might have done — "*For the first time it kind of dawned on me that woops, I wonder what has been going on, so at this time I had a little feeling of guilt because I wasn't sure what I had done*" (P11).

Patients often described how their feelings of paranoia and anxiety from the delirium episode persisted after leaving the hospital. After returning home, patients remained fearful for many reasons, including not fully understanding their hospital experience, what delirium is, and why they experienced delirium. One caregiver mentioned, "*I wondered if he would come back to 'normal'*" (C31). Patients and families were frequently not prepared for these emotions, nor had they been given the tools or resources to cope with them outside of a clinical environment. Another patient described how the fear of delirium affected their behavior, "*that experience was so bad for me that I didn't want to take any more painkillers. I was afraid I'd start taking them again and if I took them again that it would start that delirium again*" (P21). In follow-up medical appointments, delirium was rarely discussed. Delirium is usually described as a short-term, acute change in behavior and mental state. However, patients and families saw ongoing impacts following an episode. One patient felt like, even though the delirium episode was over, "*they think that's the way you are and they discount what you have to say afterward*" (P21). This idea was unintentionally reinforced with the use of words like "crazy" from family members such as, "*I mean, you can't really get mad at someone for being crazy"* (P23). Experiencing a delirium episode affected patients' self-confidence and trust with the people they interacted with afterwards.

Table 11: Patient, Family, and Staff beliefs about delirium support after hospitalization

Patients/Families: I had the support that I needed from the health care team after leaving the hospital.
Staff: Patients will get the help that they need regarding their delirium after discharge from the hospital.

	Staff		Patients		Caregivers	
Strongly Agree	4	13%	4	22%	3	15%
Agree	9	29%	9	50%	10	50%
Disagree	14	45%	5	28%	5	25%
Strongly Disagree	4	13%	0	0%	2	10%
Neither	0	0%	0	0%	4	20%

In the questionnaire, participants and staff often disagreed with a statement about patients receiving support for their delirium after a hospitalization (Table 11). Even though half of patients and families indicated they agreed with getting adequate support, the interviews and questionnaire comments indicate a strong emotional impact from a delirium experience for many. In some cases, caregivers did not fully understand the scope of impact after leaving the hospital — "*I over estimated my ability to give effective care to my wife when she returned home.*" (Survey, F01). From the experiences of patients and families, dealing with delirium is a longitudinal problem that persists well after the acute episode is over.

Strategies for improving detection: interacting with the "person who knows me best"

Throughout the study, staff, patients and participating caregivers emphasized the importance of effective engagement with family members and other caregivers. Caregivers' inherent knowledge of patients' baseline cognitive state provides great value in early detection of delirium. In the design sessions, caregivers were often referred as the "person-who-knows-me-best". The caregiver was often described as the first indicator that a patient's cognitive state had changed. "*[My son] told me later he went to the nurses' station and said, 'something's wrong with him; he's not acting* *right* (P14).'" Nurses further supported this sentiment, explaining that "*[Families] can often identify delirium probably before our testing can identify it because they know the patient's baseline very well and they know when they're not at their baseline*" (S19). One nurse practitioner explained that failing to engage families appropriately can lead to situations where, "s*ometimes I'll have families ask me questions that I know I'm sure have been addressed, but for some reason they are not understanding the answer and then it's helpful to go through everything in a really basic kind of way, so I see our role as kind of like medical translators, too*" (S05).

Family and caregiver involvement was a particularly important part of provider staff strategies to prevent reoccurrence of delirium. One interviewed physician explained how, "*you're trying to figure out what triggers happen to cause this delirium and then you're trying to set in place a plan that will kind of prevent those triggers from occurring again, trying to prevent delirium from occurring again, so it might be medications, it might be looking for signs of an infection, being aware of that, it might be sleep/wake cycle and it's going to be a little different for each person so you're going to have to talk with the family about "What's [her] life like at home? Where does she live? Is anybody else around during the day? Does she take her own medications?*" (S18). Caregivers often have knowledge about the patient that can help reduce or more quickly respond to additional episodes of delirium.

Strategies for improving management: simulating an interactive, home-like environment

Patients mentioned how they appreciated human touch as a way to mitigate their fears and concerns when experiencing delirium. P2 described an instance when a nurse, *"sat on the side of the bed and she hugged me for at least a minute, you know, and it was like one of those deals where, you know, it felt safe."* Touch helped to reorient patients emerging from a delirium episode and helped patients feel secure. Patients also described instances where nurses challenged them instead of allowing them to maintain delirious beliefs and ideas. For example, *"One nurse and I don't know her name but I'm grateful for her. She put her hand on my arm and just looked at me in the face and said, "You're not in Juneau. You're in Seattle," and it was, like, boom! She made that connection with me that no one else had been making (P17)."* Patients repeatedly mentioned that it was valuable when caregivers and nurses did not agree with their beliefs but instead challenged their behavior and words. Although caregivers or staff might go along with someone's reminiscing or incorrect understanding of the current place and time, our patient participants suggested that directly confronting the issue was a way to help them reorient. They preferred to be challenged and confronted, rather than just comforted.

Nurses and caregivers described specific strategies to help manage a patient with delirium, such as carefully controlling the patients lighting to align with their circadian rhythm and creating familiar surroundings. Nurses and other patient staff described how family members could help them know the patients' cycle of behavior and overall engagement, so they could attempt to adjust lighting and activity around the patient's normal schedule. However, patients often described the hospital environment as challenging, noisy, and disruptive—factors that could have triggered their delirium episode. "*The noisiness in the room and lights being real bright. Sometimes that's aggravating…sometimes try dimming the lights if that makes things calmer*" (P16). Patients that share rooms or are on floors with a lot of activity often experience environments that make it challenging to get adequate rest. One caregiver described how familiar settings were essential to dealing with the delirium episode, "*When he got home into the familiar surroundings that really kind of pulled him out of it"* (P19). This perspective was reinforced by interviews with staff, who would work to get patients to a state where they could be discharged from the hospital to avoid risk of delirium episodes or do their best to simulate the patient's home environment as much as possible (S18).

Designing for delirium detection and management (co-design sessions)

In the co-design sessions, participants identified new approaches to incorporating the caregiver as a team member and creating new caregiver-centered toolkits. Upon completion of the first session, participants came up with a total of nine ideas to continue to test and refine (Table 12).

During the session, participants focused on delirium throughout three settings: within the hospital, within extended clinical settings, and out in the general community (Figure 17). Many staff participants in the sessions advocated for improved structure of relevant assessment instruments and more consistent and standardized capture of a patient's baseline state. Reflecting on the notable gap in general population awareness about delirium, co-design participants also suggested ways to improve caregiver participation including giving caregivers a formal role in the patient's hospitalized care.

Figure 17: Co-design diagram of settings for delirium improvement.

The workshop focused on three domains: (1) within the hospital, (2) in the ambulatory clinic environment, and (3) in non-clinical everyday life.

Table 12: Session 1 Co-design Ideas

Category	Session 1 Co-design Generated Concepts and strategies
Population-level education and awareness	• Video with patients, spokesperson • Symposium on delirium management • Prevention-focused website: NoDelirium.com • Tent-cards for hospital cafeteria
Screening tools	• Implement functional assessment questionnaire • Implement Montreal Cognitive Assessment (MOCA) • Implement an EMR cognitive assessment folder/section • Pre-hospitalization cognitive baseline assessment via patient portal system • Hospital discharge forms incorporate cognitive assessment results for sharing with follow-on care facilities • Wallet-size alert card for caregivers
Caregiver-based monitoring tools	• Create a job description for caregivers of hospitalized patients • Monitoring sheet

The co-design sessions resulted in two broad strategies to support caregivers: (1) a succinct patient card that provides a checklist of delirium systems and suggested actions for caregivers; and (2) a symptom tracking board that caregivers update daily to provide their unique perspective on the patient's cognitive state. Specifically, the study team began prototyping in the 30 days between sessions on: (1) a job description for the "Person Who Knows Me Best"; (2) an alert card and (3) a caregiver-managed monitoring sheet. These artifacts emphasized tangible methods to engage a family member or caregiver to share their understanding of the patient and the patient’s current mental state with the clinical care team.

