"I feel like I need to split myself in half": Using Role Theory to Design for Parents as Caregiving Teams in the Children's Hospital

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ABSTRACT

When their child is hospitalized, parents take on new caregiving roles, in addition to their existing home and work-related responsibilities. Previous CSCW research has shown how technologies can support caregiving, but more research is needed to systematically understand how technology could support parents and other family caregivers as they adopt new coordination roles in their collaborations with each other. This paper reports findings from an interview study with parents of children hospitalized for cancer treatment. We used the Role Theory framework from the social sciences to show how parents adopt and enact caregiving roles during hospitalization and the challenges they experience as they adapt to this stressful situation. We show how parents experience 'role strain' as they attempt to divide caregiving work and introduce the concept of 'inter-caregiver information disparity.' We propose design opportunities for caregiving coordination technologies to better support caregiving roles in multi-caregiver teams.

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1 INTRODUCTION

During a hospitalization, family caregivers step up to take on new caregiving roles on top of their home and work tasks. Previous CSCW research has shown how technologies can support caregiving, but more research is needed to systematically understand how technology could support parents and other family caregivers as they collaborate *with each other* to enact caregiving work during a hospitalization. Specifically, little is known about how technology could best support inter-caregiver collaboration as caregivers adopt new caregiving roles at the beginning of a health crisis and how technology could help caregiving teams dynamically respond to changing circumstances and caregiving needs. In this paper, we draw from *Role Theory*, a framework from the social sciences [15], to show how parents adopt and enact caregiving roles during hospitalization and the challenges they experience as they adapt to this stressful hospitalization. Sociologists and other social science researchers use Role Theory to describe how people identify work and responsibility boundaries, and why new work is sometimes so stressful. However, HCI and CSCW research into caregiving collaboration has yet to incorporate Role Theory explicitly. We ground this research in the case of pediatric cancer, a diagnosis that can result in multiple multi-week hospital stays over a period of months. As part of our research on pediatric cancer caregiving technologies, we conducted an interview study with 14 parents of children hospitalized for cancer treatment. We show how adopting a Role Theory perspective allows for a better understanding of the challenges experienced in collaborative care work, and how it could be leveraged in the design of caregiving coordination systems.

2 RELATED WORK

2.1 Family caregiving coordination in CSCW & HCI

CSCW researchers have studied caregiving coordination extensively, often focusing on interactions between health stakeholder groups, such as patient-provider or caregiver-provider cooperation, and addressed topics such as patient safety [20, 36] or patient-generated data [19, 40]. One recurrent theme considers healthcare facilities to be workplaces, with an emphasis on provider-provider teamwork [2, 29, 35]. CSCW researchers have also shown how

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caregiving work involves significant 'hidden labor,' also known as 'articulation work,' [6] or 'ghost work' [10] that goes unnoticed most of the time. However, most of the work on family caregiving in HCI focuses on assisting family caregivers (particularly the mother of a child) and seeks to understand and support individual caregivers as "users" of coordination technologies.

Chen et al. argued that caregivers are major health stakeholders in HCI [9]. Schrugin et al. conducted a poll of carers and underlined the obstacles they confront, emphasizing the caregivers' isolation in coordinating [33]. Kaziunas et al. evaluated caregivers' roles in care management of the pediatric bone marrow transplant patients in pediatrics, emphasizing the caregivers' role in patient support [12] and advocating for hospital information systems centered on the caregivers' needs [13]. Liu et al. introduced and studied a mobile application prototype that allows carers in the Neonatal Intensive Care Unit (NICU) to select what information they wish to share with others [17]. Suh et al. created *BabySteps* to help parents monitor their child's growth[34]. In the inpatient setting, Miller and colleagues detailed the various roles performed by caregivers [20]. Recent advances include patient-caregiver cooperation, such as work on collaboration between patients with chronic disease and their caregivers [3]; work care collaboration between caregivers and children with special needs[14] or chronic illness[11]; and shared health-related decision making [6,77,78].

