

Family Resilience in Care Coordination Technologies: Designing for Families as Adaptive Systems

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When a child is admitted to the hospital with a critical illness, their family must adapt and manage care and stress. CSCW researchers have shown the potential for collaborative technologies to support and augment care collaboration between patients and caregivers. However, as a field CSCW lacks a holistic, *theory-driven* understanding of how collaborative technologies might best augment and support the family caregiving circle as a socio-technical system. In this paper, we report findings from interviews with 14 parents of children with cancer admitted for extended hospitalizations. We use the resilience-based Family Adaptive Systems framework from family therapy as a lens to characterize their challenges and practices across four key subsystems: Emotion, Control, Meaning, and Maintenance. Then, we introduce a fifth system—the Information system—and draw on our empirical findings to suggest theory-driven opportunities for designing future collaborative technology to augment collaborative caregiving and enhance family resilience.

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

Additional Key Words and Phrases: caregiving, care coordination, families, pediatrics, cancer, family resilience, qualitative

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1 INTRODUCTION

Each year, the parents of approximately 15,300 children in the US alone will hear the words “Your child has cancer” [1]. Families with hospitalized children must process great stress and play a vital role in their child’s care [38, 89]. Hospitalized children need care and assistance with processing medical information and going through their treatment [49]. Therefore, their families must take on new responsibilities such as providing care, processing medical information, getting ready for

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extensive and sometimes painful treatments, and face the fear of losing their child. They must also adjust their daily duties, chores, and jobs to provide care to their hospitalized child.

Parents who can have productive and effective conversations with each other not only experience a decrease in their own levels of stress, but their child can experience improved long-term health outcomes [30, 81]. Despite this data, parents commonly express discontent with their own communication and coordination efforts during and after their child's hospitalization.

There are many Human-Computer Interaction (HCI) and Computer-Supported Cooperative Work (CSCW) studies on the role of technology in supporting coordination and communication within families and between patients, providers, and caregivers. However, most HCI and CSCW studies on family collaboration concentrate on collaboration among family members in normal settings [7, 53, 54, 62]. They do not target families under stress when practices continuously change and unexpected events occur. Most CSCW studies relevant to connected care concentrate on collaboration among patients [3, 79], patients with providers [71, 89], or patients with caregivers [19, 20, 49]. Furthermore, there is a need to understand how collaborative technologies can help family members of hospitalized children (family caregivers) collaborate and coordinate with each other during the stressful stage of extended hospitalization.

Recently, CSCW and HCI scholars have begun exploring a new promising way forward: theories of resilience [6, 23, 86]. Of particular interest for the context of caregiving coordination is a set of theories from the fields of social work and family therapy known as *family resilience*. These theories are strengths-based models of a family's ability to process and handle stress as a system [29, 48, 87]. Family resilience can be used as a lens to understand families' collaborative processes and guide the design of collaborative technologies to support these families in adapting when they are under stress and their usual routines as a family are constantly changing due to their child's hospitalization. Therefore, there is an opportunity for HCI and CSCW to study the role that collaborative technology can play in supporting family resilience processes for families facing a crisis, such as having a hospitalized child.

However, this area of research is still in its early stages, and to date there is little guidance about how new collaborative technologies might be designed in order to increase family resilience and support the family's communication and collaboration when a child is hospitalized. Furthermore, while some progress has been made in connecting Family Resilience to HCI and CSCW research [57], Family Resilience as a theory has not been rigorously and holistically studied with CSCW in mind.

In this paper, we report findings from interviews with 14 parents of children who underwent extended hospitalization. We grounded our study in the context of pediatric cancer, which is often treated with extended hospital stays over the course of many months. We use the resilience-based Family Adaptive Systems framework from family therapy as a lens to characterize their challenges and practices across four key subsystems: Emotion, Control, Meaning, and Maintenance. Then, we introduce a fifth system—the Information system—and draw on our empirical findings to suggest theory-driven opportunities for designing future collaborative technology to augment collaborative caregiving and enhance family resilience.

The contributions of this work are as follows: First, we introduce Family Resilience to CSCW for the first time, showing the salience and applicability of the theory to the domain of caregiver collaboration during health crisis. We also extend the theory focused on the information work reported by our participants. Finally we show how Family Resilience could be used to generate and test collaboration technologies in the future.

2 RELATED WORK

2.1 Technology to Support and Connect Family Caregivers

Family caregiving is a key area of focus for HCI and CSCW researchers. Much of this work focuses on supporting the family caregiver (usually a child's mother) as a user of information and communication technologies. Notably, Chen et al. have argued for the 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 [11].

Hospitalized patients may have several close friends or family members coordinating their care. Connecting those informal networks of care is critical to support patients and caregivers. This is particularly true in the pediatric context, where effective coordination between a hospitalized child's primary caregivers has improved health outcomes for all [30]. Patients and caregivers also have increasing access to electronic medical records, often through patient portals—although, patient portals have thus far been optimized for the outpatient setting [71]. Additionally, parents frequently report dissatisfaction with their own communication and coordination practices during and following their child's hospitalization [77].

HCI and CSCW researchers have studied opportunities and challenges for communication technologies to support family caregivers, although this research has primarily focused on connecting primary caregivers to wider care networks, often within existing friends and family groups, rather than connecting caregivers to each other. Kaziunas et al. studied caregivers of pediatric bone marrow transplant patients, placing the caregiver's role in supporting patients within the broader context of a specific long-term condition affecting a particular population [38]. They argue for caregiver-focused information systems in the hospital [39]. 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 [44]. Suh et al. designed the BabySteps system to enable parents to track their child's development progress [82]. Miller and colleagues described the various roles played by caregivers in the inpatient context [49]. Moncur et al. presented a solution to help parents customize and communicate information about themselves and their child to family or friends [50]. Newman et al. identified challenges people face with sharing health information with their broader social networks [55]. Sites such as CaringBridge now provide dissemination features allowing patients and caregivers to keep wider networks of informal care up to date [3]. Researchers, such as Valdez and Brennan, have investigated the role of these and other social network site technologies in involving wider networks of care [85].

Parents who communicate effectively with each other reduce their stress [37] and improve the long-term health outcomes for their child [30]. Health sciences researchers have demonstrated that support from family caregivers improves patients' health outcomes and reduces the likelihood of further health complications [19]. The presence of family caregivers during patient-clinician interaction improves medical visit communication and increases the provision of biomedical information [89].

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 [20]. However, the needs, values, practices, and design opportunities for connecting a given pediatric cancer patient's caregivers are under-studied in HCI and CSCW. While much research has been done to explore the role of technology in supporting patients and caregivers in the hospital, less is known about the care coordination practices *among caregivers*.

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 chronic home-based care, such as Naylor et al.'s work on supporting care coordination for older adults and their caregivers [52]. 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 [83]. 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 [30].

Another thread of CSCW research on coordination technologies for patients and caregivers focuses on *cancer* treatment and recovery. Pratt and colleagues designed the HealthWeaver system for patient-centered cancer information management, which included various social support [14] features for patients to share updates with friends and family [27, 40, 78]. 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 [63]. Hong and Wilcox have investigated coordination technologies to support teenage cancer patients and their parents within the patient portal framework [31–33].

