Helping Their Child, Helping Each Other:

Parents' Mediated Social Support in the Children's Hospital

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ABSTRACT

During a health crisis, such as the hospitalization of a child with a serious illness, families must adjust and support each other in coordinating care. CSCW researchers have shown the potential for collaborative technologies to enhance social support in different settings. However, less is known about the potential for CSCW technologies to augment social support practices within family caregiving circles. In this poster, we describe findings from 14 interviews with parents of children hospitalized for cancer treatment. We categorized the support practices between parents and found that they rely heavily on technology to support each other from a distance. We identified opportunities for designing future collaborative technology to augment social support in caregiving teams.

ACM Reference Format:
Sarah Nikkhah, Swaroop John, Krishna Yalamarti, Emily L. Muller, 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 (CSCW '21 Companion), October 23–27, 2021, Virtual Event, USA.* ACM, New York, NY, USA, 4 pages. https://doi.org/10.1145/3462204.3481759

1 INTRODUCTION

During a crisis, such as the hospitalization of a child, families must adjust and adapt, taking on new roles and staying connected while they coordinate care and support each other [6]. A major protective factor in times of crisis is *social support*, the help and assistance people give to and receive from each other. Parents who communicate effectively with each other not only reduce their own stress [13] but can improve the long-term health outcomes for their child [6]. However, caregivers frequently report dissatisfaction with their communication and coordination during their child's hospitalization [22]. CSCW researchers have shown the potential for collaboration technologies to enhance social support in a variety of settings. However, less is known about the potential for CSCW technologies to augment social support practices within family caregiving circles. In this paper, we describe findings from an interview study we conducted with parents of hospitalized children. We categorize their support practices into informational, instrumental, and emotional types of support. We identify challenges parents faced in providing support and opportunities for CSCW technologies to enhance social support for informal caregiving teams.

2 RELATED WORK

Enabling social support for family caregiving is a key area of focus for CSCW researchers. Social support theory describes the protective interpersonal factors that aid people during a crisis. Crucially, it has been shown that the extent to which a person gives and receives a variety of types of support (including informational, instrumental, and emotional) is correlated with their stress levels and coping abilities after the crisis [10]. Within the inpatient context, Kaziunas et al. studied caregivers of pediatric bone marrow transplant patients, placing the caregiver's role in supporting inpatients [8] and arguing for caregiver-focused information systems in the hospital [9]. Liu et al. studied

Neonatal Intensive Care Unit (NICU), pinpointing the communication challenges between a NICU patient's caregiver and healthcare provider once the child has left the hospital[11]. Suh et al. designed the *BabySteps* system to enable parents to track their child's development progress [23]. Seo et al. studied the tensions between parenting and caregiving for parents of children with cancer [21]. In our previous work, we described the various roles of caregivers in the inpatient context [14].

CSCW researchers have also studied the interactions between caregivers and their wider networks of care, often within existing friends and family groups. For example, Moncur et al. presented a solution to help parents customize and communicate information about themselves and their child to family or friends [15]. Newman et al. identified challenges sharing health information with their broader social networks [17]. Sites such as *CaringBridge* now provide dissemination features for patients and caregivers to keep wider networks updated [1]. Researchers such as Valdez and Brennan have investigated the role of these and other social network sites in involving wider networks of care [24]. Most CSCW work on social support in healthcare concentrate on the role of online health communities in providing support [4, 7, 12, 18, 19]. However,

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CSCW '21 Companion, October 23–27, 2021, Virtual Event, USA

ACM ISBN 978-1-4503-8479-7/21/10…$15.00
https://doi.org/10.1145/3462204.3481759

the current support practices and challenges that family caregivers face in providing support to each other are less explored.

3 METHODS

The findings from this poster are drawn from a larger project studying family caregiving coordination technologies in pediatrics. We conducted semi-structured interviews with 14 parents from eight families with a child hospitalized for cancer treatment at Riley Hospital for Children in Indianapolis, Indiana, USA. 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 middle school to college. In all cases, parents considered themselves as primary caregivers. Their children were diagnosed with either Acute Myeloid Leukemia or Osteosarcoma, requiring month-long hospitalizations, and varied in age from a few years old to late teens. We asked participants about their child hospitalization journey, their collaboration, technology use, and coordination challenges during the interviews. All interviews were audio-recorded after consent from the participants and transcribed, resulting in over 200 pages of transcribed conversation. We then qualitatively analyzed the interviews over multiple sessions, using social support theory as a deductive framework. To begin, the first three authors deductively coded the transcripts looking for examples under each construct of social support theory. Then all authors discussed the findings among the team weekly, between one to two hours per week, until we achieved consensus. A note on data reporting: In this paper, 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 FINDINGS

While their child is hospitalized, parents coordinate to support each other to cope with the challenges of caregiving and parenting and maintaining tasks at work and home. We categorized the support that parents provided to each other across three constructs from social support theory: informational, instrumental, and emotional support.

