

Designing for Families as Adaptive Systems: Collaborative Emotional Support and Resilience in the Children’s Hospital

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ABSTRACT

When a child is admitted to the hospital with a critical illness, their family must adapt and manage care and stress. HCI and Computer-Supported Cooperative Work (CSCW) technologies have shown the potential for collaborative technologies to support and augment care collaboration between patients and caregivers. However, less is known about the potential for collaborative technologies to augment family caregiving circles experiences, stressors, and adaptation practices, especially during long hospitalization stays. We interviewed 14 parents of children with cancer admitted for extended hospitalizations in this work. We use the Family Adaptive Systems framework from the family therapy fields as a lens to characterize the challenges and practices of families with a hospitalized child. We characterize the four adaptive systems from the theory: Emotion system, Control system, Meaning, and Maintenance system. Then, we focus on the Emotion system, suggesting 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;

KEYWORDS

Care coordination, Parenting, Hospitalization, Pediatrics

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1 INTRODUCTION

Each year, approximately 15,300 children in the US alone will get diagnosed with cancer [30]. Families of these hospitalized children need to cope with a lot of stress, and they play an essential role in their child’s care [10, 29]. Parents provide care and assistance to the hospitalized children to process medical information and go through their treatment journey [13]. These families must undertake new tasks such as care provision, interpreting medical information, preparing for lengthy and often painful treatments, and confronting the possibility of losing their child. Additionally, they must change their regular responsibilities, tasks, and even employment in order to care for their hospitalized kid.

Prior studies on families with hospitalized children indicate that a decreased stress level and more communication among family members are important predictors of long-term health outcomes post-hospitalization [9, 27]. Family resilience was defined in social work and family therapy studies as a family’s capacity to process and manage stress as a system [8, 12, 28]. However, few technologies have yet been developed to strengthen family resilience and to facilitate communication and cooperation amongst family members during a child’s hospitalization. In this Late Breaking Work, we connect Family Resilience and the Family Adaptive Systems

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framework to HCI, grounding our analysis in the case of families caring for a child hospitalized for cancer treatment. We conducted an interview study to determine how hospitalization of a child with cancer can impact family adaptive systems and to determine the role that future collaborative technologies could play in augmenting family resilience processes and family coordination for families coping with the high stress associated with having a child with cancer during an extended hospitalization stay. In this paper, we show how the Family Adaptive Systems framework applies to our context, and take a deep dive into one in particular—the Emotion system. We show how families try to process the emotional aspects of care, ways in which their current practices are maladaptive, and show how future technologies could support emotional family resilience.

2 RELATED WORK

2.1 Collaborative care and connected care in HCI

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. Most of the HCI and CSCW studies on family collaboration concentrate on collaboration within family members in normal settings (exploring the design of calendars [14, 15, 22], boards [19], routine trackers [3]) and they do not target families under stress when practices continuously change, and unexpected events occur. Most HCI studies relevant to connected care concentrate on collaboration within patients [6, 20, 26], or patients with providers [5, 23], or patients with caregivers [4, 13]. However, 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 extended hospitalization period. Recent CHI publication [25] reports the result of a largescale survey indicating the need for future socio-technical systems that address challenges in care coordination that result in caregiver isolation. Family resilience can be used as a lens to understand family caregivers' collaborative processes and guide the design of collaborative technologies to support these families in adapting to the new hospitalization setting and manage care coordination 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.

2.2 Family Resilience and Family Adaptive Systems

Family resilience is the ability of a family to retain and manage all the family functions during a time of crisis. Emerged from theories of individual resilience, family resilience comes from family therapy and psychology studies. The core of family resilience is the ability of a family not only to maintain the family's main functions but also to protect the vulnerable members of the family and aid them to adapt

to the new situation arising from the crisis. The Morris and Harrist model of family adaptive systems is one of the prominent family resilience theories. Family's adaptive systems combine different functions of the family and enable the working of the day-to-day life of a family as well as their ability to react to stressful situations. Collaborative care coordination in healthcare discusses the family as a system by describing the role of caregivers and their impact on the family as a whole through various functions described in the family adaptive systems [7]. The four adaptive systems (1) Emotion system's goal is to develop and regulate the family's emotional climate that helps manage and maintain the emotional connections within and outside the family; (2) Control system centers on maintaining a structure and order in a family by tracking individual behavior and respect for each other; (3) Meaning system assists a family to maintain 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) 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.

