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Partners in Care: Design Considerations for Caregivers and Patients During a Hospital Stay

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Abstract

Informal caregivers, such as close friends and family, play an important role in a hospital patient's care. Although CSCW researchers have shown the potential for social computing technologies to help patients and their caregivers manage chronic conditions and support health behavior change, few studies focus on caregivers' role during a multi-day hospital stay. To explore this space, we conducted an interview and observation study of patients and caregivers in the inpatient setting. In this paper, we describe how caregivers and patients coordinate and collaborate to manage patients' care and wellbeing during a hospital stay. We define and describe five roles caregivers adopt: companion, assistant, representative, navigator, and planner, and show how patients and caregivers negotiate these roles and responsibilities throughout a hospital stay. Finally, we identify key design considerations for technology to support patients and caregivers during a hospital stay.

Author Keywords

CSCW; health informatics; caregiving; caregiver; inpatient; medical informatics

ACM Classification Keywords

J.3 Life and Medical Sciences; Health; Medical Information Systems; H.5.3 Group and organization Interfaces; Computer Supported Cooperative Work

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INTRODUCTION

The hospital is a dynamic, complex, and often stressful environment with a diverse array of clinicians coordinating patient care. Patients admitted to a hospital often face cognitive challenges because they are in a critically ill state and under the influence of pain killers or other medication that can affect their ability to process and remember information [14]. Within this setting, patients have to adjust to unfamiliar hospital routines and cope with mostly verbal information transfer filled with complex terminology and vernacular. These factors introduce obstacles for patients to obtain and manage accurate information about their care.

Close friends and family have the capacity to help mitigate these challenges by promoting engagement through establishing rapport, exchanging information, and assisting with medical decision-making [38]. Outside of the hospital, researchers have demonstrated that support from these nonprofessional or informal caregivers improves patients' health outcomes and reduces the likelihood of further health complications [9]. The presence of family caregivers during patient-clinician interaction leads to improved medical visit communication and increased provision of biomedical information [38]. However, the difficulty in being constantly present in a hospital introduces barriers for caregivers to provide this valuable emotional, practical, and informational support.

CSCW researchers have shown the potential for social computing technologies to help patients and caregivers manage chronic conditions and support health behavior change [5,15,20]. They have also begun to study how patients and caregivers collaborate and coordinate during a hospital stay and what technology they use to do so [22,29]. The unique challenges and needs within the hospital setting suggest an opportunity to explore in depth the ways in which informal caregivers collaborate and support patient and clinician activities, and to identify strategies to create high quality patient-family-physician communication processes.

In this paper, we report findings from an interview and observation study we conducted with 48 people (28 patients and 20 caregivers) undergoing a multi-day stay in a hospital. We identify what specific roles caregivers play, how these responsibilities shift in response to different contexts, and what caregivers need to support these roles. Based on our study and analysis, we make the following contributions:

- We define and describe various roles that informal caregivers adopt as they help patients in the inpatient setting.
- We characterize current patient-caregiver communication and coordination practices.
- We identify key opportunities and challenges for technology to support caregivers and patients during a hospital stay.

RELATED WORK

Patient-centered information and clinical coordination practices are well documented in the HCI, CSCW, and Biomedical Informatics communities. Researchers have investigated the information needs of patients and enumerated design considerations for patient engagement technologies. Informal caregivers as stakeholders have received significant attention from CSCW in the last several years, although the term ‘caregiver’ has been used in different ways. Additionally this work has primarily studied caregiving for chronic conditions in at-home care and ambulatory clinic settings. Inpatient collaboration and coordination has also been a focus of the medical research and CSCW communities, although with an emphasis on clinician coordination rather than the patient or caregiver as a coordination stakeholder.

Patients’ information needs in the hospital

Over the last several years, researchers have begun to study patients’ information needs in hospital settings. These studies have varied from examinations of the use of a variety of technical and non-technical tools for information exchange between patients and their clinical teams [28].

On the non-technical side, whiteboard and call buttons serve as the primary tools to facilitate patient-clinician communication. When an inpatient room has a whiteboard, patients are more satisfied, aware of their condition and knowledgeable about their hospital care. Whiteboards also serve as a helpful information resource to both clinicians and patients [26,31]. However, whiteboards have limited space and require manual upkeep by clinicians. This is problematic due to clinicians’ time constraints, and can potentially result in inaccurate or outdated information [31]. Call buttons provide a means for patients to signal nursing staff when the patients need help or have a question. However, the limited interaction afforded by the button frustrates patients and constrains communication [28].

On the technical side, Biomedical Informatics and CSCW researchers have also investigated ways to increase patient engagement and patient-clinician communication during a hospital stay, with an emphasis on novel form factors such as large displays, tablets, and mobile apps [22]. For example, Wilcox et al. developed and tested a paper based patient-centric information display prototype, providing patients with updated information about their care and treatment while in the hospital [37]. Tablet computer and mobile phone applications have also provided patients with access to personalized and updated medication, health, safety, and educational information [8,11,33,34]. Also, as a way to improve the hospital discharge process for patients, Bickmore et al. demonstrated the use of Virtual Nurse Agents that guide patients through their discharge paperwork and confirm that the patient understands important concepts [3].

On the whole, patient engagement technologies serve the information needs of the clinician or the patient, but rarely account for patients’ caregivers as stakeholders or system users. A few researchers have looked at technologies for caregivers of young patients in hospital wards, such as the neonatal intensive care unit (NICU), where parents who are physically separated from their child require access to clinical information to make decisions about care or treatment [1,24,36]. Except for these specific contexts, little is known about caregivers as

users of patient engagement technologies in the hospital. Furthermore, the focus on chronic and long-term care may mask the challenges to uptake and usability for short-term one-time hospital stays.

Definition of an informal caregiver

The HCI health-focused literature is vague on who exactly counts as a caregiver, but related papers often take one of two approaches: focusing on a ‘primary’ caregiver responsible for day-to-day care in chronic conditions [5,13] or on a broader network of care [6]. The health promotion literature often focuses on condition-specific caregiver definitions, such as family caregivers of cancer patients, [10] or adult children caring for their elderly parents [7].