Emerging literature focuses on supporting caregivers as they coordinate with each other. Nikkhah et al. showed how family caregivers give and receive social support [26], how healthcare collaboration in pediatrics can act as a testbed to identify challenges facing AI in healthcare[27], and how Family Resilience theories could be used to better understand family caregiving coordination in the hospital [23–25]. Mueller et al. conducted co-design sessions and usability testing with caregivers and created a mobile technology app to support caregivers in the medical management of their child with cancer. Moncur et al. proposed a method for parents to modify and send information about their children to family and friends [22]. Information sharing sites are now available like CaringBridge, enabling patients and caregivers to keep larger networks of informal care up to date[1], and some studies have looked at the function of these networking sites in engaging larger networks of care[37]. However, more work is needed in order to identify what *roles* family caregivers adopt when their child is hospitalized and how collaborative technologies could best support inter-caregiver work**.**

2.2 Role Theory

Role Theory is a perspective from the social sciences that describes how individuals behave within social systems. It was first codified as part of the Symbolic Interactionism movement of the early 20$^{\text{th}}$ century, and is closely associated with influential scholar George Herbert Mead [38:4]. Role theory posits that since people interact with multiple social systems simultaneously, they adopt a different set of common behaviors and attitudes—or roles—within each system. Symbolic Interactionism and Role Theory have been particularly influential in the family sciences[8,16,38]. Roles are not static: as people enter new social settings, they may acquire new roles — *role-making*[32]. Roles are not always compatible with each other: when the demands of a given role outstrip the abilities to fulfill that role, they experience *role strain,* and when roles suggest incompatible actions, they experience *role conflict*[38:4].

Researchers in the health sciences have used Role Theory to describe new caregiving responsibilities when a loved one experiences an illness or is hospitalized. For many people, the roles associated with being a 'family caregiver' can often feel like adding a second job [18], and the role-making process in the early stages of caregiving can be particularly stressful [31]. A cancer diagnosis causes acute role strain due to high caregiving burden [31], especially when the patient is a child, and the caregiver is a parent [15, 18, 30]. However, less is known about the potential for computing technologies to support role-making and reduce role strain and conflict, especially during the early stages of caregiving [32].

CSCW researchers have recently begun exploring Symbolic Interactionism in earnest[28], but CSCW has yet to engage deeply with Role Theory. The few papers in HCI and CSCW that use role theory explicitly have focused on non-caregiving contexts such as gender roles in collaborating using virtual reality[43] and the social roles of stay-at-home dads [44], and online communities contexts such as work identifying different roles in online communities such as Facebook groups [44] and online health communities [39]. CSCW and HCI researchers have studied caregiving roles but atheoretically, without invoking or directly engaging Role Theory itself [21]. As a result, little is known about how applying Role Theory to caregiving could advance the theory and practice of technologically-mediated caregiving.

3 METHODS

The findings from this paper are drawn from a larger project we are conducting to design family caregiving coordination technologies in pediatrics. We interviewed 14 parents from 8 different families who had a child undergoing treatment for cancer at Riley Hospital for Children at IU. Interviews lasted between 60 and 70 minutes and followed a semi-structured protocol. We asked parents how they coordinated with each other, and the collaboration challenges they experienced. We recruited participants after the approval of IU's IRB (Institutional Review Board). Participants aged between 18-49 and were all part of heterosexual married couples caring for their child. All families had a child with Acute Myeloid Leukemia except the child from family three who had Osteosarcoma. Each parent considered themselves and their spouse as primary caregivers in all cases. We recorded and transcribed the interviews, resulting in about 200 pages of transcribed conversation.

We used Atlas.ti, a qualitative data analysis tool[45] to conduct thematic analysis [4, 7] and iteratively and inductively analyzed the data in two rounds. The first round was approached in an open manner and was performed by three researchers to identify the most common themes that emerged from the data. These researchers began by analyzing the first few interviews through open coding, assigning codes independently, and meeting to discuss and unify the coding approach and codebook. After that, the researchers continued the procedure for further interviews until the codebook was stable. In the second round, we categorized the emerging themes based on their groundedness to identify and designate their importance. This process resulted in 15 theme clusters of 138 individual codes. Our team met twice a week to discuss the themes and individual weekly analyses in order to refine and interrelate them and reconcile codes. These sessions lasted for two months until we reached saturation in our study, which revealed that the same topics appeared again in our interview data. The 15 high-level themes were then divided into three separate analyses. The analysis reported in this paper centers on caregivers' roles, role-related challenges, and role-making processes. To inform the final stages of analysis, we used Role Theory [15] as a sensitizing concept and a deductive framework, identifying different role strains, processes related to role making, and managing the shared roles within the couple. In the findings section, we refer to the families by their family number and whether the parent is the mom (M) or dad (D).

4 FINDINGS

In this section, we use Role Theory to describe the practices and challenges of caregiving for a hospitalized child. We describe how parents adopt new caregiving roles, and the challenges they face: role strain, difficulty in role mastery, role conflict, and maladaptive role dependency.