3 METHODS

We conducted semi-structured interviews with 14 parents from eight families, each with a child hospitalized for cancer treatment at Riley Hospital for Children located on the Indiana University Campus in Indianapolis, Indiana, USA. Riley Hospital 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 [31]. This study is part of a larger study on collaborative caregiving of hospitalized children with cancer [16–18]. This paper reports our analysis of the collected data to generate themes and identify family resilience processes using family adaptive systems as an organizing framework.

We recruited participants after the approval of Indiana University's IRB (Institutional Review Board). 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. All parents considered themselves and their spouse as primary caregivers. All the participants had a child (aged from a few years old to late teens) 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).

To minimize the burden and be mindful of the participants' time, we offered to conduct interviews either in the hospital or over the phone, with caregivers being interviewed together or separately. Five families were interviewed in person in the hospital, and three families were interviewed over the phone. Interviews lasted between 60 and 70 minutes and followed a semi-structured protocol. They mainly focused on the caregivers' roles, challenges, and routines during the hospitalization. Some example questions that we

asked participants during the interview were *Can you describe a typical day at the hospital as a parent? What have been the biggest challenges from the time your child has been hospitalized*

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 [1, 2] and then applied a second round of deductive coding using family adaptive systems as the guiding theory [7]. We themed the interview insights utilizing Atlas.ti, a qualitative data analysis application [32]. We used Morris and Harrist model of family adaptive systems and family resilience as a sensitizing concept in our analysis [7]. This analysis resulted in a set of coordination challenges and family adaptive practices under each family adaptive system [deductive categorization]. In the findings section, we refer to each family by family number and whether the participant is the mom (M) or dad (D). For example, the dad from family two (F2) will appear in quotes as (F2D)

4 FAMILY ADAPTIVE SYSTEMS AND CHALLENGES: A SUMMARY

The parents in our study reported that their families experienced different challenges influencing their family adaptive systems. These challenges started from stress and negative feelings related to diagnosis and severe symptoms and the difficulties arising due to distance between home and the hospital, and feeling overwhelmed while juggling hospital tasks 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 moms 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 early analysis on how family adaptive systems can be used as a guiding framework and explain these challenges related to the different family systems. We dive deeper into one of the adaptive systems (family emotion system) and identify challenges, bonadaptive and maladaptive practices such as feelings of isolation in care and guilt. Then, we discuss how considering families as a system and a unit of analysis can help guide the design of family resilience technologies to help address these challenges.

4.1 Family Emotion system

The emotion system focuses on developing and regulating the family's emotional climate, and is the means by which families manage and maintain emotional connections during a crisis. The goal of this system is to develop and regulate the family's emotional climate through open emotional sharing and emotional support within the family. In our study, we observed more negative (maladaptive) processes than positive (bonadaptive) processes when families wanted to adapt their emotion system during their child's hospitalization.

One of the common bonadaptive processes at the very start after the diagnosis was that 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 terms nature of the pediatric cancer treatments, family members could not be present at the later stages

of hospitalization which resulted in feelings of isolation for many parents in our study. As family five dad shared how it was helpful that their pastor visited him to provide emotional support through prayers and conversations, "Our pastor comes down to pray about once a week. We'll go out to lunch and just spend a little time together. Like I said, it's always great, just to have some other adults come by and friends from home. Just someone to talk." (F5D)

Parents in our study reported that they experienced many challenges and stressors impacting their family emotion system. In section 5, we will dive deeper into family emotion system and categorize and describe the maladaptive practices related to the emotion system and challenges faced by parents in our study.