In this paper, we seek to understand informal caregiving practices within the inpatient setting, across conditions and populations. Thus, in our conversations with participants and our resulting analysis, we focus not on *caregivers* but on *informal caregiving* during the hospital stay. For our purposes, any non-professional person who the patient identified as helping with some aspect of their care counts as a caregiver. Both patient-participants and caregiver-participants described spouses, parents, children, and others from their broader social network helping with various aspects of the patient’s care. An inclusive definition of caregiver has allowed us to adopt a holistic and fluid analytical perspective.

The role of caregivers

In recent years, CSCW and health informatics researchers have begun to study the role of technology for caregivers in earnest. Chen et al. called for consideration of informal caregivers as key health stakeholders in HCI and the need for designs that treat caregivers as whole persons and help to address some of the challenges and burdens that caregivers experience in this role of patient support [5]. Within the inpatient context, Kaziunas et al. studied caregivers of pediatric bone marrow transplant patients, placing the caregiver’s role in supporting inpatients within the broader context of a specific long-term condition affecting a specific population [13].

In 2002, Schultz et al. conducted a systematic review outlining the role of technology in chronic caregiving, primarily with caregivers of patients diagnosed with dementia. Examples of the roles that technology plays in supporting the caregiver include: communicating information efficiently, providing a means for social support, and acting as a delivery mechanism for the caregiver’s health promotion and health management [25]. Schultz et al. also proposed a series of recommendations for the use of caregiver technologies, such as addressing training needs related to the use of these technologies, recognizing potential harms, and gaining a better understanding of how these technologies complement and apply to existing conceptual frameworks [25].

Others have focused on the patient’s perspective to manage caregiver networks for support. Skeels et al. conducted participatory design exercises and developed a tool for cancer patients to help manage and facilitate social support from friends and family members [29]. Liu et al. examined pediatric patients’ information sharing practices, seeking to understand how communication technologies allow patients in the hospital to achieve a sense of

normalcy [18]. Newman et al. identified challenges people face with sharing health information with their broader social networks [21].

Researchers have also investigated the role of pervasive computing in support of chronic care. Studies of this type focus on the use of remote sensor and monitoring systems to track a person's health activity and report it to a designated family member or caregiver [6,35]. Barish et al. examined leveraging mobile sensors and input from the caregiver in the context of outpatients with mental health disorders [2]. Topo discussed the use of technology among at-home patients diagnosed with dementia and their caregivers, and acknowledged informal and formal caregivers as end users of technology to support their diverse needs, in addition to the ability for technology to improve caregiver wellbeing [32].

Technologies to support parents as informal caregivers have also received significant attention in recent years. Suh et al. designed the Baby Steps system to allow parents to track their child's development progress [30]. Liu et al. studied a Neonatal Intensive care Unit (NICU), pinpointing the communication challenges that exist between a NICU patient's caregiver and healthcare provider once the child has left the hospital, and introduced a mobile application prototype allowing caregivers' to choose information they wanted to share with others [17]. Moncur et al. presented a solution to help parents customize and communicate information about themselves and their child to family or friends [19].

The work presented in this paper builds on and is complementary to this thread of caregiver support in CSCW and health informatics. In our study, we look for themes across contexts and conditions, in both adult and pediatric populations. We consider the broad range of caregivers throughout patients' network of care, from those involved with the patient on a daily basis to occasional caregivers and those providing assistance remotely.

METHODS

We conducted 28 interviews and observations of adult and child patients and their caregivers across two sites in the Seattle area: an adult tertiary care hospital (Virginia Mason) and an academic children's hospital (Seattle Children's). At each site, we conducted 40-60 minute semi-structured interviews with patients and their caregivers combined with 60-90 minute bedside observation periods with each patient we interviewed. We followed up with 15-30 minute phone interviews after patients were discharged. Details of our participants and sampling strategy are described below. The authors' institutional review board and the hospitals approved this work.

Sites

We conducted our study at one adult and one pediatric care hospital in a large urban area in the US, both serving patients from a wide geographic region. Both hospitals serve as tertiary referral centers in their immediate areas and beyond. Virginia Mason (the adult hospital) admits over 16,000 inpatients per year, and Seattle Children's (the pediatric hospital) admits over 15,000 inpatients annually. Virginia Mason's inpatient demographics mirror the local population, with two thirds of patients insured through private insurance. Seattle Children's

sees a slightly more ethnically diverse patient population than the surrounding area, and just under half of patients are insured privately.

Participants

Our site selection and sampling criteria allowed us to observe interactions with patients of a wide range of ages, with and without caregivers, and ensured maximal diversity of hospital care experiences. A total of 48 people participated in our study: 28 patients and 20 caregivers across the two sites. Our recruitment focused on maximizing the diversity of patients. We recruited patients using a purposeful sampling framework based on age, gender, ethnicity, as well as specific medical attributes such as the primary medical service and disease complexity. We did not collect income demographic information from participants. Interviews and observations took place from February to May 2015. Research coordinators employed by each hospital recruited and consented participants on behalf of the research team.

We interviewed 20 caregivers who were present in the hospital room when we recruited patients. Half of participating caregivers were 18-39 and half 40-59. Caregivers were predominantly female, especially in the pediatric hospital. Of the 20 caregivers who participated in our interviews, 16 were parents of pediatric patients and 4 were caregivers of adult patients.

Patient participants had diverse medical conditions that related to varying levels of complexity and lengths of stay. Patients' medical conditions ranged widely, from appendicitis to congenital heart disease requiring a heart transplant to Crohn's disease to complications from diabetes. Patients were equally divided between the following categories: surgical vs. medical, pediatric vs. adult patients, complex vs. non complex and chronic vs. non-chronic medical conditions. Patients' ages ranged from 7 to 76. In the pediatric hospital, half of the patients were age 7-12 and half were 13-17. In the adult hospital, patients were evenly split between 18-39, 40-59, and 60-76. Half of the patients were male and half were female. Patients were more ethnically diverse than the American population: 18 were White/Caucasian, 6 Black/African-American, 3 Hispanic, 2 Asian and 1 American Indian/Alaska Native. Adult patients had a range of education levels, with most having had at least some college education.

