Family Care Coordination in the Children's Hospital: Phases and Cycles in the Pediatric Cancer Caregiving Journey

Sarah Nikkhah, IU School of Informatics and Computing at IUPUI, Indiana, USA
Swaroop John, IU School of Informatics and Computing at IUPUI, Indiana, USA
Krishna Supradeep Yalamarti, IU School of Informatics and Computing at IUPUI, Indiana, USA
Dr. Emily L Mueller, IU School of Medicine, Indiana University, Indianapolis, Indiana, USA
Andrew D Miller, IU School of Informatics and Computing at IUPUI, Indiana, USA

When a child is hospitalized with a serious illness, their family members must process emotional stress, quickly absorb complicated clinical information, and take on new caregiving tasks. They also have to coordinate with each other and with other family caregivers without abandoning existing work and home life responsibilities. Previous CSCW and HCI research has shown how the patient's experience changes across the illness journey, but less is known about the effect of this journey on family caregivers and their coordination work. CSCW technologies could support and augment family care coordination work across the journey, reducing stress levels and improving families' ability to stay connected and informed. In this paper, we report findings from an interview study we conducted with 14 parents of children undergoing extended hospitalization for cancer treatment. We propose the concept of caregiving coordination journeys and describe caregivers' current communication and coordination practices across different phases of the hospitalization journey, from diagnosis and early hospitalization to extended hospitalization and beyond. We characterize families' caregiving coordination routines across different time scales, and describe the current role of communication technologies in families' coordination practices. We then propose design opportunities for social computing technologies to support and augment families' communication and caregiving work during the hospitalization journey of their child.

CCS Concepts: • Human-centered computing → Human computer interaction (HCI) → Empirical studies in HCI; • Human-centered computing → Collaborative and social computing →Empirical studies in collaborative and social computing

Additional Key Words and Phrases: Care coordination; Parenting; Hospitalization; Pediatrics

ACM Reference Format:

Sarah Nikkhah, Swaroop John, Krishna Supradeep Yalamarti, Emily L. Muller, Andrew Miller. 2021. Family Care Coordination in the Children's Hospital: Phases and Cycles in the Pediatric Cancer Caregiving Journey. Proc. ACM Hum.-Comput. Interact. 4, CSCW, Article 224 (December 2020), 28 pages. https://doi.org/10.1145/3555187

1. Introduction

When a patient is hospitalized, existing networks of support spring into action. Friends, family, and loved ones buffer stress for the patient[77] and provide vital context and continuity for the

Authors' address: Sarah Nikkhah, snikkhah@iu.edu Swaroop John, swajohn@iu.edu; Krishna Supradeep Yalamarti, kyalama@iu.edu; Andrew Miller, Andrewm@iu.edu, IU School of Informatics and Computing at IUPUI, Indiana, USA; Emily L. Muller, elmuelle@iu.edu, Indiana University School of Medicine

2573-0142/2022/10 – Article#?... $15.00
https://doi.org/10.1145/3555187

clinical team [35]. These informal caregivers—often referred to as 'family caregivers'—are critical to pediatric care [35]. They help patients process information, assist with decisions about their care, and advocate for them within the hospital [43].

When the hospitalized patient is a child, caregivers are most commonly the child's close family and parents. On top of their role as parents, they have to take on additional caregiving tasks, such as absorbing complicated clinical information, handling the emotional impact of the diagnosis, and comforting their child, all without abandoning other responsibilities. Indeed, research from the health sciences literature shows that parents are critical stakeholders in ensuring a hospitalized child's long-term recovery [24].

HCI and CSCW researchers have shown how social computing technologies such as health forums and disease-specific groups can connect caregivers across families [28] and how patients and caregivers can work with clinical providers [26]. CSCW researchers have shown how caregivers coordinate with each other to support chronic care, particularly in the case of older adult patients[74]. However, less is known about the communication and coordination practices within a caregiving circle (the parents and other close-knit caregivers) during the hospitalization of a child. Furthermore, while CSCW researchers have shown how patients' needs evolve across the adult cancer journey, less is known about how caregivers'' coordination practices change in concert with that journey, and the implications for caregiving coordination technologies.

In this paper, we report findings from a larger study with families of children diagnosed with cancer. Cancer is the second leading cause of death in children after accidents [1]. Unlike adult cancers, childhood cancers appear to have no behavioral cause and result from genetic mutations early in a child's life [1]. Encouragingly, major treatment advances in recent years mean that 84-90% of children diagnosed with cancer are expected to survive [1,29]. However, these treatments come at a cost: children are often given far higher doses of chemotherapy than adults, and cancer treatments in children often require severely limiting or suppressing the patient's immune system [1]. Sometimes, pediatric cancer treatment requires extended hospitalizations across a period of six months, with hospital stays of up to 5 weeks at a time [60]. These repeated extended hospitalizations place acute stress on family caregivers [24].

To better understand the experiences and technology needs of family caregivers during their child's extended hospitalization, we began with one core family caregiving group: parenting couples. We conducted a series of qualitative interviews with parents of hospitalized children with cancer. We interviewed 14 parents from eight families, either during or immediately following an extended hospitalization (a hospitalization of at least a week. All families in our study experienced much longer hospitalization). We asked about parents' experiences in coordinating care while balancing their other responsibilities, how they divided responsibilities, and how they dealt with a variety of challenges associated with their child's hospitalization. We did not interview the child patients or other caregivers for this study, choosing for this first study to focus closely on the care coordination needs and practices of parents.

This paper makes several contributions to CSCW research. We describe parenting couples' caregiving experiences, communication practices, and coordination challenges within the family during a child's hospitalization. Specifically, we show that family caregiving coordination practices change across different phases of the hospitalization journey, with differing technology needs and design opportunities at each phase. We then propose and describe the concept of caregiving coordination journeys, showing that just as patients' needs change across illness and treatment phases, so do the care coordination needs and practices of their family caregivers. We show how parents and other family caregivers engage in often 'hidden' technologically-mediated caregiving work during their child's hospitalization and propose specific opportunities for CSCW design. These findings, the concept of caregiving coordination journeys, and design opportunities will have implications for a number of CSCW contexts

beyond pediatric cancer, helping us better understand and support caregivers' collaboration in the health context and close-knit family collaboration during times of crisis.

2. Related Work

Collaborative care management and care coordination in healthcare has received considerable attention from the HCI and CSCW communities; nevertheless, the caregiver-caregiver relationship in the pediatric inpatient setting remains a less explored area within this field of investigation. CSCW researchers have also examined the role of family caregivers, usually concentrated on patient-centered technology for care coordination in the home setting. There is also work concentrated on healthcare journeys, explored extensively in CSCW concerning cancer treatment of adult patients but less extensively related to prolonged child hospitalization with a focus on caregivers.

This section highlights some related research on collaborative care coordination in healthcare, describes existing work on the role of family caregivers, discusses relevant HCI and CSCW literature on non-healthcare family coordination, explains the changing needs over time and healthcare journeys, and shows the opportunity to build on previous work on the chronic outpatient adult care and family coordination technologies, concentrating on shifting needs of caregivers across cancer journey for care coordination of a hospitalized child in the inpatient setting. The section ends with a discussion of the ways in which this paper builds on and extends related work.

2.1. Collaborative care coordination in healthcare

A significant portion of the care coordination research in CSCW focuses on interactions between stakeholder groups, such as patient-provider or caregiver-provider collaboration, covering issues such as patient safety [43,81] or patient-generated data in the clinic [79,82]. CSCW researchers have been successful at disentangling the different roles and practices of various stakeholder groups, including providers (such as doctors, nurses, and pharmacists); caregivers (such as parents, adult children, or other family members); and patients themselves. One common thread looks at healthcare settings as workplaces, focusing on provider-provider collaboration[73,83]. For instance, Reddy and Dourish conducted an ethnographic study on medical work in the hospital context. They characterized the work rhythms and information seeking in the hospital. They found how the cyclic and temporal nature of information work and rhythms in the hospital setting can help identify patterns of former actions and expectations about future activities and provide opportunities for design for medical providers [59]. Patients and caregivers now have increasing access to electronic medical records, often through patient portals that need to be optimized for the caregivers' use [58]. Broad hospital-led efforts such as the Patient-Centered Medical Home aim to connect all relevant stakeholders, including clinicians, patients, and caregivers, from primary to intensive care [62]. Parents or legal guardians are often granted proxy access to their child's medical record. However, these accounts have limited functionality for inter-caregiver interaction and still suffer from information delays and other design constraints. Indeed, parents frequently report dissatisfaction with their own communication and coordination practices during and following their child's hospitalization [68].

Researchers in CSCW, HCI, and Health Informatics have shown the key information role of informal or family caregivers as they support patients and each other. These family members and friends perform critical and often unacknowledged 'hidden work' (also known as 'articulation work'[7] or 'ghost work'[17]) [9,52]. Caregivers' work supports other work, and thus is often hard to account for in contrast to direct clinical care such as performing surgeries or administering medications. Caregivers ensure the success of clinical care and treatments, to

keep others informed, to act as buffers and supports in interactions with clinicians, and to support long-term maintenance outside of clinical contexts[35]. One particularly productive line of research focuses on the needs of the caregiver as an individual "user" of information technologies, as they interact with other caregivers in online communities, coordinate with clinicians, or manage information disclosure to wider friend and family networks. In their landmark 2013 CHI paper Caring for Caregivers: Designing for Integrality, Chen, Ngo, and Park showed the effects of caregiving on the physical, emotional, reflective, and social self of the caregiver[10]. They evocatively described the importance of accounting for caregivers' interactions with other stakeholders, arguing for an increased focus on integrated care coordination technologies to support caregivers.

In the years since, HCI and CSCW researchers have taken up this challenge in various ways. Schrugin et al. surveyed caregivers and identified the challenges they face highlighting the isolation in coordination for the caregivers [66].In pediatrics, Kaziunas et al. studied caregivers of pediatric bone marrow transplant patients, placing the caregiver's role in supporting patients [35], arguing for caregiver-focused information systems in the hospital [36]. 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 the information they wanted to share with others [40]. Suh et al. designed the BabySteps system to allow parents to track their child's development progress [71]. Miller and colleagues described the various roles played by caregivers in the inpatient context [43]. These prior works suggest the importance of caregivers and understanding their various roles and shifting needs to inform design decisions.

More recently, CSCW researchers have focused more closely on patient-caregiver collaboration, such as Berry et al.'s work on identifying how values shape collaboration between patients with chronic illnesses with their caregiver partners [4] or work on pervasive computing on care collaboration between caregivers and children with special needs[37] or chronic illness[23], shared decision making in healthcare settings [6,84,85] and supporting goal-based collaboration with child patients[86]. Researchers have also studied patient and caregiver collaboration with others beyond their immediate care network, including research on online health communities[20,31,87] such as Jacobs et al. work on rare disease care coordination and the role of online health communities in supporting coordination practices[31]. There is also a small but growing literature on multi-stakeholder interactions in which more than two stakeholder groups coordinate care. These studies show the intricate sociotechnical connections in diverse interpersonal interactions such as collaborations between patients, medical providers, center administrators, and behavioral health providers and describe the parallel journeys between patients' cancer journey and depression[72]. Another example is the work on longitudinal care plans for children with medical complexity, including care collaborators such as caregivers and five groups of providers including complex care, primary care, subspecialists, emergency care, and care coordinators[14,76].

2.2. Design for family caregivers

Family caregiving is a key area of focus for CSCW researchers. Much of this work focuses on supporting the family caregiver (especially a child's mother) as a user of information and communication technologies (ICTs). Notably, Chen et al. have argued for consideration of informal caregivers as key health stakeholders in HCI, calling 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 [10].