Improving awareness: breaking assumptions around delirium

An important component of the co-design sessions involved an activity where patients, caregivers, and staff collectively brainstormed common assumptions that they held about delirium (Figure 18). The ideas from this activity guided follow-on group discussions informed designs that could address some of the commonly held assumptions about the acute condition. Of the assumptions generated by participants, they converged on the following three: (1) “It will never happen to me”, (2) “The best person to detect delirium is the patient’s blood relative”, and (3) “Everyone learns the same way”.

Figure 18: Staff, Patient, and Caregiver generated assumptions about delirium

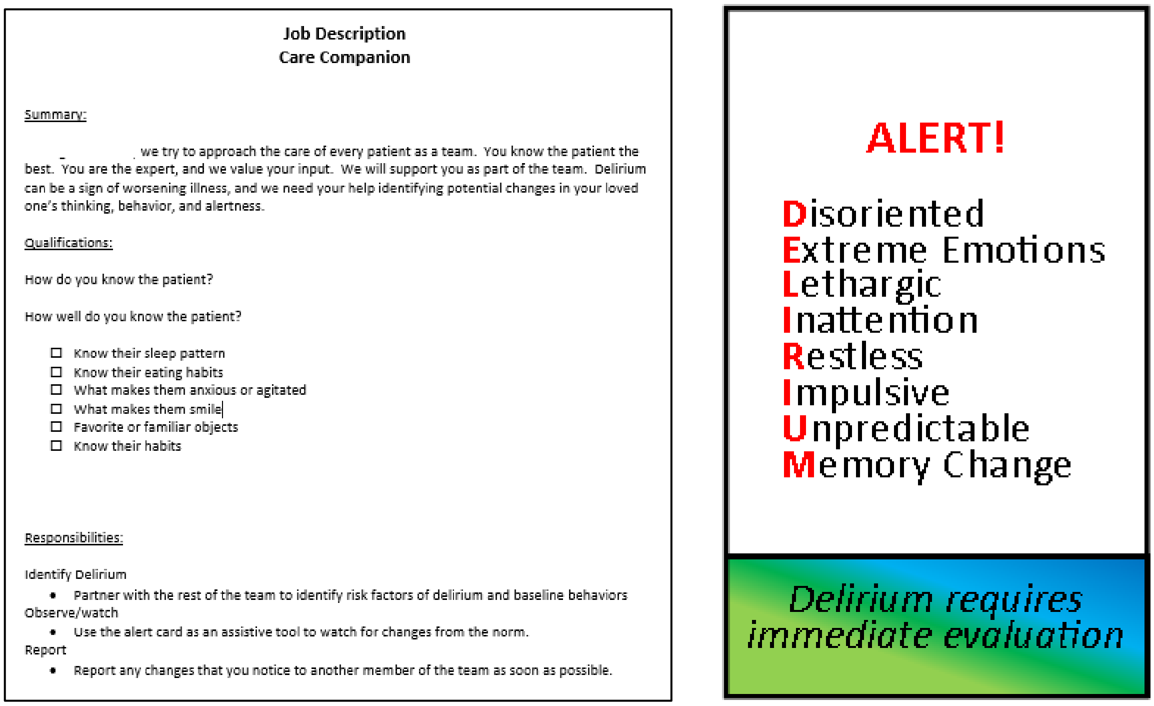
The feeling that delirium “won’t happen to me” was voiced by several of the patient participants in the co-design sessions and in the interviews. Participants believed the risk was distant from their own experience. Staff also added that they have a bias of focusing delirium prevention on patients with alcohol withdrawal symptoms instead of more generalized risk indicators. The researchers worked with the co-design participants to incorporate these three priority assumptions into themes that would guide follow-on generation of new ideas, processes and prototypes. For example, in order to improve general awareness of delirium risk, an early participant design was a mock-up of tent cards with information on what is delirium, who it affects, signs to look for, and actions to take.

Early detection, early interaction

An important part of the design discussions involved figuring out ways to involve families and caregivers into the conversation about delirium risk as early as possible. Some ideas suggested included giving family members an orientation upon arriving at the hospital, or giving caregivers the ability to alert staff through a hotline that triggers a code response from a dedicated team. Staff often mentioned seeing a lot of variability in how delirium is discussed and managed. They questioned existing educational tools to help inform patients and families about delirium risk that led to an emphasis on incorporating structured cognitive and functional assessment instruments with every patient interaction. For example, participants suggested leveraging the patient portal to capture patient’s baseline cognitive state before a patient is admitted into the hospital.

Over the course of the two co-design sessions, participants solidified their ideas of early detection around a wallet-sized card to help standardize communication and make the information available in a format that family members and patients can easily hold onto (Figure 19). Staff, working with caregivers and patients, also introduced a formalized job description for caregivers.

Figure 19: Co-design artifacts focused on supporting caregiver role definition within a care team



Job Description
Care Companion

Summary:

we try to approach the care of every patient as a team. You know the patient the best. You are the expert, and we value your input. We will support you as part of the team. Delirium can be a sign of worsening illness, and we need your help identifying potential changes in your loved one's thinking, behavior, and alertness.

Qualifications:

How do you know the patient?

How well do you know the patient?

- ☐ Know their sleep pattern
- ☐ Know their eating habits
- ☐ What makes them anxious or agitated
- ☐ What makes them smile
- ☐ Favorite or familiar objects
- ☐ Know their habits

Responsibilities:

Identify Delirium
- Partner with the rest of the team to identify risk factors of delirium and baseline behaviors

Observe/watch
- Use the alert card as an assistive tool to watch for changes from the norm.

Report
- Report any changes that you notice to another member of the team as soon as possible.

ALERT!

Disoriented
Extreme Emotions
Lethargic
Inattention
Restless
Impulsive
Unpredictable
Memory Change