Out of consideration to the strenuous nature of hospital recovery, we only interviewed caregivers and patients whose conditions were stable and who felt strong enough to speak at length about their hospital stay. As a result, we typically interviewed patients and their caregivers toward the end of their stay.

Interviews and observations

In the interviews, we asked patients and caregivers about their current hospital stay and about their experience receiving and communicating their care information. We also asked all participants (caregivers and patients, separately) to read through and respond to a set of probing cards that included structured statements about their attitudes toward active engagement in their care as well as management of information during a hospital stay. We developed the cards based on prior patient/caregiver surveys and iteratively piloted the cards

with physicians, former patients, and caregivers. The cards contained statements such as “It’s important that I keep track of things by writing them down so that I remember them” and “It’s important that I have a positive relationship with my doctors and nurses.” For each statement, we asked participants to assess their agreement with the statement and reflect on whether it applied to their own situation. We conducted a second, follow-up phone interview after each patient participant was discharged from the hospital. With participants’ permission, we took photographs of their hospital room and any devices or technology they used to manage information about their care. We audio-recorded all interviews.

We also conducted bedside observations with each patient and their caregivers, typically directly after the interview, although we tried to observe a variety of encounters, sometimes conducting our observations hours after the interview or the next day. These observations generally lasted one hour, during which a researcher sat in the hospital room and took notes. During the observations, we paid special attention to discussions about the patient’s care, any communications between patients, caregivers, and providers, and technology use in the hospital room.

Analysis

Throughout the observations and interviews, our research team met regularly to discuss preliminary findings and identify emergent themes in our data. Based on these emerging themes, we narrowed our analysis to focus on caregiver coordination with patients and clinicians. Four members of the research team reviewed the observation field notes, photographs, and interview recordings and transcripts to identify information about patient-caregiver role definition, social uses of data about the hospital stays, and communication between patients, caregivers, and clinicians. Despite the broad diversity of experiences of participants, as we continued the study strong themes of caregiving roles and opportunities for design emerged. During the analysis, our research team iteratively reviewed the thematic schema about patient-caregiver coordination to ensure comprehensive representation of supporting and contrasting examples related to these themes.

FINDINGS

Our study revealed a picture of patients’ and caregivers’ information practices and needs, respective roles, and coordination during an inpatient hospital stay. In this ‘findings’ section, we report findings emerging directly from our observations and interviews. In the ‘design considerations’ section that follows, we extrapolate from our findings and explore opportunities for CSCW technology.

We begin this section by describing the experience of being in a hospital room from an information perspective. We then describe five roles caregivers adopt: companion, assistant, representative, navigator, and planner. We show how caregivers shift between these roles and negotiate responsibility as the patient’s condition stabilizes. We examine the coordination and collaboration practices caregivers adopt as they solicit help, set up shifts, and maintain duties outside the hospital. Finally, we discuss how patients and caregivers share information about their care with others.

We refer to patient-participants and caregiver-participants throughout, using the following scheme: a letter prefix to indicate the hospital (A for adult, Y for youth/pediatric), the patient number within that hospital, and then “Caregiver” if the quote or example is from a caregiver we interviewed. Caregivers that are mentioned but not interviewed are described using their relation to the patient rather than a code number.

Coordination within the hospital room

During their hospital stay, the patient’s hospital room becomes the information hub for patients and caregivers, but information flow beyond the hospital room is constrained. Although participating patients’ rooms were filled with computing technology—from in-room computer terminals to laptops, tablets, and smartphones—communication about patients’ health and care was relatively low-tech. Clinicians delivered information to patients and caregivers in person, talking them through updates or changes, and answering questions. Patients and caregivers also largely communicated with each other in person, over the phone, or via text message, and rarely took their own notes. For caregivers, physical presence in the hospital room was often required to receive detailed information about patients’ care or interact with clinicians. This requirement limited caregivers’ ability to coordinate and communicate, with patients, clinicians, and other caregivers alike.

Rounds—Clinicians coordinate with each other through daily patient rounds that allow physicians to receive clinical updates, perform medical decision-making, and communicate findings and care plan updates with both patients and other clinical staff. In the adult hospital in our study, these rounds usually consisted of one to three clinicians. The pediatric hospital in our study practiced family-centered rounds [27], during which the patients and caregivers in the hospital room were invited to observe and participate. Pediatric rounding groups were quite large, often including seven or more clinicians.

Patients and caregivers highly valued these daily conferences for their regularity, completeness, and insight into clinical coordination practices.

“What they do here, they have like a team and I notice they communicate with each other, like when they brief each other because they do it right in front of me, and update. They communicate it to me about who’s doing what and what’s going on.” – A02

Rounds were very information dense, and participants often felt overwhelmed by the jargon and technical terms used by clinicians both during and after rounds. Y04’s caregiver described her difficulties in communicating with clinicians:

“Some of the doctors can use really big words and like the genetic—the biochemical genetic people—they are so brilliant they cannot dumb it down for you, and so then you leave and like, what the heck just happened. ... you gotta be able to understand it to know what’s going on. ... And even when you ask questions...they’re like so brilliant, like they don’t understand your questions and how to answer it in a way that you can understand it. ... The one biochemical geneticist came to see us...he talked for 10 minutes about genetics and tests and everything and, and I was like ok, I didn’t understand a word you said and he was

like, he was like, ‘What didn't you understand? I explained everything.’” – Y04, Caregiver

Waiting—Various clinicians (such as physical therapists, surgeons, and other specialists) stopped in throughout the day to check in or deliver updates, but most of our patient and caregiver participants spent their time waiting, sleeping, or passing the time as patients healed or adjusted to new treatments. Patients and visiting caregivers watched TV, played games, or read books.