2.2 Family Coordination Beyond Healthcare: Domestic HCI and Family Informatics

Most HCI and CSCW studies on family coordination concentrate on collaboration among 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. Home-based tools usually support collaboration on schedules, such as digital or physical collaborative calendars, or managing activities, such as shared to-do lists and reminder systems, and tools to enhance communication, such as individual or group messaging systems. Some parents manage the schedule and plan for family activities from work [22, 53, 54]. 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 [46, 72].

Mobile applications can support family members' collaboration outside the home setting and increase family members' awareness of schedules to prevent conflicts [54], locations to manage routines [16], and activities to assign tasks [53, 54, 62, 80]. Davidoff et al. suggested that calendars and reminders can be augmented with routine trackers to better support coordination activities within a family [16].

Research has shown that 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 [5, 45]. There has also been CSCW research on the collaboration of immigrant family members concentrating on collaborative online information problem solving [68] and some work on family members providing care for older adults to maintain health and safety [35, 64].

There is also a growing body of literature on Family Informatics, showing how families collaboratively use technology to manage their health. Pina et al. conducted interviews and design sessions to understand family practices around health monitoring and suggested a move from personal informatics to Family Informatics [69]. There are a variety of works on families' collaboration to manage their health; some concentrate on family healthy living [22] and fitness tracking [43, 74], some on food tracking [76] and diet management [75], and some on sleep tracking [12]. However,

most of these works usually target families in everyday settings. There is a need to study family care collaboration in a crisis when the family is under stress and unexpected events occur.

In this paper, we focus on understanding the challenges and coordination practices of families who have a child hospitalized with cancer. The hospitalization of a child with cancer as a context provides the opportunity to characterize family coordination practices in unexpected and stressful hospital settings and identify emerging themes beyond normal settings.

2.3 Family Resilience

Families experience a member's health crisis as a collective trauma. Studies have shown that the health and wellbeing of the caregiving network has a significant impact on the recovery of the ill family member, as well as long-term repercussions on the development of all family members. Qualitative studies (especially in nursing journals) have long shown the interdependencies involved in family care, and stressed importance of caregiving as coordination work [24, 41]. In parallel, over the past decade, researchers in the family sciences have developed theories of family resilience to explain the different ways families process stressful situations, and to place protective practices and factors in context.

Theories of family resilience emerged from theories of individual resilience, which describe the various protective factors that comprise a person's ability to cope and bounce back to the pre-crisis mode or not show negative effects after a crisis [18]. Resilience can also result in an individual's ability to attain post-traumatic growth [84]. The initial studies on resilience focused on what made the children function correctly after a trauma or adversity [66]. Resilience includes processes that help individuals withstand stressors and protect themselves when a crisis occurs. The role that protective factors such as a caring family, a healthy relationship with a friend, or financial stability can result in resilience when a crisis or cumulative risk factors occur [70]. However, individual resilience models do not adequately account for the interpersonal processes affecting close-knit kin networks [88].

Developed by researchers in social work and family studies, theories of family resilience describe how a family can process and cope with collective trauma, transitions and challenges and recover to pre-crisis status. Different types of health crises, such as chronic conditions [37], or severe health conditions, such as the physical illness of a parent [4], child disability [21], mental health condition of a family member [47], or cancer diagnosis of a child [67] can cause stress and challenges for the family and require family resilience.

The diagnosis of one member in a family with a serious illness such as cancer is a strong example of a collective crisis that the whole family must cope with. In addition to the patient, family caregivers must adjust their daily duties and jobs to provide proper care. These changes and transitions can cause stress and, on top of all, the fear of losing the patient. A lower level of stress and a higher level of communication among family members are significant predictors of long-term health outcomes after the child's hospitalization [30, 81]. Therefore, using family resilience theories as a lens to study families with a hospitalized child with cancer can help guide the research to identify the common family processes and protective factors that lead to positive health outcomes for the patients and their families. Indeed, in recent years nursing scholars have begun using Family Resilience models to better characterize and address these challenges, and have used these models to understand childhood leukemia in particular [34].

There have been three main 'waves' of family resilience models [29]. One of the earliest was Patterson's Family Adjustment and Adaptation Response Model (FAAR) [65] that conceptualizes periods of adjustment when there is a balance between family capabilities and demands and periods of imbalance or crisis when demands overshadow the capabilities. Walsh's 'Family Resilience Framework' is characteristic of the second wave, and describes three clusters of resilient practices:

families' shared beliefs, organizational behaviors, and communication practices [87, 88]. Walsh's model successfully describes the various strengths a family can bring to bear during a crisis, but its three sets of practices (and commitment to interdependence within the model itself) make it a challenging model to use. To address these, Morris and Harrist introduced the Family Adaptive Systems (FAS) model, a self-described 'third wave' family resilience model. It is this model that forms the basis of the analysis in this paper.



Fig. 1. Family Resilience

In FAS, a family's resilience consists of four distinct but interconnected adaptive systems: the Emotion system, Control and management system, Meaning system, and Maintenance system [28]. (1) the Emotion system's goal is to develop and regulate the family's emotional climate which helps manage and maintain the emotional connections within and outside the family; (2) the Control and management system centers on maintaining a structure and order in a family by tracking individual behavior and respect for each other; (3) the Meaning system assists a family in maintaining the family's identity such as the influence of ethnic heritage, cultural backgrounds and utilize this aspect to help them stay grounded during a time of crisis and (4) the Maintenance system that focuses on maintaining the basic needs of the family such as food, shelter, safety, economic stability while also protecting the vulnerable members of the family during a time of crisis [26, 28].

FAS describes how the concept of resilience can be applied to the family level. FAS goes beyond an individual level and trait-based lens to relational, contextual, and process-oriented resilience analysis. The relationships, mutual support, interdependencies between individuals, the quantity and quality of resources, and protective factors, in addition to the constraints and risk factors, are essential in analyzing resilience. FAS concentrates on the key role that the context plays in relational resilience and describes how different protective factors, constraints, and resilience processes occur for families when facing different types of adversities or chronic multi-stress conditions that change over time. FAS does that by providing information on different adaptive systems that help families adapt during a crisis.

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. This study is part of a larger study on collaborative caregiving of hospitalized children with cancer [56, 58]

Three research questions guided this project:

- (1) What are the current communication and coordination practices, challenges, and stressors between family caregivers?
- (2) How does the application of the FAS framework perform within the context of collaborative care? (We identified family adaptive system as the theory with the highest descriptive power leading to the third research question listed below.)
- (3) What resilience processes under each family adaptive system can help these families address the stressors and challenges and tackle the health crisis of having a child with cancer?

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. To inform our analysis, we deductively coded using multiple social theories, including Social Support [13], Role Theory [42], and theories of resilience, such as Walsh's *Family Resilience Framework* [88] and the *Family Adaptive Systems* model [65].

3.1 Participants

After the approval of our 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 mothers from the seventh and eighth couples. Participants' level of education ranged from high school to some form of college degree. In all cases, each parent considered themselves and their spouse 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 mother (M) or father (D). For example, the father 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 generate 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.