HCI and CSCW research on opportunities and challenges for communication technologies to support family caregivers traditionally focused on connecting primary caregivers to wider

networks of care, often within existing friends and family groups. For instance, Moncur et al. presented a solution to help parents customize and communicate information about themselves and their child to family or friends [44]. Newman et al. identified challenges people face with sharing health information with their broader social networks [48]. Sites such as CaringBridge now provide dissemination features allowing patients and caregivers to keep wider networks of informal care up to date [2], and researchers such as Valdez and Brennan have investigated the role of these and other social networking sites in involving wider networks of care [75].

Encouragingly, a growing body of literature in CSCW and HCI research investigates the needs and practices of caregivers and their care coordination within families. Much of this work has been done in the context of chronic home-based care, such as Naylor et al.'s work on supporting care coordination for older adults and their caregivers[19,56]. Tang and colleagues elucidated challenges faced during home-based care coordination of older adults, such as managing mutual awareness of care needs and health information and coordinating handoffs when one caregiver assumes primary responsibility from another [74]. Hospitalized patients may have several close friends or family members coordinating their care. Connecting those informal networks of care is critical to supporting patients and caregivers. This is particularly true in the pediatric context, where effective coordination between a hospitalized child's primary caregivers has been shown to improve health outcomes both for the child and caregivers [24]. Parents who communicate effectively with each other reduce their own stress [37] and improve the long-term health outcomes for their child [24]. Health sciences researchers have demonstrated that support from family caregivers improves patients' health outcomes and reduces the likelihood of further health complications [15]. The presence of family caregivers during patient-clinician interaction improves medical visit communication and increases the provision of biomedical information [78]. As a result, many pediatric hospitals have adopted a family-centered model of care, in which parents, guardians, and other family caregivers are involved in clinical decision-making [16] and medical management of the patient's care[45].

2.3. Family coordination beyond healthcare: Domestic HCI and Family Informatics

Most HCI and CSCW studies on family coordination concentrate on collaboration within family members in normal home settings. Family collaboration has been examined to identify how families work together to ensure the completion of tasks and daily activities and attend events. Homebased tools usually support collaboration on scheduling such as digital or physical collaborative calendars or manage activities such as shared to-do lists and reminders systems and tools to enhance communication such as individual or group messaging systems. Some parents manage the schedule and plan for family activities when they are at work [18,46]. Therefore, some studies suggested the importance of extending the usability of these home-based collaborative tools beyond the home walls so that family members can coordinate when they are not at home [42,63]. Mobile applications can support family members' collaboration outside the home setting and increase family members' awareness of schedule to prevent conflicts[47], locations to manage routines[13], and activities to assign tasks[46,47,53,70]. Davidoff et al. suggested that the calendars and reminders can be augmented with routine trackers to better support coordination activities within a family.

Research has shown when family members are not together at home or in long-distance, they heavily rely on their phones to stay connected and increase their awareness of each other to coordinate practices [3,41]. There has also been CSCW research on the collaboration of immigrant family members concentrating on collaborative online information problem solving [57] and some work on family members providing care for older adults to maintain health and safety[55,88].

There is also a growing body of literature around family informatics, showing how families collaboratively use technology to manage their own health. Pina et al. conducted a set of

interviews and design sessions to understand family practices around health monitoring and suggested a move from personal informatics to family informatics[80]. There are a variety of works on families' collaboration to manage their health; some concentrate on family healthy living [18] and fitness tracking[39,64], some on food tracking [89]and diet management[65], and some on sleep tracking[11,90]. However, most of these works are usually targeting families in normal everyday settings such as home settings. There is a need to study family care collaboration in a crisis when the family is under stress, and unexpected events occur.

2.4. Cancer care coordination in CSCW and cancer journeys

CSCW researchers have long studied opportunities for collaboration technologies to support cancer patients and their families. Pratt and colleagues designed the HealthWeaver system for patient-centered cancer information management, which included various social support [12] features for patients to share different kinds of updates with friends and family [21,38,69]. There is also CSCW work on pediatric cancer, studying parents' interactions and tensions with their children, and identifying the needs and values of the child patients themselves. Park and colleagues also describe positive adaptations in children with cancer [54]. Hong and Wilcox have investigated coordination technologies to support teenage cancer patients and their parents within the patient portal framework [25–27].

Cancer and cancer treatment also present a challenge compared to other conditions: cancer takes on aspects of both chronic and critical conditions throughout the treatment experience, often involving waves of hospitalization and home care over the course of months. Hayes and colleagues introduced the concept of cancer journeys in HCI, showing that cancer patients' needs differ across their experience and treatment journey [22]. According to Hayes et al. in their work on opportunities for pervasive computing in chronic cancer care, the Cancer Journey for patients includes three phases. First, the screening and diagnosis phase, where a patient needs help to find a well-recommended physician. Second, the acute care and treatment phase, where they need information related to multiple treatments. Third, after discharge, they seek advice regarding the steps to ensure long-term health outcomes[22]. Jacobs and colleagues have deepened this exploration, showing how tablet-based technologies can holistically support cancer patients across the journey [30,32,33]. Most of such work concentrates on adult cancer patients and takes a patient-centered approach toward the design of technology to support patient cancer journey; for example, Jacobs and Mynatt in [34] introduced design principles to support patient-centered journeys for patients diagnosed with breast cancer. However, less work has examined applying journeys in the family setting, when the cancer patient is a child, and in addition to the patient, family caregivers are deeply involved in care coordination. There is a need to explore how the parents' care coordination practices can change across their child's cancer journey.

In this study, we grounded our research into caregiving coordination in the specific condition of pediatric cancer treatment. Of particular relevance to our study, Seo and colleagues have investigated the caregiving and parenting conflict for parents of children, focusing mainly on the parents' role conflict between parenting and caregiving in chronic condition management, and challenges with respect to communicating with their children during their cancer journey [67]. However, this and other studies focus primarily on the long-term chronic condition management challenges in collaboration between patients with caregivers or providers. A holistic, formative study of caregiving communication practices in the inpatient pediatric hospital setting is needed to identify and characterize barriers and opportunities for family caregiving teams, and CSCW researchers have not thoroughly investigated this complex sociotechnical issue.

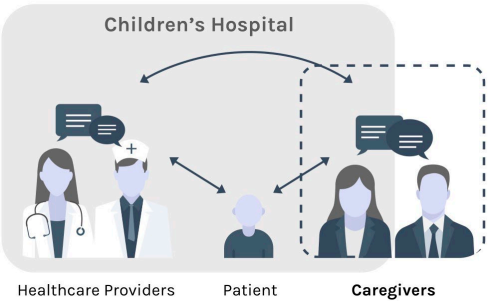

Figure 1. An example of the ecology of care for a hospitalized child. While much research has been done to explore the role of technology to support patients and caregivers in the hospital, less is known about the care coordination practices within the family caregiver network during hospitalization (dotted line).

2.5. Relationship to related work

Our study extends prior research in several ways. We build on prior work in collaborative care coordination in healthcare by focusing specifically on caregiver-caregiver collaboration within a family, focusing on pediatric patient populations, and focusing on the pediatric inpatient setting instead of chronic or home-based care (see Figure 1). Inspired by the cancer journey framework, we introduce the concept of caregiving coordination journey. We build on existing research into family-based collaboration by examining the needs, challenges, values, practices, and design opportunities for connecting a given patient's caregivers to each other across the illness journey, using our data from extended hospitalization for pediatric cancer care as an example.

3. Methods

We conducted semi-structured interviews with 14 parents from eight families with a child hospitalized for cancer treatment at Riley Hospital for Children at IU. Riley Hospital for Children, located on the Indiana University campus in Indianapolis, treats more than 80 percent of all children diagnosed with cancer in the state and provides the only pediatric stem cell (bone marrow) transplant program in the state. It is affiliated with IU School of Medicine and is a tertiary care hospital[61]. We asked participants about their journey from diagnosis to their current hospitalization experience, their collaboration strategies as a couple, their technology use, and the coordination challenges they experienced. We then qualitatively analyzed the interviews, generating themes and identifying hospitalization phases as an organizing framework.

3.1. Participants

After the approval of Indiana University's IRB (Institutional Review Board), we recruited and interviewed 14 parents from eight couples who were caregivers of a child hospitalized for cancer treatment at Riley Hospital for Children. All participants were part of heterosexual married couples caring for their child. We interviewed both parents from the first six couples and the moms from the seventh and eighth couples. Participants' level of education ranged from high school to some form of a college degree. In all cases, each parent considered themselves and their spouse as primary caregivers. Additional demographic information is listed in Table 1. In the findings section, we refer to each participant by family number and whether the participant is the mom (M) or dad (D). For example, the dad from family two will appear in quotes as (F2D).

All the participants had a child diagnosed with acute myeloid leukemia (AML) except the child from family three who was diagnosed with osteosarcoma. In both AML and osteosarcoma, patients are hospitalized for at least a month at a time. All the children were in their extended hospitalization phase except family 2, who had completed the first round and was in between hospitalization phases (typically a week-long break). Participants' children varied in age from a few years old to late teens, allowing us to interrogate themes common to family caregiving but limiting our ability to draw age-specific conclusions. We provide additional comments on this in the discussion and limitations sections.

Table 1: Participants

Family	Child Age (In Years)	Diagnosis	Number of Children	Distance to Hospital	Interview Format	Parent	Education Level	Age Range
1	12-15	AML (Acute Myeloid Leukemia)	2	1 hour	Together At Hospital	Mother	College	40-49
						Father	College	40-49
2	0-3	AML	3	0.5 hours	Together At Hospital	Mother	Some College	30-39
						Father	Some High School	30-39
3	15-18	Osteo-sarcoma	3	1.5 hours	Together Phone Call	Mother	High School	30-39
						Father	College	40-49
4	15-18	AML	3	3 hours	Together Phone Call	Mother	College	40-49
						Father	High School	40-49
5	0-3	AML	3	3 hours	Separate At Hospital	Mother	College	18-29
						Father	College	18-29
6	3-6	AML	3	2 hours	Separate At Hospital	Mother	Some High School	18-29
						Father	Some College	30-39
7	0-3	AML	3	0.5 hours	At hospital	Mother	High School	18-29
8	3-6	AML	2	0.5 hours	Phone Call	Mother	College	30-39

Table 1: demographic information of participants and their hospitalized child

3.2. Interview

To minimize burden and be sensitive to participants' time, we offered to conduct interviews either in the hospital or over the phone, with caregivers being interviewed together or separately. For hospital interviews, we arranged for interviews to take place either in the hospital room or in a separate consultation room close by. Five families were interviewed in person in the hospital, and three families were interviewed over the phone. We conducted four interviews where both parents were present together during the interview. In the next four interviews, we interviewed the mother and father separately from two couples. For the first six families, we were able to speak with both parents. In family seven, the father was unresponsive, and in family eight, the father declined to be interviewed. Interviews were conducted from March 2018 to February 2020. Participants were incentivized at the end of each session with a

$20 gift card (for the in-person interviews, we provided the option of a gift card at the end of the session, and for the remote interviews, we mailed the gift card).

Interviews lasted between 60 and 70 minutes and followed a semi-structured protocol. We began by asking about the trajectory behind the hospitalization of the child, then asked questions about the caregiver's role in the hospitalization schedule and how this changed their communication practices. We then asked parents about their existing communication practices and the technologies they use to share information with each other during hospitalization. We also asked the participants to traverse the different concerns, barriers, and challenges the family caregivers faced related to their communication and otherwise. In closure, the participants were asked to define the role of other family members and how they fit into the caregiving process.