Adjusting to the rhythm of the hospital took some getting used to.

“It's a lot of hurry up and wait. You know, when you first come to the hospital you're like ‘I want to know what's going on’, this that and the other. And then after a while you start realizing it's gonna move at the pace it's gonna move. You can't rush it.” –Y13, Caregiver 1

As we saw time and again in our observations, an hour could pass in near-silence, interrupted by a one-to-two minute clinician encounter that changed the plan for the day, or even extended the patient's stay. Some participants felt they had a good sense of the hospital's routine. Y04's caregiver commented that in one department in the hospital “[rounding] was like clockwork, it was at 9:50 every morning they were there.” Y05's caregiver described not just rounding as predictable, but also clinicians' followup visits:

[The primary doctor]'s always here around 8 ... and he says what they're gonna do for the day ... And then the leading doc comes usually about half hour, 45 minutes after him, and she checks him over and then she reexplains everything again, so we're all, everybody really knows what's going on, and then they do their rounds. – Y05, Caregiver 1

Other participants, however, found these brief and vital interactions with clinicians hard to predict. For example, although patient A3 nearly always had a caregiver in the room, clinical encounters sometimes occurred before a caregiver arrived. As A3 told us, “When they come early morning, seven o'clock, eight o'clock, my daughter is not here.” A3 tried to convince clinicians to come later in the morning, but this was not always possible so her daughter occasionally missed hearing updates directly from clinicians. Y06's caregiver described being unwilling to leave the room for fear of missing a clinician encounter:

I thought ok I'll take [Y06] for a walk, and then I thought what if someone's looking for her. Like we don't know when people are coming, so. And we just stayed. –Y06, Caregiver

In observation, Y07's caregiver was waiting for a resident to come around for one last meeting before discharge. After she had waiting for some time, she learned that the resident had come around earlier in the morning, so she had been waiting for nothing. In a follow up conversation, Y07's caregiver expressed displeasure and mistrust over this situation:

“Well, it was annoying that we never saw the doctor. I'm still not totally convinced that the residents were in in the morning. That, that piece was very vague, like someone had checked on her...but no one talked to me.” – Y07, Caregiver

Information capture—Information about patients' care is documented extensively in electronic medical records throughout a hospital stay. However, no patient or caregiver in our study used a patient portal or personal health record to access information about their care while in the hospital. This is partly due to access: the pediatric hospital did not provide a portal. Yet a portal was available and accessible to adult patients and several participants mentioned accessing it before their hospital stay. Instead, patients and caregivers preferred to remember information rather than looking it up or keeping track of it themselves; only 6 participants reported taking their own notes. Participants trusted that clinicians would be able to provide the information if it was really necessary. The following exchange is typical of our interviews:

“Interviewer: Are you actually looking through your own chart, or your history in some way?”

A6: No, just from memory. And then talking with the doctors, yeah. They have access to the actual files.”

Critical updates, context, and plan of care decisions were thus limited to those within earshot at the time of the provider's visit, and largely unrecorded by patients and caregivers. This created a number of barriers to caregiving and patient care, as patient/caregiver-clinician communication that is not easily accessible to the patient cannot be easily disseminated to other caregivers or used by patients themselves for later reference. However, patients and caregivers do have ample time throughout the day between clinical encounters to review and process information. We discuss these opportunities in the ‘design considerations’ section that follows.

Caregiving roles

Caregivers play many different roles in patients' care during a hospital stay. In our study, participants described several ways in which their friends and family provided care. In this section, we report the types of caregiving we observed and our participants described to us. We found five key caregiving roles during a patient's hospital stay: **companion, assistant, representative, navigator, and planner**. These roles are neither exhaustive nor mutually exclusive: caregivers can and did switch between these roles across the patient's hospital stay. However, each role represents distinct activities with their own design considerations for CSCW. In this section we describe each role with examples from our interviews and observations.

Companion—Caregivers played an important role as companion, offering fellowship and emotional support to patients. Pediatric participants were almost never without their parent as a companion. In the adult context, several participants, like A05 and A14, had caregivers visit them and provide companionship. A12 described an even more social picture:

I: So it sounds like you've had a lot of people come by and visit and people hanging out here?

P: Yeah my friend spent the night with me last night just to keep an eye on me and my grandma and my mom both stayed with me the first night....P: Actually my mom has been chilling with me and my husband was in. – A12

As companions, caregivers also brought the comforts of home into the hospital room. Patients often had a favorite blanket or book, provided by a caregiver. Some caregivers even brought home-cooked meals when possible. Y13's aunt arrived with a freshly made quiche during our interview. Both the patient and her caregivers agreed it was a definite improvement over typical hospital fare.

Both patients and caregivers at times expressed frustrations at externally-imposed restrictions to companionship. Several participants who were in isolation told us they felt pent up inside the confines of their hospital room, and were eager to receive day passes to get outside for a while. Y08's caregiver, for example, expressed frustration at the fact that her other children could not come to visit (and thus act as companions) because of the risk of contagion from Y08.

Although overall both patients and caregivers saw companionship as desirable, it is worth noting the difficulty of the enforced companionship that comes with being in isolation. Many participants mentioned to us that our interview was a relief not only from the waiting inherent in a hospital stay, but from having only each other to talk to.

Assistant—Caregivers at times acted as assistants to patients in managing their care. In some cases, caregivers provided instrumental support, helping patients by giving them a ride to or from the hospital and getting the doctor when the patient was not feeling well. In other cases, caregivers aided patients in managing information about their care. Several of the caregivers among our participants helped patients by acting as memory aids, taking notes and keeping track of appointments and other care information. Patients recognized the importance of caregivers in filling this role. For example, A13 stated:

“It’s important for me to get the help and information and it’s also important for my family because they’re the ones that are going to be helping me out with this day to day.” – A13

Y06, who had been newly diagnosed with a chronic condition, also mentioned her need for help, “especially at the beginning,” although she hoped to be more independent as time went on. One of A13's caregivers took this role to the extreme. Her spouse took classes and got an EMT certification so that he would know what to do “if things go haywire.”