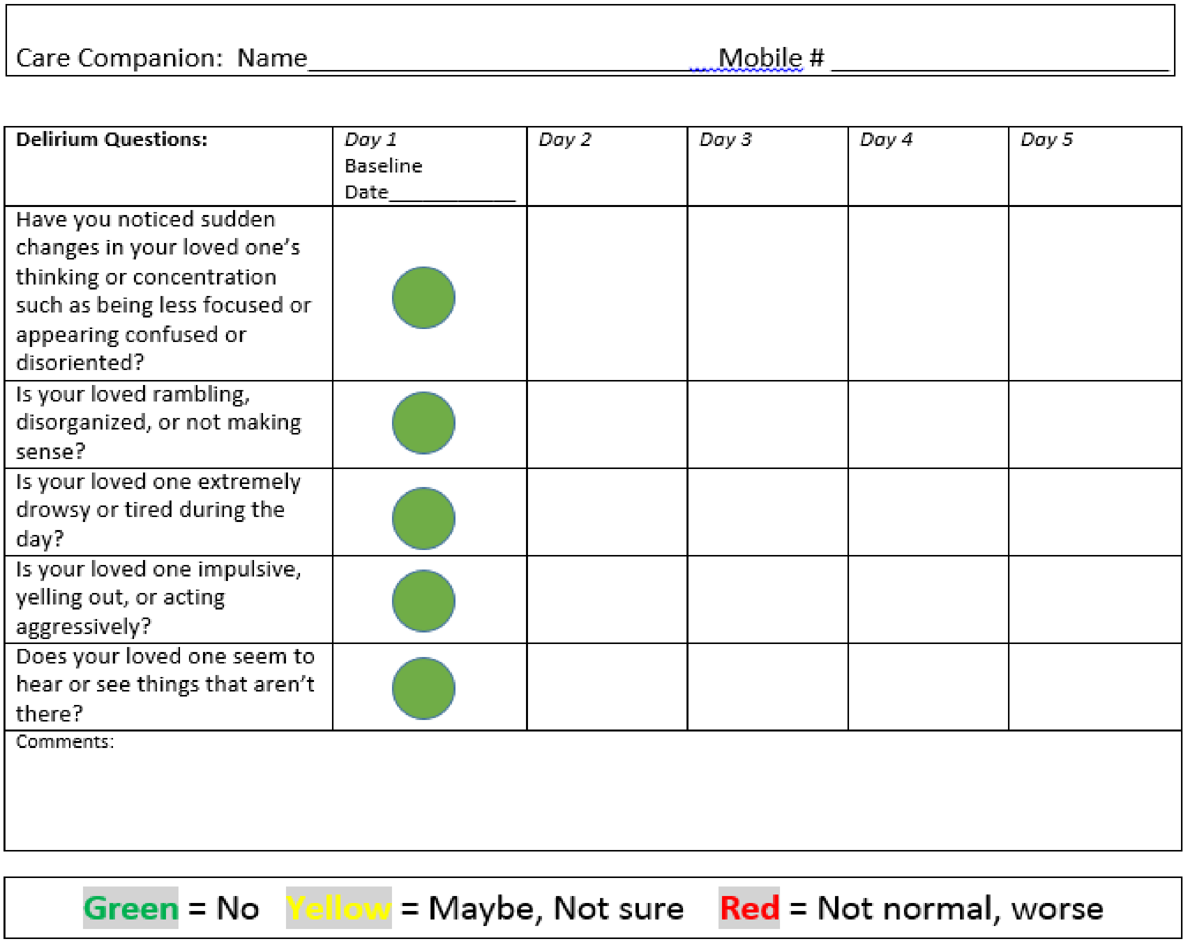
Delirium requires immediate evaluation

Tracking and monitoring: supporting caregivers in delirium surveillance

During both interviews and the co-design sessions, participants mentioned challenges with physicians and nurses not knowing a patient's baseline state and lack of ability to interact with caregivers at the right time. "*Oftentimes the doc shows up at 10:00 and the family member's not there and the family member wanted to talk to the doc but it just doesn't happen that day because people get too busy, right? And the family member comes back at 6 p.m. and the doc has to go pick up his or her kid from daycare*" (S18). Participants agreed that the challenges with in-person coordination between caregivers and hospital staff complicates communication about changes to patients' cognitive state.

To address the lack of consistency in delirium monitoring and the limited availability of both staff and caregivers, design session participants suggested creating a dedicated whiteboard managed by the caregiver (Figure 20). Participants brainstormed a limited set of questions that caregivers could easily respond to that are highly correlated with delirium-induced cognitive changes, such as “Is your loved one impulsive, yelling out, or acting aggressively?” The caregiver would then mark the board with their judgment of each question using red, yellow or green magnets. This activity begins as soon as the patient arrives in the hospital and is captured daily to ascertain any changes from the baseline date.

Figure 20: Mock-up of caregiver managed whiteboard to monitor changes to patient's cognitive state



Care Companion: Name________________________________ Mobile # ____________________

Delirium Questions:	*Day 1* Baseline Date__________	*Day 2*	*Day 3*	*Day 4*	*Day 5*
Have you noticed sudden changes in your loved one’s thinking or concentration such as being less focused or appearing confused or disoriented?	🟢				
Is your loved rambling, disorganized, or not making sense?	🟢				
Is your loved one extremely drowsy or tired during the day?	🟢				
Is your loved one impulsive, yelling out, or acting aggressively?	🟢				
Does your loved one seem to hear or see things that aren’t there?	🟢				
Comments:					

Green = No Yellow = Maybe, Not sure Red = Not normal, worse

Over the course of the two design sessions, participants generated a full-size mock-up. The participants further iterated on the idea, suggesting ways to incorporate their ideas in a mobile-accessible way, through responding to SMS texts or a mobile app. The focus on the whiteboard served as a bridge to a possible future-state mobile-based questionnaire to learn about the patient's baseline cognitive state regardless of caregiver location and provide a more accessible way for patients to learn about delirium.

Summary

Co-design participants emphasized the importance of formalizing the caregiver role. Caregivers often serve as early detectors of delirium signs and symptoms. They are frequently discussed as the person who best understands the patients' baseline cognitive state and behavior. Moreover, patients and staff described caregivers as invaluable for helping patients re-orient during lucid moments of a delirium episode.

Discussion: Designing to support caregivers of patients with delirium

Through this mixed-methods research, we reinforced the idea that family members and caregivers are performing valuable work that offers an opportunity to formalize their role in the care team. Through our analysis of conversations with study participants, we found that caregivers: (1) often serve as early detectors of delirium; (2) are invaluable for helping patients re-orient during episodes of delirium; (3) often lack adequate preparation and training to be actively involved in delirium detection and response; and (4) can also create challenges to the delirium management and response. However, they are frequently discussed as the person who best understands the patient's baseline cognitive state and behavior. Patients and staff described caregivers as invaluable for helping patients re-orient during lucid moments of a delirium episode. Patients also emphasized instances where their immediate clinical provider established consistent, repeated messages that helped them re-orient.

We heard from numerous stakeholders that caregivers sometimes create challenges to effective delirium management. Caregivers might be absent at critical times, inadvertently create barriers to staff interventions, and increase patient anxiety because of a lack of understanding of how to approach patients with delirium. Our findings suggest this challenge was due in part to caregivers' lack of understanding of how to approach patients with delirium because of common communication breakdowns in a hospital setting. Participants emphasized the value of addressing upstream community awareness and information needs— preparing patients for the possibility of delirium through pre-surgical delirium awareness and education—as one valuable area to focus hospital program efforts.

Participants throughout the survey and interviews described the lasting impact of a delirium episode. Nurses cited strategies designed to provide emotional support for both patients and their caregivers as important elements of overall delirium management. Appropriate education and training could be one way to help mitigate this, but through formalized engagement of family members, medical staff can coach and support helpful communication with caregivers.

Limitations

As with any qualitative study, our findings might not be fully representative of the populations under consideration. Instead, this work provides a deep exploration of a small sample of individuals to understand caregiver and patient perspectives on delirium and identify patient-centered designs for delirium management. Despite making considerable effort to sample a representative patient population, it is possible that our participants differ from other patients in terms of self-efficacy or their organization with managing their care. To mitigate potential bias associated with this sample, we used multiple methods of data collection—surveys, interviews, observations, design sessions— and explored the issues from diverse perspectives of staff, patients, and caregivers.

Through an iterative, mixed methods approach, we were able to develop a comprehensive perspective on the delirium experience and consider new strategies that leverage caregiver expertise.

Conclusion

Our study incorporates a comprehensive approach towards understanding and developing strategies for improving the delirium experience in hospitals. Importantly, we compare the experience of delirium from three perspectives: clinical staff, patients, and caregivers. Our mixed-methods, experience-based design approach validated perceptions of gaps and challenges at key touch points, such as how patients cope with a delirium episode after leaving the hospital.

Through this research, we intended to increase understanding of the caregiver perspective and role in episodes of delirium as well as describe strategies to support increased caregiver involvement in the hospital. The notion of leveraging caregiver involvement with delirium detection and management suggests distinct opportunities for practice management and care strategies. Recognizing this shift in roles can promote policies and tools to enable families as care partners (Black et al. 2011). Research in nursing wards has shown that confusion around expectations and roles is a major barrier to participation (Tobiano et al. 2015). Formalizing the caregiver role through greater information-sharing and involvement in shared decision-making can lead to better engagement and support of a high-risk medical issue that has a tremendous emotional impact on patients and their caregivers. This type of partnership creates a more collaborative, trusting environment that will enhance the patient’s care experience and potentially improve clinical outcomes through enhanced detection and response.

Chapter 7. Summary and Conclusion

A growing number of researchers have conducted studies about patient engagement and communicating quality concerns. Their work not only provides a multi-faceted perspective of patient involvement in health care quality, but also provide an overview of the research opportunities and unexplored or poorly understood aspects of patient participation in this domain. The research to date provides substantial evidence for the benefits of patient participations and strategies and tools to increase engagement. Below, I explain how I build on this prior work through a summary of my studies presented in previous chapters, their significance, and the limitations of my research approaches. I also discuss areas for future work and my contributions to this topic.