Family	Child		Num. Children	Hospital		Parent	Education	Age
	Age	Diagnosis		Distance	Format			
1	12-15	AML	2	1 hour	Together	Mother Father	College College	40-49 40-49
2	0-3	AML	3	0.5 hours	Together	Mother Father	Some College Some High School	30-39 30-39
3	15-18	Osteosarcoma	3	1.5 hours	Together	Mother Father	High School College	30-39 40-49
4	15-18	AML	3	3 hours	Together	Mother Father	College High School	40-49 40-49
5	0-3	AML	3	3 hours	Separate	Mother Father	College College	18-29 18-29
6	3-6	AML	3	2 hours	Separate	Mother Father	Some High School Some College	18-29 30-39

Family	Child Age	Child Diagnosis	Num. Children	Hospital Distance	Format	Parent	Education	Age
7	0-3	AML	3	0.5 hours		Mother	High School	18-29
8	3-6	AML	2	0.5 hours		Mother	College	30-39

3.2 Interview

To minimize the 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 to the room. Five families were interviewed in person in the hospital, and three were interviewed over the phone. We conducted four interviews where both parents were present together during the interview. In the following four interviews, we interviewed the mother and father separately from two couples. We were able to speak with both parents for the first six families. In family seven, the father was not available; 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 child's hospitalization, 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 a 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 [8, 9]. We themed the interview insights utilizing Atlas.ti, a qualitative data analysis application [2]. 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 openly 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, and games.

To refine and interrelate themes and reconcile codes, our team met twice per week to discuss the themes and individual weekly analyses. 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 separate analyses: themes relating to the caregiving journey [59] and evolving coordination processes during and following extended hospitalization, themes relating to Social Support [58] and Role Theory [60], and themes around care coordination and the role of family resilience [56, 57]. In this paper we report findings from this last cluster of themes.

Following our inductive analysis, we then deductively coded our interview transcripts using theories of family resilience, focusing on *Walsh's Family Resilience Framework* [88] and the *Family Adaptive Systems* framework (FAS) [26]. Ultimately, we found the FAS to be the most productive framework and chose to use it for the in-depth analysis presented in this paper. Following an analysis of the four Family Adaptive Systems sub-systems (emotion, meaning, maintenance, and control) we discovered a set of our inductive themes which did not match any of the existing systems. We chose to group them into a fifth subsystem—the Information system—and present that analysis in this paper.

3.4 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 work), 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 and primarily relational in nature. In two families (7 and 8), we were unable to speak with both parents. The mother in family seven mentioned that father had expressed willingness to participate, but he did not answer our follow-up calls, and we were unable to schedule him. The mother in family eight mentioned that father 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 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 the grandparents of the hospitalized child; similarly, we did not interview or survey clinicians to understand their perspectives on caregivers' needs. Additionally, two of our interview participants (both mothers) had healthcare-related professions, which means our participants may collectively have more healthcare expertise than the typical family.

4 FAMILY RESILIENCE: EMOTION, MEANING, MAINTENANCE, AND CONTROL SYSTEMS

The parents in our study reported that their families experienced different challenges influencing their Family Adaptive Systems. These challenges started from the stress and negative feelings related to their child's diagnosis and severe symptoms, the difficulties arising from the distance between home and the hospital, and feeling overwhelmed while juggling hospital and other daily tasks. For most parents, becoming a caregiver added a lot of extra work and burden; for some, it turned into a full-time job, as some of the mothers in our study either changed to a part-time job or left their job to provide appropriate care to their child at the hospital. In this section, we show our analysis of how Family Adaptive Systems can be used as a guiding framework and explain these challenges related to the different family systems. Then, in the next section, we introduce a fifth adaptive system—the Information system.

4.1 Family Emotion System

The emotion system focuses on developing and regulating the family's emotional climate and is how families manage and maintain emotional connections during a crisis. This system aims to develop and regulate the family's emotional climate through open emotional sharing and emotional support. Our study observed more negative (maladaptive) processes than positive (bonadaptive) ones when families adapted their emotions during their child's hospitalization. Parents in our study reported that they experienced many challenges and stressors that impacted their family's emotional system.

4.1.1 Negative Feelings, Fear, and Unexpectedness. Parents in our study experienced negative feelings such as feeling sick due to their child's severe health status or even fear of losing their child. To combat unexpectedness, parents updated each other daily, focusing on the immediate future rather than the long term. As the mother from family six described, *"You could prepare for some things. We prepare for the vomiting, we prepare for the diarrhea, but this time, she has a bacterial infection that's contagious by touch. You can't prepare for something like that. 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."* (F6M).

4.1.2 Isolation and Guilt. After the diagnosis, parents tried to be connected and be there for each other by staying physically close. Most parents took days off work and went to the hospital as a family. *"When [the hospitalization] first started, we kind of all went as a family."* (F4M). However, due to the long-term nature of pediatric cancer treatments, family members could not be present at the later stages of hospitalization, which resulted in feelings of social isolation for many parents in our study. For instance, in family eight, the mother describes her experience of feeling isolated while having to stay alone with the child in the hospital. She considers this challenge the second stressor for her after their child's cancer. She said, *"The second stressor for me... was just pretty much isolation ... you're sitting in a hospital room for hours and hours on with your child, but the only people that you see are nurses coming in and out."* (F8M). The uncertainty of when the home-based parent would get in touch with the parent at the hospital could worsen this feeling of isolation. The mother from family seven struggled with her partner's infrequent visits, telling us that calls alone were not enough. As she said, *"[When dad would call and ask how the child is doing], I was like, 'I just wish you would come up and see her, and you could see how she's doing.'"* (F7M).

For parents with other children, the distress of being unable to provide care for both the hospitalized child and their home-based siblings could be intense, often manifesting as a feeling of guilt. As the father from family six put it, *"The biggest thing for me is obviously I'm away from my other*

kids when I'm here, and when I'm at home with other kids, I'm away from her." (F6D). One mother described her guilt when reflecting on a conversation with her other child. *"When I'm not here, I feel terribly guilty... and she's like, 'I miss you. I miss spending time with you. I want to do things with you.' And I'm like, 'I do too, but I've got to take care of [brother]."* (F1M).

4.1.3 Less Attention to Their Relationship. The most common maladaptive practices we observed that affected the emotion system related to managing relationships. When caring for the hospitalized child, other kids became a secondary priority. The couple no longer spent time on their relationship as spouses as well, and they considered time spent together as a couple as something to prioritize after the hospitalization is over.

F1 Mom: We don't want to leave him. The few hours we get with him at night... It's not like we both have FMLA, and we can sit here for three months straight with him. We don't have that luxury. If we did, then maybe we would go and have a date night...

F1 Dad: We'll have a date night when this is all over. It'll be fine.

To combat these challenges to relationship maintenance, many couples turned to humor. Humor provided a way for couples to reconnect with their role as a romantic couple, not just caregivers, but they shared the level of communication about themselves as a couple reduced due to their child's hospitalization with cancer. *"We still try to joke and at least attempt to have conversation just about us. Probably not near as much as we used to, but we have a 2-year-old with cancer."* (F2M).

4.1.4 Long-Term Effects on Mental Health. Considering pediatric cancer treatments are long-term, the length of being exposed to these negative feelings and experiences could result in the progression of some other maladaptive practices. An example of such maladaptive practices was drinking to cope with depression caused by their child's hospitalization in an attempt to adapt to the situation. The mother from family eight shared with us that her husband did not open up and share his emotions with her, resulting in depression while trying to cope with the maladaptive behavior of drinking. *"When he was at the hospital, I think he was fine. It's when he wasn't at the hospital he got depressed. My husband's mom passed away just two months before my daughter was diagnosed, so he was already grieving and kind of depressed from that situation, so this just added on to it. I noticed that he was drinking alcohol a lot more when he was at home trying to... deal with his anxiety and depression."* (F8M).