Representative—Caregivers frequently assumed the role of the patient's representative, taking on the responsibility of communicating the patient's desires and needs to clinicians on the patient's behalf. Caregivers took on this role when patients were either uncomfortable speaking with clinicians directly, or unable to communicate their needs on their own. This situation arose frequently in the pediatric context, where patients were often more comfortable speaking to their parents than to the doctors. For example, Y13 confessed that she preferred to go through her parents than to communicate directly with clinicians; similarly, Y8 stated, “I don't talk that much so I tell it to my mom.” Y4's caregiver described her sense of obligation to speak up on the patient's behalf regarding decisions about his care:

“He hasn’t been able to speak up a lot for himself, you know, ‘cause ... he’s had a lot of ups and downs and doesn’t understand what’s going on and so being that I am his care provider and everything, yeah...feel like I need to [speak up], sometimes.” –Y04, Caregiver

One caregiver also described taking on a relationship management role. She commented on the importance of modeling a good relationship with clinicians hoping that the patient would follow her example:

“If I don’t have a positive relationship with them, she won’t have a positive relationship with them, and that makes a big difference in how she feels about everything moving forward.” – Y6, Caregiver

Navigator—Caregivers also acted as navigators for patients, guiding their decisions and helping them understand their condition. As opposed to the ‘representative’ role, which was outward-facing, the ‘navigator’ role was more often expressed in caregivers’ interactions with patients. For example, A3 reported having her family guide a decision about her care, describing a family meeting where she changed her mind about receiving dialysis based on counsel from her family members.

Caregivers also often explained to patients information provided by clinicians. In both the pediatric and adult contexts, patients reported relying on caregivers to understand information about their care, either because they did not understand what the clinician had said or because the clinician had bypassed them entirely. A3 recounted how her daughter, a medical doctor, helped her understand what her doctor was saying. In observation, Y4’s caregiver described to clinicians how she set aside time with the patient to help him understand and cope with what was happening to him. Y5 also relied on caregivers to get information when clinicians bypassed him because of his young age:

“I’ve had pneumonia once and it’s stressful for me but because only my parents knew what was going on really. Because they didn’t really expect me to want to know, like, everything”. – Y05

Caregivers’ role as an interpreter between clinicians and patient occurred frequently in the pediatric setting, possibly because caregivers, who were also the patient’s parents in all the cases we observed, perceived it as a normal part of parenting.

In a few cases from the children’s hospital, parent caregivers sometimes withheld information from patients in an effort to shield them from anxiety. Y11, for example, had a chronic condition that could adversely affect his future life. His caregiver said she purposefully shielded him from information about how the disease could affect him down the road on the grounds that she didn’t want him to worry about it until he was old enough to handle it. Y5’s caregivers also shielded him from certain information by choosing to go outside in the hallway for rounds instead of inviting the clinician group into the patient’s room.

Planner—Patients often needed greater support from caregivers as they prepared to be discharged from the hospital. Sometimes caregivers were only called upon for help getting home, although this was not often a simple task. As A6 put it:

I: I noticed when you were talking with the doctor earlier, you mentioned it would be helpful to get a couple days heads up of when to coordinate your discharge. What's the primary reason for that?

P: In case I'm not feeling comfortable enough, that I can coordinate with my family, because my one daughter works nights and goes to school days. My other daughter works nights but is available during the day because she does her graphic web design during the day. And my boys both work pretty much the same shift I do...so between the boys and their girlfriends and my daughters, we can find a couch for me to lay on... And they got to bring my car back or come get me in my car. Big trouble on Easter if I have to take a taxi. There will be one less deviled egg for you! – A6

In other cases, caregivers needed to prepare to assume responsibilities that had been handled by clinicians during the hospital stay, such as dispensing medications and monitoring certain levels. This occurred frequently in the pediatric context. For example, Y14's caregiver asked clinicians to show her how to use a complicated pillbox so that she would be able to use it when they got home. Y04's caregiver requested training in administering Y04's medications:

I wanted to be comfortable doing his meds before we ended up leaving the hospital, so I started learning three weeks ago and then last night I just started learning the care of the wound. – Y04, Caregiver

Y01's caregiver described having to monitor and record certain statistics about the patient:

And we have it in a place where...so we have to take her blood pressure, we have to check her respirations, and we have to listen to her heart, and we have to take her temperature. So that's all in a bin in our coffee table with this binder, so everything is there, all together. – Y01, Caregiver

Sharing responsibilities, shifting roles

As caregivers adopt different roles throughout a patient's hospital stay, patients and caregivers also renegotiate responsibilities and boundaries. Caregivers take a more active role at certain times and a more supportive role at others. They help to stabilize the patient, but even once the patient appears stable, they must be ready to jump in and assist whenever the situation changes, sometimes quite abruptly.

Even patients and caregivers with similar initial arrangements as each other can diverge substantially across the hospital stay. For example, A3 and A6, both middleaged women, were brought into the hospital by their adult daughters, who took a *navigator* role in encouraging their mothers' admission and a *planning* role in facilitating that admission.

“Sunday night was the worst. I could barely breathe, I could barely dial [my daughter’s] number. She lives a block from me... I thought oh, my God, I’m going to die, then I just dialed her and then we called 911.” –A3

“Sunday morning, my daughter came by, not hearing from me, wondering what the heck’s going on with Mom and took one look at me and took me to...urgent care.”
–A6

Their stories soon diverged, however. Since admission, A3 almost always had a caregiver in a *companion* role, staying with her in hospital room while she was awake. Her children organized regular shifts. They also continued to play a *navigator* role throughout her stay. A3 (who did not finish high school and for whom English is a second language) spoke candidly about her challenges understanding medical terms and procedures relating to her care, and how her caregivers helped her.