Summary of Findings

I conducted four studies across different clinical settings that explore how patient and caregiver participation relates to care quality and safety.

In my first study, I conducted a series of observations and interviews to evaluate how patients increase the reliability of their self-care behaviors through reminder systems. To mitigate failures, many patients incorporated key characteristics from reliability science into their personal reminder systems—characteristics such as redundancy, diversity, and monitoring behaviors. I also highlighted how study participants used formal reminder systems as well as environmental cues that are less visible support systems for chronic care management. Technologies that recognize and integrate with these tacit signals have the potential to provide more context-sensitive reminders.

In another study, I employed a series of in-hospital observations and surveys from patients and caregivers to characterize the typical hospital information workspace from a patient and caregiver perspective. The experiences related by patients and caregivers show that inpatients face many information and communication challenges during their hospital stay that are not adequately supported by current tools. Patients and caregivers found it quite challenging to obtain the patient's plan of care for each day and expressed a desire to track metrics and events about their experience. Most implementations of patient portals to date do not adequately serve these needs but the data often exists within the patient's medical record. Through analyzing the patient's room as an information workspace in the hospital, I illustrated opportunities for tools and displays that can enhance patient interaction with their care information.

In my third study, I extended the inpatient information workspace study through a set of interviews with hospitalized patients and caregivers using Q methodology. Patients emphasized a desire for improved situation awareness about their current situation and cared about how information was communicated. Caregivers prioritized tracking needs and the importance of receiving information in the context of patient safety. Participants from both the patient and caregiver groups converged on an attitude that highlighted being empowered and an active participant in this complex care setting. Through this work I found that the attitudes on information needs do not necessarily align across traditional demographic or medical segmentations. Using Q analysis, I explored how patients and caregivers converged along distinct attitudes about information needs in the hospital.

In my final study, I focused on the role of caregivers as actors in supporting patients with delirium. I evaluated the experience of delirium from three perspectives: clinical staff, patients, and caregivers to identify gaps and challenges at key touch care points and to understand how patients and caregivers employ strategies to cope with a delirium experience. I employed an experience-based co-design methodology to design and prototype different tools that formalize the role of caregivers as partners in delirium detection and response.

Contributions

From my four studies, I’ve shown that even in complex care settings, patients and caregivers have a desire for opportunities to be active participants in their care as it relates to quality assurance.

Understanding patient and caregiver contributions to quality of care

The work within Aim 1 provides an exploration of distinct activities that patients with chronic diseases and their caregivers engage in to enhance the quality and safety of their self-care and the care received in different clinical settings. There is strong consensus in the research community about the benefits of informed, activated patients in areas such as chronic disease management (Coleman et al. 2009). Our study on the use of reminder systems in the home emphasized the fact that patients are actively engaging in activities and leveraging cues outside of the clinic environment to manage their health. Through this study of self-care strategies, I introduce a framework of reliability engineering and memory aids applied to patient health behaviors. The observations on the ways that patients increase the reliability of self-care provides insight and opportunities for health care systems to more effectively support and engage patients when they leave the clinic.

Understanding and supporting the information work of patients and caregivers in the hospital

Through Aim 2, I contribute a better understanding of information-based barriers to patient and family member participation in their care while in the hospital. The analysis of the online questionnaire from previously hospitalized patients and caregivers combined with in-depth hospital observations identified key areas that affect information access and sharing that patients experience during their hospital stay. Through this work, I characterized the patient's room as an information workspace and illustrated challenges and opportunities for tools and displays that can enhance patient interaction with their care information.

Gaining Insights for Patient-Centered Design in the Hospital

I leveraged the learnings from the studies in the inpatient space to evaluate current gaps in existing functionality of patient-facing tools such as patient portals. These are typically used in an outpatient setting as a strategy to support enhanced patient access to their medical records. I found that inpatients need additional support within the hospital context. Patients and caregivers highly desired yet found it quite challenging to obtain the patient's plan of care for each day. In addition, most patients wanted to track key aspects of their experience. Neither of these categories of data are available in most patient portals but often exist as metadata within the electronic medical record system at a hospital. Our work highlights these important needs and suggests new functionality that emerging inpatient information systems need to support. This type of new functionality has the potential to transform inpatient care by empowering these patients and caregivers with the information they need to have a satisfying care experience.

In addition to patient portal functionality, my work with caregivers and patients who experienced episodes of delirium provided further insight into mechanisms to enhance caregiver participation. The results of this research provide a vision and set of recommendations for tools that can encourage greater involvement with providers to track changes in the patients' conditions and report any concerns. The design of tools in Aim 3 can help support this process by reducing the cognitive load for patients and family members and creating triggers for increased cross-checking dialogue with their providers.

My work on delirium detection also suggests ways of formalizing a caregiver role in information collaboration in an inpatient setting. The tools we prototyped in the study shift the role of a caregiver from a passive stakeholder that may engage with nurses and physicians in ad hoc ways, and instead positions the caregiver as a participatory member of the care team. This principle of patients as partners is part of a broader industry trend that is extending to other areas of care as well. Other research in this area shows that empowering patients through improved dialogue with their providers can enhance satisfaction, adherence to care, and potentially safety (Longtin et al. 2010; Roter 1977). Through this work, I demonstrate the value that patients and their family members offer for improving the quality and safety of hospital care and suggest design strategies through which hospitals can enhance the patient experience.

Limitations

Through the work presented in this dissertation, I relied extensively on qualitative methods to characterize the patient and caregiver experience. As with any qualitative study, my findings might not be fully representative of the populations under consideration. Within each study, my collaborators and I made considerable efforts to sample for a representative patient population in the region we conducted the work. However, it is possible that our participants differ from other patients in terms of self-efficacy, disease-specific challenges, and their attitudes and priorities for managing their care. Below I review other limitations specific to each chapter and study.

Reliability Assessment of Chronic Disease Self-Management

In my chapter on reliability techniques employed by patients with chronic diseases, the diabetic population in this study encompassed a narrow demographic of mostly elderly, retired individuals, it is possible that we did not adequately capture a wide enough array of experiences and strategies for managing diabetes. However, we were able to contrast their experiences with those of young mothers taking care of their children with asthma. These mothers were often working and were more likely to use technology. In addition, the way that the participants used reminder systems in this study could reflect disease-specific needs of our two cohorts. Our assessment of reliability is also limited in a qualitative study in that we did not capture causal effect of the strategies employed by patients to improve the reliability of their care.

Survey of Inpatient Experience

In our survey of patients and caregivers about a prior hospital stay, the web-based survey creates a potential response bias to those with Internet access, those who are more tech-savvy, and is limited to those with adequate English literacy levels. Furthermore, the convenience sampling approach limits the ability to generalize the findings broadly. To help address this limitation, I tracked the provenance of recruited respondents in order to assess the diversity and geographic spread of the survey findings. In addition, I engaged in additional patient and caregiver interviews to help validate and compare findings from the web-based survey. However, these interviews are limited to two hospitals and therefore creates separate limitations on my ability to generalize themes for other institutions. Finally, limiting my interviews and design sessions to English-speaking populations could bias my exploration of patient experiences and responses to patient safety events. Individuals that speak non-native languages could have a greater risk of experiencing a patient safety incident due to greater communication challenges.

Q Method Analysis of Inpatient Stays

My study using Q methodology to gather attitudes and preferences among hospitalized patients and caregivers relies on a small sample and may limit our ability to extend their experiences to a broader population. To mitigate this as much as possible, we used purposeful sampling to increase the diversity of our study population and conducted our research in two very different hospital systems. A related limitation is that the caregiver population in this study is mostly represented by recruitment from our pediatric population site and could lead to a sample of attitudes specific to a pediatric care environment. Finally, the attitudes and preferences captured by the Q sort reflect a particular moment in time. It is possible that patients and caregivers might shift their ranking preferences over the course of the hospital stay, or the views could be anchored around a specific time period in the hospitalization episode. The alignment of views across different care settings and medical scenarios validates the attitudes to a certain extent, but it's possible that individual participants in this study could shift between factor groupings over time.