4.1 Role-making and mastery

Parents in our study initially tried to adopt caregiving roles that were as close to their current family roles as possible and made decisions about roles quickly. Most families reported that the selection of the 'primary' hospital-based caregiver was a natural decision for them. The parent who was more involved in childcare continued that role as the main caregiver during the hospitalization. As one dad said: "As soon as it happened, . . .There wasn't even a conversation to be had, because we've been together long enough that I knew she wasn't going to leave him" (F1D)

Becoming *good* at their new caregiving tasks ('role mastery') was a more complex challenge. The responsibilities and capabilities required for caregiving work differed markedly from their previous roles as parents in the family context, with aspects closer to workplace activities. Role mastery was complex because there were a lot of new things to manage, and care coordination for the hospitalized child was more like a new full-time job than a daily or normal family activity. As family two dad said: "Like we had to learn, our daughter has a central line in her chest, and it literally is a tube that goes in there. [When we went home] we had to learn how to change the dressing around it. [Mom's] explaining to me that we have to learn how to change it at home in case of emergencies, and the way she's making it sound was like, 'oh wow, I've got to get a Ph.D. just to learn how to do this because there's a lot involved.' Then she took me across the hallway, showed me how to do it, and I said, 'oh, that's easy.' [. . .] That's kind of how I learned." (F2D) For parents in our study, role mastery itself became a job that required a new role of being strong and concentrated on caregiving and parenting. As one mom put it, "It was all focused on our duty, what we were doing. We had a calendar; we had a timeline; we had a job to do with our kids [. . .] it was day-to-day. You just kept going. You just kept going, and you didn't have time to do anything else. That was our job for six months is doing this routine." (F8M)

4.2 Role strain and role conflict

Even though parents quickly divided the caregiving work to be done during hospitalization, their new caregiving roles often stretched the limits of their capacity to help ("role strain"). Parents in our study experienced role strain due to multiple roles that they had to hold during their child's hospitalization, in addition to existing daily parental, spousal, and work-related roles. To address role strain, most parents deprioritized other roles to focus on their roles as caregivers. Most parents reported that their role as a caregiver to the hospitalized child became their first priority, and their parenting role to other children and ensuring they are affected by the new situation the least was second priority. As a result, many parents reported their role as a spouse became less important. The demands of their new caregiving roles were sometimes so extreme that parents sometimes even abandoned existing roles ('role exit'). For example, some hospital-based parents changed to a part-time job or quit their jobs. "I could put my job on hold, so I became the primary person that was there most of the time with my daughter." (F8M)

Parents also experienced role *conflict*, when their different caregiving roles suggested opposite actions. The most common conflict parents in our study reported was between caring for their hospitalized child and parenting their other children. For example, in family four, both parents wanted to be with the hospitalized child, but they had an 11-year-old child at home As the mom from this family explained " [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) To accomplish all this, she said: "I feel like I need to split myself in half." (F4M).

4.3 Role interdependency and inter-caregiver information disparity

Parents also reported that their new caregiving-related roles were hard to disentangle from each other, making it hard to simply 'divide and conquer'. Roles such as in-person caregiver, update recipient, update disseminator, etc., were at least somewhat shared between parents. Sometimes the interdependent nature of caregiving became acute. When the parent who adopted the hospital-based roles (such as note-taker, representative, etc.) was unable to be present for a clinical encounter such as morning rounds, the other parent (or sometimes a grandparent) took over these tasks. However, assuming another person's caregiving *role* is not something parents could do without engaging in their own role-making and mastery processes. Instead, our analysis shows that these other caregivers took on a 'proxy' role, temporarily taking on the other parent's role. However, the proxy role made parents uncomfortable. For example, when the mom in family three was not able to be present at rounds, she would often provide dad with some questions to ask, and she expected him to track that information in the family's physical binder. However, as mom put it: "He felt like he was inconveniencing [the clinical team during the rounds]. Not because they acted that way but just because he's like, 'They're doing their job, and I don't need to manage them.'" (F3M)

Parents also had trouble balancing effort between roles, sometimes turning *healthy role interdependency* into *maladaptive role* *dependency.* As one mom told us "I would say we definitely argue about who does more. I feel like he lives out here in this happy-go-lucky fantasy world [. . .] 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) Often, within the same couple, one parent became far more informed than the other about their child's status, underlying medical processes, and specific care tasks required to help the child recover. We term this "*inter-caregiver information disparity*", and we propose that it occurs precisely because parents adopt distinct roles but yet still must collaboratively perform care tasks and make key care decisions together. 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 third (and in some ways even more pernicious) challenge: Inter-caregiver information disparity. The disparity of the length of time spent and information learned and received between (first primary caregiver) mom and (second primary caregiver) dad could result in a knowledge gap of what is going on and medical information disparity between parents. As one dad said, "She gets the information more because she's here more." (F2D) Parents were well aware of this disparity, and they did try to create processes and artifacts to reduce the disparity. Parents tried to address information disparity through paper binders, notebooks, and in-room whiteboards, and stayed in touch via text messages and phone calls, but the challenge of information disparity persisted.