4.1.5 Pile-Up of Stressors. A combination of the above emotional stressors on top of challenges caused by the distance from the hospital, such as managing work and caring for the kids, and challenges affecting other systems within the parenting dyad and family could result in conflict and arguments. In family stress theory, this cumulative effect is known as a "pile-up of stressors" [65]. It refers to the combination of all the stressors (such as work-related or financial concerns) on top of the primary risk factor (in our study, the hospitalization of the child with cancer), contributing to cumulative family stress. The specific family risk rarely happens in isolation; therefore, it is vital to consider families' vulnerabilities, including the accumulation of co-occurring or precedent stresses, as well as the demands placed on families when they address the particular risk [48, 73]. Many families in our study encountered this compounded challenge to their family emotion system. As the mother from family five told us,

"I have to make sure the bills are paid, the mortgage is paid, the medical bills are paid, that the kids have their 18-month checkup, or that they have their three-year appointment, and I try to make sure that life goes on and [dad], a lot of times, just goes with the flow and doesn't push to have anything happen." (F5M).

4.2 Family Meaning System

The meaning system focuses on maintaining the family's identity during a crisis. This includes ethnic heritage, gender-defined roles, how the family makes a shared understanding of the crisis, and how family beliefs, ritual, and identity can influence their response to the crisis. We observed more bonadaptive processes in the family meaning system.

4.2.1 Making Shared Meaning of the Crisis as a Family. One of the most common bonadaptive processes at the very start after the diagnosis was that parents tried to be there for each other by staying physically at the hospital, bringing other kids, and being there with the hospitalized child as a family. During the first days after the admission, most parents stayed together at the hospital to be with their children. In some cases, the whole family tried to be at the hospital, as the mother from family four said, *"When she first started, it was through the summer, so we kind of all went as a family. We didn't have to worry about our son missing school."* (F4M). This was the same for most of the families who had support from grandparents as well; for instance, the father from family five introduced us to the child's grandma. *"This is my mother-in-law, [hospitalized child]'s grandma. We're all in this together."* (F5D).

4.2.2 Positive Outlook, Sharing Happy Memories, and Celebrating Milestones. One of the most common bonadaptive processes was focusing on the positives and increasing hope through support from community groups (such as church) and making a positive meaning of the crisis. Another bonadaptive process was sharing happy memories. The mother from family four said, *"The nurses there, and the doctors ... brought our daughter in some gift cards, and they sang happy birthday to her, and she had cake with them. I videotaped that, and I did share that with my husband since he wasn't there."* (F4M). Understandably, their child having cancer affects how the family reacts to positive milestones. Moments that once seemed impossible are passionately celebrated. As such, the mother from family two joyously stated, *"The first time [hospitalized child] was able to go and play, everybody was taking pictures of her. Even though she had to sit down to play instead of standing up like a normal 2-year-old, we were taking pictures and videos because we were so excited. We were sending them to everybody like, 'Look, she's playing again!'"* (F2M). Media sharing with close family and friends also acted as a journaling method and as a way to share their child's milestones and mark her journey during the hospitalization. As she shared, *"We send pictures, we send videos; we do what we can to make sure that we're basically marking her journey. As she's going through all of it."* (F6M).

4.2.3 Religion and Beliefs. Families' beliefs and religion also played a role in the support they received. Some families in our study received support from their church family, which supported them through prayer, food, and even financial support. *"We have a large church family, and they, on the weeks that we were in the hospital, would make meals for us one day a week."* (F3M). Family members even tried to adapt their identities to the new situation in positive ways, changing from the mindset of rigid thinking about handling everything on their own to being open to receiving support. The father from family five mentioned, *"Our pastor comes down to pray about once a week."* (F5D). The mother from family 6 added that friends and the community also provide prayer support. *"A lot of it is, like, prayer chains and stuff. A lot of people are praying for her and supporting her."* (F6M).

4.2.4 Shared Activities and Entertainment. Most parents made daily phone calls for families to stay connected and send and receive positive vibes when one of them was in the hospital with the hospitalized child and the other was at home with their other children. As the mother from family three said, *"About eight o'clock, 8:00 or 9:00, we would try and call home... to say, 'Hey, how*

was your day? I hope you had a good evening.' And say hi to the kids." (F3M). The ritual of calling each other was usually helpful to help them stay connected as a family. The mother from family one shared with us that their children made Skype calls to connect the hospitalized child with their other child at home. "But when they Skype, they Skype for just a few little conversations, and they're both satisfied." (F1M). During the home visits between the inpatient hospitalizations, family members also tried to be together and plan fun activities. "...when I get home, we try to do something together. Whether it be watching a movie with the kids, we try to at least do something to spend time with them" (F6M).

4.3 Family Maintenance System

The maintenance system focuses on maintaining processes that meet the family's basic needs during a crisis. These include food, shelter, safety, and economic stability. It also aims at protecting the vulnerable members of the family.

4.3.1 Their Job and Financial Ability. One of the main things that impacted the maintenance system of families in our study was that some parents changed to a part-time job or entirely left their job. They mentioned that this change caused financial concerns for their family. For example, the mother from family seven said, "I'm just not going to work until all of this is said and done. And it's stressful... Money is an issue up here because I'm not working. And her dad tries to help me out... when he gets paid." (F7M). As the mother from family eight noted, "I could quit at that time and put on hold my job, so I became the primary person that was there most of the time with my daughter." (F8M).

4.3.2 Medical Billing and Insurance. Another common financial challenge for families was understanding complex medical billing (our study was conducted in the USA). The father from family one shared, "I understand finances, and I don't understand the medical billing procedures. I don't understand that at all." (F1D). The mother from family four shared that their choice of insurance policy helped them to manage financially. "We did take out a cancer policy that does help pay." (F4M). The father from family five shared that the online portal for the insurance is helpful to know about their claim status "Through [our insurer], they have an online portal... Anything we have going on, you can see it online, which is very nice." (F5D). He added that there are times when insurance sends information that is not a bill but needs communication back and forth; therefore, they put information all together and will be ready for the time that is ready to make a payment.

4.3.3 Financial Support and Fundraisers. Fundraisers were one of the most common types of financial support the families utilized. The father from family five said, "We've had a few different fundraisers. Two of her friends had actually put something together and made these bracelets. Says, [Son hospitalized] Strong, on there. Some of our other friends have helped. They put stuff on Facebook and stuff." (F5D). The mother from family six shared that updating other members of their social network about their child's health on Facebook helped raise awareness and receive social support from their community. "I think Facebook has been a huge help, just because I can tell everybody what's going on. We didn't tell anybody what was going on for a while... In the beginning, we told them she was in the hospital, but we didn't tell them why and what was going on. But, after we updated everybody and told everybody her story, the newspaper did an article on her in our town. When I came back from work, they did fundraising for us. They paid all of our bills for like four months..." (F6M). She added that sharing through social media helped her coworkers gather together for more support.

4.3.4 Instrumental Social Support. As mothers usually stayed with the hospitalized child, fathers tried to provide instrumental support, such as doing home chores, taking care of the other kids, and taking on some responsibilities for the mother. Overall, depending on who stayed in the hospital

with the child, the other person tried to provide different instrumental support. For example, the mother from family three said, *"I think we just sort of figured out what needed to be done. If you were the parent that was at home, what needs to be done? [Hospitalized child's dad started] loading the dishwasher or running the dishwasher, he would do that kind of thing. And I would be mindful of making sure the trash can got brought back in."* (F3M). She also mentioned that they were more understanding and flexible about the situation and tried to all be responsible for what they could do to reduce work for each other: *"It wasn't whose job is this. It was, 'This needs to be done.' But we definitely boiled it down to just the essentials, the house didn't always get vacuumed, and the bathroom didn't always get cleaned."* (F3M).