Caregiver Collaboration to Detect and Management Delirium

In my chapter on delirium detection and response, I provide a deep exploration of a small sample of individuals to understand caregiver and patient perspectives on delirium and identify patient-centered designs for delirium management. To mitigate potential bias associated with this sample, our study team used multiple methods of data collection—surveys, interviews, observations, design sessions— and explored the issues from diverse perspectives of staff, patients, and caregivers. Through an iterative, mixed methods approach, we were able to develop a comprehensive perspective on the delirium experience and consider new strategies that leverage caregiver expertise.

Future Work

The focus of my work emphasized an exploration and analysis of patient roles in a nascent research area. As this research space is still in its infancy, there are a number of areas with potential for greater exploration. Peat suggests a useful framework where any patient-centered system should:

(1) evaluate the conditions necessary for patients to adopt behaviors and make an effective contribution, (2) question the support provided by the intervention to ensure that the necessary condition can be fulfilled, and (3) consider the potential negative effects of the intervention (Peat et al. 2010). Using this work, I suggest areas for future work and consideration on this topic of patient engagement in care quality.

Formalizing a taxonomy of undesirable events

Currently, there are no agreed-upon standards for defining patients' undesirable events. However, there is value in having a shared taxonomy that can support easier data analysis and integration across reporting systems. Many current patient safety incident management systems use the NQF/AHRQ Common Formats data standard to structure the data collected. The World Health Organization (WHO) has also established an International Classification for Patient Safety Framework comprised of ten high-level classes and approximately 600 concepts that group incidents into clinically meaningful categories (Runciman et al. 2009). These two standards are the most widely referenced approaches to developing a common data model for understanding and sharing safety incidents. The approaches used to develop these taxonomies can provide guidance for extending this same categorization to define a patient-centric view of breakdowns in care quality.

Existing research has shown that open-ended narratives are easier for patients to use and can lead to a greater likelihood of reporting. King, et al., evaluated publications from OVID and PubMed to understand the effect of different solicitation methods on what patients can and do contribute to safety-related surveillance (King et al. 2010). Although the authors show that patient reporting is reliable, they observed higher incident rates among studies with open-ended questionnaires versus structured reporting data models. This also creates a challenge for a consumer-oriented incident reporting system to align with the AHRQ Common Formats. It can also be difficult for a health care system to adequately address the problem if key pieces of medical information are missing. The researchers exploring this area argue that future systems need to balance the efficiency and reliability benefits of structured reporting with open-ended narratives that allow for patients to explain their experiences in their own words.

Adding patients and caregivers to reporting systems

Choices about the structure and design of hospital-based patient-centered systems critically influence who participates in participating in care events and reporting failures and unsafe activities. From a perspective of patient participation in safety, very little research has considered the design and approach to engaging patients with a system of reporting.

There are still open questions on what makes a consumer-oriented incident reporting system different from existing incident reporting systems. In contrast to traditional incident reporting systems used by staff, a consumer reporting system should consider characteristics unique to this stakeholder group. First, this type of system must recognize that most health care consumers (patients, family, or other) do not have the technical language and medical expertise often required to describe an issue that would align with traditional taxonomy requirements. Second, prior research has demonstrated that consumers spot issues that are different from traditional definitions of adverse events. Third, consumers often face different social normative barriers that might inhibit their likelihood to report an issue. For example, a patient might not want their concerns to affect the treatment that they are currently receiving. Ultimately, this boils down to how anonymous the system is. One option would be to use an intermediary, such as administrative staff, to capture the concern and help interpret the patient’s voice for the clinical and administrative audience of a health system. The challenge here is that patients might be less likely to report to an employee of the institution that they have concerns with. Another approach would be to have an electronic reporting tool that captures their concerns anonymously, or with the ability to maintain patient confidentiality with the people involved in the patient’s care. The concerns about potential adverse consequences current care treatment must also consider how to create changes to improve future treatment for other patients. When bringing in patients as collaborators in safety reporting, hospital systems need to develop capture improvement processes that will adequately close the loop with the individual reporting a concern.

All of this is framed with the intention of creating a structured system for systematically capturing patient and family concerns. This type of research extends and reconsiders existing initiatives like AHRQ’s Speak Up campaign in that the focus is providing patients an avenue to express their voice but in a way that can scale and support secondary analysis across a corpus of patient-elicited concerns.

Concerns/Unintended Consequences for Involving Patients

A final area for future work should consider the potential negative consequences of engaging patients around care quality. Although the patients offer a valuable perspective on the quality and safety of health care delivery, explicit attempts to engage patients should acknowledge the risks of participating in this domain. The leadership of hospital systems could fear punitive responses and malpractice litigation as a result of establishing a more open dialogue with patients about accidents and safety concerns, even if a growing number of researchers argue for the value of disclosure about harmful events (Gallagher et al. 2007). At the very least, hospitals would need to adjust to greater accountability for appropriately responding and closing the loop to patient-reported issues. Administrators of hospital safety programs might also have less confidence in the usefulness and reliability of data gathered from non-medical sources such as patients and their family members

(Lyons 2007). Greater expectations from patients in reporting their concerns can also create a perception of reduced responsibility and watchfulness by hospital staff.

From a patient perspective, initiatives designed to involve patients and families in safety risks increasing a sense of responsibility and burden for safety among patients and family members (Entwistle et al. 2005). Encouraging patients to participate in error detection could tunnel their perspective to focus on deviances from safe practices and negatively impact their satisfaction with the care provided. There are numerous unanswered questions about possible inequalities created by programs that promote patient involvement in safety. Health literacy, self-efficacy, and language and cultural norms can create further barriers for select patient populations to take on safety-related responsibilities. Strategies to support patient involvement in their care should avoid creating further divides in the quality of care provided to different groups.

Concluding Remarks

Understanding how patients and caregivers interface with notion of improving care quality is an exciting shift in the medical industry’s approach to safety and quality today. Through my research, I’ve shown that it’s possible for patients and caregivers to provide meaningful improvement to care quality in diverse clinical settings. Care systems can benefit from these patient and caregiver contributions in the sense that it can provide an additional layer of quality assurance on top of existing initiatives driven by clinical and administrative staff. Despite some of the risks and potential drawbacks mentioned above, I argue that patient and caregiver participation in this regard is ultimately a good thing. Formalizing the role of patients in contributing to the quality of their care is an area with rich potential for additional research. There are numerous challenges for the field of Human-Computer Interaction to address as future research continues to drive new designs that support patients and caregivers behaviors for better reliability and failure management. This work emphasizes putting greater control in the hands of patients and caregivers through improvement information access and tools. The experiences and examples presented here provide evidence towards the notion that even in complex inpatient settings, patients and caregivers have a desire to be active partners in the care delivery process.

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Appendix A. Patient Survey Design

The questions below are survey questions used to collect data presented in Chapter 4.

Background on Hospitalization

We would like to learn more about your most memorable experience within a hospital - as either a patient or a person caring for a patient.

How long has it been since that hospitalization?

	Logic destinations
○ Less than one year ago	➡ Don't skip (default)
○ 1 to 3 years ago	➡ Don't skip (default)
○ 3 to 5 years ago	➡ Don't skip (default)
○ More than 5 years ago	➡ Don't skip (default)
○ I have never been hospitalized or taken care of someone while they were hospitalized	➡ You answered, "I have never...

In what country was the hospital located? If in the US, in what state was the hospital located?

Were you the patient that was hospitalized?

	Logic destinations
○ Yes	➡ Patient
○ No	➡ Caregiver

Patient

How long were you in the hospital?

- ○ Less than one day
- ○ 1 day (staying overnight)
- ○ 2 to 5 days
- ○ 5 to 7 days
- ○ More than 7 days

What was the primary reason for your hospitalization?