“She’ll be in the morning and then she have kids, so she’ll be here at noon and when she leaves, my younger daughter comes back from work and stays till I want to sleep. I go: I want to sleep now. Now you don’t have to worry about big words that people give me.” –A3

Initially, A6 also relied heavily on her daughter as *companion* and *assistant*. However, once her condition was stabilized, her daughter returned to her job, and the two kept in touch by phone.

I had my daughter with me, and whenever something goes wrong and I need to go to the hospital, I bring my two girls for everything, because of the fact that two minds are better than one, especially if one is sick and distressed. For the most part I retain everything that’s said to me, but I had just come out of a delirium state of fever, so I was pretty out of it there for a little bit. Once they got enough oxygen in my brain, though, I was feeling better. —A6.

At the time of our interview, A6 had since been visited by various family members, and even some of her daughter’s friends, acting as intermittent *companion* caregivers but leaving much of the responsibilities in the patient’s hands.

Stabilizing—Caregivers often took more active roles at the beginning of a patient’s stay until they stabilized. Patients often needed caregivers as *assistant* and *navigator* to help them keep track of details or make decisions by themselves at the beginning of a stay, but once their condition was more under control, some sought more independence. For example, patient A13 relied on her caregivers during the early part of her stay, but was eager to take more initiative once she started feeling better.

“My mom has been chilling with me and my husband was in...He was really helpful...trying to keep things running correctly as well as he could. Especially when I’m used to being a little bit more acute mentally, that’s kinda disturbing not being able to function on that level and it’s good to have the support that I do, it’s a relief. But I don’t like to just dump it on them and leave it there either.” –A13

At the time of our interview, A13 had once again become the primary coordinator of information about her care. Although she was grateful for the support of her caregivers, she

didn't want to be a burden, and sought to be an active participant in her own care whenever possible.

Being ready to step in—Although patients in our study had generally stabilized at the time of our interviews and observations, caregivers still played an important role. Patients' condition could worsen, or their acuity be reduced, and caregivers we spoke to felt it was part of their job to be ready to step in.

Sometimes, this reassertion of influence was dramatic. Patient A3 recounted a previous hospital visit when she was almost discharged far too soon.

“The nurse came [and said] I can leave now. Then I get down, I was going to use the bathroom, and something happened and I kind of fainted. So then my daughter went and got somebody and they check the blood pressure, the blood pressure was low, and then the staff went again and called the surgeon's nurse.” –A3

Inter-caregiver coordination

Patients often had a primary caregiver supporting them; in the pediatric context this role was filled by the mother for each of our participants. However, this primary caregiver often worked in conjunction with several secondary caregivers supporting them, both in person and behind the scenes. These caregivers collaborated and coordinated with each other to support patients. Sometimes, as in the case of A3, caregivers set up shifts so someone would always be with the patient. Caregivers also balanced patients' needs with other responsibilities, such as work and parenting other children.

Needing help—Although most patients had a primary caregiver, caregivers benefited greatly from the ability to share the informational and emotional load with another person. Y04's caregiver, a single parent who did not have help, expressed her difficulty, saying, “When we first got here...I'm a single mom, so I'm all by myself, and a total disaster.” As the patient's condition developed, Y04's caregiver was ultimately able to find help at least some of the time, mentioning a sitter who looked after the patient while she prepared food for him.

Y08's caregiver commented on the emotional support she got from her partner:

“That's when we start doing the workup for her transplant and I would like for my husband to be here so you know I'll get emotional and he's like the rock.” –Y08, Caregiver 1

Y08's caregiver also described to us how she and her partner worked together, complementing each other's abilities: her husband provided emotional support and understood the big picture, but “couldn't tell you half the things” because he didn't remember all the “small details”. By contrast, Y08's primary caregiver “ask[ed] the more probing questions,” and communicated information to others within the family “step by step and then they kinda calm down and then they'll ask some questions and everything is fine.” Ultimately, they worked together to “[make] decisions as a family.” At home, Y08's caregiver expected work-sharing to continue.

“Hopefully they'll give me some kind of paperwork .. [and I'll] make sure it's up on the refrigerator ... so we can all have an idea of what to do, how often and that kind of schedule... There is no ‘I'm doing it all.’” –Y08, Caregiver 1

Within the hospital, caregivers working alone also faced difficulties in the basic task of getting food. In the pediatric context, several participants complained that because they did not want to leave their young children alone in their rooms, they were unable to get food from the hospital cafeteria.

Setting up Shifts—When multiple caregivers were available, caregivers sometimes worked in shifts, to make sure someone was there with the patient for as much of the time as possible. For example A3's caregivers took regular shifts to try to have someone with A3 as much as possible while still attending to their outside duties. In order to make things easier for them, A3 herself let her caregivers know when she was unlikely to need them.

Y06's caregiver also described working in shifts with her partner:

And for caregiver too, because my husband has a job, so when can he be here, what does he have to schedule around. Try to have someone here all the time so she's not alone. Had one friend over, going to have a couple more tonight. –Y06, Caregiver 1

In general, caregivers appeared to divide up the shifts based on their schedules rather than on roles. Y13's caregivers similarly divided their time based on outside factors rather than roles, and strove to share information with each other. While one caregiver was in the hospital for her own surgery, the other observed rounds and took notes that he could later share with his partner.

Shifts and handoff are common practice for clinical caregivers in the hospital, where patients are followed by clinical care teams that consist of multiple physicians each taking a primary role in the patient's care over a specific period of time. Clinicians hand off to each other through formal processes [23]. However these processes are not formalized or accounted for to support informal caregivers during a hospital stay.

Maintaining other duties—One frequent obstacle mentioned to us by caregivers in this study was the constant intrusion of non-caregiving tasks. Even when a hospital stay is planned, it does not mean that caregivers' other work goes away. In observation, Y10's caregivers joked about how they could never take time off from work again after spending so much time in the hospital.

Sometimes this other work was in itself caregiving work. During our interview, Y14's caregiver struggled to put her other children to bed while spending the evening in the hospital with the patient, soothing them over the phone in between sharing care information with her spouse and keeping the patient company.