4.2 Family Meaning System

The meaning system focuses on maintaining the family's identity during a time of 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. One of the most common bonadaptive processes was focusing on positive and increasing hope through support from the church and making positive meaning of the crisis. As family three mom mentioned, "yesterday afternoon, and so we found out the cancer also has infiltration in his leg muscles, which isn't a good thing, but I'm going to say optimistic that it's not in his heart or as lymph nodes or any other organs." (F5M) Families' beliefs and religion also took a role in the amount of support they received. Most families in our study received support from their church family, who 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 identity to the new situation in positive ways for changing from the mindset of rigid thinking about handling everything on their own to being open to receiving support as family two dad mentioned, "My pastor's wife texted me the other day, she said, "are you guys okay on snacks and drinks?", and I'm getting to the point where I'm able to say, "okay, we maybe need some drinks or whatever". Because I'm stubborn, I'll be the first person to tell you, "I got it, I'll figure it out", but there are sometimes like this where your hands are completely tied, you can't do a thing about it." (F2D) However, it was still difficult for him to ask for support if the offer for help was open-ended. It could be because they did not feel comfortable asking for specific support or did not even know what kinds of support they needed. "But still if they ask me an open-ended question, I'm not going to answer it. If they ask me a specific question like, "what do you want to eat for dinner?", like the other night, I said "tacos", I mean, like I can be... if you ask me a specific question, I will answer it specifically. But if you leave it open-ended because it is very difficult. Because sometimes we don't know what we need.)" (F2D) This example shows the importance of learning to be open to help and being able to identify needs at the time of crisis and utilize corresponding resources.

One of the parents mentioned how they considered going through such a difficult experience helped their relationship become

stronger, as family eight mom mentioned. "We've been through it together, and we always said until you go through something like that together, people just don't understand. So, since we did go through that together, it's like we have an extra special bond he and I have because we know what the other one's been through. So, I think it made us stronger together" (F8M)

4.3 Family Maintenance System

The maintenance system focuses on maintaining processes that meet the family's basic needs during a time of crisis. These include food, shelter, safety, economic stability. It also aims at protecting the vulnerable members of the family. One of the main things that impacted the maintenance system of families in our study was that some moms changed to a part-time job or fully left their job, and they mentioned this change caused a financial concern. For example, family seven mom mentioned, "I was working on the weekends when I would go home. But this time 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) Another financial challenge for families was understanding the complex medical billing as family one dad shared, "I understand finances, and I don't understand the medical billing procedures. I don't understand that at all." (F1D) In this family not having a house of their own could result in more stress on top of hospitalization of the child and financial concerns to the extent that family one mom described the experience as a nightmare. "So, we live with his parents, and then our nephew that is a junior in college lives there as well. So, there's seven of us. In a 1,400-square-foot house with basically one bathroom. It's been really a nightmare. It's been really a nightmare." (F1M)

At times parents also had to talk to the hospitalized child siblings when they were sad or worried about money as family two dad shared, "we've had to had several conversations with her even on her own birthday. She seemed like, "what did you get me? There's no money?", like "whoa, whoa, whoa you little ungrateful child, what's going on?", I mean we've had those conversations. . . that's almost like you have to remind your children . . . sometimes people have it worse than you do." (F2D) In most families in our study, the financial and instrumental support in the form of funds and food and help with daily activities that most families received from friends, church, and schools helped them manage the financial burden caused by the hospitalization of their child. Family eight mom, for example, mentioned how she was worried that after she left her job they could have financial problems, but they were able to manage finances through her husbands' income and financial support from their daughter's preschool. "We got support that way. We got financial support from where my daughter went to preschool. They were constantly raising money to give to our family to help out since I wasn't working, that sort of thing. So financially, that was really nice as far as that support goes. (F8M)

4.4 Family Control System

The control system focuses on maintaining order during a crisis situation. This includes shared responsibilities, respect, and maintaining a structure in the family. In order to maintain order, most families in our study assigned one of the parents, usually mom, to

take most caregiving responsibilities and stay at the hospital. In most families, it meant that dads or an immediate family member such as grandparents took mom's responsibilities at home, such as doing laundry and taking care of other kids. As family three mom mentioned, "[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)

Moms who had more than one kid could not be in the hospital and handle their caregiving role all the time as they wanted to ensure they provide enough care for the siblings of the hospitalized child. However, this role conflict in the family control system could cause anxiety and stress. For example, mom from family one mentioned how it was challenging to be happy and spend time with the other kid at home while thinking about what is happening in the hospital while she is 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)