Were you able to physically perform the following activities during the hospitalization?
(always, often, sometimes, rarely, never)

Talk with others (e.g. speak with family members or nurse)

Operate a computing device (e.g. cell phone, tablet, computer)

Caregiver

How long was the patient in the hospital?

- ○ [See options at left]

What was the primary reason for the patient's hospitalization?

At the time of the hospitalization, what was your relationship to the patient?

- ○ Parent
- ○ Adult child
- ○ Spouse/Partner
- ○ Relative
- ○ Friend
- ○ Other caregiver

How often were you in the hospital during the patient's stay?

- ○ Every day
- ○ Most days
- ○ Some days
- ○ Not frequently
- ○ Once
- ○ I don't remember

On average, how many hours did you spend with the patient each day during the hospital stay?

- ○ Less than 1 hour
- ○ 1 to 4 hours
- ○ 4 to 8 hours
- ○ More than 8 hours

Was the patient physically capable of performing the following activities during the hospitalization?

Accessing Information

Other than information given right before leaving the hospital (i.e. at discharge), did you receive any printed, written, or electronic information from the doctors or nurses during the hospital stay?

Printed	○Yes	○ No	○ I don’t remember
Written	○Yes	○ No	○ I don’t remember
Electronic	○Yes	○ No	○ I don’t remember

If so, what type of information did you receive?

How important would it have been for you to have information about any of the following items during the hospital stay?

At-home medications
Past medical history (e.g. allergies, previous health events)
Medications administered while hospitalized
Upcoming lab and imaging test schedule
Results for lab and imaging tests
Current and previous vital signs (e.g. temperature, blood pressure, heart rate)
Information about the doctors, nurses, or other staff providing your medical care
Expected next visit from nurse or doctor
How busy the nurses are
Expected length of stay
Information on other treatment choices
Information on experiences of other patients with a similar health situation

Options:
○ Unimportant
○ Somewhat Unimportant
○ Neither unimportant nor important
○ Somewhat Important
○ Important
○ Not applicable

How challenging was it for you to get information about any of the following items during the hospital stay?

At-home medications
Past medical history (e.g. allergies, previous health events)
Medications administered while hospitalized
Upcoming lab and imaging test schedule
Results for lab and imaging tests
Current and previous vital signs (e.g. temperature, blood pressure, heart rate)
Information about the doctors, nurses, or other staff providing your medical care
Expected next visit from nurse or doctor
How busy the nurses are
Expected length of stay
Information on other treatment choices
Information on experiences of other patients with a similar health situation

Options:
○ Very easy
○ Somewhat easy
○ Neither easy nor difficult
○ Somewhat difficult
○ Difficult
○ Not applicable

Is there other information that you would have liked to have known more about during the hospital stay? Please explain.

Managing Information

How important would it have been for you to keep track of any of the following items during the hospital stay?

Changes in symptoms (e.g. when fatigue is worst, what drugs work best)	Options:
Pain level	○ Unimportant
Activity level (e.g., # of steps)	○ Somewhat Unimportant
Meal (e.g., how much you ate, what you ate)	○ Neither unimportant nor important
Bowel movement	○ Somewhat Important
Emotion or stress level	○ Important
Visits from family and friends (e.g., who came to visit & when)	
Customized care needs (e.g. allergies)	
Questions for the care team	

How challenging was it for you to keep track of any of the following items during the hospital stay?

Changes in symptoms (e.g. when fatigue is worst, what drugs work best)	Options:
Pain level	○ Very easy
Activity level (e.g., # of steps)	○ Somewhat easy
Meal (e.g., how much you ate, what you ate)	○ Neither easy nor difficult
Bowel movement	○ Somewhat difficult
Emotion or stress level	○ Difficult
Visits from family and friends (e.g., who came to visit & when)	○ Not applicable
Customized care needs (e.g. allergies)	
Questions for the care team	

Have you had any experience keeping track of the items listed above while hospitalized?

○ Yes

○ No

How did you capture this information?

What were the reasons that you captured this information?

Were there any reasons that you did not keep track of this kind of health information? Please explain. (optional)

Communicating Information

Please indicate how much you agree with each of the following statements:

I was involved as much as I wanted to be in decisions made about the care and treatment provided.	Options:
I was able to stay informed about all of the activities that occurred relating to the care provided.	○ Strongly agree
I felt comfortable asking the doctor(s) questions about the care that was provided.	○ Agree
I felt comfortable asking the nurses questions about the care that was provided.	○ Undecided
When I had important questions to ask the doctor or nurse, I was able to get answers that I could understand.	○ Disagree
I was able to keep friends and family informed as the health situation evolved.	○ Strongly disagree

During the hospitalization, did you have any concern (such as a miscommunication or misunderstanding) about the care that was provided?

○Yes

○No

If so, what kind of concerns did you have?

Did you communicate those concerns to anyone? If so, who?

Appendix B. Q Method Caregiver Statement Set

Num	Statement
1	to know the names and responsibilities of our doctors, nurses, and other health care providers
2	to know what will happen with the patient's care today
3	to know why each medication is given to the patient
4	to know when the patient can leave the hospital
5	to know the cost of being in the hospital
6	to speak up to doctors and nurses when I have a question
7	to know about different options for how to treat the patient's illness
8	to know how to get help if I am worried or need information
9	that I know what we will need to do for the patient's health after leaving the hospital
10	to know when we will see my doctor next
11	to get information in a way that I can understand
12	that I am not a bother to the doctors and nurses
13	to know what to ask the doctors or nurses
14	to feel like our doctors have time to answer my questions
15	to know how serious the patient's illness is
16	that I get information about how the patient's health condition is changing over time
17	that I be an active participant in the patient's healthcare
18	that I keep track of things by writing them down so that I remember them
19	that someone else helps me keep track of things
20	I like to keep track of things by just paying attention and remembering
21	that the doctors and nurses listen to me
22	to know how the doctors and nurses are communicating with each other when there are shift changes
23	that I know right away when there is a change of plan for the patient's care
24	to get information in a way that's easy to share with others
25	to know what kinds of safety errors can happen with patients in our situation
26	that the doctors and nurses agree with my decisions for the patient's care
27	that I have a positive relationship with the doctors and nurses
28	that the hospital respects my need for privacy
29	to know what activities are okay based on the patient's current condition
30	I prefer to leave decisions about the patient's medical care up to the doctor
31	I only want to know what the doctors think is important
32	to get information at a time when I can focus
33	that I understand the doctors' reasoning when they give a recommendation
34	that the doctors and nurses understand what is most important to me

Appendix C. Q Analysis Patient Results

Factor 1

#	Statements	Factor 1		Factor 2		Factor 3		Distinguishing
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	
	Items Ranked at +4							
3	to know why each medication is given to me	**4**	**1.50**	4	2.26	2	0.92	X*
15	to know how serious my illness is	**4**	**2.02**	-1	-0.42	4	1.97	
	Items Ranked Higher in Factor 1 Array than Other Factors							
8	to know how to get help if I am worried or need information	**3**	**1.35**	0	0.29	0	-0.26	X
12	that I am not a bother to my doctors and nurses	**-1**	**-0.41**	-3	-1.68	-4	-1.63	X*
16	that I get information about how my health condition is changing over time	**3**	**1.19**	2	0.69	1	0.07	
21	that my doctors and nurses listen to me	**3**	**1.23**	1	0.57	2	1.00	
28	It's important that the hospital respects my need for privacy	**0**	**-0.31**	-3	-1.08	-1	-0.47	
	Items Ranked Lower in Factor 1 Array than Other Factors							
1	to know the names and responsibilities of my doctors, nurses, and other health care providers	**-2**	**-0.86**	1	0.29	0	0.04	X*
14	to feel like my doctors have time to answer my questions	**-1**	**-0.58**	2	1.01	2	0.94	X*
20	I like to keep track of things by just paying attention and remembering	**-3**	**-1.26**	-2	-0.69	-1	-0.34	X
22	It's important to know how my doctors and nurses are communicating with each other when there are shift changes	**-3**	**-1.51**	2	0.72	0	-0.15	X*
23	It's important that I know right away when there is a change of plan for my care	**0**	**0.19**	2	0.91	1	0.80	X
	Items Ranked at -4							