In this way, personal communication technologies like phones and laptops were both a blessing and a curse. Performing external work from a hospital room is now technically possible, allowing caregivers to manage their job of performing tasks in two places at once.

DESIGN CONSIDERATIONS

Our findings point to many opportunities for CSCW systems. Looking at the hospital room as an information hub, we see opportunities for information sharing and coordination beyond in-person interaction; in this section we suggest considerations for designing across the CSCW matrix. We also examine design considerations for caregivers in their various roles, and tease out how these roles place different demands on collaboration systems for caregivers. We discuss how to support caregivers beyond the hospital, and the potential for CSCW technology to expand opportunities for caregiving. We also discuss designing for the uncertainty inherent in a hospital stay. Finally, we caution designers against interfering with or supplanting existing in-person interactions, encouraging designs that augment and extend current inpatient practices.

Designing across the CSCW matrix

The current patient and caregiver experience of information during a hospital stay is largely devoid of groupware. While patients are in the hospital, most clinical communication with patients and caregivers is synchronous and collocated; face-to-face conversation dominates. As we observed in this study, visits from individual clinicians were not strictly scheduled, so caregivers were not always able to be present for these crucial opportunities to exchange information and communicate priorities. Few patients or caregivers reported taking notes during clinician encounters. In many cases, the patient's hospital room was more than just an information hub; it often became an information bubble, easily popped with its information fleeting.

CSCW technologies have the potential to extend caregivers' ability to help patients, both within the hospital room and from afar—both during and between clinician meetings. To help explicate this potential, in this section we use Johansen's groupware matrix (often referred to as the CSCW matrix) [12] to explore opportunities for design. Although several models and frameworks have been developed to explain CSCW systems—for example, the recently-described Model of Coordinated Action (MoCA)[16]—we have found the targeted framing of Johansen's groupware matrix to be a useful lens for the meeting-centric world of inpatient clinician encounters. Of the four quadrants in the matrix—face to face interactions, continuous tasks, remote interactions, and communication & coordination—only face to face interactions are currently well supported.

Remote participation—To communicate with clinicians or observe patient-clinician interaction directly, caregivers in our study had to be physically present *and* time their visit to overlap with a clinician encounter. CSCW technologies to facilitate remote caregiver participation in these meetings could allow caregivers to be informed about the patient's condition and care, ask questions the patient might have forgotten, and reduce patients' information burden. Promisingly, the adoption of video-conferencing or other telepresence technologies need not require massive infrastructural investment or even the creation of custom technology. Both hospitals in our study had robust wireless Internet access in hospital rooms, and a few patients and caregivers even used commercial technologies such as Skype and FaceTime to communicate with others during their hospital stay. However,

more study is needed to facilitate planning of these encounters, assure patient and clinician comfort, and minimize disruption to care.

Capture now, process later—Patients and caregivers in our study found clinician conversations extremely valuable, yet fleeting. In both our interviews and our direct observations of these encounters, we have come to understand the deep and multi-faceted value of clinicians, patients, and caregivers simply talking to each other. And yet, these conversations represent a tension: valuable face time and active listening in order to form questions leaves little opportunity for recording notes, remembering specific regimens, or unpacking jargon.

CSCW technology holds the potential to resolve this tension by stretching time, capturing sporadic information-dense meetings, and allowing patients and caregivers to process them later. Patients and caregivers have ample time between clinician encounters, and technologies that can help them step through an interaction and fully understand a change could reduce the burden on memory and improve patients' awareness. Furthermore, once this data is captured and processed with computers, it can be recalled later or even accessed by remote caregivers.

Asynchronous communication—Technologies that support asynchronous communication would benefit both remote and occasionally-present caregivers alike. In our interviews and observations, we saw two intriguing examples of this approach in action. Both A13 herself and Y13-Caregiver 2 emailed clinicians directly. We even watched Y13's caregiver send and receive emails with a nurse practitioner during our interview. However, these were the exceptions to the rule and this sort of direct, unaccounted-for communication between caregivers and clinicians may not be scalable.

On the whole, asynchronous communication among patients, caregivers, and clinicians is supported poorly at this time. A technology such as a 'virtual whiteboard' accessible to both local and remote participants in care could provide valuable common context, allowing caregivers to better understand the patient's status and possible caregiving needs. Doing so while minimizing disruption would also be beneficial.

Supporting caregivers in their various roles

Caregiving is not a monolithic activity, and social systems for caregivers should account for the different roles caregivers play. For example, telepresence, video conferencing and even chat technologies could allow nonlocal caregivers to act as companions. Caregivers as assistants will benefit from systems that facilitate, structure or automate note-taking. Systems that give increased agency to caregivers will support their representative role, allowing them to pass on patient concerns in a transparent way. Systems that allow patients, clinicians and caregivers to coordinate discharge will smooth recovery and support caregivers as planners.

Systems for patients and caregivers should also account for multiple simultaneous roles through mutual awareness. As we showed in the findings section, caregivers often perform multiple roles and negotiate responsibilities with patients throughout and beyond a hospital

stay. Many of these roles will benefit from systems that simply allow caregivers, patients, and clinicians to keep track of each others' status, questions, and current roles. Such flexible mutual awareness systems would allow caregivers to jump in with communication wherever necessary while still keeping the patient in the loop, and support caregivers in their role as assistant. They would also allow caregivers to take the lead and set an example for the patient on how to communicate with clinicians. Finally, a mutual awareness and communication tool could also allow caregivers to convey patient requests to clinicians when patients do not feel comfortable speaking directly with clinicians.

Designing for uncertainty

A hospital stay is an inherently uncertain time. Patients arrive for a myriad of reasons, both planned and unplanned. While pathways of care exist for many conditions, with expected acuity levels and lengths of stay, every patient is unique. Patients may feel aware and alert one moment, and need a caregiver to take over the next; caregivers themselves may cycle through over the course of an inpatient stay. A hospital stay tests a patient's networks of care, and each caregiver or set of caregivers is as unique as the patient.