Being in constant communication and being prepared was a bonadadaptive practice that most families shared with us as a way to handle the situation and be prepared for the unexpected as family six mom said, "You could prepare for some things. We prepare for the vomiting, we prepare for the 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 in 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)

Many parents reported their own relationship as spouses became less important and they put less time for each other to be able to manage caregiving and parenting. Their new caregiving tasks were sometimes so extreme and demanding that parents even abandoned their jobs. For example, some of the parents who stayed at the hospital (usual moms) either changed to a part-time job or totally lost their jobs. "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)

5 DEEP DIVE: FAMILY EMOTION SYSTEM

In the previous section, we briefly showed how the Family Adaptive Systems framework characterizes families' resilience in responding to their child's hospitalization. In this section, we dive into one of the Adaptive Systems: The Family Emotion System. We focus on parents' maladaptive practices, such as paying less attention to their relationship, negative feelings and fear of unexpected, isolation and guilt, depression, drinking, and a pile up of stressors.

5.1 Negative Feelings, Fear and Unexpectedness

The negative emotions that parents experienced could be strong enough that family five dad described it as being impacted as much as their child with a difference that he was the one who was physically impacted "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) Parents in our study experienced negative feelings such as feeling sick due to child's severe health status or even fear of losing their child as the mom from family seven said: "There was a day my mom stayed up there with us, for a couple weeks, because we were taking it hourly, we didn't know what was going to happen. So, I was sick. So, I was staying at the [temporary accommodation near hospital] that day, well actually it was that night, and I guess they had called ...in, and they told my mom that she needed to call me immediately because they didn't think she was going to make it." (F7M).

To combat unexpectedness, parents update each other on a day-to-day basis, focusing on the immediate future rather than on the long term. As the mom from family two put it: *"But it's like just take advantage of every single little moment with your kids ... because they may not be here tomorrow. They may not be here eight hours from now, you know, and I think that's important."* (F2M). As a bonadadaptive response for not being able to prepare for what's next meant that parents' communications usually focused on each day as it came. As the mom from family six described: "You could prepare for some things. We prepare for the vomiting, we prepare for the 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 in why we update day by day." (F6M)

5.2 Isolation and guilt

The next important emotional challenge faced by parents in our study has been overcoming the feeling of social *isolation*. 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 as the second stressor for her after their child's cancer. She said, "The second stressor for me...was just pretty much isolation from people in general when you're sitting in a hospital room for hours and hours on end 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 mom 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, this distress at not being able to provide care for both the hospitalized child and their home-based siblings could be intense. As the mom from family four said: "I feel like I need to split myself in half" (F4M) In this family, both parents wanted to be with the hospitalized child, but they had an eleven-year-old child at home who went to school, and dad took

care of his school and sport-related activities. Here family four mom explains how one of them have to provide care for the other kid and his schoolwork "I mean, [dad] feels like he needs to be there for [the hospitalized child] but then neither one of us want to pull [the other kid] out of school and make him ... especially when it's the first part of school because he does football." (F4M)

Isolation from home life also manifested as a feeling of *guilt*. Parents described guilt at not being able to provide care for all their children equally like before hospitalization. As the dad from family six put it: "I mean, 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 mom described her feeling of 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 my brother. You know, when you were a baby, I had to take care of you, and daddy and brother did things together. Now, brother needs mommy. Daddy doesn't know hospitals, so daddy and grandma need to take care of you while I take care of brother.' And she gets that. She's smart. She's too smart for her own good. But that same night, of course, came at 3:30 in the afternoon. He spikes a fever. Well, here I've already got plans with her, and he's having a fever, and it just kept getting worse." (F1M)

5.3 Less attention on their relationship

The most common maladaptive practices we observed that affected the emotion system was when caring for the hospitalized child and other kids became the only main priority and the couple no longer spent time on their own relationship as spouses, 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.

F1 Mom: I don't want a date night. That's not a drink on the porch. We just want to try to forget all this has happened, and move on.