4.1 Informational Support: Summarizing, translating, re-explaining, and reminding

Parents in our study exchanged a high amount of informational support. This support was primarily provided by the parent in the hospital, who shared information and summarized, translated, and re-explained what hospital providers said to the other parent. "Every morning after we would talk to the doctors, there would be a short, quick update.. it wasn't a lot; it was enough to where he would know what was going on." (F2M). This re-explaining sometimes involved information brokering and translating: "I explain it in terms that he can understand, or at least I think I do." (F4M) Parents also shared detailed medical information with each other, such as a photo of the lab results or other clinical handouts, "He has sent me a picture or two of lab results. . . it's more if I'm wanting to know certain things on that and he might not know which one it is, or just because I'll have all the information..." (F1M).

One of the main challenges in providing informational support was the information gap between the parents. One parent (usually mom) stayed more in the hospital and was more exposed to medical terminology and procedures. Overcoming information disparity put more burden on moms' shoulders. Most moms had a way of keeping notes and sharing with dads; some held a binder, some relied on the daily text updates. As one mom described: "So on the calendar, I'll write don't forget, and then I'll write a list of things, or I'll text him, don't forget this. I'll text him to make sure he's up in the morning. Usually, it's me more so writing notes to him, just because he knows that I remember better when it comes to that than he would." (F6M)). Managing all the information could be challenging, as F2 mom mentioned her concern about typing notes on small screens, managing hospital visits, and tracking everything simultaneously. She wished she had a portable information desk: "Something that I could write notes on, write responses, . . . like who's going to be home, who's going to be at the hospital.. So just something like a desk organizer all in one that we can take in the size of a tablet, and just take with us where we go." (F2M).

4.2 Instrumental Support: Leaving their job, re-assigning tasks, and managing work from a distance

In most families in our study, one parent left their job or changed to a part-time job to provide instrumental support in caring for the hospitalized child at the hospital, while the working parent offered financial support and instrumental support at home. Parents reshuffled many domestic tasks and re-assigned them to the parent who was not at the hospital. They both tried to take care of chores that needed to be done. For example, F3 mom said, "I think we just sort of figure what needed to be done if you were the parent that was at home. [dad]'s not really a housekeeper. . .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). This theme of doing what needs to be done, and flexibly re-assigning tasks, was repeated by many families in our study, especially when the non-hospital based parent came to do a 'shift' in the hospital, to give the hospital-based parent a break. As F6 dad said, "I try not to like leave a sink full of dishes just try not to leave more for the other person." (F6D).

Although parents tried to adapt and provide instrumental support to each other, they still had challenges. One of the challenges for providing instrumental support for dads was not remembering the newly generated tasks due to their child hospitalization and moms having to manage all the tasks and remind them. This does not just refer to tasks related to the hospital but also home chores associated with caring for the other kids. For instance, F6 mom said she had to remind dad for each task by text at the exact time: "For the other kids like my son has to go to school tomorrow, I already picked clothes out and put them on the dresser. Got everything ready, and I'm going to send him a text tomorrow, don't forget to pack his lunch." (F6M) F7 mom also added, "[Dad] called me, while I was at work, and said, 'I don't know how to giver her medicine.' So, I mean, it just I had shown him before how to do it."(F7M).

4.3 Emotional Support: Companionship, levity, and strengthened bonds

Most parents reported that after the hospitalization started, their emotional support as a couple dropped off as the hospitalized child became the top priority. However, parents faced severe emotional burden during hospitalization. F5 mom described a typical example of emotional toll: "Yesterday, when we got the results from the PET scan, I could just tell [my husband] was devastated; he was upset. . . You can just tell when he's going through it, and then try to cheer him up. I try to bring my fun side out, right?" (F5M) Many parents echoed the value of humor as a support strategy. Sometimes this was as simple as sending a video clip: "I'll be watching something that I think is funny, and I'll send it to him be like, 'You need to watch this. It's hilarious."' (F7M). Humor also provided a way for couples to reconnect as a romantic couple, not just caregivers: "We still try to joke and at least attempt to have conversation just about us. Probably not near as much as we used to, but we have a 2-year-old with cancer." (F2M)

At the very start, parents tried to 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). While this physical proximity became increasingly untenable across extended hospitalization, couples still reported that emotional support benefits galvanized their relationship. As F8 mom told us: "[my husband] is very understanding and loving. He and I both have the same thought. . . since we did go through it together, it's like we have an extra special bond because we know what the other one's been through." (F8M). However, the emotional strain of their child's illness can still complicate even these silver linings. F8 mom noted that while the experience "made us stronger together; I just wish . . . he's still drinking alcohol, I think related to depression and anxiety and that sort of thing. I'm hoping that he finds some healthier behaviors to help with that instead of the alcohol." (F8M).