4.4 Family Control and Management System

This control and management system focuses on maintaining order during a crisis. This includes shared responsibilities, respect, and maintaining a structure in the family.

4.4.1 Primary Caregiving Role and Conflict with their Existing Roles. In order to maintain order, most families in our study assigned one of the parents, usually the mother, to take on most caregiving responsibilities and stay at the hospital. In most families, this meant that fathers or an immediate family member such as grandparents took on the mother's role and responsibilities at home, such as doing laundry and taking care of other kids. The mother from family three shared that the father took the caregiving role in her absence and accomplished the tasks at home to reduce the burden on her. *"[Dad] is 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."* (F3M).

Mothers with more than one child could not be in the hospital and handle their caregiving role for all their children all the time as they wanted to ensure they provided enough care for the siblings of the hospitalized child as well. However, this role conflict in the family control and management system could cause anxiety and stress. For example, the mother from family one mentioned how it was challenging to be happy and spend time with the other kid at home while thinking about what was happening in the hospital while she was not there. *"I'm trying to be up and positive and happy and spending a good time with her, the whole time, in the back of my head, I'm going, 'Oh my God, what's happening at the hospital? I'm not there, and it's going to be all messed up, and I'm not there to handle it.'" (F1M).*

4.4.2 Staying Prepared, Connected, and Informed. Being in constant communication and being prepared was a bonadaptive practice that some families shared with us as a way to handle the situation and be prepared for the unexpected. The mother from family six said, *"You could prepare for some things. We prepare for the vomiting, we prepare for diarrhea, but this time, now she has a bacterial infection that's contagious by touch. You can't prepare for something like that. 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."* (F6M).

4.4.3 Alerts and Reminders. Families typically split their parenting and other duties amongst themselves. But, since they rarely spent time together, it was hard for them to keep track of everything. Almost all families mentioned how they had to keep track of various activities, be it household chores or medical appointments with different specialists. Most of the time, the parents communicated about these tasks through text messaging. Some parents created a list of tasks to coordinate. This added significant burden to the hospital-based caregiver. For example, the mother from family three shared her concern about having to remind the father multiple times and stated that she managed the schedule for the family and had to keep reminding her husband about the various activities that were planned; *"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, 'We need to be here on Saturday,' whatever it is... So I usually have to remind him a couple of times about different things that we're doing, but he's a go-with-the-flow for the most part, ... I think he recognizes that that's my strong suit and not so much him.' (F3M).

4.4.4 Shared Calendars and Notes. Having to split time in the hospital while managing work or other family commitments meant families tried to follow a strict schedule. The father from family five talked about how Google Calendar was a great tool that helped his family stay organized. He said, *"Google Calendar is amazing because [mom] and I can adjust however we need to. You can see my work schedule. My mom's going to pick the kids up. That was a birthday we had. [Mom]'s at work. I have a field day on the 19th, and we're going... to go to a waterpark on Saturday and Sunday. So it kind of shows you our daily schedules."* (F5D). Some families used traditional, physical calendars to inform each other of upcoming events and appointments. It was helpful since it was in one place and did not require families to rely on internet service to access the needed information. This was especially important to families with poor internet connectivity at home and with poor mobile data in the hospital. The mother from family six said, *"We have a calendar. We just write on the calendar at home. Yeah, because everything's written down, and then there's a note. We leave little notes for each other. More so me than him."* (F6M).

4.4.5 Distributing Tasks Among Family Members. We found that supporting the recovery of a family member with cancer was very taxing on families. As such, they requested help from extended family members to complete non-medical tasks. The mother from family five talked about helping the external family has been. She said, *"We've had other family members help... they've helped with the chores around the home."* (F5M). Alternatively, the mother from family one talked about how she and her partner take on the medical tasks while the grandparents entertain their child.

We also noticed families splitting the task amongst themselves based on who was home and who was at the hospital. Many families in our study repeated this theme of 'Doing what needs to be done,' and showed flexibility in reassigning tasks. This was especially true when families were preparing for a shift change. As the father from family six told us, *"I try not to like leave a sink full of dishes... You'd be like, 'Oh well, you're coming home from being in the hospital, okay, now go clean the house.' So I'm trying not to leave messes at the house. Like if we can make a sink full of dishes, we do the dishes or whatnot. Just covering our own butts, I guess. Just try not to leave more for the other person."* (F6D). Couples reported this switch to 'What needs to be done' tended to just happen without the need for rules or tracking. As the mother from family five told us, *"You see it needs to be done, we just do it. We don't have like a chore chart that says [mom] is doing stuff."* (F5M).

5 THE FAMILY INFORMATION SYSTEM

In the previous sections, we described the challenges and practices of family caregivers of children with cancer and characterized them deductively using the family adaptive systems as a lens. However, when looking at themes from our inductive coding phase, we found some themes challenging to put under any of those clusters: themes related to medical information and information sharing among the parents. Coordinating the care of a hospitalized child with cancer requires significant information sharing and management. Parents in our study reported that they received and managed much information, yet they reported dissatisfaction with information relay resulting in challenges in care coordination, tension among caregivers, and stress.

Figure 3 shows our affinity diagram of the themes and is included as a summary of the findings in this section.

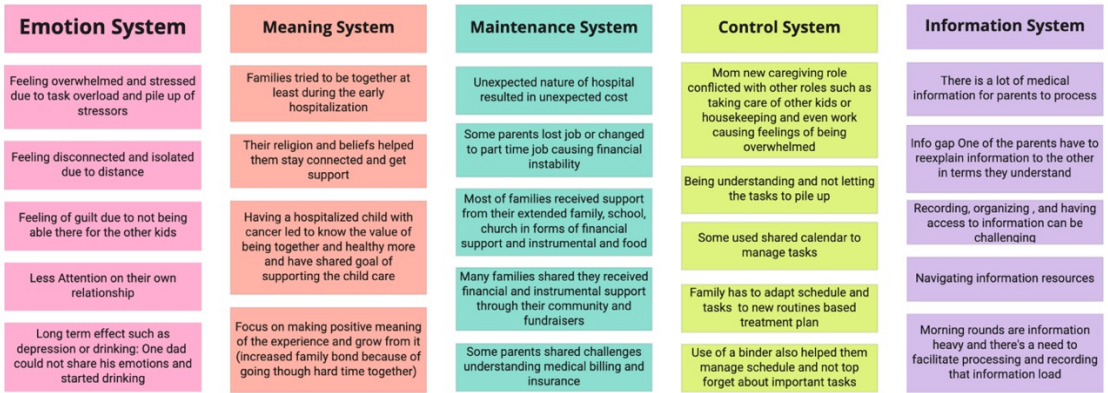


Fig. 2. Example of Themes Clustered under FAS

5.1 Inter-Caregiver Information Disparity

Parents’ long physical separation, with one parent staying in the hospital most of the time and the other parent handling shorter shifts, combined with managing different roles and role strain, often compounded to create a pernicious challenge: *Inter-Caregiver Information Disparity*. The disparity in time spent and information learned and received between mother (first primary caregiver) and father (second primary caregiver) could result in a knowledge gap of what is going on and a medical information disparity between parents. As one father said, “*She gets the information more because she’s here more.*” (F2D).