30	I prefer to leave decisions about my medical care up to my doctor	**-4**	**-1.55**	-4	-1.95	-4	-1.92	
31	I only want to know what my doctors think is important	**-4**	**-2.00**	-3	-1.66	-3	-1.19	
	Other Notable Items (distinguishing, or diff from one other Factor)							
11	to get information in a way that I can understand	**2**	**0.68**	4	1.47	0	-0.15	X*
17	that I be an active participant in my healthcare	**1**	**0.60**	0	0.00	4	1.75	X
25	It's important to know what kinds of safety errors can happen with patients in my situation	**1**	**0.59**	3	1.12	-3	-1.32	X
27	It's important that I have a positive relationship with my doctors and nurses	**1**	**0.49**	-1	-0.37	2	0.98	X
7	to know about different options for how to treat my illness	**2**	**1.11**	-2	-0.64	3	1.05	
5	to know the cost of being in the hospital	**-3**	**-1.11**	-4	-2.20	-2	-1.18	
33	It's important that I understand my doctors' reasoning when they give a recommendation	**2**	**0.78**	0	-0.31	3	1.08	

Factor 2

#	Statements	Factor 1		Factor 2		Factor 3		Dis-tinguishing
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	
	Items Ranked at +4							
3	to know why each medication is given to me	4	1.50	**4**	**2.26**	2	0.92	X*
11	to get information in a way that I can understand	2	0.68	**4**	**1.47**	0	-0.15	X*
	Items Ranked Higher in Factor 2 Array than Other Factors							
1	to know the names and responsibilities of my doctors, nurses, and other health care providers	-2	-0.86	**1**	**0.29**	0	0.04	
2	to know what will happen with my care today	2	1.06	**3**	**1.15**	1	0.71	
10	to know when I will see my doctor next	0	-0.34	**1**	**0.35**	-1	-0.41	X*
19	that someone else helps me keep track of things	-2	-0.84	**0**	**-0.07**	-2	-1.10	X*
22	It's important to know how my doctors and nurses are communicating with each other when there are shift changes	-3	-1.51	**2**	**0.72**	0	-0.15	X*
23	It's important that I know right away when there is a change of plan for my care	0	0.19	**2**	**0.91**	1	0.80	
25	It's important to know what kinds of safety errors can happen with patients in my situation	1	0.59	**3**	**1.12**	-3	-1.32	X
26	It's important that my doctors and nurses agree with my decisions for my care	-1	-0.82	**3**	**1.18**	-1	-0.43	X*
	Items Ranked Lower in Factor 2 Array than Other Factors							
7	to know about different options for how to treat my illness	2	1.11	**-2**	**-0.64**	3	1.05	X*
15	to know how serious my illness is	4	2.02	**-1**	**-0.42**	4	1.97	X*
17	that I be an active participant in my healthcare	1	0.60	**0**	**0.00**	4	1.75	X
21	that my doctors and nurses listen to me	3	1.23	**1**	**0.57**	2	1.00	
27	It's important that I have a positive relationship with my doctors and nurses	1	0.49	**-1**	**-0.37**	2	0.98	X*

28	It's important that the hospital respects my need for privacy	0	-0.31	**-3**	**-1.08**	-1	-0.47	X
32	It's important to get information at a time when I can focus	-1	-0.68	**-2**	**-0.65**	0	0.01	
33	It's important that I understand my doctors' reasoning when they give a recommendation	2	0.78	**0**	**-0.31**	3	1.08	X*
	Items Ranked at -4							
5	to know the cost of being in the hospital	-3	-1.11	**-4**	**-2.20**	-2	-1.18	X*
30	I prefer to leave decisions about my medical care up to my doctor	-4	-1.55	**-4**	**-1.95**	-4	-1.92	
	Other Notable Items (distinguishing, or diff from one other Factor)							
8	to know how to get help if I am worried or need information	3	1.35	**0**	**0.29**	0	-0.26	X
12	that I am not a bother to my doctors and nurses	-1	-0.41	**-3**	**-1.68**	-4	-1.63	
14	to feel like my doctors have time to answer my questions	-1	-0.58	**2**	**1.01**	2	0.94	
9	that I know what I will need to do for my health after leaving the hospital	0	0.43	**0**	**0.26**	3	1.51	
4	to know when I can leave the hospital	-1	-0.53	**-1**	**-0.45**	1	0.63	

Factor 3

#	Statements	Factor 1		Factor 2		Factor 3		Dis-tinguishing
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	
	Items Ranked at +4							
15	to know how serious my illness is	4	2.02	-1	-0.42	**4**	**1.97**	
17	that I be an active participant in my healthcare	1	0.60	0	0.00	**4**	**1.75**	X*
	Items Ranked Higher in Factor 3 Array than Other Factors							
4	to know when I can leave the hospital	-1	-0.53	-1	-0.45	**1**	**0.63**	X*
5	to know the cost of being in the hospital	-3	-1.11	-4	-2.20	**-2**	**-1.18**	
7	to know about different options for how to treat my illness	2	1.11	-2	-0.64	**3**	**1.05**	
9	that I know what I will need to do for my health after leaving the hospital	0	0.43	0	0.26	**3**	**1.51**	X*
20	I like to keep track of things by just paying attention and remembering	-3	-1.26	-2	-0.69	**-1**	**-0.34**	
27	It's important that I have a positive relationship with my doctors and nurses	1	0.49	-1	-0.37	**2**	**0.98**	X
32	It's important to get information at a time when I can focus	-1	-0.68	-2	-0.65	**0**	**0.01**	X
33	It's important that I understand my doctors' reasoning when they give a recommendation	2	0.78	0	-0.31	**3**	**1.08**	
	Items Ranked Lower in Factor 3 Array than Other Factors							
2	to know what will happen with my care today	2	1.06	3	1.15	**1**	**0.71**	
3	to know why each medication is given to me	4	1.50	4	2.26	**2**	**0.92**	X
11	to get information in a way that I can understand	2	0.68	4	1.47	**0**	**-0.15**	X*
13	to know what to ask my doctors or nurses	0	0.21	0	-0.04	**-2**	**-0.69**	X
16	that I get information about how my health condition is changing over time	3	1.19	2	0.69	**1**	**0.07**	X

24	It's important to get information in a way that's easy to share with others	-2	-0.92	-2	-0.45	**-3**	**-1.29**	
25	It's important to know what kinds of safety errors can happen with patients in my situation	1	0.59	3	1.12	**-3**	**-1.32**	X*
34	It's important that my doctors and nurses understand what is most important to me	1	0.57	1	0.56	**0**	**-0.26**	X*
	Items Ranked at -4							
12	that I am not a bother to my doctors and nurses	-1	-0.41	-3	-1.68	**-4**	**-1.63**	
30	I prefer to leave decisions about my medical care up to my doctor	-4	-1.55	-4	-1.95	**-4**	**-1.92**	
	Other Notable Items (distinguishing, or diff from one other Factor)							
22	It's important to know how my doctors and nurses are communicating with each other when there are shift changes	-3	-1.51	2	0.72	**0**	**-0.15**	X*
8	to know how to get help if I am worried or need information	3	1.35	0	0.29	**0**	**-0.26**	X
26	It's important that my doctors and nurses agree with my decisions for my care	-1	-0.82	3	1.18	**-1**	**-0.43**	
19	that someone else helps me keep track of things	-2	-0.84	0	-0.07	**-2**	**-1.10**	
14	to feel like my doctors have time to answer my questions	-1	-0.58	2	1.01	**2**	**0.94**	