5 DISCUSSION

In addition to explaining a number of the challenges experienced by parents when they take on caregiving work in hospital settings, Role Theory provides a language to understand and address the various strains and conflicts they experience (and why working in parallel is not always possible and creates its own challenges). In the findings section, we showed how Role Theory could be applied in order to characterize caregiving coordination challenges. We also believe that Role Theory could be useful in designing CSCW systems to support caregiving coordination. For example, CSCW technologies could help parents in more easily and efficiently achieving *role mastery*, allowing them to keep track of their work and responsibilities and reassign as needed. These tools could be simple, such as a collaborative checklist or workflow support system that suggests the scope and duties of a particular role and helps caregivers learn and remember the relevant processes and knowledge for a given role. CSCW technologies could also help identify and mitigate *role strain.* While no technology cannot make the overwhelming amount of caregiving work needed to support a hospitalized child go away, systems that make an individual's caregiving work more visible to the rest of the caregiving team could allow other caregivers to recognize when one person has taken on too much and allow them to absorb some of that person's work into new caregiving roles. Such systems could also proactively identify *role conflict* when the system's recommended next steps are incompatible with each other, although reducing role conflict remains a grand challenge. Technologies that more visibly communicate a person's role and the activities associated with that role could also help reduce another pernicious challenge of caregiving work: the unnoticed labor referred to as 'articulation work,' [6] or 'ghost work' [10].

CSCW technologies could also help caregivers achieve positive interdependence and reduce inter-caregiver information disparity. The biggest opportunity during the hospitalization stage is in better supporting morning rounds, where the medical team shares and discusses the child's status. This information-dense event is difficult to capture and share with remote caregivers. We believe that caregiver-focused rounding summaries that could be easily chunked and shared with the remote parent would make a significant impact on information disparity. This brief summary could include visualizations or highlighted notes to help the other caregiver easily understand what is going on. It might be generated by clinical staff during the rounds, summarized by AI, or generated by parents themselves by recording rounds and then allowing parents to annotate/extract during downtime. This approach could also be extended to other ad-hoc clinical encounters. These technologies could help parents stay connected and have an idea of what is happening on the other side, and be updated about their child's health status.

Many of the design features mentioned here could be accomplished with technologies with features very similar to existing workplace collaboration tools, such as Slack or Teams. However, off-the-shelf collaboration technologies would need to be modified for this specific use case, and Role Theory helps explain why: many current office collaboration technologies assume a *workplace role* such as co-worker, employee, or boss. But we know that caregiving roles and caregiving work do not necessarily fit workplace conventions, such as an assumption of training, synchronous availability, and persistent availability. Which features from existing systems would still work and which would be modified are exciting design questions begging to be explored.

6 CONCLUSION

In this paper, we showed how using the Role Theory framework from the social sciences can help HCI to better understand complex family caregiving coordination work. We ground this exploration in the case of parents of children hospitalized for cancer care. We conducted a hospital-based interview study with 14 parents, and demonstrated how parents adopt and perform caregiving roles (role-making), and how they work towards effectively carrying out those roles (role mastery). We showed how parents encounter 'role strain' while attempting to split caregiving responsibilities and proposed the concept of 'inter-caregiver information disparity.' We offered design opportunities for care coordination systems to enable caregiver roles to be more effectively supported in multi-caregiver teams. Our research lens and implications can also be used in future studies that research caregiver work and collaboration in a health crisis. And our results can be transferred to similar illnesses that require longer hospitalization or care coordination for a child patient, such as organ transplants, diabetes, and inflammatory bowel disease, and more broadly to contexts such as small-scale teams working at a distance.

7 LIMITATION

Our study was constrained by the fact that most of the families in our participant group were Caucasian and fluent in English and we were unable to recruit any same-sex couples or single parents, although our inclusion criteria would have permitted both family types as long as the single parent had another contact listed in the clinical database. This limits the diversity of family structures and expeirences represented in our study. We also did not interview other family members involved in care, such as the hospitalized child's grandparents, and we did not survey or ask clinical staff members about their viewpoints on caregivers' needs.