Parents were well aware of this disparity and tried to create processes and artifacts to reduce it. Parents tried to address information disparity by re-explaining, summarizing, translating, and reminding. They also used different tools and artifacts, such as paper binders, notebooks, and in-room whiteboards, and stayed in touch via text messages and phone calls, but the challenge of information disparity persisted. We believe that in the context of pediatric cancer care coordination, another system needs to be developed for the family to manage information and help reduce information disparities. we introduce a new system called the Information System to the Family Adaptive Systems model. The Information System is an adaptive system to help the family absorb, navigate, and share medical information in the pediatric cancer care coordination context. In this section, we explain the challenges and practices of the families in our study under the Family Information System.

Parents adopted several strategies to manage information disparities. The hospital-based parent often had to share the information with other caregivers so they could stay informed about their child’s health status and the next steps in the treatment. Based on our findings, the flow of information was primarily from the parent in the hospital to the other parent. The hospital-based parent shared information and translated or explained it to the other parent. As one mother put it, “*I explain it in terms that he can understand, or at least I think I do.*” (F4M). From the parent’s perspective, this information-sharing usually occurred through phone calls or messages. As the mother from family two shared, “*Well, even last round with chemo, every morning after we would talk to the doctors, there would be a short, quick update on what was going on just so he would know. And it wasn’t a lot; it was enough to where he would know what was going on.*” (F2M).

Given the severity of the medical diagnosis of cancer, families in our study wanted as much medical information as possible. Ideally, they wanted the information to be precisely synthesized

into small snippets. The mother from family one was frustrated due to the poor information relay. She said, *“So I’m not here for anything, and 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). Her partner also echoed her frustration with poor information management. *“Why couldn’t there be a little transcript of morning rounds? They sit around, and they write down everything they say anyway. Why can’t there just be a little blurb about, ‘This is good. Maybe we’re going to have to do the CT because of this.’ And then she would know that, and it wouldn’t have to be a problem with us trying to track things down.”* (F1D). The father from family five added that the information in the morning rounds could be stored and shared with all family members. *“It would be nice to have some sort of platform where we could communicate. Maybe on the rounds. So they’ll come around and do rounds, and then they could put it to whatever platform this might be, and we could view it. [mom] and I could view it, screenshot to my grandma and grandpa, whoever it might be.”* (F5D).

Some parents used a binder to keep track of symptoms and medicines. The mother from family one shared that she had a little binder where she kept track of symptoms. *“Sometimes the nurses aren’t in there when you have meals, or when you do certain medications, or 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.’”* (F1M). When she was not at the hospital, she was frustrated with how the medical staff did not communicate medical information with the primary caregivers, and she had to rely on the child’s grandparents to be informed. *“I’ve asked them to write down things. I even gave them, like, ‘This is how I want things written down,’ and she’ll write down, ‘10:00. White coat. Curly hair.’ And I’m like, ‘Mom, I need you to get people’s names.’ That didn’t kick into her until, what, three weeks ago? That I have to have these people’s names. And she’d write down, ‘2:00. He wants a hug.’ Okay, well, that’s awesome, but that is not information that I need. And they’ll [grandparents] write down how many Oreos he eats, but they won’t write down what medication he got.”* (F1M).

Even for families that did not share frustrations with information disparity, other difficulties still arose. The mother from family three shared, *“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.”* (F3M). She shared that they lost the binder and said that she preferred to have a digital substitute for the binder by saying, *“Well, I think for me, it would have been something to replace the binder. Now the problem would be if you lost your phone, you would lose all the info, but if it could be stored in the cloud. I would have had the app connected to all three of us so [hospitalized child] could put info in. Like I took two Tylenol at 11 pm because she’s not a six-year-old. Maybe even a place for notes or symptoms or something. As I’m here at home and [dad] would have been in Indy, he could have said or [the hospitalized child] could have said, ‘I feel really nauseous.’ And we could have looked back and said, ‘Oh, well, she didn’t get one of her nausea meds.’”* (F3M).

5.2 Sharing Medical Updates by Text

As highlighted earlier, families are very busy with task splitting, managing a work-life balance, and providing their children with the best care possible. With this, asynchronous communication via text was the optimized form of staying in touch for some families. As such, we had multiple families in our study using text to keep each other up to date. The mother from family two said, *“I would call or text him [dad], and if I had to text him, I’d say, ‘Hey, call me when you get a second.’”*

(F2M). Similarly, the father from family five said, *“As I said, phone, verbal communication, email, and texting are the big ones. 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.”* (F5D). Moreover, the mother from family three highlighted how she kept everyone in the family up to date via group text messaging to reduce the burden of updating everyone individually. She said, *“So I would send a group text to our family in situations like, ‘Hey, her counts are still too high. She’s not coming home today,’ or, ‘Hey, the surgery went well. The surgeon said everything was good.’ Just so it was easy to manage one group.”* (F3M).

The father from family one talked about how he would immediately update his partner with any new medical information he received. He said, *“If I hear anything else, immediately, while they’re still talking, I’m texting her to let her know, ‘They said they’re going to do this.’”* (F1D). This family gave another example of ensuring that everyone was up to date with what was happening, even when the medical staff was not cooperating. *“[the doctor] and the nurse are trying to basically push [the hospitalized child] out of the bed and into the hallway to get him out, and he’s sick. So I’m texting [mom] like a madman, and I’m telling the nurse my problems, but that’s kind of the thing where she’s texting back and forth, and I’m asking questions, and she’s texting me in real-time.”* (F1D). Text messaging was also a way for this family to maintain privacy while keeping each other informed. The mother from family one exhibited this privacy concern. She said, *“If anything has to be said that we don’t want anybody to hear, it’s all text message.”* (F1M).

Parents also occasionally shared detailed medical information, such as a photo of a paper lab result or another clinical handout. For instance, the mother from family two explained. *“And there were a couple of times that I actually sent him a picture of the information that we were given, and then I would do my best to explain it to him the way that the doctors explained it to me.”* (F2M). There were also times that parents shared a picture of the lab results to find specific information or to ensure at least one parent had access to all the information. *“He has sent me a picture or two of lab results because there’s a lot of information on that, but it’s more if I’m wanting to know certain things on that and he might not know which one it is, or just because I’ll have all the information if I just send her this picture.”* (F1M).

5.3 Connecting in Real Time: Audio and Video Calls

Parents shared that they usually use text messaging to share medical updates. They also shared that they used phone and video calls to update each other with both medical and non-medical information. There were usually rituals around making a video call at a time when all family members could be on the call and update each other about their day and get to know the health status of the hospitalized child. The mother from family three talks about how the parents checked in on each other via a phone call every night. She said, *“The person that was home would be the one to make the phone call because it was crazier at home than at the hospital, to say, ‘Hey, how was your day?...And say hi to the kids.’”* (F3M).

Furthermore, it allowed the families to quickly update each other with information and ensure they did not miss anything. The father from family five spoke about how he made sure the mother of the hospitalized child was kept up to date via phone calls. *“I’ll have [mom] hear the doctors. I’ll have [mom] be the point of contact. Call me, if you can’t get ahold of [Mom].”* (F5D). Similarly, the mother from family four spoke about how the family mostly used phone calls to keep everyone up to date. She said, *“We’d just call. I mean, that’s about all you can do is just call on the phone, and let them know. 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).

