Designing for Resilient Caregiving Coordination Journeys: Prioritizing Features Across Families and Phases

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ABSTRACT

When a child is hospitalized with a serious illness such as cancer, parents and other close family often take on new roles as caregivers. Previous qualitative studies indicate that caregiving coordination work changes systematically across illness and treatment phases, but less is known about individuals' technology preferences and how technology needs might change over time. In this study, we employed Q-methodology, a sorting technique for quantitatively analyzing subjective opinion. We interviewed 20 caregivers of children with cancer, who sorted 25 statements about potential design solutions. We describe four distinct caregiving coordination technology archetypes at diagnosis, and show how caregivers' preferences change over time, eventually converging on one set of priorities during extended hospitalization.

CCS CONCEPTS

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

KEYWORDS

patient-centered care, caregiving, social computing, healthcare, caregiver, care coordination, pediatrics, cancer

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1 INTRODUCTION

During hospitalization of their child, family caregivers must coordinate with healthcare providers, with each other, and with other friends and family. CSCW researchers have shown how patients [23] and family caregivers [40] experience cancer treatment as a journey. Researchers have also shown how caregiving coordination work requires distinct stage-based technology support needs across phases of their journey, from diagnosis to extended hospitalization to home care [40]. However, prior research gives little indication of the diversity of families' preferences and support needs, and how those needs might change as they move from diagnosis to treatment and extended care. To explore these issues, we employed Q-methodology, a sorting technique for quantitatively analyzing subjective opinions. Q-methodology allows researchers to identify clusters of participants with similar perspectives on multi-dimensional issues. We interviewed 20 family caregivers of children who had undergone treatment and hospitalization for cancer, and asked them to rank 25 statements that describe coordination challenges and suggested design features. We asked participants to rank three times, placing themselves at key moments in their cancer caregiving journey: 1) initial diagnosis and treatment; 2) early hospitalization; and 3) extended hospitalization.

Our analysis reveals distinct caregiving coordination preferences at each stage of the caregiving coordination journey. In the early stages, participants adopt one of four caregiving coordination technology 'archetypes': *Informed Organizer*, *Collaborative Communicator*, *Financial Navigator*, and *Emotional Advocate*. However, these preferences are not static; by the time they reach the extended hospitalization stage, almost all participants report needs and preferences aligned with the *Informed Organizer* archetype.

In this paper, we demonstrate that family caregivers approach a health crisis with a variety of coordination technology preferences, meaning there can be no 'one size fits all' approach to design—especially in the early days of treatment. We further show that family caregivers' coordination challenges and design priorities

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shift markedly (and possibly even systematically) during extended treatment, and in some cases (such as pediatric cancer treatment) may actually converge. These findings point the way towards the design of technologies for caregiving coordination that respond not only to individual preferences but also to the stage of the caregiving coordination journey.

2 RELATED WORK

2.1 Study Context: Caregiving Coordination Technologies for Childhood Cancer

When a child is diagnosed with a serious illness like cancer, parents and close family members often find themselves thrust into new roles as family caregivers. Common care coordination tasks include keeping in sync with healthcare providers, managing various aspects of care, and providing emotional support to the child [33]. Caregiving work involves various complex tasks and responsibilities and is frequently associated with negative health consequences including increased stress, burden, and depression [8]. But support from family caregivers also has the ability to improve health outcomes [13], and the presence of family caregivers during care can improve communication and biomedical information sharing [54]. Pediatric cancer treatment may involve one or more hospitalizations, followed by monthly day-long visits to the hospital. Hospital stays in pediatric cancer can be quite long because of the intensity of the immune suppression required for many treatments. This is especially true for leukemia, the most common form of pediatric cancer [3]. In these circumstances, families must move beyond 'survival mode' and form new coordination practices in order to best support their child patient [37, 40, 41].