Below are some example questions that we asked in the interview:

Can you describe a typical day at the hospital as a parent?

Who is the primary caregiver? Is there anyone else who directly contributes as caregiver?

How do you keep each other updated? Can you give us an example of such an experience?

What have been the biggest challenges from the time your child has been hospitalized?

3.3. Analysis

All the interviews were audio-recorded after consent from the participants and were later transcribed for future analysis, resulting in over 200 pages of transcribed conversation. We analyzed the insights from the interviews using thematic analysis[5,8]. We themed the interview insights utilizing Atlas.ti, a qualitative data analysis application[91]. Our analysis process consisted of dozens of qualitative analysis sessions where the research team met to discuss themes. The coding happened in two rounds. The first round was approached in an open manner and was performed by three researchers to identify the most common themes that emerged from the data. These researchers began by analyzing the first few interviews through open coding, assigning codes independently and meeting to discuss and unify the coding approach and codebook. The researchers then repeated that process for additional interviews until the codebook stabilized. In the second round, we classified the themes that emerged based on their groundedness to determine and label the prominence of the emergent themes. This process resulted in 15 theme clusters of 138 individual codes. For example, one of the themes was around communication and coordination using technology, and the codes under this theme were text, phone call, voice message, video message, video call, Facebook, Google Calendar, email, picture, Instagram, UberEats, games. To refine and interrelate themes and reconcile codes, our team met twice per week to discuss the themes and individual weekly analysis. These meetings continued over the span of two months until reaching saturation in our analysis, where the same themes repeated again and again in our interview data. We then grouped the 15 high-level themes into three separate analyses: themes around care coordination and the role of family resilience[49,50], themes relating to social support[51], and themes relating to the caregiving journey and evolving coordination processes during and following extended hospitalization (reported in this paper). To inform the final stages of analysis on this third cluster of themes, we used Jacobs et al.'s patient journey for breast cancer [34] as a sensitizing concept in developing our theory of caregiving coordination journeys. This analysis resulted in a set of coordination phases, dimensions of coordination that differ across the phases, and specific coordination cycles and rituals during the extended hospitalization phase.

4. Findings

Parents reported starkly different coordination needs and practices as they moved along the cancer journey from diagnosis to later stages of hospitalization, which led them to adjust their

collaboration routines and rhythms. In this section, we report parents' coordination practices across the cancer hospitalization journey, as well as the routines and rhythms they established in order to perform coordination work. We also describe the role of communication technologies and tools parents used to communicate and describe the nature of communication, including communication channels (such as phone calls or texts), level of synchronicity in the communication (such as synchronous or asynchronous), and scale (how many people participated in the communication).

4.1. Caregiving coordination across the hospitalization journey

In our analysis, we found that parenting couples' communication patterns and challenges are different across distinct 'phases' of their hospital journey: diagnosis, early hospitalization, and extended hospitalization. In this section, we describe their coordination experiences and practices in each phase.

4.1.1. Diagnosis

> "...She kind of started to feel kind of rough. So, we thought maybe it was just a little cold... We took her to the doctor, found out she had strep throat, and she started having some other strange aches and pains, and then she ended up with some bruising along her jawline. And this kind of happened over about two weeks, and I was calling her pediatrician like every other day… [and then] they called. It was an on-call doctor called and said, 'you need to take her to [the hospital] immediately. Her white blood cell count is pretty much out of this world.' She said she had never seen numbers that high. So, we came to [the hospital], and within just a couple hours, there was a leukemia diagnosis." (F2M)

While every family's journey is different, they all shared with us a story similar to the one described above: a series of confusing symptoms that didn't seem to go away, tracked over days and weeks, and then a diagnosis followed almost immediately by hospitalization. The rapidity and seriousness of the shifts were emotionally challenging for parents, as they had to confront both their own fears while also keeping their role as parents to their child with cancer as well as other children. As the dad from this family put it, it was challenging for him to share and communicate the diagnosis of their child with cancer to his other children: "the first 48 hours was the toughest thing I've ever gone through. I mean, we found out on a Thursday night, Friday morning that she had cancer. Then that Friday afternoon, I had to tell our other two girls that their two-year-old sister had cancer. I had to do it with a straight face and tell them that she was going to be okay, although I was a wreck... I was sobbing. I was in tears. I was angry. I was scared. I was nervous. Every emotion you can imagine." (F2D) The mom from family six described the early first day as "Stressful. Hard. Yeah… Well, we just found out everything, and she had to go in for immediate surgery because she had so much pressure built up in her head, that they didn't know how she was functioning at that point. So she went in for surgery, and she was in the ICU, which is very busy and loud and a lot going on at one time." (F6M) During the first hours post-diagnosis, families in our study appeared to experience few coordination challenges, describing the diagnosis experience as a shared challenge with simple tasks: get the child to the hospital so they can be stabilized and begin treatment.

4.1.2. Early days of hospitalization: 'Survival mode.'

Within the first few days after getting admitted to the hospital, parents had to adapt to the situation quickly, and caregiving coordination work emerged at this phase. As one mom

described: "I shifted into survival mode immediately." (F1M) Typically, both parents stayed in the hospital full-time during the early days. Working parents took time off from their jobs to be able to stay at the hospital.

Parents described the early phase of hospitalization as a stressful but unified time: they were facing the challenges together and got the same information at the same time. Parents felt that their child's illness truly impacted them all in different ways, and experienced the diagnosis as if it happened to a part of themselves. As the father from family five put it: "We're all in this together. It's interesting being a parent. If I could take it from him today, I would of course. You'd take it from your child. But man, we are just as impacted as him, but he is physically the one doing it." (F5D)

Some parents even brought the whole household to the hospital. As one mom told us: "Well, when this first started, it was during the summer, so I mean we kind of all went as a family. I mean, we didn't have to worry about our son missing school. We just all went up there together, and of course, my husband and son stayed in a hotel at night once visiting hours were over." (F4M) Other families called on friends and other family members to take care of home life responsibilities during this phase. As the dad from family six put it: "For the first, I think, eight something days, it was [mom] and I both here. Grandparents had the other two for the longest time"." (F6D)

4.1.3. Beyond the first week: figuring out new routines

After a week or so, parents eventually found the 'survival mode' of the first days to be unsustainable, and couples switched to a more organized and normal schedule as one dad put it, after the first week, "...we kind of just figured out a schedule. [mom] had to go back to work, and then we just kind of developed this whole... She bunched her days off, and that's when she's here. And then any other time, it's someone else, either me or [mom's] parents." (F6D)

Some couples seemed to know instinctively how to balance duties during this phase. Here what dad from family one had to say: "As soon as it happened, ...There wasn't even a conversation to be had, because we've been together long enough that I knew she wasn't going to leave him, so I know that I'm going to be the one that's going to be taking laundry back and forth and going to stores." (F1D)

For most families, this transition to a new routine was tough. As the mom from family two put it: "[dad] was trying to go back to work, he was trying to still be here at the hospital, and he was trying to do it all. I just stayed here at the hospital, I'm just a stay-at-home mom, so it was not an issue for me to just be here. So things were kind of crazy like that first, even in probably into the first two weeks with him trying to figure out what he could and couldn't do." (F2M). While other transition points were tied to easily identified external processes (such as moving from a local clinic to the hospital, or being discharged or transferred to outpatient care), the inflection point between early and extended hospitalization required families to set up more robust coordination cycles. In our analysis, we found that families established routines across two scales: daily routines, such as clinical check-ins and family calls, and weekly routines, such as 'shift changes' and weaving in normal life.

Daily routines in extended hospitalization: rounds, clinical check-ins, and staying in touch

From a parent's perspective, rounds are the key information event on a typical day at the hospital. Every morning, the clinical team gathers in and just outside the patient's hospital room to update each other and the family about the patient's current status, progress, and plans for the day. The team, sometimes including as many as ten clinicians from a variety of disciplines, makes their way around the inpatient oncology unit, rolling laptops on standing carts. This brief but intense conversation is often the key medical information event of the day. The team

discusses the patient's vital signs and laboratory values over the last 24 hours and includes the patient and any physically present family members in the conversation.
While information about the patient's status and test results are extensively documented in the hospital's electronic medical record, parents' primary source of information for test results and updates is the in-person rounds briefing. As one mother told us, "...we wait on rounds anxiously for them to come by, and tell us everything that's updated, if they have blood results or anything. You're just clinging to that next piece of information that can get you on. It's one day at a time." (F5M)

Moms and dads in our study took distinct approaches to rounds (all participants were part of heterosexual married couples). Moms were more likely to be present during rounds and more likely to be the caregiver in charge of recording and sharing any updates. Moms took a variety of approaches to the information work created by rounds. Several moms kept notes to use to ask questions of the doctors and record their responses. For example, in family three, the mom kept a binder to maintain records across and between hospitalizations and updated the binder each day during and following morning rounds. As she told us: "It was all in this big binder that went with us every time we were admitted to the hospital and was in a central location every time we were home." (F3M) Not all moms kept notes, as the mom from family 7 put it: "I'm not that organized. I wish I was." (F7M)

However, when dads in our study were present during rounds, they described themselves almost as proxies who took notes to share with moms or who asked questions on behalf of moms. The difference between their notetaking practices with moms was that they did not record information in a binder or a notebook; rather, they mainly took notes to share with moms. For example, the dad from family five explained that he developed a practice of writing notes on the glass door of the hospital room during rounds, so he could remember what was said and could share it with mom afterward: "Then I usually jot down a few notes, just so I know... Then I remember, then that way, I can tell [mom]... Then I just text [mom] some notes. Just want to tell her: just did rounds. Everything looks good." (F5D) Writing notes helped this dad share more details about what was said beyond the general status, so mom felt in the loop.

Dads' proxy role made them somewhat uncomfortable. For example, when the mom in family three was not able to be present at rounds, she would often provide dad with some questions to ask, and expected him to track that information in the family's physical binder. However, as mom put it: "He felt like he was inconveniencing [the clinical team]. Not because they acted that way but just because he's like, 'They're doing their job, and I don't need to manage them.'" (F3M)

Whichever parent is present for morning rounds, he or she shares the information or plan with the other parent and, in some cases, close family. Parents in our study told us they kept this ritual even if there was no news to report. As the mom from family six put it: "About rounds, we send a text every morning. Whoever's here, so: 'rounds just happened, this is what they said, this is the plan, we're watching this.' Or: 'everything's the same, nothing's changed" (F6M)

This key daily information-sharing ritual is made much more difficult in the case that neither parent is present during rounds. Sometimes another family member, such as a grandparent, would be present, but these caregivers were not always as informed, and parents reported frustration in these situations. As the mom from family one put it:"...that aggravates me to death, because I know what they're talking about and I know the questions I want to ask, and I'm not here to do it. And I cannot depend on the people that are here during the day to do anything that I need them to do, and that's extremely frustrating." (F1M) The mother from this family then provided an example of this frustration from the day of our interview: "[the hospitalized child] just told me today that...they said he's going to have a CT. No one said a thing to me about a CT at this point, and I want to know what for and why and why did we come to that and when is it going to happen and why are we doing it." (F1M) Parents also kept

each other posted about clinical updates throughout the day. As the mom from family four explained, "anytime the doctor came in, or they did something new, I would make a phone call to [dad] just to keep him up to date on what's going on." (F4M)