Appendix D. Q Analysis Caregiver Results

Factor 1

#	Statements	Factor 1		Factor 2		Factor 3		Dis-tinguishing
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	
	Items Ranked at +4							
15	to know how serious the patient's illness is	**4**	**1.41**	0	0.02	4	1.84	
3	to know why each medication is given to the patient	**4**	**1.29**	1	0.32	3	1.34	
	Items Ranked Higher in Factor 1 Array than Other Factors							
14	to feel like our doctors have time to answer my questions	**3**	**1.17**	2	0.65	2	0.85	
7	to know about different options for how to treat the patient's illness	**3**	**1.14**	2	0.85	1	0.58	
11	to get information in a way that I can understand	**2**	**0.98**	0	0.21	1	0.72	
27	that I have a positive relationship with the doctors and nurses	**2**	**0.93**	0	0.21	0	0.05	X*
9	that I know what we will need to do for the patient's health after leaving the hospital	**2**	**0.92**	0	0.09	1	0.76	
18	that I keep track of things by writing them down so that I remember them	**0**	**-0.15**	-3	-1.68	-3	-1.48	X*
	Items Ranked Lower in Factor 1 Array than Other Factors							
20	I like to keep track of things by just paying attention and remembering	**-3**	**-1.37**	1	0.32	0	-0.21	X*
4	to know when the patient can leave the hospital	**-2**	**-1.09**	0	0.09	-1	-0.44	X*
16	that I get information about how the patient's health condition is changing over time	**1**	**0.79**	3	1.05	3	1.48	
23	that I know right away when there is a change of plan for the patient's care	**1**	**0.83**	3	1.06	3	1.33	
33	that I understand the doctors' reasoning when they give a recommendation	**1**	**0.83**	2	1.04	4	1.53	
6	to speak up to doctors and nurses when I have a question	**1**	**0.90**	3	1.58	2	0.77	
	Items Ranked at -4							
5	to know the cost of being in the hospital	**-4**	**-2.15**	-1	-0.34	-1	-0.49	X*
31	I only want to know what the doctors think is important	**-4**	**-1.62**	-3	-1.58	-1	-0.48	
	Other Notable Items (distinguishing, or diff from one other Factor)							
21	that the doctors and nurses listen to me	**3**	**1.14**	4	1.69	-2	-0.71	
17	that I be an active participant in the patient's healthcare	**2**	**1.02**	4	2.10	2	0.84	
25	to know what kinds of safety errors can happen with patients in our situation	**-1**	**-0.23**	-2	-0.73	2	1.01	
30	I prefer to leave decisions about the patient's medical care up to the doctor	**-2**	**-1.17**	-4	-1.90	0	0.08	

Factor 2

#	Statements	Factor 1		Factor 2		Factor 3		Dis-tinguishing
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	
	Items Ranked at +4							
17	that I be an active participant in the patient's healthcare	2	1.02	**4**	**2.10**	2	0.84	X*
21	that the doctors and nurses listen to me	3	1.14	**4**	**1.69**	-2	-0.71	
	Items Ranked Higher in Factor 2 Array than Other Factors							
6	to speak up to doctors and nurses when I have a question	1	0.90	**3**	**1.58**	2	0.77	X
1	to know the names and responsibilities of our doctors, nurses, and other health care providers	-1	-0.36	**2**	**0.63**	-2	-0.64	X*
34	that the doctors and nurses understand what is most important to me	0	0.02	**1**	**0.52**	-1	-0.43	
20	I like to keep track of things by just paying attention and remembering	-3	-1.37	**1**	**0.32**	0	-0.21	
4	to know when the patient can leave the hospital	-2	-1.09	**0**	**0.09**	-1	-0.44	
	Items Ranked Lower in Factor 2 Array than Other Factors							
25	to know what kinds of safety errors can happen with patients in our situation	-1	-0.23	**-2**	**-0.73**	2	1.01	
10	to know when we will see my doctor next	0	-0.14	**-1**	**-0.72**	1	0.42	
29	to know what activities are okay based on the patient's current condition	0	0.08	**-1**	**-0.34**	0	-0.15	
15	to know how serious the patient's illness is	4	1.41	**0**	**0.02**	4	1.84	X*
9	that I know what we will need to do for the patient's health after leaving the hospital	2	0.92	**0**	**0.09**	1	0.76	
11	to get information in a way that I can understand	2	0.98	**0**	**0.21**	1	0.72	
3	to know why each medication is given to the patient	4	1.29	**1**	**0.32**	3	1.34	X*
	Items Ranked at -4							
12	that I am not a bother to the doctors and nurses	-3	-1.24	**-4**	**-2.10**	-2	-1.14	X
30	I prefer to leave decisions about the patient's medical care up to the doctor	-2	-1.17	**-4**	**-1.90**	0	0.08	X
	Other Notable Items (distinguishing, or diff from one other Factor)							
5	to know the cost of being in the hospital	-4	-2.15	**-1**	**-0.34**	-1	-0.49	
32	to get information at a time when I can focus	-2	-0.84	**-2**	**-0.73**	-4	-1.74	
31	I only want to know what the doctors think is important	-4	-1.62	**-3**	**-1.58**	-1	-0.48	
18	that I keep track of things by writing them down so that I remember them	0	-0.15	**-3**	**-1.68**	-3	-1.48	X
16	that I get information about how the patient's health condition is changing over time	1	0.79	3	1.05	**3**	**1.48**	

Items flagged as Distinguishing Statement (X) are significant at P < .05 ; asterisk (*) indicates significance at P < .01.

Factor 3

#	Statements	Factor 1		Factor 2		Factor 3	
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR
	Items Ranked at +4						
15	to know how serious the patient's illness is	4	1.41	0	0.02	**4**	**1.84**
33	that I understand the doctors' reasoning when they give a recommendation	1	0.83	2	1.04	**4**	**1.53**
	Items Ranked Higher in Factor 3 Array than Other Factors						
25	to know what kinds of safety errors can happen with patients in our situation	-1	-0.23	-2	-0.73	**2**	**1.01**
10	to know when we will see my doctor next	0	-0.14	-1	-0.72	**1**	**0.42**
30	I prefer to leave decisions about the patient's medical care up to the doctor	-2	-1.17	-4	-1.90	**0**	**0.08**
31	I only want to know what the doctors think is important	-4	-1.62	-3	-1.58	**-1**	**-0.48**
	Items Ranked Lower in Factor 3 Array than Other Factors						
28	that the hospital respects my need for privacy	-1	-0.41	-2	-0.74	**-3**	**-1.19**
21	that the doctors and nurses listen to me	3	1.14	4	1.69	**-2**	**-0.71**
1	to know the names and responsibilities of our doctors, nurses, and other health care providers	-1	-0.36	2	0.63	**-2**	**-0.64**
34	that the doctors and nurses understand what is most important to me	0	0.02	1	0.52	**-1**	**-0.43**
2	to know what will happen with the patient's care today	1	0.58	1	0.53	**0**	**0.09**
7	to know about different options for how to treat the patient's illness	3	1.14	2	0.85	**1**	**0.58**
	Items Ranked at -4						
24	to get information in a way that's easy to share with others	-2	-1.20	-2	-0.84	**-4**	**-1.83**
32	to get information at a time when I can focus	-2	-0.84	-2	-0.73	**-4**	**-1.74**
	Other Notable Items (distinguishing, or diff from one other Factor)						
3	to know why each medication is given to the patient	4	1.29	1	0.32	**3**	**1.34**
17	that I be an active participant in the patient's healthcare	2	1.02	4	2.10	**2**	**0.84**
20	I like to keep track of things by just paying attention and remembering	-3	-1.37	1	0.32	**0**	**-0.21**
5	to know the cost of being in the hospital	-4	-2.15	-1	-0.34	**-1**	**-0.49**
18	that I keep track of things by writing them down so that I remember them	0	-0.15	-3	-1.68	**-3**	**-1.48**
16	that I get information about how the patient's health condition is changing over time	1	0.79	3	1.05	**3**	**1.48**

Items flagged as Distinguishing Statement (X) are significant at P < .05 ; asterisk (*) indicates significance at P < .01.