CSCW researchers have shown that family collaboration technologies hold the potential to meaningfully improve caregiver coordination during health crises such as the hospitalization of a child. Much of this work focuses on supporting the family caregiver (usually a child's mother) as a user of information and communication technologies. A decade ago, Chen et al. first argued for the consideration of informal caregivers as key health stakeholders in HCI [11]. Since then, researchers have deepened our understanding of the potential for CSCW technologies for caregiving coordination, including Kaziunas et al.'s study of pediatric bone marrow transplant patients, [27, 28]. Liu et al.'s work in the Neonatal Intensive Care Unit (NICU) [31], and Miller et al.'s work describing the roles a caregiver can take in the inpatient setting [34].

One of the key roles of caregiving is coordinating—with other caregivers and with clinicians and friends, family, and acquaintances. However, caregiving coordination remains a key challenge for CSCW: the multiple factors at play and the lack of fixed boundaries mean that coordination technologies must support caregivers as they become boundary negotiators[7] and deal with multiple challenges simultaneously[51]. With respect to pediatric cancer, Park et al. showed how caregivers develop new strengths [44], and Hong et al. investigated care coordination for teenage cancer patients and their families [20–22]. In our own previous work in pediatric cancer caregiving coordination, we have shown how caregivers provide critical social support [39], adopt new caregiving roles and experience role strain during extended hospitalization [41], and experience challenges as a family system [37, 38, 40].

To address these needs, HCI and Healthcare researchers have designed novel tools to support caregivers, such as *HealthWeaver* [16, 29, 48], *Cope360* [36], *BabySteps* [49], and *BabyTalk-Clan* [35]. *CaringBridge*, which provides features to help keep informal care networks updated, can help with some coordination tasks [4, 30]. However, none of these systems directly supports caregiver coordination during extended hospitalization, and CSCW lacks a systematic understanding of roles and preferences that coordination technologies could support during a family health crisis.

2.2 Theoretical Framing: *Family Resilience* and *Caregiving Coordination Journeys*

Family Resilience. The topic of Resilience, or bouncing back from adversity, has become the focus of attention for a number of HCI and CSCW researchers in recent years [14]. In this study we adopt the perspective of Family Resilience, a strengths-based model of recovery and coping with crisis, drawn from the family therapy fields [15, 19, 32, 45, 46]. Family resilience theories help explain how families work as a unit to process and recover from stressful events, and provide context for protective practices families employ. In this paper, we adopt one prominent theory of Family Resilience: the The Family Adaptive Systems (FAS) model. FAS consists of four systems— Emotion, Control and management, Meaning, and Maintenance. [18]. The emotion system describes the family's emotional environment, which aids in managing and maintaining the emotional ties both within and beyond the family. Keeping a family structured and orderly is the major goal of the control and management system, which does this through monitoring each member's behavior. The Meaning system helps a family maintain its identity, including the effect of its ethnic heritage and cultural roots and uses this component to keep the family grounded in difficult times. Finally, the maintenance system prioritizes meeting the family's essential requirements for food, shelter, safety, and financial stability while also guarding the most vulnerable members of the family in times of crisis [15, 18].

HCI researchers have begun to adopt Family Resilience and similar perspectives. Shin et al. call for an 'assets-based approach' to family caregiving, that could surface caregivers' strengths, which Family Resilience is ideally suited to support [47]. Tachtler et al. calls for looking beyond individuals to support 'social-ecological resilience', of which Family Resilience is a good example [50]. In our own prior work, we have validated the salience of Family Resilience and FAS in particular for CSCW and pediatric cancer, and have proposed a fifth system to FAS: the Information system, which describes the strengths families develop in managing, interpreting, and sharing complex technical and medical information throughout a health crisis [37, 38, 40].

Caregiving Coordination Journeys. The concept of the patient journey was introduced by Hayes et al. and then substantially developed by Jacobs et al. with respect to journeys in adult cancer [17, 24–26]. Jacobs et al. developed a model called the 'cancer journey framework', showing how patients' experiences of illness and their resulting technology needs vary systematically across multiple stages [23]. At each phase, patients must manage responsibilities, experience challenges, and adjust to the personal journey. In our prior work, we extended the 'journeys' approach and developed a new model, which we termed 'caregiving coordination journeys' [40]. Inspired by Jacobs' approach and grounded in the case of extended hospitalization for pediatric cancer treatment, our model includes four phases: Diagnosis & Treatment Planning;Early Hospitalization; Extended Hospitalization; Home care & post-treatment. However, more work is needed to best understand the implications for the design of caregiving coordination technologies over time.