Parents also planned daily phone or video chats to stay connected with each other, their hospitalized child, and any other children in the family. These calls were usually tied to a particular daily ritual, such as bedtime calls or eating dinner together virtually. As one mom explained, "we try to do it at least once, so we can see each other and say, 'Hey, what did you learn at school today? Or what did you'... It's more about the kids than it is about him[dad] and I." (F5M) These regular calls were an important part of a feeling of normalcy and togetherness for parents as mom from family four said, "every day we talk at least in the morning and at bedtime. That relieves stress for both of us because then I can make sure [the other kid] 's up dressed and ready for school. [dad] can see how [the hospitalized child] 's night went and what's going on with her in the morning." (F4M)

Weekly routines in extended hospitalization: weaving in normal life, 'shift changes'

Because their children were hospitalized for weeks at a time, parents in our study reported developing weekly routines, balancing caregiving duties in the hospital with work and life demands. Almost all parents in our study reported that they developed a pattern of 'shifts' to allow them to provide care to the hospitalized child while also meeting their other responsibilities such as their jobs, taking care of other kids, or home chores. In all but one family (family six), moms spent more time in the hospital and took care of the hospitalized child, while dads were usually responsible for going to work and take care of the other kids and home chores. For example, the mom in family one said she stays at the hospital every night:" So I stay here all the time, every night. He[dad] comes and goes back and forth to the house a little bit, but I stay here." (F1M) These new routines often required a parent to adapt to new responsibilities at home. For example, the mom in family three explained that "[dad] 's not really a housekeeper particularly, but he did start doing laundry just to help out so I wouldn't have as much to do when I would come home. And loading the dishwasher or running the dishwasher, he would do that kind of thing." (F3M)

For parenting couples, shift changes are a time for updates and planning for hospital *and* home. The parent at the hospital has to let the other parent know what has been happening during their shift. Moreover, at the time of the shift change, parents can discuss what to do or expect during their shift. As one mom describes: "We just relay what they've told us to do or what's going on to each other when we switch off...And if we miss something, we'll call each other and say hey..." (F6M) In addition to hospital updates, parents use shift changes to set up plans for outside hospital activities for the upcoming week, such as home chores, taking care of the other kids, and preparing food for the next week. This might also include managing other secondary caregivers, such as friends and family, who offered to pitch in. As mom from family eight described: "So we had to not only arrange care of who was going to be with our daughter in the hospital all the time, but who was going to be with my son, getting him off the bus, on the bus, all those sorts of logistics. We were working on two different schedules. We did have some neighbors that helped out with my son, too, getting him off the bus, and having him there until my husband could pick him up." (F8M)

Several families timed their shift changes to include one weekend day for each parent, so that dad could provide care for the hospitalized child. At the same time, mom could go home to see and take care of the other kids and her responsibilities for the upcoming week. As the mom from family two told us: "well really after those first two weeks, we kind of figured out that he[dad] couldn't really do anything here at the hospital, so he would go to work, staying home throughout the week. If he had some extra time, he would come out [to the hospital], but mainly he's just here on the weekends now so he can still work and do the things he needs to do at home." (F2M)

In most families, moms were the main schedulers; in fact, one mom in our study said: "Well, I'm the schedule. I'm kind of the manager for a lack of a better term. So I usually just say, 'Hey, I've made this appointment for this day and this day,' or, 'So and so has athletics this evening,' or,' "We need to be here on Saturday.'" (F3M)

In some families, both parents could rotate and be in the hospital as their jobs were more flexible than the other parents. For instance, some parents could work online or from home, and some others had a flexible job schedule that they could manage to stay at the hospital. Family five had a hospitalized child who was less than three years old, and therefore they usually had to have two people at the hospital. A positive factor in this family was that dad could work online, and therefore he could stay at the hospital to be there for the child: "You look at a seven day week, I am usually here, probably, three days and [my wife] usually here four. So she spends a little more than I do. I spend a few more weekends at home, maybe with the boys or working. We have [my mother-in-law], her and my father-in-law, they farm. So I help my father-in-law farm too. I spend more time at home, but I try to spend about three days here a week or so. Depending on what's going on, usually, when he was having chemo or just after chemo, and he's feeling really crummy, I want to be around. I want to be here for him." (F5D)

4.2. Communication practices and coordination tools

Most of the communication between parents in our study happened remotely via mobile phones, as one of them was usually at the hospital and the other at work or home. In this section, we categorize parents' technology use and communication practices based on the nature of communication: level of synchronicity, physical distribution, and number of members involved in the communication. Then we describe other tools that helped family members coordinate care and manage their child's health information.

4.2.1. Mostly remote, mostly asynchronous

Parents in our study relied heavily on technology to stay connected and update each other because they were so often apart. Furthermore, because of incompatible schedules, most of their coordination was asynchronous. As mentioned earlier, all parents we interviewed except family five, who preferred phone calls, considered text messaging as their main communication channel. The mother from family one provided a typical response: "Neither of us really like to talk on the phone, so text is always our preferred method of interaction." (F1M) While parents did try to connect in real-time whenever possible, asynchronous coordination was still required to set up a time to chat and to confirm availability just before a phone call or video chat. As family two mom said, when she was in the hospital, but her husband was remote, "I would call or text him, and if I had to text him I'd say, 'hey, call me when you get a second.'" (F2M) but in general she preferred texting over phone calls as it does not require an instant synchronous reply, she said: "texting is the easiest because if I don't have time to reply to you, or if I don't feel like sitting on the phone for an hour with somebody else, I'll get back to you when I can" (F2M)

Parents predominantly texted or spoke about updates on the hospitalized child and coordinating tasks. These included general questions about how the child is doing, how other kids are doing at home, or recent updates at the hospital. When we asked him for an example, the dad from family five (who was the hospital-based parent at the time of our interview) scrolled through his texts from the day: "We've already exchanged a bunch of texts back and forth, today, about just different updates, how [the hospitalized child] is doing, what doctors have said so far, nurses have said so far. When [hospitalized child] has been in treatment, it lasts about a month, [mom] and I don't see each other much" (F5D)

Parents did report using social media tools such as Facebook or Instagram, but none of the parents in our study used these tools to connect with *each other*. Instead, parents used these

channels to update extended family and friends about their child's health status. As the mom from family six put it, "on Facebook, I probably do an update a week. Because of all our family is on there, everybody's been following her. But to send a text message to everybody is just insane." (F6M) In most families, in addition to the parents, other caregivers were involved in providing care to the child. These caregivers were usually grandparents. In some cases, parents sent updates to them and other family caregiving team members as a group message. For example, family six mom mentioned why and how she updated other family members on a daily basis and what type of updates she sent, "You literally have no idea how her body's going to react, so it is a day by day thing. That's why we update day by day. When we send out an update, it's first I text him in the morning; then I text my mom, then I text my other mom. So, I'm updating, we update all of each other, or we send it in one group text. To let everybody know, this is her day; this is what it looked like. She struggled with this; she did really good with this. We update not only bad news but update good news. Today was a good day; she got out of bed." (F6M)

Parents also used group messages to update the immediate family about the child's health status. A discussion between mom and dad in family 2 highlighted that group text messages to immediate family members were the easiest way to communicate (e.g., sending updates and pictures). However, there were instances that grandparents were not tech-savvy enough, and texting for updates could be challenging; for example, family five mom explained, "[grandma] doesn't technology very well… We just got [grandma] a smartphone, so she's a ... When all this started, my dad made her get a smartphone because her flip phone, the slider wouldn't hold the charge, so we couldn't get a hold of her... But we've got her almost sending text messages regularly. Most of them are just okay or yes and no, but it's okay." (F5M)

4.2.2. Real-time conversations

Parents did try to connect in real-time but had to work around the remote parent's schedule. Some parents wove real-time interaction into their daily rhythms. (In some cases, these calls were between just the two parents and in some cases between parents, child, and other family members). As the mom from family eight described it: "It was dependent on the time of the day. When he was at work, so during the day, we would do texting mostly. Then when he wasn't at work, we would do a phone call, and then when it was time to go to bed at night, we would do a family FaceTime where we would use the iPads or whatever, or our phones, to do FaceTime as a whole family together to just go down, how everybody's doing, and what the kids did for the day. The kids got to see each other before they went to bed and that sort of thing." (F8M)

Family three in our study was the only family that rarely texted, preferring real-time communications almost exclusively. The parents in this family had not texted frequently before their child's illness, and the physical separation came as a shock. "I think in 20 years we had only spent total a couple weeks apart… we spend weekends together and lunches throughout the week together. So it was a culture shock to be sure." (F3M) She added that they managed to coordinate through phone calls and when they met in person in the hospital but less text since it was not her husband's preference. "It's more of morse code … he's just not a texter. And phone calls, at bedtime we would call and kind of run down our days. So probably 45 minutes to an hour but and then the face to face. But because we'd arranged to it usually be face to face in the middle of the day, you know what I'm saying? We did see each other. I mean between the phone calls and the face to face. We did see each other and communicate just not as much through text I would say." (F3M)

In addition, there were instances that even when the parents were in person in the same place, they chose texting over in-person communication (hybrid communication) due to privacy concerns and in cases where they wanted to share sensitive information related to child health status. This could be to discuss information they did not want to share with the hospitalized

child, siblings, or grandparents. For example, here's an exchange we had with the mom and dad from family one:

> **Dad:** We hardly ever have a conversation without a kid there, without [hospitalized kid] or [other kid], because there's no place to go.
>
> **Mom:** Yeah. We don't have anywhere to go at either place.
>
> **Dad:** Yeah. So basically it's text, as far as anything important, or-
>
> **Mom:** Yeah. If anything has to be said that we don't want anybody to hear, it's all text message.
>
> **Dad:** And we don't have any time ... We'd have to get in the car and go somewhere to have a conversation without somebody being there.
>
> **Mom:** Yeah. Because at where we're living, there's people everywhere all the time, and they're nosy as crap, so you can't breathe without everybody knowing everything

4.2.3. Other communication tools: information management artifacts

Parents used some artifacts, such as the glass door of the hospital room, binder, and notebook, to coordinate and manage information about their child's care. Writing on the hospital room glass door and window was a strategy that two families used to make sense of the information and as a reminder for clinical encounters. As one mom explained, "...then it is just in the morning with rounds that we get. We can ask questions throughout the day, but it's through nursing staff that has to relay it or have to take it practically to the doctor. So, if you have a big question, it's like it's done. So, we try to make lists, write on the door, and that way we don't forget and keep everything for that." (F5M)

The other artifacts that some families used to manage information were binders. Binders are information tracking tools usually used by moms that could facilitate their information sharing and guided their communication with the other caregivers and providers. Family three mom said she used binders to record information such as symptoms, medication, and write about the conversation with the doctors, be able to predict their child's health and refer to it when needed. She used to ask questions from doctors and nurses and record all the answers in one binder. She also tracked medicine that their child took in the hospital and stated how the binder could help her at the home visits between hospitalizations. "So, I did a lot of reading and, like I said a lot of asking questions. I would ask our pediatric oncologist and our ortho oncologist, and our nurse practitioner almost always the same sets of questions to get their own feedback on it. And I tried to create like I created a binder for all of us. It was just one binder, and everything that had to do with her went in the binder so that all the meds when she was scheduled to be home and all the meds I would have to give her were in a chart. So, I knew what was given when it was given, and I could tell you even right now I could tell you in February what medicine she was given every day. And I can tell you what the dosage was. So, some things were like pain meds, and they weren't given just as prescribed they were as needed." (F3 M)

The mom from family one also explained what she wrote in a paper journal helped her answer the hospital providers' questions. "Do they want to know; did you poop today? And you're like, 'Okay, I don't remember.' So, I go back and look, and no, he hasn't since Friday. But I just have a little journal that I write down okay; this time, this happened. This time, this happened. This time, this happened. I reference that a lot. He doesn't. He didn't even know about it until like a week ago, because I lost it-..." (F1M) The journal was important to her, and

she considered it like her Bible; when we asked whether dad also used that journal, she said, "He didn't even know it was mine. And it's been like my Bible." (F1M)

In this section, we described parents' coordination practices throughout their cancer hospitalization journey, as well as the routines and rhythms they developed to perform coordination activities. Additionally, we discussed the role of communication technologies and tools used by parents, as well as the nature of communication, including communication channels (such as phone calls or texts), the degree of synchronicity in the communication (such as synchronous or asynchronous), and scale (how many people participated in the communication). Our findings suggest that parents coordination requirements and practices changed as they progressed through the cancer journey, necessitating the adjustment of collaboration routines and rhythms from diagnosis to later stages of hospitalization.