5.4 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 progression of some other maladaptive practices. An example of such maladaptive practices was drinking to cope with depression caused by the hospitalization of their child to adapt with the situation as family eight mom shared with us that her husband does not open up and share his emotions with him, resulting in depression, and he tries to cope with maladaptive behavior of drinking, "He got depressed, the same thing. 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 ...So he was drinking more alcohol when he was at home to deal with his anxiety and depression." (F8M)

Family 8 mom added that if she were to design an app it would be a therapy app focused on helping parents receive emotional and mental support to decompress. "But as far as an app goes that may help with other people, I don't know if there's something ... I'm not quite sure, actually. I think what was missing in the hospital for parents was support for the parent in general, or support when the parent got out of the hospital because it's kind of like you're in the hospital and you can call a social worker if you needed to talk to somebody, but there wasn't a lot of emotional support for the parent in general. But then when you left the hospital, there was pretty much no support for the parents. So something to do, I think, that would be effective, when the families leave the hospital, some sort of app or informational thing about where they can get help if they need to find a therapist to decompress from the whole traumatic experience that the family went through. Something maybe along those lines I think more than anything may be helpful." (F8M)

5.5 Pile-up of stressors

A combination of these 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" [21]. It refers to the combination of all the stressors (such as work-related, financial concerns, etc.) on top of the primary risk factor (in our study, hospitalization of the child with cancer) contributing to the cumulative family stress. It is rare that the specific family risk happens in isolation, therefore it is important to consider families' vulnerabilities, including accumulation of co-occurring or precedent stresses, as well as the demands placed on families when they address the particular risk [11, 24]. As the mom from family five told us: "I would say we definitely argue about who does more... and he will agree with me 110%. I know he will. I've said it a thousand times. I feel like he lives out here in this happy-go-lucky. I call it his fantasy world where he's just happy all the time, and sometimes that drives me nuts because then I have to stress out for the both of 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 he, a lot of times just goes with the flow and doesn't push to have anything happen." (F5M)

6 TOWARDS FAMILY RESILIENCE TECHNOLOGIES: AN OPPORTUNITY FOR HCI

As our findings show, families attempt to meet the needs of caregiving in a crisis along several dimensions, enacting caregiving coordination processes across multiple adaptive systems. In this paper, we particularly focused on the emotion system of a family—what it entails and how it affects the family when a child is hospitalized for a prolonged period. We showed how family members experience a sense of disconnectedness due to the distance or a parent may find it challenging to provide care and attention to the

hospitalized child and their other children at home. Our finding that caregivers face isolation aligned with a previous study on isolation in care [25]. Our work shows even the parent who is not in the hospital can feel this feeling of isolation which can result in long-term mental health strain and maladaptive coping behaviors.

While no technology is a panacea, caregiving collaboration technologies could still have a profound impact on families' resilience in times of crisis. Each of the adaptive systems described in this paper has the potential to be strengthened by sensitively designed and implemented interactive technologies. Many of the building blocks are already in wide deployment. However, further research is needed in order to understand which technologies and features would work best for family resilience. Families cannot rely on workplace assumptions such as shared work hours, clearly defined roles and duties, and a clear separation of work and personal life. As our findings show, families face different obstacles to effective teamwork that impacted family adaptive systems.

Technologies could support practices under different family adaptive systems. 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 hospitalization of the child. 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 family meaning system. Collaborative technologies to support the *control 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. Some collaboration technologies such as calendars, to-do lists, polls, reminders that are designed for the workplace are already being used by parents in our study, but there are challenges to using them, such as each family member has different types of calendars or one parent is more likely to use them than the other—possibly exacerbating information disparity or role strain if done incorrectly! 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. [3] but focused on supporting more equitable division of labor between caregivers, but much research is needed in order to understand how such automated technologies could best fit the needs of family caregiving. With respect to the *maintenance system*, technologies for collaborative caregiving could augment practices in maintenance systems through providing training and help with navigating economic sources of support and financial management in our study specifically medical billing that 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 for planning, help them find financial support through social media fundraisers or community support.