2.3 Study Approach: Q-methodology

To conduct our study, we adopted Q-methodology, an approach from psychology that is used to explore, analyze, and understand a group of participants' subjective experiences, attitudes, and opinions, and organize them in a way that can identify trends within a population [9, 10]. Q-methodology is well-suited for small sample sizes, typically less than 50 people [43]. Q-methodology was first introduced to HCI a decade ago by O'Leary et al in their 2013 CHI paper "Q-methodology as a Research and Design Tool for HCI" [43]. As O'Leary et al. argue, while qualitative techniques (which the authors of this paper frequently employ themselves!) can provide essential insight, using an approach like Q-methodology can provide a more targeted understanding of how subjective assessments might best support design requirements [43]. Since that time, others in HCI have also used Q-methodology when examining multidimensional preferences. For example, Agapie et al. also used Q-methodology to identify the priorities of patients and their caregivers with respect to hospital information technologies [1]. Q-methodology is also widely used in healthcare research, and in studies of family caregivers in particular[6, 12, 52, 53].

3 METHODS

To understand caregivers' preferences for caregiving coordination technologies, we conducted an interview study in which we employed Q-methodology, asking participants to rank statements about potential design features. To understand how these preferences change across extended hospitalization, we asked participants to sort three times: once as if they had been newly diagnosed, a second time based on their experiences during early hospitalization, and a third time to represent their perspectives during extended hospitalization. We categorized questions and performed analysis according to the five systems in Nikkhah's extension of the Family Adaptive Systems model: Control and Management, Information, Maintenance, Emotion, and Meaning [38].

To identify a list of statements to use in our Q-study, we followed the standard protocol in Q-methodology, which first requires researchers to compile a comprehensive set of statements to describe the relevant topic, then refine the statements to a number that includes only the most informative ones.[2] Each Q study shows participants a different number of statements, but in general a statement set of at least 20 is acceptable[9]. We first conducted a design feature-focused literature review, resulting in a set of 83 statements. We then narrowed down to a set of 25 statements, distributed evenly across the 5 family adaptive systems. Each family adaptive system was assigned 1 Challenge statement (C), 2 Design suggestion statements (D), and 2 Feedback statements (F).

The study sessions were conducted remotely, and lasted just over an hour. Participants were first briefed about the four cancer journey phases and prompted to recount their experiences during the initial phase. Presented with the 25 statements, they were tasked with categorizing them into three groups based on their preferences during the first phase. This was followed by a more granular sorting round, where participants arranged these statements on a quasi-normally distributed histogram. After sorting, participants explained placement of the most and least helpful statements. This process was reiterated for the subsequent two phases. Participants were encouraged to reevaluate their preferences for each phase without being constrained by their previous choices.

Participant rankings were transcribed and processed using the KADE software [5]. 7 participants reported that they had the same phase of Diagnosis and Treatment and Early Hospitalization as their child was immediately hospitalized. The data for those 7 participants was duplicated for Phase 1 and Phase 2. Principal Component Analysis yielded eight factors, ordered by explained variance. After experimentation, we retained four factors for further analysis. This decision was informed by the observation that subsequent factors, beyond the fourth, exhibited patterns already encapsulated in the initial four, and the cumulative explained variance reached a satisfactory 60%. These factors were subjected to varimax rotation, followed by judicious judgmental adjustments to accentuate distinctions of FAS in participants' preferences. Using a significance threshold set at $p<0.05$, participants were distributed across the factors: 9 in Factor 1, 5 in Factor 2, 3 in Factor 3, and 2 in Factor 4, with one participant not aligning with any specific factor. Subsequently, a set of distinguishing statements was extracted for each factor following a similar significance threshold of $p<0.05$.

Once the factors were identified, we used the Q factors as a deductive analysis frame for a qualitative analysis, looking for themes within each factor at each stage, and tracking participants' factors across stages. The research team met frequently over multiple weeks to assemble and refine the archetypes.