5. Caregiving coordination journeys

As patients' needs and practices differ across the illness journey, so do the responsibilities and coordination efforts of their family caregivers. Parents in our study reported starkly different priorities, experiences, and coordination practices across distinct phases, such as diagnosis and treatment planning, early hospitalization, extended hospitalization, home care, and post-treatment. Parents also reported challenges managing transitions between phases, especially the transition from early hospitalization to extended hospitalization.

Our findings strongly suggest that caregivers experience their own *caregiving coordination journey*. Caregiving responsibilities, coordination practices, and relational experiences vary systematically across phases of the caregiving journey, in concert with the patient's own journey. Patient journeys were first introduced to HCI by Hayes et al. [22] and studied extensively by Jacobs et al.[30,34], focusing on the case of breast cancer. For that condition, the journey progresses across distinct phases (Screening and Diagnosis, Information Seeking, Acute Care and Treatment, and No Evidence of Disease), across which individuals' Responsibilities, Challenges, and Personal Journey vary.

In this section, we describe the phases and dimensions of a caregiving coordination journey for extended hospitalization in pediatric cancer. In the next section, we then use the journey concept to propose design opportunities. Finally, we discuss the implications of caregiving coordination journeys as an approach to studying and designing CSCW technologies for caregiving.

5.1. Phases

In our conceptualization of caregiving coordination journeys, as applied to our context of pediatric cancers requiring extended hospitalization, we identify the following phases: Diagnosis & Treatment Planning, Early Hospitalization, Extended Hospitalization, Home Care, and Post-treatment (Figure 2). In contrast to the case of adult breast cancer, the diagnosis and hospitalization events follow each other almost immediately, making the Diagnosis & Treatment Planning phase brief but intense. As our participants evocatively shared, tentative diagnoses almost immediately result in hospitalization for final diagnosis (e.g. F2) and sometimes even emergency surgery (F6). Hospitalization coordination work differs starkly between the Early and Extended phases, with the Early phase characterized by collaborative co-present caregiving, (for example, F4 all "went there together") and the Extended phase involving more asynchronous and long-distance caregiving work. For cases requiring multiple rounds of treatment, caregivers often experienced a brief Home Care phase, followed by re-hospitalization (which shared many of the characteristics of the initial Extended Hospitalization phase). For example, Families 3 and 4 were interviewed during a break between hospitalizations, which they used to stay connected as a family while monitoring for infections or other symptoms

which might cause an early end to the break. Finally, caregiving coordination takes on new characteristics during the Post-treatment phase, which can consist of caregiving more similar to chronic condition management, adjustment to loss, palliative caregiving, or a return to relatively normal life, depending on the individual case. The families in our study had not yet entered this phase; in conceptualizing the caregiving needs for this phase we draw from related work in pediatric cancer caregiving [24,27,35,54].

The *Extended Hospitalization* phase is particularly challenging in terms of caregiving coordination. Caregivers are more geographically distributed, and their schedules are often not well aligned, forcing them to rely on remote asynchronous technologies (in our study, mostly group text message threads). Caregivers work to establish daily and weekly *coordination cycles* during this time, including daily reports from morning rounds, regular video calls for family togetherness or bedtime, and weekly 'shift change' rituals, as one parent takes over hospital-based caregiving duties from the other. The specific practices families choose to adopt vary widely, with some parents dividing the work almost 50/50 (F5) while others decided early on that one parent would be hospital-based (F7). Others relied on grandparents or other family members to take some shifts (F1). Families in our study also reported that the transition into the extended hospitalization phase was tough, because unlike the other transitions in the caregiving coordination journey, its timing is uncertain and it is not associated with a key event, such as hospital admission or discharge.

5.2. Dimensions

Caregiving coordination journeys differ systematically across phases along the dimensions of Caregiving Responsibilities, Coordination Practices, and the Relational Journey. Caregiving Responsibilities begin in the Diagnosis & Treatment Planning phase, where caregivers must share the diagnosis with others and arrange logistics for a hospital stay. In the Early Hospitalization phase, responsibilities include comforting the child patient, learning about the disease and treatment, and beginning to settle in for the long haul. In the Extended Hospitalization phase, caregivers must stay informed, monitor progress, and share updates, while also managing home needs (especially for families with multiple children). During the initial Home Care phase, whether temporary or long-term, caregivers must monitor symptoms more actively, administer medication, and clean and sanitize the home environment more actively.

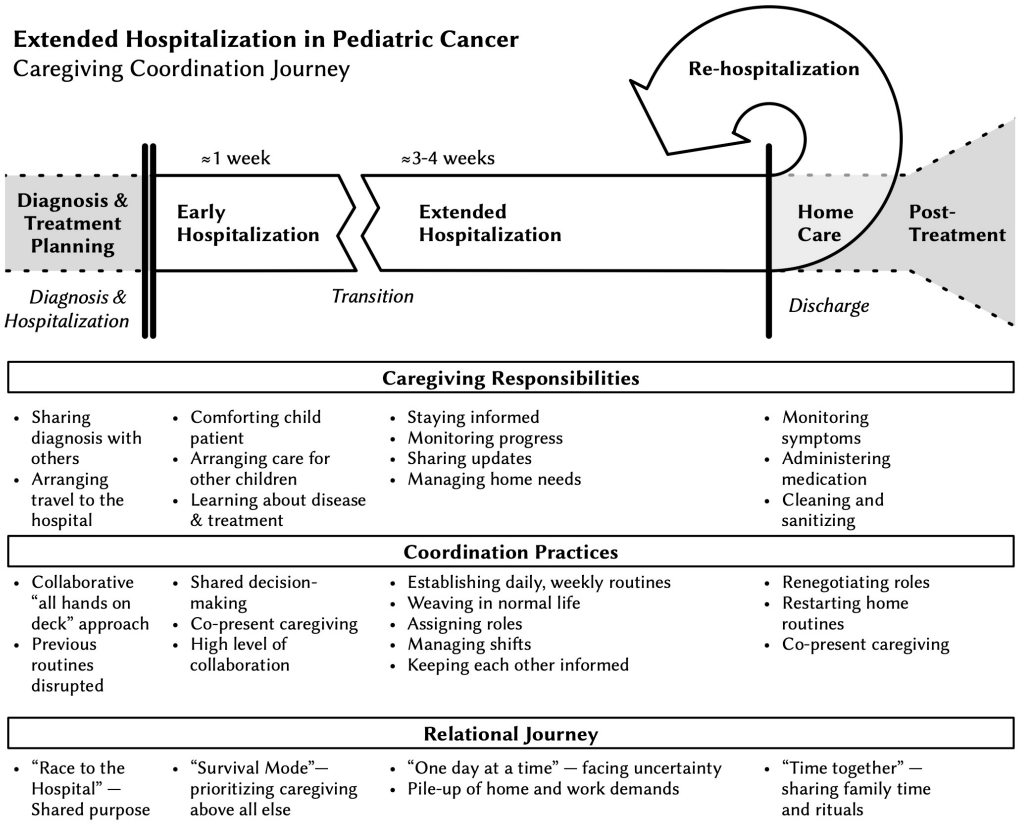

Figure 2: A caregiving coordination journey for extended hospitalization in pediatric cancer

Coordination practices are also different across the phases. During the Diagnosis & Treatment Planning phase, caregivers take a collaborative "all hands on deck" approach to caregiving coordination (as F5D described "we're all in this together"), disrupting most previous routines in order to begin treatment at the hospital as soon as possible. During the Early Hospitalization phase, caregiving coordination is characterized by high levels of collaboration, co-present caregiving, and shared decision-making. At some point (often around the 1-week mark), caregiving coordination shifts into the Extended Hospitalization phase. During this phase, caregivers establish new routines and *cycles*, adapting to the daily and weekly rhythms of a long hospital stay. Daily routines include waiting for and sharing the results of rounds, connecting around home duties, and participating in bedtime remotely. Caregivers try to take on distinct roles and shifts. The transition to this can be tough, as some caregivers still try to "do it all" (F2). However, eventually caregivers weave in normal life. Keeping each other informed becomes a more distinct task, since natural opportunities for updates and awareness are less frequent during this phase. Caregivers set up both daily and weekly rituals for informational updates. Daily updates occur either pervasively across the day (F7) or at particular moments (F7). During the Home Care phase, caregivers must renegotiate their roles, restart previous home routines, and return to more co-present caregiving coordination.

Finally, just as the patient experiences a personal journey, caregivers also experience a relational journey across the phases, as their relationships change to match the varying

responsibilities and resulting coordination practices. In the Diagnosis & Treatment Planning phase, caregivers experience a sense of shared purpose as they race to the hospital (or, in the case of F6, their child being airlifted to the hospital). In the Early Hospitalization Phase, they enter "survival mode" (F1), prioritizing caregiving above all else. Then in the Extended Hospitalization phase, caregivers face uncertainty by taking things "one day at a time" (F5), while demands from home and work begin to creep in again. In the Home Care phase, caregivers relish time together, sharing family rituals and reconnecting.

6. Design opportunities: supporting *Caregiving Coordination Journeys* in the children's hospital

As families move through the caregiving coordination journey, from diagnosis to later stages of hospitalization and beyond, family caregivers adjust their coordination routines and rhythms, and these adjustments can be challenging and stressful. Coordination technologies are not designed with changing phases in mind, and most caregivers in our study arrived at the hospital with insufficient technical infrastructure to support their coordination work, particularly in the extended hospitalization stage. For example, participants in our study primarily used phone calls and text messages to coordinate care, with some caregivers using analog artifacts such as paper binders or the glass doors of the hospital rooms themselves. In this section, we propose ways in which CSCW technologies could support caregiving coordination journeys within and between caregiving coordination phases, and discuss design opportunities to support rituals and rhythms within caregiving coordination cycles during the Extended Hospitalization phase.

Parents in our study described unique challenges at each phase of their child's illness: the initial diagnosis; the stress and confusion during the early days of hospitalization; and multiple challenges associated with extended hospitalization, including the monotony of prolonged hospitalization, the intensity of time at home between hospitalizations, and changes in support for subsequent hospitalizations. One common contributing factor to these challenges appears to have been the unexpected nature of the changes. For example, many parenting couples initially tried to both be physically present in the hospital but quickly realized that other responsibilities made such an approach unfeasible in the long term. Our findings are in line with Miller et al.'s work in [43] on identifying what specific roles caregivers play, how these responsibilities shift in response to different contexts. However, our research shows that the balance of those roles, their relative importance, and the balance with other coordination work vary across phases, and designers of coordination technologies in the children's hospital must take the caregiving coordination journey into account.