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REFERENCES

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

[2] Jakob E. Bardram. 1997. "I love the system—I just don't use it!" In *Proceedings of the international ACM SIGGROUP conference on Supporting group work: the integration challenge* (GROUP '97), Association for Computing Machinery, New York, NY, USA, 251–260. DOI:https://doi.org/10.1145/266838.266922

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

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

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

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

[7] 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

[8] Wesley R Burr, Geoffrey K Leigh, Randall D Day, and John Constantine. SYMBOLIC INTERACTION AND THE FAMILY. 70.

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

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

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

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

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

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

[15] Amie Koch, Arthi S. Kozhumam, Erika Seeler, Sharron L. Docherty, and Debra Brandon. 2021. Multiple Roles of Parental Caregivers of Children with Complex Life-Threatening Conditions: A Qualitative Descriptive Analysis. *Journal of Pediatric Nursing* 61, (November 2021), 67–74. DOI:https://doi.org/10.1016/j.pedn.2021.03.017

[16] Ralph LaRossa and Donald C Reitzes. 1993. Symbolic Interactionism and Family Studies. In *Sourcebook of family theories and methods: a contextual approach.* Plenum Press, New York, 135–166.

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

[18] D. A. Major. 2003. Utilizing role theory to help employed parents cope with children's chronic illness. *Health Education Research* 18, 1 (February 2003), 45–57. DOI:https://doi.org/10.1093/her/18.1.45

[19] Helena M. Mentis, Anita Komlodi, Katrina Schrader, Michael Phipps, Ann Gruber-Baldini, Karen Yarbrough, and Lisa Shulman. 2017. Crafting a View of Self-Tracking Data in the Clinical Visit. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (CHI '17), Association for Computing Machinery, New York, NY, USA, 5800–5812. DOI:https://doi.org/10.1145/3025453.3025589

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

[21] 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

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

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

[24] 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

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

[26] 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

[27] 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

[28] Aswati Panicker, Kavya Basu, and Chia-Fang Chung. 2020. Changing Roles and Contexts: Symbolic Interactionism in the Sharing of Food and Eating Practices between Remote, Intergenerational Family Members. *Proceedings of the ACM on Human-Computer Interaction* 4, CSCW1 (May 2020), 1–19. DOI:https://doi.org/10.1145/3392848

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

[30] Jacob E. Robinson, David Huskey, Jonathan Schwartz, and Meaghann S. Weaver. 2019. The Many Roles of the Rock: A Qualitative Inquiry into the Roles and Responsibilities of Fathers of Children with Brain Tumors. *Children* 6, 10 (October 2019), 113. DOI:https://doi.org/10.3390/children6100113

[31] Karen L. Schumacher. 1996. Reconceptualizing family caregiving: Family-based illness care during chemotherapy. *Res. Nurs. Health* 19, 4 (August 1996), 261–271. DOI:https://doi.org/10.1002/(SICI)1098-240X(199608)19:4<261::AID-NUR1>3.0.CO;2-G

[32] Karen L Schumacher. Family Caregiver Role Acquisition: Role-Making Through Situated Interaction. *Scholarly Inquiry for Nursing Practice*, 17.

[33] 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

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

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

[36] Kenton T. Unruh and Wanda Pratt. 2007. Patients as actors: The patient's role in detecting, preventing, and recovering from medical errors. *International Journal of Medical Informatics* 76, (June 2007), S236–S244. DOI:https://doi.org/10.1016/j.ijmedinf.2006.05.021

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

[38] James M. White, Todd F. Martin, and Kari L. Adamsons. 2019. *Family theories: an introduction* (Fifth edition ed.). SAGE, Los Angeles.

[39] Diyi Yang, Robert E. Kraut, Tenbroeck Smith, Elijah Mayfield, and Dan Jurafsky. 2019. Seekers, Providers, Welcomers, and Storytellers: Modeling Social Roles in Online Health Communities. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, ACM, Glasgow Scotland Uk, 1–14. DOI:https://doi.org/10.1145/3290605.3300574

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

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

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

[43] Give-Me-A-Hand: The Effect of Partner's Gender on Collaboration Quality in Virtual Reality | Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems. Retrieved January 12, 2022 from https://dl.acm.org/doi/10.1145/3411763.3451601

[44] "Thanks for your interest in our Facebook group, but it's only for dads" | Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing. Retrieved January 12, 2022 from https://dl.acm.org/doi/10.1145/2818048.2819927

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