3.1 Participants

We conducted interviews with 20 caregivers from across the United States who had taken care of a child who was hospitalized for cancer treatment. Our interviews included 10 mothers, 1 stepmother, 8 fathers, and 1 grandmother, each interviewed separately. Participants were educated either up to high school or had a graduate degree. We recruited through online recruiting firm UserInterviews.com, including anyone who cared for a child who experienced extended hospitalization within the last three years. Pediatric cancer treatments can last for a substantial period of time, anywhere from 6 weeks up to 2 years depending on a number of factors,[3] and researchers studying supportive care in this population typically recruit participants after their hospital stay, up to 33 months from diagnosis (for example:[6, 52, 53]).

All participants reported experiencing an extended hospitalization of at least one week. Most participants had a child diagnosed with either acute lymphoblastic leukemia (ALL), acute myeloid leukemia (AML), or some form of Lymphoma. In some cases, the child had either fibrolamellar hepatocellular carcinoma (FHC), immature teratoma of the brain, or thyroid cancer. 12 participants reported their race/ethnicity as White, 2 Asian, 1 Black, 1 American Indian, 1 Native Hawaiian, and 3 Other. 8 were the child's father, 11 mother, 1 grandmother. Participants' children varied in age from 4 years to late teens. 7 participants earned less than $75,000 a year, 8 participants earned between $75,000-$150,000 and 4 participants earned above $150,000. 6 had a high school degree or some college, 9 had a college degree, and 5 had a graduate degree.

4 FINDINGS

Participants in our study hold distinct preferences with respect to family caregiving coordination technologies, and those preferences change across the caregiving coordination journey. In the first phase (diagnosis and treatment planning), four factors emerged from the Q-methodology analysis, which we describe as caregiving coordination technology 'archetypes'. Only three remained during the second sort for early hospitalization, and only one remained during extended hospitalization.

4.1 Phase 1: Diagnosis and Treatment Planning

Four distinct caregiver archetypes emerged during the first Phase of Diagnosis and Treatment. 9 participants fell into the archetype of "The Informed Organizer", an archetype with a factor type of CM-I/Ma/E-Me with 23% explained variance. 5 participants fell into the archetype of "The Collaborative Communicator" with a factor type of CM-I/E-Me/Ma and 14% explained variance. 3 participants fell into the archetype of "The Financial Navigator" with a factor type of Ma/CM-I/E-Me and 13% explained variance. Lastly, 2 participants fell into the archetype of "The Emotional Advocate" with a factor type of E-Me/CM-I/Ma and explained variance of 9%.

4.1.1 Phase 1 Factor 1: The Informed Organizer. We labeled this factor the "Informed Organizer". The two key distinguishing statements for this factor both belonged to the Information System: "overwhelming amounts of medical information" (#11) and "collaborative tracker of symptoms" (#13). Informed organizers are caregivers who prioritize control and information management above all. For them, the integration of vast medical data into shared calendars is important, indicating a strong desire to have every appointment, medication, and task meticulously organized. This emphasis on structure and organization is a reflection of their need for a semblance of control in the unpredictable world of caregiving. This group put a strong focus on Control and Management System which focuses on maintaining order during a crisis. The integration of medical information and a shareable calendar emerges as a primary need. For participants in this group, effective management and communication of medical information is of utmost importance, more than any other factor in Phase 1. They face significant challenges in processing vast amounts of medical data while grappling with the complexities of the illness. Central to their approach is the use of collaborative symptom and medication tracking, and ensuring data synchronization across devices. Caregivers in this group prioritize their child's well-being above all, often sidelining their own emotional needs.

4.1.2 Phase 1 Factor 2: The Collaborative Communicator. We labeled Factor 2 the "Collaborative Communicator:" a caregiver who champions the integration of control and information management. The two key distinguishing statements for this factor belong to the Control Mangement System: "integrating medical data with a shared calendar" (#19) and Emotion System: "integrated platform to keep everyone connected" (#2).