Systems to support patients and caregivers should also scale from short-term to long-term. Cumbersome registration processes may be highly unsuitable for short stays, even if those stays extend into longer ones. Designs that allow for nimble setup and can transition to longer-term use will be more likely to be used and useful. Similarly, caregiver roles may change quickly, and one caregiver may play many roles; designs to support caregivers will need to account for this fluidity.

These complex requirements and tensions may seem daunting, but they also represent a rich opportunity for CSCW research to advance the state of the art and contribute to broader impact.

Designing for partnership within & beyond the hospital

Caregiving in the inpatient environment is an inherently multiparty activity, and systems designed to support it must accommodate caregivers, clinicians, and patients. Systems to support caregivers should support collaboration among caregivers and clinicians, patients, and other caregivers. Others have identified this same finding for chronic caregiving in the home. Indeed, although we have focused on the inpatient experience in our study, the lines between chronic and acute care are blurred; those living with chronic or long-term care often experience frequent hospitalizations, and most inpatients will continue their recovery and healing at home.

Thus, designs for caregiving partnership in the hospital can and should take cues from related work supporting family caregivers in the home environment. For instance, Chen et al. [3] suggest that systems to support family caregivers facilitate task coordination between caregivers, a finding echoed in the work presented here. Inpatient-focused systems could support coordination between these caregivers by allowing them to articulate and delegate tasks in a structured way.

Chen et al. [3]'s recommendations that systems support caregivers' emotional and social welfare can also be applied to the inpatient context. These recommendations could be deployed to support partnership not just between caregivers, but also between caregivers and clinicians. Caregivers could benefit from a system that helps clinicians gauge their emotional state and ability to handle incoming information. In our study, Y04's caregiver described how over the course of Y04's stay clinicians developed the ability to tell if the caregiver was feeling overwrought or if was able to handle new information; if the former, they came back later, when she was better able to process the information.

Brereton and Nolan describe the potential of the PREP system [4], an intervention based on a partnership between caregivers and clinicians, to help caregivers of stroke victims attain the skills and confidence they need to carry on their work at home. Systems supporting this type of partnership-based intervention could support inpatient caregivers in their role as planner as well as helping them transition to home care.

As these examples show, designs that support informal caregiving during a hospital stay can and should incorporate the needs of long-term and at-home caregiving. However, there are still unique elements of the inpatient experience that may require special attention. A given hospital stay may be the patient's first or indeed only major inpatient experience. The blooming, buzzing confusion of an unexpected and unfamiliar environment, combined with the challenges of the setting itself may lead to different constraints from the needs of more expert or long-term care. We hope this work can form the beginning of a discussion of how CSCW systems can support informal caregiving throughout a patient's journey, and how groupware systems for caregiving can react to the different needs placed upon them within and beyond the hospital.

Designing to augment, not interfere

Patients and caregivers in our study highly valued in-person unmediated communication with their clinicians as part of the healing and caregiving process. Conversations, updates, questions and answers all proceeded directly and naturally. Similarly, patients and caregivers valued companionship and navigation, both roles ideally suited to being in person and involving complete attention.

And yet as a result of this offline paradigm, currently the information and context exchanged between patients, caregivers, and clinicians is static and confined, not updated despite frequent changes, and often never reaching beyond the hospital room door. The benefits of CSCW technologies will be much greater if patient-facing and caregiver-facing information in the inpatient setting can be digitized and shared.

However, in designing tools and coordination systems, researchers and designers must take great care not to take away from valuable face-to-face interaction, but instead enhance or complement it. Caregiver-inclusive technologies should also never disrupt or interfere with essential clinical care. Technologies to support patients and caregivers during a hospital stay should augment the valuable existing communication, not interfere with it. Solutions that allow patients and caregivers to record or capture interactions automatically and return to them later to annotate or share may allow for both.

LIMITATIONS AND FUTURE WORK

Medical care is incredibly diverse, and although we tried to ensure a wide spectrum of patients, our findings are based on interviews and observations at two hospitals in one urban area. These sites attract patients from a wide geographic area and diverse medical conditions, but they are not necessarily representative of all hospitals and populations. In the future, we would like to verify and extend these findings in other inpatient facilities and other regions.

Our technique of interviewing patients and caregivers in the hospital room also necessarily limited our direct access to the full range of hospital experiences. We interviewed and observed patients and caregivers when the patients' condition had stabilized, and again once they were discharged. This timing allowed us to gain reflections on the whole hospital stay experience, but our direct observation of admission and initial hospital experiences was limited. Furthermore, both patient-participants and caregiver-participants spoke to us about other caregivers, but we did not have an opportunity to interview these third parties directly, nor did we ask participants to systematically articulate their networks of care. In future, we hope to complement our current work through additional techniques, such as participatory design, technology probes, and a broader survey of patients and caregivers.

Our study also raised questions without clear answers. For example, much work remains to be done in studying how caregivers coordinate with each other during a patient's hospital stay, and how practices and patterns established in the hospital setting translate to long-term or at-home care. It is also unclear to what extent hospitals or healthcare organizations themselves should provide coordination technology, and which solutions would work better if provided by nonprofits or technology corporations. Finally, great opportunities exist for caregiver-support systems to also involve clinicians, but more work is needed to understand how patients' two teams of care—formal and informal—can best coordinate to support patients' health and wellbeing.

CONCLUSION

Informal caregivers are active participants in patients' care during a hospital stay. They play various roles, from companion to representative to navigator. Caregivers coordinate communication with clinicians, care for patients' overall wellbeing, and activate wider networks of care. In this paper, we have shown how caregivers of both adult and pediatric patients support those patients during a hospital stay. We have provided a set of design considerations for CSCW researchers and designers to support caregivers in their important role in the hospital. Support for these important caregivers should enhance hospitalized patients' care, potentially improving clinical outcomes and even reducing medical errors.

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