Some of the families in our study used video calling to stay in touch with each other. While it was not the primary form of communication, it was used to connect on a deeper level than texting

could provide. The mother of family five shared, *“I’d say most of it is text. I don’t want to put a number on [it]; I put like 85, 90% of it is the text message. And then at night, we usually FaceTime at least once or twice, especially when he [dad] has the other boys. We FaceTime, just so we can see each other, and he [the hospitalized child] doesn’t feel [left out].”* (F5M).

Video calling made it easier for the family to ‘see’ each other when the situation did not allow visitation. As the mother from family seven expresses, *“But I would call him [dad]; he’d like to video chat a lot just to look at her [the hospitalized child] [to] see how she was doing that day. But it was... yeah, I mean, it was definitely tough”* (F7M). Similar thoughts were echoed by the mother from family two when she talked about how two siblings shared moments, *“There was one point where our oldest was sick, and she couldn’t come to the hospital, so our oldest and [the hospitalized child] would send video messages to each other so they could see each other, so that’s always really helpful when they’re not able to see each other.”* (F2M).

5.4 Beyond the Caregiving Circle: Using Social Media

When we asked the parents about the use of social media, we learned that most families used social media platforms such as Facebook and Instagram to share updates on their child’s health. The mother from family seven said, *“I actually have a group on Facebook called [hospitalized child]’s Journey; that is where I put her updates.”* (F7M).

The mother from family two shared that she used to share updates using group messaging at first but later used social media instead of sending so many messages. *“To immediate family, we would send pictures to [them]; we would send updates to group text messages... some of the videos and pictures, it was just easy to do that. And then it got to the point where his wonderful sister was like, ‘Let’s start an Instagram page because we can just update people instead of having to send out a trillion text messages every day.’”* (F2M).

The father from family one also shared that it was a burden to keep people updated on social media. *“...we finally just went on Facebook and said, ‘Thanks for your prayers. You guys talk about it with each other. We can’t talk right now. Leave us alone.’ But not that mean, but... that was the gist of what we put.”* (F1D).

The mother from family five shared that they did not use social media a lot for updates as they were concerned about their child’s opinion on that in the future. *“We try not. [The hospitalized child]’s brother has been using Snapchat... when he’s over there. They’re little, they can have a say when they’re 18, and they want to do what they want to do, then that’s their decision... But again, I try not to put too much. I don’t put my whole life story out there. Right. I like to leave some of it to a mystery. But I just worry about my own kids.”* (F5M).

6 DISCUSSION: TOWARDS FAMILY RESILIENCE TECHNOLOGIES

As our findings have shown, adopting a Family Resilience perspective allows us to think holistically about families’ coordination challenges, including (but not limited to) their information work. Understanding the various adaptive systems that families leverage (or struggle to leverage) during a crisis gives CSCW researchers a powerful toolkit. The Family Adaptive Systems model, as our findings show, is not only highly salient to the context of coordination during a health crisis, but has a high level of explanatory power. Furthermore, Family Resilience also comes with *application power*, that is, the ability to not only explain phenomena but also to guide the design and implementation of new technologies. In this section, we first describe the design implications of each Family Adaptive System in turn, then show how designs can work across the systems. Finally, we compare and contrast Family Resilience and FAS to other related theories frameworks.

6.1 Designing for Family Adaptive Systems

Family Resilience also offers us a productive lens to identify and create novel collaboration technologies to support caregiving coordination. Indeed, the Family Adaptive Systems model—with the addition of the Information system alongside the existing Emotion, Meaning, Maintenance, and Control systems—is particularly well suited to teasing out design implications. For example, the main contributors to the family **meaning system** in our study were families' religion and spiritual beliefs, church community, and making positive meaning of the child's hospitalization. A system that helps the family understand their shared values and beliefs and helps families connect their situation or crisis context to certain external or internal cultural backgrounds could support the family meaning system.

Imagine that the hospital has provided an app, called *OurCareCircle*, designed for family caregivers to use during and following extended hospitalization of their child. *OurCareCircle* could support the meaning system in a number of ways. Some families might prefer a collective devotional: the app could display a daily inspirational on the home or login screen. Other families might prefer a collective journal or values clarification exercise, in which family members are invited to complete a sentence such as... "Our family is a family who...". Other features could embed the meaning system more subtly, by facilitating meaningful family rituals or events even during hospitalization. For example, if a family's Sunday dinner is a key event for them, the app could allow them to schedule a video call during the time they'd traditionally be eating together, or support the home-based parent in preparing traditional foods.

Collaborative technologies to support the **control and management system** of a family can help the family define goals and set plans and maintain rhythm in their routines, set boundaries, make shared decisions, and maintain structure. One key decision for designers of control and management features is whether to build new tools (such as our hypothetical *OurCareCircle* app), or to leverage existing tools in ways that are more tailored to families' control and management needs. Some collaboration technologies such as calendars, to-do lists, polls, and reminders designed for the workplace are already being used by parents in our study. However, there are challenges to using them. These challenges include each family member using different types of calendars or one parent being more likely to use these collaboration technologies than the other—possibly exacerbating information disparity or role strain if done incorrectly. Furthermore, the caregiving coordination context varies significantly from the workplaces and work tasks for which many coordination tools were created. Next-generation technologies could help with this workload by automating as much coordination work as possible, such as location trackers and routine learners studied by Davidoff et al. [17]. Another design opportunity is tools that support a more equitable division of labor between caregivers, or at least surface the relative workload of caregivers. In *OurCareCircle*, for example, it might be useful for families to see the list of tasks or responsibilities each caregiver has assumed, so that others can volunteer to handle certain tasks or at least be aware of the overall workload.

With respect to the **maintenance system**, technologies for collaborative caregiving could augment practices in maintenance systems by providing training and help with navigating economic sources of support and financial management in our study, specifically medical billing, which can be challenging to understand. Such tools can help the family members find the best insurance, manage their spending, set reasonable expectations of the future costs associated with their child's treatment, and help them find financial support through social media fundraisers or community support. As with the Control and Management system, these tools need not be entirely custom-built. Indeed, the maintenance system gives CSCW researchers and designers the opportunity to design tools that facilitate coordination and conversation around maintenance topics (such as a

discussion in *OurCareCircle* or even a wizard or 'quiz' feature), and then guide families to dedicated tools they can use to actually complete their tasks (such as budget trackers). Other tasks might be situationally-specific enough that bespoke tools are needed, such as a billing code explainer built into *OurCareCircle*.

Technologies to foster the **emotion system** could improve family connectedness and result in emotional growth. An example of such technology can be a system to help a family stay connected in a virtual shared space through video, audio, or text, where family members can engage in shared activities and rituals. Such a system could live within a more task-oriented system such as *OurCareCircle* so that families could see both informational and emotional content in the same place. For instance, the parent at the hospital could share a video to *OurCareCircle* of how the child is doing, for example, playing in the hospital room, or the parent at home could share a photo of the other kids eating food. *OurCareCircle* could save these positive moments into a family journal so family members can take a look and share them with others. A technology to support the family emotion system could support families by promoting family rituals such as games and family meditation activities. Tools such as mood trackers, journaling, and reflection applications can be used collaboratively within a family to help improve family emotional growth during a crisis.

However, due to potential negative implications, family emotional system technologies must strike a particularly delicate balance. For example, if not designed carefully, a video-sharing application could increase the sense of isolation, or technologies that encourage the open sharing of negative emotions could further contribute to mental health challenges rather than ameliorate them.