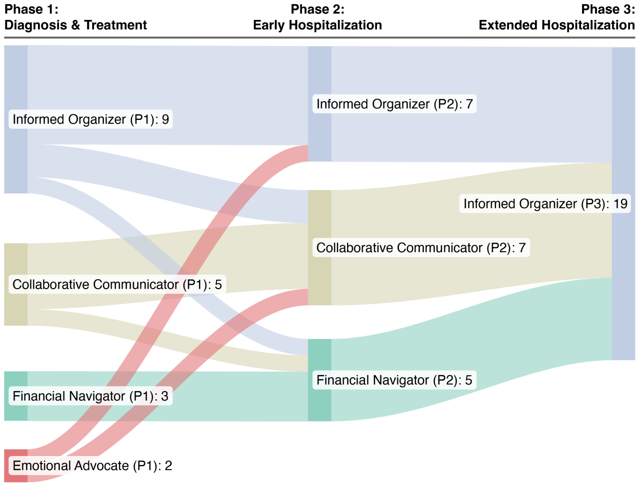

Figure 1: Archetypes across journey phases.

Participants in this factor see immense value in collaborative communication, believing that information is most potent when shared, discussed, and collaboratively used for decisions. Emotionally, they understand that their well-being is crucial for effective caregiving. They lean on connections within their family and the broader caregiver community, valuing the shared experiences and mutual support. Financial management isn't their primary focus during the early stages of caregiving. Factor 2 caregivers, similar to those in Factor 1, emphasize the importance of managing schedules, tasks, and reminders. However, their approach is more utilitarian, showcasing a proactive and positive attitude towards task management tools. While Factor 1 caregivers view coordination technologies with cautious optimism, acknowledging the potential benefits but with reserved sentiments, Factor 2 caregivers are more assertive in their need for such tools. Factor 2 caregivers are characterized by their independent approach to information, often conducting their own research and striving to understand every intricacy of the treatment. In contrast, Factor 2 caregivers see the Information System as more intertwined with the Control and Management System (CM). Their emphasis is not just on gathering information but on how it integrates with management and task coordination. Caregivers in this group also value the emotion system more than caregivers in Factor 1. Their emotional well-being is intertwined with their ability to provide care.

4.1.3 Phase 1 Factor 3: The Financial Navigator. We labeled participants in factor 3 "The Financial Navigator:" a caregiver who places the highest priority on navigating the intricate financial landscape of caregiving. The two key distinguishing statements for this factor belong to the Maintenance System: "searching and filtering financial resources" (#25) and "managing their finances" (#22).

Factor 3 caregivers place a paramount emphasis on the Maintenance System, starkly distinguishing themselves from Factor 1 and 2 caregivers who didn't prioritize financial management during the initial stages of diagnosis. The weight given to this system in Factor 3 suggests a deep understanding of the intricate relationship between financial stability and effective caregiving. Participants in this factor are deeply invested in the seamless integration of medical data with task coordination, emphasizing the critical relationship between medical care, financial stability, and meticulous organization. Their secondary priority is control and information management, showcasing their desire for tools that not only provide medical information but also facilitate collaboration and communication. While they value these systems, they sometimes choose to focus on immediate concerns, indicating their adaptability in crisis situations. Emotionally, their feelings are complex; they exhibit a resigned acceptance of the long-term nature of caregiving. This becomes their lowest priority, as they believe that while technology is helpful, it cannot fully replicate the depth of human connection.

4.1.4 Phase 1 Factor 4: The Emotional Advocate. The final factor in Phase 1 we labeled "The Emotional Advocate:" a caregiver who deeply values emotional connections and finds meaning in every step of the caregiving journey. The two key distinguishing statements for this factor belong to the Emotion System: "emotional distress" (#1) and the Meaning System: "setting milestones in the treatment process" (#10). Their highest priority is to foster moments of connection, celebrate small victories, and seek solace in shared experiences amidst the unpredictable nature of caregiving. They approach information with caution, trusting professionals, emphasizing the essentials, and are more willing to delegate responsibilities and tasks to medical professionals. Financial challenges, although pressing, are often set aside. For Factor 4 caregivers, addressing these concerns can intensify the emotional strain, leading them to prioritize their child's well-being and emotional support over immediate financial considerations. Factor 4 caregivers exhibit a nuanced approach to the Control and Management System. Unlike Factor 1 and 2 where there was a clear emphasis on maintaining order during a crisis, Factor 4 participants were more willing to adapt and adjust based on the evolving needs of the situation.