A particularly impactful moment for design intervention identified by the caregiving coordination journey model is the *transitions* between phases. Since these 'phases' are not directly tied to clinical stages and may differ for each family, even detecting and preparing for phase transitions could be beneficial. While some transitions are easy to recognize—such as diagnosis and the early phase of hospitalization—other transitions—such as the transition to extended hospitalization or meeting different needs during subsequent hospitalizations—may require more extensive investigation. CSCW technologies could help the parenting couples set up coordination strategies and decide when to switch phases. One big advantage of these systems is that they could support different communication needs at different stages, allowing caregivers to control how they connect with each other. It is possible that these technologies could be as simple as a set of checklists and recommendations. However, there might also be opportunities for machine learning approaches that analyze couples' communications and predict or anticipate new phase-based needs.

Within and across phases, families in our study enacted caregiving routines and rhythms, especially during the extended hospitalization phase. Parents in our study used a variety of tools to try to accomplish these tasks, such as a physical calendar at home to manage home chores, a

binder to track hospital information, or even the glass door of their hospital room (to track information and questions for daily morning rounds). One family also used a shared digital calendar to keep track of appointments and schedule time to call, but this was the exception rather than the rule. Our work supports the findings of Reddy et al. in [59] that there exists temporal work and cyclic rhythms in coordinating care, and our work extends that study from coordination within providers and hospital clinicians to collaboration within the caregiving circle. We believe that these work *coordination cycles* can help connect previous activities to current practices and help expect and plan for future coordination based on the current coordination of the tasks. Our work also supports the findings of Chen et al. in [10] that there is invisible work that contributes to imbalance in workload between caregivers and that a proper design should support a practice that make these articulation work[7] and ghost work[17] visible and shared with other family members in proper, comfortable and non-intrusive ways. In addition, our findings on parents' coordination are in line with the inter-caregiver coordination practices identified by Miller et al. [43], including the emotional support that caregivers provide to each other, scheduling for shifts, and maintaining other daily duties.

There are many existing CSCW technologies that support similar activities, such as shared calendars, task or chore management systems, or shared notetaking services. However, our families were largely not using these tools. Part of this may have been the challenge of recognizing the need for more robust solutions associated with extended hospitalization or handling phase transitions more effectively. Another challenge is regulations surrounding protected health information which (for a good reason!) complicate the direct transfer of health data out of the patient portal. Using today's technology, any test results, imaging, or clinical encounter summaries would have to be manually moved over to a groupware platform by one or more caregivers—an onerous task. Finally, it might also be the case that couples in this situation need a platform to manage their caregiving tasks and information in one place. This one 'coordination point' could allow parents to assign tasks between each other and reassign based on different phases and take different responsibilities across different phases of the hospitalization, such as caregiving tasks in the hospital or new tasks transferred to another parent who is not at the hospital. Having tasks, schedule information, and updates all in one place could potentially reduce the burden on family caregivers and allow them to adjust their support strategies flexibly.

7. Discussion

The caregiving coordination journey presented here, drawn from our empirical work with family caregivers of children experiencing extended hospitalization for cancer care, shows how caregiving coordination needs and practices differ across phases, and the importance of coordination cycles in the extended hospitalization phase in particular. Other CSCW researchers studying pediatric cancer caregiving [27,36,67,72] (such as Suh et al., Seo et al., Hong et al., and Kaziunas et al.) should be able to construct caregiving coordination journeys of their own, enriching their work while contributing refinements to the model.

Caregiving coordination journeys also have utility beyond the case of pediatric cancer. We have shown how a 'coordination journeys' approach can help identify opportunities for design for our specific context. However, our initial conceptualization is just the first step towards the construction of a more generalizable caregiving coordination journeys model, which we and other researchers can develop over time. The concept of the caregiving coordination journey itself has utility across a variety of contexts. The phases and dimensions in our model should generalize to other hospitalization journeys, even if the specific timings are different. For example, in our study, the diagnosis and treatment planning phase is extremely compressed, but in adult cancers, there is significant coordination work during this phase, including time between the "diagnosis" event and the "hospitalization" event, which are as close as possible in

the case of pediatric cancer. In some pediatric cancer treatments, rehospitalization is actually part of the treatment plan, and somewhat expected by caregivers. But in other conditions, rehospitalization might require its own distinct phase. In conditions where patient journeys have been developed and proven useful—such as breast cancer—it would also be useful to construct a caregiving coordination journey for those conditions, and to study how the patient journey and caregiving coordination journeys interact.

The concept of a caregiving coordination journey allows us to not only recognize that caregiving needs and practices may differ over time (and that some of the transitions may be particularly challenging), but also points the way towards a systematic way of accounting for journey-based needs in caregiving coordination. That is, not only can we design technologies to support coordination work during different stages of caregiving, but we can also design them to prepare caregivers for the challenges of the next phase (or possibly even to proactively recognize a phase transition and actively support the new coordination work required in that new phase).

8. Limitations

Our study has several limitations. Our participant group consisted primarily of Caucasian families and were all native English speakers, limiting the diversity of experiences. Due to scheduling challenges (many of which are encapsulated by the distance and schedule coordination challenges described in this paper), we conducted several interviews separately rather than as a couple. Nevertheless, in all interviews, parents spoke predominantly about their experience in coordinating with the other parent, so we still feel these interviews were primarily relational in nature. In two families (7 and 8), we were unable to speak with both parents. The mom in family seven mentioned that dad had expressed willingness to participate, but he did not answer our follow up calls, and we were unable to schedule him, and the mom in family eight mentioned dad did not wish to be interviewed because the diagnosis and treatment had been traumatic for him. As a result, the interviews of the mothers in families seven and eight lacked some of the comparison and depth we were able to glean from the first six families.

The age difference between hospitalized children in our study (spanning from young children to older teens) allowed us to look for common caregiving experiences across developmental stages but also limited our ability to draw age-specific conclusions given the small sample size of each age range. Our participants also represent limited family structure diversity: we could not recruit any same-sex couples or single parents (although our inclusion criteria would have allowed both family types, as long as the single parent had another contact listed in the clinical database). We also chose not to interview additional family members, such as grandparents of the hospitalized child; we similarly did not interview or survey clinicians to understand their perspectives on caregivers' needs. Additionally, two of our interview participants (both moms) had healthcare-related professions, which means our participants may collectively have more healthcare expertise than the typical family.

9. Conclusion

In this qualitative interview study with 14 parents, we characterized current coordination practices of parents concerning the hospitalization of their child with cancer in transitions across distinct 'phases' of their hospital journey: diagnosis, early hospitalization, and extended hospitalization. We described family caregivers' current communication and coordination practices across different phases of the hospitalization journey and across different time scales, and we described the current role of communication technologies in families' coordination practices. We then proposed design opportunities for social computing technologies to support and augment families' communication and caregiving work during the hospitalization of their

child. The concepts of caregiving coordination journeys and caregiving coordination cycles introduced in this study can be used as a framework in future studies that research the coordination within informal caregiver teams in a health crisis. We believe that our results can ultimately be transferred to similar contexts or situations where parents provide care to their hospitalized child for an extended hospitalization period, such as diabetes, inflammatory bowel disease, and organ transplants, and more broadly to small-scale teams coordinating at a distance.

ACKNOWLEDGMENTS

This study was funded by grants from the National Science Foundation under Grant No. IIS-2047432 and IIS-1850273. We appreciate the parents who took part in our interviews and shared their insights with us.

REFERENCES

[1] American Cancer Society. 2020. Cancer in Children. Retrieved May 31, 2020 from https://www.cancer.org/cancer/cancer-in-children.html

[2] Isolde K Anderson. 2011. The uses and gratifications of online care pages: a study of CaringBridge. *Health Commun* 26, 6 (September 2011), 546–559. DOI:https://doi.org/10.1080/10410236.2011.558335

[3] Elizabeth Bales, Kevin A. Li, and William Griwsold. 2011. CoupleVIBE: mobile implicit communication to improve awareness for (long-distance) couples. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work* (CSCW '11), Association for Computing Machinery, New York, NY, USA, 65–74. DOI:https://doi.org/10.1145/1958824.1958835

[4] Andrew B. L. Berry, Catherine Lim, Andrea L. Hartzler, Tad Hirsch, Edward H. Wagner, Evette Ludman, and James D. Ralston. 2017. How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal Caregivers. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (CHI '17), Association for Computing Machinery, New York, NY, USA, 5257–5270. DOI:https://doi.org/10.1145/3025453.3025923

[5] Ann Blandford, Dominic Furniss, and Stephann Makri. 2016. *Qualitative Hci Research: Going Behind the Scenes*. Morgan & Claypool Publishers.

[6] Laura Boland, Ian D. Graham, France Légaré, Krystina Lewis, Janet Jull, Allyson Shephard, Margaret L. Lawson, Alexandra Davis, Audrey Yameogo, and Dawn Stacey. 2019. Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implementation Sci* 14, 1 (January 2019), 7. DOI:https://doi.org/10.1186/s13012-018-0851-5

[7] Geoffrey C. Bowker and Susan Leigh Star. 2000. *Sorting Things Out: Classification and Its Consequences*. MIT Press.

[8] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (January 2006), 77–101. DOI:https://doi.org/10.1191/1478088706qp063oa

[9] Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers: designing for integrality. *CSCW '13: Proceedings of the 2013 conference on Computer supported cooperative work* (February 2013), 91–102. DOI:https://doi.org/10.1145/2441776.2441789

[10] Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers: designing for integrality. *CSCW '13: Proceedings of the 2013 conference on Computer supported cooperative work* (February 2013), 91–102. DOI:https://doi.org/10.1145/2441776.2441789

[11] Anna Cherenshchykova and Andrew D. Miller. 2019. Family-Based Sleep Technologies: Opportunities and Challenges. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*, ACM, Glasgow Scotland Uk, 1–6. DOI:https://doi.org/10.1145/3290607.3312907

[12] Sheldon Cohen, Lynn Underwood, and Benjamin H Gottlieb. 2000. *Social Support Measurement and Intervention*. Oxford University Press. Retrieved from http://books.google.com/books?id=I_0HZQXQk2gC&printsec=frontcover&dq=intitle:social+support+intervention+and+measurement&hl=&cd=1&source=gbs_api

[13] Scott Davidoff, Brian Ziebart, John Zimmerman, and Anind Dey. 2011. Learning Patterns of Pick-ups and Drop-offs to Support Busy Family Coordination. 1175–1184. DOI:https://doi.org/10.1145/1978942.1979119

[14] Arti D Desai, Grace Wang, Julia Wignall, Dylan Kinard, Vidhi Singh, Sherri Adams, and Wanda Pratt. 2020. User-centered design of a longitudinal care plan for children with medical complexity. *Journal*

of the American Medical Informatics Association 27, 12 (December 2020), 1860–1870. DOI:https://doi.org/10.1093/jamia/ocaa193

[15] Gary Epstein-Lubow, Rosa R Baier, Kristen Butterfield, Rebekah Gardner, Elizabeth Babalola, Eric A Coleman, and Stefan Gravenstein. 2014. Caregiver presence and patient completion of a transitional care intervention. *Am J Manag Care* 20, 10 (October 2014), e349-444.

[16] M Foster, L Whitehead, and P Maybee. 2016. The Parents, Hospitalized Childs, and Health Care Providers Perceptions and Experiences of Family-Centered Care Within a Pediatric Critical Care Setting: A Synthesis of Quantitative Research. *Journal of Family Nursing* 22, 1 (January 2016), 6–73. DOI:https://doi.org/10.1177/1074840715618193

[17] Mary L. Gray and Siddharth Suri. 2019. *Ghost Work: How to Stop Silicon Valley from Building a New Global Underclass*. Houghton Mifflin Harcourt.