In this paper, we looked closely at the family *emotion system*, which is the set of processes whereby families regulate and work to foster open emotional sharing and connectedness. Technologies to foster emotional support and collaboration could improve family connectedness and result in emotional growth. An example of such technology can be a system to help a family stay connected on a virtual shared space, through one or a combination of video, audio

or text, where family members can engage in shared activities and rituals. Such a system could enable rich media sharing with a focus on sharing beyond informational updates. For instance, the parent at the hospital could share a video 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. The system could save these positive moments into a family journal so that family members can take a look and share with others. A technology to support family emotion system could support families through promoting family rituals such as games and family meditation activities. Messaging platforms can adapt to conduct sentiment analysis of texts and identify signs of negativity or depression, bots could be added to recommend predefined messages to share with family members such as automated affirmations, jokes or movie quotes. Tools such as mood trackers and journaling and reflection applications can be designed to be used collaboratively within a family to help improve family emotional growth in crisis. However, family emotion system technologies will need to strike a particularly delicate balance because of the great potential for negative implications. For example, if not designed carefully, a video sharing application could have the effect of increasing 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.

Designing Family Resilience technologies will not be done overnight, and each adaptive system will have different design implications, but there is reason to believe that addressing even one system can have a positive impact on the family, and secondary benefits for other systems. Our evidence from the families in this study shows how changes in one system can result in effects on the other systems, although in our data set these effects tended to be negative. For example, if the lack of proper division of tasks in the control system continues to exist in the long term, it will result in conflicts and grievances that impact the family emotion system when one family member feels overwhelmed and under pressure. However, this ripple effect should cut both ways, and relieving pressure on the emotion system may give more space for other communication and coordination processes to function resiliently.

7 CONCLUSION

In this Late Breaking Work paper, we interviewed 14 parents of children with cancer who were hospitalized for lengthy hospitalizations. We utilized the adaptive systems of families as a lens to classify the problems and behaviors of families with a hospitalized child into four adaptive systems: Emotion system, Control system, Meaning system, and Maintenance system. Then, we provide recommendations for future collaborative technologies that will augment collaborative caregiving and family resilience. Concentrating on pediatric cancer, which is the leading cause of disease-related mortality in children and adolescents as the context. Childhood cancer is acute, chronic, and treatment is very expensive. This work can advance knowledge in HCI and Collaborative technologies through designing technologies to support practices within the small and close-knit groups outside the work setting, within family members and not in normal settings. The approach and implications from

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.

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REFERENCES

- [1] Ann Blandford, Dominic Furniss, and Stephan Makri. 2016. *Qualitative Hci Research: Going Behind the Scenes*. Morgan & Claypool Publishers.
- [2] 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>
- [3] Scott Davidoff, John Zimmerman, and Anind K. Dey. 2010. How routine learners can support family coordination. In *Proceedings of the 28th international conference on Human factors in computing systems - CHI '10*, ACM Press, Atlanta, Georgia, USA, 2461. DOI:<https://doi.org/10.1145/1753326.1753699>
- [4] Gary Epstein-Lubow, Rose 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.
- [5] 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>
- [6] 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>
- [7] Amanda W. Harrist, Carolyn S. Henry, Chao Liu, and Amanda Sheffield Morris. 2019. Family resilience: The power of rituals and routines in family adaptive systems. In *APA handbook of contemporary family psychology: Foundations, methods, and contemporary issues across the lifespan, Vol. 1*. American Psychological Association, Washington, DC, US, 223–239. DOI:<https://doi.org/10.1037/000099-013>
- [8] Carolyn S.1 Henry carolyn.henry@okstate.edu, Amanda1 Sheffield Morris, and Amanda W.1 Harrist. 2015. Family Resilience: Moving into the Third Wave. *Family Relations* 64, 1 (February 2015), 22–43. DOI:<https://doi.org/10.1111/fare.12106>
- [9] 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>
- [10] Elizabeth Kaziuma, Ayse G. Buyuktur, Jasmine Jones, Sung W. Choi, David A. Hanauer, and Mark S. Ackerman. 2015. Transition and reflection in the use of health information: The case of pediatric bone marrow transplant caregivers. In *CSCW 2015 - Proceedings of the 2015 ACM International Conference on Computer-Supported Cooperative Work and Social Computing*. Association for Computing Machinery, Inc, 1763–1774. DOI:<https://doi.org/10.1145/2675133.2675276>
- [11] Hamilton I. McCubbin and Joan M. Patterson. 1983. The Family Stress Process. *Marriage & Family Review* 6, 1–2 (April 1983), 7–37. DOI:https://doi.org/10.1300/J002v06n01_02
- [12] Marilyn McCubbin, Karla Balling, Peggy Possin, Sharon Friedrich, and Barbara Bryne. 2002. Family Resiliency in Childhood Cancer*. *Family Relations* 51, 2 (2002), 103–111. DOI:<https://doi.org/10.1111/j.1741-3729.2002.00103.x>
- [13] 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 *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*. Association for Computing Machinery, New York, NY, USA, 756–769. DOI:<https://doi.org/10.1145/2818048.2819983>
- [14] Carman Neustaedter and A. J. Bernstein 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>