4.2 Phase 2: Early Hospitalization

Three distinct caregiver archetypes are retained during the second phase of Early Hospitalization. All participants that belonged to the fourth archetype of "The Emotional Advocate" changed their preference to the archetype of either Factor 1 "The Informed Organizer" or Factor 2 "Collaborative Communicator" in early hospitalization. There is a distinct shift in priorities across all factors characterized by prioritizing systems that were neglected in the earlier phase. In the context of Factors 1 and 2, this was expressed by an increase in the preference for the Maintenance system highlighting that finances have started to become more of a priority as hospitalization starts. The increase in preference for Maintenance systems is also reflected in two participants shifting into the archetype of "The Financial Navigator" which in this phase has 5 participants with an increase explained variance of 16%. Similar to the shift in Factors 1 and 2, there is a distinct shift in priorities toward systems that were neglected in the earlier phase with an increase in preference for Control and Management systems with an emphasis on communication with the increased workload during Hospitalization.

4.3 Phase 3: Extended Hospitalization

In the final phase of the cancer journey that we examined, all factors converge into the archetype of the "The Informed Organizer". The shift in preferences that began in Phase 2 has now fully advanced, with systems that were negligent in each factor now balanced out to a fairly homogeneous mixture of preferences that manifest themselves as "The Informed Organizer" archetype across all factors.

The stabilization of all factors in the third phase of extended hospitalization may be explained by the need for balanced strategies in the face of long-term treatment that could possibly extend beyond the hospital extending into post-treatment. The extended nature of the treatment also relegates caregivers to prioritize their own needs in addition to the needs of their child. This is characterized by Factor 3 where caregivers in addition to the need for stronger communication and collaboration as highlighted in Early Hospitalization also reflected an increase in the prioritization of Emotion Systems. The shift to prioritize their own needs is also underscored by an acceptance that their ability to take care of their child is dependent on their own well-being.

5 DISCUSSION

5.1 Designing for multiple archetypes

One of the key insights from our study is that not only are caregivers' preferences for coordination technology diverse, but they are *clustered.* At diagnosis and during early hospitalization in particular, participants had diverse opinions about which features to prioritize. This mirrors findings from previous studies [42, 44]. However, our findings take a meaningful step forward. While no one-size-fits-all solution exists, our findings show it is possible to design for different user typologies within the caregiving coordination context, without having to build custom tools for every single person.

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 Informed Organizers through a centralized information management hub. Existing medical record features—such as lab results, discharge instructions, and medication lists—could be integrated with family-centric features such as shared calendars and task management, as well as a searchable document repository for all caregivers' notes and reports. To support the 'Collaborative Communicator' archetype, *OurCareCircle*'s emphasis would shift from individual control and information management to shared understanding, communication, and joint task management. The primary view or feature set used by the Collaborative Communicator' would be social status, rather than an information summary. For example, the Collaborative Caregiver would value features in *OurCareCircle* that support effective family meetings, and communication features that not only allow for informaiton sharing but also foster a sense of collective action. The Collaborative Communicator prioritizes features that allow for task delegation and progress tracking, so that everyone has their responsibilities and knows how those tie into the broader caregiving work of the family.

The 'factors' generated by Q-methodology and interpreted in our analysis into 'archetypes' should allow designers of caregiving coordination technologies to translate these diverse perspectives into design. In some cases, the same app or tool may be able to address the needs of multiple archetypes. However, some caregivers (especially those in the "Emotional Advocate" archetype) may initially reject tools that are too focused on medical information or features such as task tracking. Our findings don't provide easy answers to these design problems. Nonetheless, having archetypes in hand during design should help researchers and designers of coordination technologies make key decisions, such as which features to prioritize, and how to identify and support specific archetypes.