[18] Andrea Grimes, Desney Tan, and Dan Morris. 2009. Toward technologies that support family reflections on health. In *Proceedings of the ACM 2009 international conference on Supporting group work* (GROUP '09), Association for Computing Machinery, New York, NY, USA, 311–320. DOI:https://doi.org/10.1145/1531674.1531721

[19] Francisco J. Gutierrez and Sergio F. Ochoa. 2017. It Takes at Least Two to Tango: Understanding the Cooperative Nature of Elderly Caregiving in Latin America. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, ACM, Portland Oregon USA, 1618–1630. DOI:https://doi.org/10.1145/2998181.2998314

[20] Shefali Haldar, Sonali R Mishra, Yoojung Kim, Andrea Hartzler, Ari H Pollack, and Wanda Pratt. 2020. Use and impact of an online community for hospital patients. *Journal of the American Medical Informatics Association* 27, 4 (April 2020), 549–557. DOI:https://doi.org/10.1093/jamia/ocz212

[21] Andrea Hartzler, Meredith M Skeels, Marlee Mukai, Christopher Powell, Predrag Klasnja, and Wanda Pratt. 2011. Sharing is caring, but not error free: transparency of granular controls for sharing personal health information in social networks. *AMIA Annu Symp Proc* 2011, (January 2011), 559–568.

[22] Gillian R. Hayes, Gregory D. Abowd, John S. Davis, Marion L. Blount, Maria Ebling, and Elizabeth D. Mynatt. 2008. Opportunities for Pervasive Computing in Chronic Cancer Care. In *Pervasive Computing* (Lecture Notes in Computer Science), Springer, Berlin, Heidelberg, 262–279. DOI:https://doi.org/10.1007/978-3-540-79576-6_16

[23] Gemma Heath, Albert Farre, and Karen Shaw. 2017. Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling* 100, 1 (January 2017), 76–92. DOI:https://doi.org/10.1016/j.pec.2016.08.011

[24] Sarah Hile, Sarah J Erickson, Brittany Agee, and Robert D Annett. 2014. Parental stress predicts functional outcome in pediatric cancer survivors. *Psycho-Oncology* 23, 10 (May 2014), 1157–1164. DOI:https://doi.org/10.1002/pon.3543

[25] Matthew K. Hong, Udaya Lakshmi, Kimberly Do, Sampath Prahalad, Thomas Olson, Rosa I. Arriaga, and Lauren Wilcox. 2020. Using Diaries to Probe the Illness Experiences of Adolescent Patients and Parental Caregivers. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (CHI '20), Association for Computing Machinery, Honolulu, HI, USA, 1–16. DOI:https://doi.org/10.1145/3313831.3376426

[26] Matthew K Hong, Lauren Wilcox, Clayton Feustel, Karen Wasileski-Masker, Thomas A Olson, and Stephen F Simoneaux. 2016. Adolescent and Caregiver use of a Tethered Personal Health Record System. *AMIA Annu Symp Proc* 2016, (January 2016), 628–637.

[27] Matthew K Hong, Lauren Wilcox, Daniel Machado, Thomas A Olson, and Stephen F Simoneaux. 2016. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. *Proc SIGCHI Conf Hum Factor Comput Syst* 2016, (May 2016), 5337–5349. DOI:https://doi.org/10.1145/2858036.2858508

[28] Jina Huh and Mark S. Ackerman. 2012. Collaborative Help in Chronic Disease Management: Supporting Individualized Problems. *CSCW* 2012, (2012), 853–862. DOI:https://doi.org/10.1145/2145204.2145331

[29] IU School of Medicine. 2020. Clinical Care: Pediatric Hematology and Oncology. Retrieved May 31, 2020 from https://medicine.iu.edu/pediatrics/specialties/hematology-oncology/clinical-care

[30] Maia Jacobs, James Clawson, and Elizabeth Mynatt. 2016. A Cancer Journey Framework: Guiding the Design of Holistic Health Technology. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*, ACM, Cancun, Mexico. DOI:https://doi.org/10.4108/eai.16-5-2016.2263333

[31] Maia Jacobs, Galina Gheihman, Krzysztof Z. Gajos, and Anoopum S. Gupta. 2019. "I think we know more than our doctors": How Primary Caregivers Manage Care Teams with Limited Disease-related Expertise. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (November 2019), 159:1-159:22. DOI:https://doi.org/10.1145/3359261

[32] Maia Jacobs, Jeremy Johnson, and Elizabeth D. Mynatt. 2018. MyPath: Investigating Breast Cancer Patients' Use of Personalized Health Information. *Proc. ACM Hum.-Comput. Interact.* 2, CSCW (November 2018), 78:1-78:21. DOI:https://doi.org/10.1145/3274347

[33] Maia L Jacobs, James Clawson, and Elizabeth D. Mynatt. 2014. My Journey Compass. *CHI '14: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (January 2014), 663–672. DOI:https://doi.org/10.1145/2556288.2557194

[34] Maia Jacobs and Elizabeth D. Mynatt. 2017. Chapter 2 - Design Principles for Supporting Patient-Centered Journeys. In *Designing Healthcare That Works*, Mark S. Ackerman, Sean P. Goggins, Thomas Herrmann, Michael Prilla and Christian Stary (eds.). Academic Press, 19–38. DOI:https://doi.org/10.1016/B978-0-12-812583-0.00002-X

[35] E Kaziunas, A G Buyuktur, J Jones, and S W Choi. 2015. Transition and reflection in the use of health information: the case of pediatric bone marrow transplant caregivers. *Proceedings of the 18th …* (January 2015), 1763–1774. DOI:https://doi.org/10.1145/2675133.2675276

[36] Elizabeth Kaziunas, David A Hanauer, Mark S Ackerman, and Sung Won Choi. 2016. Identifying unmet informational needs in the inpatient setting to increase patient and caregiver engagement in the context of pediatric hematopoietic stem cell transplantation. *J Am Med Inform Assoc* 23, 1 (January 2016), 94–104. DOI:https://doi.org/10.1093/jamia/ocv116

[37] J. A. Kientz, G. R. Hayes, T. L. Westeyn, T. Starner, and G. D. Abowd. 2007. Pervasive Computing and Autism: Assisting Caregivers of Children with Special Needs. *IEEE Pervasive Computing* 6, 1 (January 2007), 28–35. DOI:https://doi.org/10.1109/MPRV.2007.18

[38] Predrag Klasnja, Andrea Hartzler, Christopher Powell, and Wanda Pratt. 2011. Supporting cancer patients' unanchored health information management with mobile technology. *AMIA Annu Symp Proc* 2011, (January 2011), 732–741.

[39] Qingyang Li, Clara Caldeira, Daniel A. Epstein, and Yunan Chen. 2020. Supporting Caring among Intergenerational Family Members through Family Fitness Tracking. In *Proceedings of the 14th EAI International Conference on Pervasive Computing Technologies for Healthcare* (PervasiveHealth '20), Association for Computing Machinery, New York, NY, USA, 1–10. DOI:https://doi.org/10.1145/3421937.3422018

[40] Leslie S Liu, Sen H Hirano, Monica Tentori, Karen G Cheng, Sheba George, Sun Young Park, and Gillian R Hayes. 2011. Improving communication and social support for caregivers of high-risk infants through mobile technologies. *CSCW '11: Proceedings of the ACM 2011 conference on Computer supported cooperative work* (March 2011), 475. DOI:https://doi.org/10.1145/1958824.1958897

[41] Mirca Madianou and Daniel Miller. 2011. Mobile phone parenting: Reconfiguring relationships between Filipina migrant mothers and their left-behind children. *New Media & Society* 13, 3 (May 2011), 457–470. DOI:https://doi.org/10.1177/1461444810393903

[42] Panos Markopoulos, Natalia Romero, Joy van Baren, Wijnand IJsselsteijn, Boris de Ruyter, and Babak Farshchian. 2004. Keeping in touch with the family: home and away with the ASTRA awareness system. In *CHI '04 Extended Abstracts on Human Factors in Computing Systems* (CHI EA '04), Association for Computing Machinery, New York, NY, USA, 1351–1354. DOI:https://doi.org/10.1145/985921.986062

[43] Andrew D Miller, Sonali R Mishra, Logan Kendall, Shefali Haldar, Ari H Pollack, and Wanda Pratt. 2016. Partners in Care: Design Considerations for Caregivers and Patients During a Hospital Stay. In *CSCW: proceedings of the Conference on Computer-Supported Cooperative Work. Conference on Computer-Supported Cooperative Work*, 756–769. DOI:https://doi.org/10.1145/2818048.2819983

[44] Wendy Moncur, Judith Masthoff, Ehud Reiter, Yvonne Freer, and Hien Nguyen. 2014. Providing Adaptive Health Updates Across the Personal Social Network. *Human–Computer Interaction* 29, 3 (March 2014), 256–309. DOI:https://doi.org/10.1080/07370024.2013.819218

[45] Emily L. Mueller, Anneli R. Cochrane, Madison E. Campbell, Sarah Nikkhah, and Andrew D. Miller. 2022. An mHealth App to Support Caregivers in the Medical Management of Their Child With Cancer: Co-design and User Testing Study. *JMIR Cancer* 8, 1 (March 2022), e33152. DOI:https://doi.org/10.2196/33152

[46] Carman Neustaedter and A. J. Bernheim Brush. 2006. "LINC-ing" the family: the participatory design of an inkable family calendar. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '06), Association for Computing Machinery, New York, NY, USA, 141–150. DOI:https://doi.org/10.1145/1124772.1124796

[47] Carman Neustaedter, A J Bernheim Brush, and Saul Greenberg. A Digital Family Calendar in the Home: Lessons from Field Trials of LINC. 8.

[48] Mark W Newman, Debra Lauterbach, Sean A Munson, Paul Resnick, and Margaret E Morris. 2011. "It's not that I don`t have problems, I`m just not putting them on Facebook": Challenges and Opportunities in Using Online Social Networks for Health. *CSCW '11: Proceedings of the ACM 2011 conference on Computer supported cooperative work* (January 2011).

[49] Sarah Nikkhah. 2021. Family Resilience Technologies: Designing Collaborative Technologies for Caregiving Coordination in the Children's Hospital. In *Companion Publication of the 2021 Conference on Computer Supported Cooperative Work and Social Computing*. Association for Computing Machinery, New York, NY, USA, 279–282. Retrieved January 7, 2022 from https://doi.org/10.1145/3462204.3481794

[50] Sarah Nikkhah. 2022. Designing for Families as Adaptive Systems: Collaborative Emotional Support and Resilience in the Children's Hospital. (2022), 8.