The **information system** also has a wealth of potential from a design implications perspective. The maladaptive inter-caregiver information disparity that emerged in many caregiving circles in our study could be meaningfully addressed by more sensitively-designed collaboration tools and practices, such as shared spaces to access medical information, and regular updates to all caregivers. Bots or other proactive information delivery tools could also play a role in summarizing and distributing updates, so the hospital-based parent is relieved of some of that additional articulation work. Families could also be better supported in their information dissemination efforts, through templates and automated workflows built into an app like *OurCareCircle* that also connect beyond it. Technologies that have benefits for other family adaptive systems, such as real-time rich media chat (video, audio, or other live interactions) could also incorporate information-sharing features.

6.2 Designing Across Adaptive Systems

In this vein, our findings give us reason to believe that addressing even one system can positively impact the family and secondary benefits for other systems. Our evidence from the families in this study shows how changes in one system can affect the other systems, although, in our data set, these effects tended to be negative. For example, suppose the lack of proper division of tasks in the control and management system continues to exist in the long term. In that case, it will result in conflicts and grievances that impact the family's emotional system when one family member feels overwhelmed and under pressure. However, this ripple effect should be cut both ways, and relieving pressure on the emotional system may give more space for other communication and coordination processes to function resiliently.

Indeed, while there are benefits to designing new tools and socio-technical practices for each of the adaptive systems independently, the true power of Family Resilience as an approach may be felt in creating all-encompassing technologies which incorporate features for multiple adaptive systems. Families' challenges and resilient practices are interconnected, and there may be substantial benefits to designing **across systems**. That is, an all-in-one solution such as *OurCareCircle* may in fact be

greater than the sum of its parts. This question deserves serious investigation, as the answers could dramatically alter the kinds of tools that would work best for families.

In our own future work, we will put FAS to the test to ensure it can be used as a guide in the design process and identify Family Resilience Technologies and show how design can expand FAS as a theory in the pediatric care context. Specifically, we will use FAS to design a card-sorting study to help prioritize Family Resilience Technologies and provide design implications for future FR technologies to augment and support family resilience processes and caregiving coordination in the children's hospital. But we also believe that the evidence from this paper is strong enough that other researchers in other caregiving coordination contexts could already benefit from adopting the Family resilience perspective in their own work. In the next section, we discuss the powers of Family Resilience and FAS specifically, and compare it to other theories and models used in CSCW research.

6.3 Putting Theories to Work

In this paper, we have made a case for the value of the Family Resilience perspective in CSCW and the particular applicability of the Family Adaptive Systems model. We have also responded to the specific needs that CSCW researchers have for such a theory. Our addition to FAS, the Family Information System, allows us to extend the power of the model while still leveraging the four existing systems. However, Family Resilience is not the only salient perspective when it comes to caregiving coordination, and Family Resilience theories do not exist in a vacuum. As Christine Halverson convincingly argued over 20 years ago, CSCW needs theories that offer descriptive, rhetorical, inferential, and application power[25]. Within the caregiving coordination literature in CSCW, researchers have adapted theories such as Social Support Theory[78], Ecological Systems Theory (EST)[51], and Role Theory[61] to help explain and predict users' behaviors and needs with respect to coordination technology. These theories' power is in describing some of the protective factors (related to caregiving roles and support practices) that exist within a family to handle the crisis of having a hospitalized child with cancer. However, they struggle to provide appropriately scoped inferential or causal explanations (that is, at the scale of the caregiving group, rather than the individual caregiver or patient, or at the other extreme, society at large). For example, Social Support Theory[14] can explain that specific types of support, such as emotional support, exist within family caregivers but does not look at how the emotional well-being of the family changes during the cancer journey. Because Family Resilience theories are compatible with Social Support theory, we were able to show how different types of social support affect different family adaptive systems (e.g. instrumental social support as a bonadaptive practice within the Family Maintenance System). Similarly, Family Resilience is compatible with Role Theory; in our study, role strain (a concept from Role Theory) is a key challenge to the control and management system within FAS. Ecological Systems Theory (EST)[10] shows how families act as a protective layer for an individual undergoing health crisis, and places the family within the other social structures at play. This theory has been widely adopted within CSCW and has significant explanatory power.[15]. However, we argue that EST's emphasis on naming stakeholders and influences reduces their ability to provide guidance for which processes could be improved in order to reduce burden. That is, from the perspective of designing collaborative systems for interpersonal processes, EST on its own lacks *application power*. Family Resilience theories were designed to be compatible with EST, and allow researchers and designers to characterize the processes at work within the mesosystem.

It is *application power* that CSCW researchers and designers are most desperately lacking when it comes to the design of theory-driven caregiving coordination technologies. Theories of Family Resilience hold much promise here, because, as we have shown in this paper, Family Resilience is a theory of *sociotechnical systems* and *interpersonal processes* by which care is enacted. As a

process-focused model, it is better equipped to help designers plan interventions. We should note, however, that not all Family Resilience models are created equal. Indeed, we began our own analysis by trying to use one popular model, Walsh's model, to analyze our interview data. However, as we got closer to the data, we found the sub-constructs of the theory overlapping again and again. Ultimately, we found Family Adaptive Systems (FAS) to be the theory with the most application power; its constructs are distinct and it is able to absorb a fifth system (the Information System) without becoming unrecognizable.

This paper is merely the first step in putting Family Resilience to work in CSCW. More research will be needed in order to show that the FAS approach used in this paper can actually be translated into design. The scope and limits of this theory (and our own modifications to it) have yet to be tested. For example, do Family Resilience theories and the Information System in particular only apply to extreme situations such as extended hospitalization, or could the theory be applied to more everyday aspects of family life? Does the theory become salient only when there are barriers to offline communication, such as distance or hospitalization? One particularly interesting area of future work is understanding of how Family Resilience theories apply across phases of the illness journey. Recent CSCW scholarship indicates that caregiving coordination work (and thus families' technological needs) varies systematically across a hospital stay, from diagnosis, to early hospitalization, to extended hospitalization, to home-based care[59]. However, further work is needed in order to connect this stage-based set of needs to specific care coordination features, and to determine whether Family Resilience (and FAS specifically) holds up to temporal scrutiny. There is reason for optimism: Johnson et al.'s 2019 'Nurture-Empower-Support' model[36] for designing for ICU families identified six classes of needs across three stages of hospitalization. While this model is primarily aimed at individual caregivers' interactions with providers (rather than the caregiving coordination work within the family), the needs and stages echo findings from Family Resilience and both theories are complementary. These and more questions will have to be answered if family resilience is to make the contribution we hope and believe it can make. But we believe that FAS's potential descriptive, explanatory, inferential, and application power make it worth the effort.

7 CONCLUSION

In this paper, we demonstrated—through an empirical interview study of parents with children experiencing extended hospitalization—that Family Resilience is a descriptive and generative lens which has the potential to drive the development of future collaborative technologies. We used Family Adaptive Systems as a guiding theory and conducted deductive coding of the interviews to reveal the resilience processes and linked them to the stressors faced by families in our study. We found the family resilience processes that assist families in managing the crisis and coordinating the care they provide for their child with cancer. We also broadened the scope of the theory by proposing a novel family adaptive system that we called the Information System. This system assists families in managing medical information, as well as in remaining informed and connected to coordinate the care for their hospitalized child. Finally, we presented initial design implications of a Family Resilience approach, and identified open questions which will need to be addressed in future design-focused work.

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