5.2 Designing across the caregiving coordination journey

As our findings clearly show, family caregivers' coordination technology preferences are not static, but instead correspond to their caregiving coordination journey. In their first sort, participants clustered into four archetypes: 'The Informed Organizer', 'The Collaborative Communicator', 'The Financial Navigator', and 'The Emotional Advocate'. However, once they had been in the hospital for a few days, no participants remained 'The Emotional Advocate'. By extended hospitalization, all participants converged on 'The Informed Organizer'. This clear and distinct shift across phases validates the stage-based model of caregiving coordination journeys [40], showing that coordination practices and technology needs change over the course of illness and treatment. Our findings also suggest that caregiving coordination archetypes are at least partially relational and situation-dependent. In this way, they are more similar to *roles* than to personality types or other 'static' traits.

Thus, in designing for caregiving coordination journeys, we should expect individual family caregivers to adopt different archetypes at different stages, and our technologies should be able to adapt to their changing needs. For example, imagine a family caregiver who begins as an 'Informed Organizer', shifts to a 'Collaborative Communicator' during early hospitalization, and ends up as an 'Informed Organizer' again by the time of discharge from the hospital. This caregiver requires a data-rich platform immediately after diagnosis, prioritizing access to medical information. Technologies to support this caregiver in this phase should facilitate research, access to and help interpreting medical records, and disease understanding. As they settle into the early hospitalization phase, this caregiver's needs shift to the relational, as they focus on organizing caregiving tasks, facilitating communication, and managing schedules. Then towards the end of their hospital stay, they focus once more on informational tasks, such as learning how to care for their child at home and deal with potential emergencies, as well as tasks with a flavor of the Financial Navigator, such as managing insurance claims and understanding prognosis and future treatment options.

However, it is not yet clear how and when participants' preferences form and shift. Deciding when and how to transform a coordination technology (or when to introduce new tools) is a challenging task that depends a lot on the specific situation and disease progression of each family. From this retrospective study, we are able to show that these shifts occur, but an open question remains: how should designers anticipate and support changing preferences without confusing or alienating users? As a first step, we believe a short-form version of the sorting exercise used in this study could be deployed to help show caregivers the most relevant features and encourage them to adopt caregiving coordination tools. But knowing when to begin showing them other ways to use coordination features is a tricky balance of detection and prediction, one which warrants significant attention in future work.

5.3 Designing for family resilience

Overall, the findings from this study validate the salience of Family Resilience to both HCI and design. The Family Adaptive Systems (FAS) model of family resilience was able to guide our feature selection and analysis, and the 'archetypes' produced by the Q-methodology factor analysis were distinguishable according to the adaptive systems. Interestingly, in the case of pediatric cancer caregiving coordination, there were some overlaps in preferences. Specifically, the Control/Management and Information systems were highly correlated in our findings, as well as the Emotion and Meaning systems. This is not a surprise; Family Resilience theorists spend a lot of time in textbooks and papers describing the inherently inter-relatedness of sub-concepts, but it is intriguing as far as design is concerned. Further deepening our understanding of family resilience theories as applied to HCI is thus a worthwhile and potentially fruitful endeavor.

5.4 Limitations

This study involved multiple sorts performed in chronological order, so it's possible that changes in the factors across the stages could be influenced by order effects from the study design. However, we felt that doing the sorts in this order for everyone allowed for the most comprehensible participant interaction. Participants in this study reflect multiple racial and ethnic identities, gender identities, education levels, and income levels, yet participants in our study are more white and more high income than the averages in the US, where the study was conducted. Furthermore, our participant population was entirely US-based, which likely affected our findings.

6 CONCLUSION

In this paper, we present findings from a Q-methodology study to better understand caregivers' coordination technology needs across different families and across the caregiving coordination journey. We used a model of Family Resilience to identify different family 'archetypes' at specific points across the journey and show how families have diverse needs and preferences for coordination technologies that change over their journey. We also provided evidence that these needs ultimately converge on one particular set of priorities during extended hospitalization. We discussed these findings and showed a way forward for the design of technologies to support the caregiving coordination journey.

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