[15] Carman Neustaedter, A. J. Bernstein Brush, and Saul Greenberg. 2007. A digital family calendar in the home: lessons from field trials of LINC. In *Proceedings of Graphics Interface 2007 (GI '07)*, Association for Computing Machinery, New York, NY, USA, 199–20. DOI:<https://doi.org/10.1145/1268517.1268551>

[16] 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>

[17] 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>

[18] 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>

[19] 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*, ACM Press, Vancouver, BC, Canada, 207–210. DOI:<https://doi.org/10.1145/2685553.2699008>

[20] Srikanth Parameswaran and Rajiv Kishore. 2018. Social Support in Online Health Communities: A Social-Network Approach. In *Proceedings of the 2018 ACM SIGMIS Conference on Computers and People Research (SIGMIS-CPR'18)*, Association for Computing Machinery, New York, NY, USA, 93–94. DOI:<https://doi.org/10.1145/3209626.3209725>

[21] Joän Patterson. 2002. Integrating family resilience and family stress theory. *Journal of Marriage and Family* 64, 2 (2002), 349–360. DOI:<https://doi.org/10.1111/j.1741-3737.2002.00349.x>

[22] Catherine Plaisant, Aaron Clamage, Hilary Browne Hutchinson, Benjamin B. Bederson, and Allison Druin. 2006. Shared family calendars: Promoting symmetry and accessibility. *ACM Transactions on Computer-Human Interaction (TOCHI)* 13, 3 (September 2006), 313–346. DOI:<https://doi.org/10.1145/1183456.1183458>

[23] Jennifer E Prey, Janet Woollen, Lauren Wilcox, Alexander D Sackheim, George Hripesak, 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>

[24] Michael Rutter. 1987. Psychosocial resilience and protective mechanisms. *Am J Orthopsychiatry* 57, 3 (July 1987), 316–331. DOI:<https://doi.org/10.1111/j.1939-0025.1987.tb03541.x>

[25] 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>

[26] C. Estelle Smith, Zachary Levonian, Haiwei Ma, Robert Giaquinto, Gemma Lein-Mcdonough, Zixuan Li, Susan O'Conner-Von, and Svetlana Yarosh. 2020. "I Cannot Do All of This Alone": Exploring Instrumental and Prayer Support in Online Health Communities. *arXiv:2005.11884 [cs]* (May 2020). Retrieved January 8, 2021 from <http://arxiv.org/abs/2005.11884>

[27] R. Streisand, S. Braniecki, K. P. Tercyak, and A. E. Kazak. 2001. Childhood illness-related parenting stress: the pediatric inventory for parents. *J Pediatr Psychol* 26, 3 (May 2001), 155–162. DOI:<https://doi.org/10.1093/jpepsy/26.3.155>

[28] Froma Walsh. 2015. *Strengthening Family Resilience, Third Edition*. Guilford Publications.

[29] 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>

[30] Childhood Cancer Statistics | CureSearch. *CureSearch for Children's Cancer*. Retrieved January 9, 2021 from <https://curesearch.org/understanding-childrens-cancer/childhood-cancer-statistics/>

[31] Research & Innovation. *Riley Children's Health*. Retrieved March 2, 2022 from <https://www.rileychildrens.org/research>

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