[51] Sarah Nikkhah, Swaroop John, Krishna Supradeep Yalamarti, Emily L. Mueller, and Andrew D. Miller. 2021. Helping Their Child, Helping Each Other: Parents’ Mediated Social Support in the Children's Hospital. In *Companion Publication of the 2021 Conference on Computer Supported Cooperative Work and Social Computing*. Association for Computing Machinery, New York, NY, USA, 140–143. Retrieved March 2, 2022 from https://doi.org/10.1145/3462204.3481759

[52] Sarah Nikkhah and Andrew D Miller. 2021. AI in the Family: Care Collaboration in Pediatrics as a Testbed for Challenges Facing AI in Healthcare. *Realizing AI in Healthcare: Challenges Appearing in the Wild Online workshop held in conjunction with CHI 2021 on May 8th and 9th 2021* (2021). Retrieved from http://francisconunes.me/RealizingAIinHealthcareWS/papers/Nikkhah2021.pdf

[53] Rui Pan, Azadeh Forghani, Carman Neustaedter, Nick Strauss, and Ashley Guindon. 2015. The Family Board: An Information Sharing System for Family Members. In *Proceedings of the 18th ACM Conference Companion on Computer Supported Cooperative Work & Social Computing* (CSCW'15 Companion), Association for Computing Machinery, New York, NY, USA, 207–210. DOI:https://doi.org/10.1145/2685553.2699008

[54] Sun Young Park, Woosuk Seo, Andrew B.L. Berry, Hyeryoung Kim, Sanya Verma, Sung Won Choi, and Ayse G. Buyuktur. 2020. Learning from Positive Adaptations of Pediatric Cancer Patients to Design Health Technologies. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (CHI '20), Association for Computing Machinery, Honolulu, HI, USA, 1–12. DOI:https://doi.org/10.1145/3313831.3376397

[55] Samantha J. Parker, Sonal Jessel, Joshua E. Richardson, and M. Cary Reid. 2013. Older adults are mobile too!Identifying the barriers and facilitators to older adults' use of mHealth for pain management. *BMC Geriatr* 13, 1 (May 2013), 43. DOI:https://doi.org/10.1186/1471-2318-13-43

[56] Dr Mary D. Naylor PhD, RN, FAAN, Karen B. Hirschman PhD, MSW, Kathryn H. Bowles PhD, RN, M. Brian Bixby MSN, CRNP, CS, JoAnne Konick-McMahan RN, MSN, CCRN, Caroline Stephens MSN, APRN, and BC. 2007. Care Coordination for Cognitively Impaired Older Adults and Their Caregivers. *Home Health Care Services Quarterly* 26, 4 (August 2007), 57–78. DOI:https://doi.org/10.1300/J027v26n04_05

[57] Laura R. Pina, Carmen Gonzalez, Carolina Nieto, Wendy Roldan, Edgar Onofre, and Jason C. Yip. 2018. How Latino Children in the U.S. Engage in Collaborative Online Information Problem Solving with their Families. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (November 2018), 1–26. DOI:https://doi.org/10.1145/3274409

[58] Jennifer E Prey, Janet Woollen, Lauren Wilcox, Alexander D Sackeim, George Hripcsak, Suzanne Bakken, Susan Restaino, Steven Feiner, and David K Vawdrey. 2014. Patient engagement in the inpatient setting: a systematic review. *J Am Med Inform Assoc* 21, 4 (July 2014), 742–750. DOI:https://doi.org/10.1136/amiajnl-2013-002141

[59] Madhu Reddy and Paul Dourish. A Finger on the Pulse: Temporal Rhythms and Information Seeking in Medical Work. 10.

[60] Riley Children's Health. 2020. Leukemia. Retrieved May 31, 2020 from https://www.rileychildrens.org/health-info/leukemia

[61] Riley Children's Health. 2020. Leukemia. Retrieved May 31, 2020 from https://www.rileychildrens.org/health-info/leukemia

[62] Diane R Rittenhouse and Stephen M Shortell. 2009. The patient-centered medical home: will it stand the test of health reform? *JAMA* 301, 19 (May 2009), 2038–2040. DOI:https://doi.org/10.1001/jama.2009.691

[63] Natalia Romero, Joy van Baren, Panos Markopoulos, Boris de Ruyter, and Wijnand IJsselsteijn. 2003. Addressing Interpersonal Communication Needs through Ubiquitous Connectivity: Home and Away. In *Ambient Intelligence* (Lecture Notes in Computer Science), Springer, Berlin, Heidelberg, 419–429. DOI:https://doi.org/10.1007/978-3-540-39863-9_32

[64] Herman Saksono, Carmen Castaneda-Sceppa, Jessica Hoffman, Vivien Morris, Magy Seif El-Nasr, and Andrea G. Parker. 2020. Storywell: Designing for Family Fitness App Motivation by Using Social Rewards and Reflection. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM, Honolulu HI USA, 1–13. DOI:https://doi.org/10.1145/3313831.3376686

[65] Herman Saksono, Ashwini Ranade, Geeta Kamarthi, Carmen Castaneda-Sceppa, Jessica A. Hoffman, Cathy Wirth, and Andrea G. Parker. 2015. Spaceship Launch: Designing a Collaborative Exergame for Families. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing* (CSCW '15), ACM, New York, NY, USA, 1776–1787. DOI:https://doi.org/10.1145/2675133.2675159

[66] Mark Schurgin, Mark Schlager, Laura Vardoulakis, Laura R. Pina, and Lauren Wilcox. 2021. Isolation in Coordination: Challenges of Caregivers in the USA. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, ACM, Yokohama Japan, 1–14. DOI:https://doi.org/10.1145/3411764.3445413

[67] Woosuk Seo, Andrew B.L. Berry, Prachi Bhagane, Sung Won Choi, Ayse G. Buyuktur, and Sun Young Park. 2019. Balancing Tensions between Caregiving and Parenting Responsibilities in Pediatric Patient Care. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW (November 2019), 153:1-153:24. DOI:https://doi.org/10.1145/3359255

[68] M Shudy, M L de Almeida, S Ly, C Landon, S Groft, T L Jenkins, and C E Nicholson. 2006. Impact of Pediatric Critical Illness and Injury on Families: A Systematic Literature Review. *PEDIATRICS* 118, Supplement_3 (December 2006), S203–S218. DOI:https://doi.org/10.1542/peds.2006-0951B

[69] Meredith M Skeels, Kenton T Unruh, Christopher Powell, and Wanda Pratt. 2010. Catalyzing social support for breast cancer patients. *CHI '10: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (April 2010), 173–182. DOI:https://doi.org/10.1145/1753326.1753353

[70] Timothy Sohn, Lorikeet Lee, Stephanie Zhang, David Dearman, and Khai Truong. 2012. An examination of how households share and coordinate the completion of errands. In *Proceedings of the ACM 2012 conference on Computer Supported Cooperative Work* (CSCW '12), Association for Computing Machinery, New York, NY, USA, 729–738. DOI:https://doi.org/10.1145/2145204.2145315

[71] Hyewon Suh, John R Porter, Alexis Hiniker, and Julie A Kientz. 2014. @BabySteps: design and evaluation of a system for using twitter for tracking children's developmental milestones. *CHI '14: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (April 2014), 2279–2288. DOI:https://doi.org/10.1145/2556288.2557386

[72] Jina Suh, Spencer Williams, Jesse R. Fann, James Fogarty, Amy M. Bauer, and Gary Hsieh. 2020. Parallel Journeys of Patients with Cancer and Depression: Challenges and Opportunities for Technology-Enabled Collaborative Care. *Proc. ACM Hum.-Comput. Interact.* 4, CSCW1 (May 2020), 1–36. DOI:https://doi.org/10.1145/3392843

[73] Gillian Symon, Karen Long, and Judi Ellis. 1996. The coordination of work activities: cooperation and conflict in a hospital context. *Comput. Supported Coop. Work* 5, 1 (September 1996), 1–31. DOI:https://doi.org/10.1007/BF00141934

[74] Charlotte Tang, Yunan Chen, Karen Cheng, Victor Ngo, and John E. Mattison. 2018. Awareness and handoffs in home care: coordination among informal caregivers. *Behaviour & Information Technology* 37, 1 (January 2018), 66–86. DOI:https://doi.org/10.1080/0144929X.2017.1405073

[75] Rupa Sheth Valdez and Patricia Flatley Brennan. 2015. Exploring patients' health information communication practices with social network members as a foundation for consumer health IT design. *Int J Med Inform* 84, 5 (May 2015), 363–374. DOI:https://doi.org/10.1016/j.ijmedinf.2015.01.014

[76] Grace Wang, Julia Wignall, Dylan Kinard, Vidhi Singh, Carolyn Foster, Sherri Adams, Wanda Pratt, and Arti D Desai. 2021. An implementation model for managing cloud-based longitudinal care plans

for children with medical complexity. *Journal of the American Medical Informatics Association* 28, 1 (January 2021), 23–32. DOI:https://doi.org/10.1093/jamia/ocaa207

[77] Karen Weihs, Larry Fisher, and Macaran Baird. 2002. Families, health, and behavior: A section of the commissioned report by the Committee on Health and Behavior: Research, Practice, and Policy Division of Neuroscience and Behavioral Health and Division of Health Promotion and Disease Prevention Institute of Medicine, National Academy of Sciences. *Families, Systems, & Health* 20, 1 (January 2002), 7–46. DOI:https://doi.org/10.1037/h0089481

[78] Jennifer L Wolff and Debra L Roter. 2011. Family presence in routine medical visits: a meta-analytical review. *Soc Sci Med* 72, 6 (March 2011), 823–831. DOI:https://doi.org/10.1016/j.socscimed.2011.01.015

[79] Haining Zhu, Joanna Colgan, Madhu Reddy, and Eun Kyoung Choe. 2017. Sharing Patient-Generated Data in Clinical Practices: An Interview Study. *AMIA Annu Symp Proc* 2016, (February 2017), 1303–1312.

[80] 2021. From Personal Informatics to Family Informatics | Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing. Retrieved January 8, 2021 from https://dl.acm.org/doi/10.1145/2998181.2998362

[81] Patients as actors: The patient's role in detecting, preventing, and recovering from medical errors - ScienceDirect. Retrieved April 9, 2021 from https://www.sciencedirect.com/science/article/abs/pii/S1386505606001420?via%3Dihub

[82] Crafting a View of Self-Tracking Data in the Clinical Visit | Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems. Retrieved April 9, 2021 from https://dl.acm.org/doi/abs/10.1145/3025453.3025589

[83] "I love the system—I just don't use it!" | Proceedings of the international ACM SIGGROUP conference on Supporting group work: the integration challenge. Retrieved April 12, 2021 from https://dl.acm.org/doi/10.1145/266838.266922

[84] What Is Known about Parents' Treatment Decisions? A Narrative Review of Pediatric Decision Making - Ellen A. Lipstein, William B. Brinkman, Maria T. Britto, 2012. Retrieved October 28, 2021 from https://journals.sagepub.com/doi/abs/10.1177/0272989X11421528

[85] Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis - ScienceDirect. Retrieved October 28, 2021 from https://www.sciencedirect.com/science/article/abs/pii/S1876285915000820

[86] Supporting Goal-Based Collaboration for Hospitalized Children | Proceedings of the ACM on Human-Computer Interaction. Retrieved October 28, 2021 from https://dl.acm.org/doi/abs/10.1145/3449238?casa_token=6UIdGqhkutIAAAAA:zUnAJkf_M3ZmaDKz-xdmWThGrwlIinOyOmo6DYaHKkml_k-TrdsKk73dFgR-XGLpUMy_Z27IKdQe

[87] Opportunities and Design Considerations for Peer Support in a Hospital Setting | Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems. Retrieved October 28, 2021 from https://dl.acm.org/doi/abs/10.1145/3025453.3026040?casa_token=FCK5k7w2r4sAAAAA:IYXxkvsWa-8pfxd0bMd7n6z6vo4VWyghP638YlmsgbVaCaJKuREmdkgZyzepZd3vpa4b7sFR6q2L

[88] Older adults and mobile phones for health: A review - ScienceDirect. Retrieved January 9, 2021 from https://www.sciencedirect.com/science/article/pii/S153204641300083X

[89] Snack Buddy | Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing. Retrieved April 9, 2021 from https://dl.acm.org/doi/10.1145/2675133.2675180

[90] Family-Based Sleep Technologies | Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems. Retrieved January 9, 2021 from https://dl.acm.org/doi/abs/10.1145/3290607.3312907?casa_token=TGyM_0CnXWcAAAAA:0Ya300A1gewdJ87NPMqXMi25udSm62WH_dvT2RI1f0caE9dLxvktqSbDPL1JgOCS7fuGYwowHAM11w

[91] What is ATLAS.ti. *ATLAS.ti*. Retrieved August 1, 2021 from https://atlasti.com/product/what-is-atlas-ti/