Most parents reported that the emotional support exchanged was still not enough to shield them from the weight of their child's hospitalization. Moms in our study reported being isolated in the hospital as the child was usually in pain or asleep under medication, and they could not talk with anyone at that time. Most parents did not have time to care for themselves and emotionally support each other as a couple, "We don't have time, and we don't want to leave him. The few hours we get with him at night ... It's not like we both have FMLA [Family and Medical Leave Act], 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. . ." (F1M)

5 DESIGNING TECHNOLOGY TO AUGMENT SOCIAL SUPPORT WITHIN FAMILY CAREGIVERS

Our findings suggest the caregiving tasks on top of distance from the hospital and lack of time spent together result in information disparity, physical and emotional gap between parents, and cause multiple challenges to support each other. As family members must add new caregiving works to their other daily responsibilities, care coordination is often asynchronous and geographically distributed, with limited opportunities for in-person collaboration. This adds a burden on the parent at the hospital to provide technology-mediated informational and instrumental support. Technology such as texting plays a direct role in enabling informational support between parents daily. Our findings suggest, unlike online health communities where informational support is reciprocated and multidirectional[7], within the parents as caregiving teams, the direction of informational support in the form of medical information is primarily one-directional: from the parent at the hospital (usually mom) to the other parent.

Our study also revealed that the type of informational support between parents goes beyond simply re-sharing what the doctors said but includes storing, typing, organizing, explaining, brokering, re-explaining, summarizing information, and finding the right time to share it with dads. Most of these invisible work is similar to the 'ghost work[5]' or 'articulation work[3,20]' concepts from CSCW research. Collaborative technologies could reduce some of this workload by augmenting information support with tools such as digital information organizers for managing documents; AI-enabled summarizing or transcribing of a doctor visit to share with the other parent; Turning audio recordings into notes to reduce typing (especially for families where the child was younger and they needed to hold the child for hours during the day); Photo sharing features enabling annotation for highlighting or writing notes on the lab results; Routine trackers to suggest the best time to send information updates to the other parent based on their daily routine. Technology also enhanced task coordination around instrumental support. For instance, some moms used text messaging to remind dads of the daily tasks or used physical or digital calendars to coordinate around who is taking the child to the hospital visits. One other way to augment informational and instrumental support could be to provide all features of calendar, note-taking, to-do list in one place in the form of a portable desk organizer.

Most moms suffered from isolation in the hospital and lack of emotional support, such as going on a date or open emotion sharing with dads. When designing technology to augment emotional support between parents of hospitalized children, our study suggests that we need to consider the importance of distance and the challenges it causes to providing emotional support. One approach to augment technology for emotional support is considering the importance of humor and learning from previous literature on technologies to support long-distance relationships. These technologies can help increase connection, intimacy and provide a shared living experience through video calls[16], or enable partners to coordinate a future shared activity and provide peace of mind about each other's physical and emotional wellbeing[2]. Such a shared living experience can be enabled through calls on portable technologies such as mobile phones or tablets or TVs in hospital rooms with a TV screen. The impact of others in the hospital room is another essential factor in designing technology. When in the hospital room, the hospitalized child is usually in the same room with the primary caregiver limiting their ability to talk at times when the child is asleep or in pain or share sensitive information or openly sharing their emotions (especially negative emotions) on a phone or video call with the other parent. Therefore the technology should provide some workarounds for the parents to openly share both information and their feelings.

Finally, yet importantly, the culture, routines, technology literacy, and preferences of a family can also impact the design. Each family has its own family rituals and processes on how specific tasks are done and may use different practices and technologies to resolve their challenges. Thus, as designers, we must ensure we understand these differences and preferences of each family not to negatively impact current processes and create more burden. A proper design can be customizable and adaptable to accommodate the differences between families and even between parents in the same family. We must understand each parent's role in care coordination, their current roles as a caregiver, parent, and spouse, and take cognitive capacities into account when we introduce new interventions to the family facing a crisis. We need to account for the high amount of workload, pressures, and stress on the parents, the trade-off between the amount of task new technology reduces and the amount of hidden work it will introduce. The technology will need to reduce the overall burden from both parents, especially from the hospital-based parent.

6 CONCLUSION

In this research, we reported the findings from 14 interviews with parents of hospitalized children with cancer, categorized social support practices within the parenting caregivers. We found coordination and information management challenges that impacted the proper exchange of social support within the informal caregiving circle. Then, we proposed design opportunities for social computing technologies to augment social support and enhance parents' cooperation during their child's hospitalization. Our results can be transferable to similar circumstances where parents care for sick children over an extended period, such as diabetes, inflammatory bowel disease, and organ transplantation.

ACKNOWLEDGMENTS

This material is based upon work supported by the National Science Foundation under Grant No. IIS-2047432 and IIS- 1850273. We are also deeply indebted to the parents who shared their experiences with us.

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