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The dynamics and processes of social support: families' experiences coping with a serious paediatric illness

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Abstract

A large body of research reveals that social support helps buffer the negative consequences of stressful life events. Yet research also suggests that social support exchanges involve complex interpersonal dynamics. Using in-depth interview data from seventy-six parents of paediatric cancer patients in the US, findings demonstrate that parents experienced difficulty sustaining support after the diagnosis crisis, uncertainty of how to request the support they needed, and challenges managing support efforts. Given these complexities in negotiating social support, this paper examines the mechanics of effective social support exchanges. Findings emphasize the importance of the nature of the pre-existing relationship between the support recipient and provider, as well as the interactions throughout the period of support. For example, parents found support efforts that involved frequent interactions and involvement in families' daily lives (such as help with child care) most effective when the support provider was a close network member. In contrast, support offered from members of extended networks was most effective when the effort required little marshalling from the parent, did not need to be requested, and did not intrude in families' private lives. Findings contribute to the medical sociology and social support literatures by analysing the conditions under which effective support efforts are marshalled.

Keywords

social support; family; social networks; health care navigation

Introduction

Having a child diagnosed with cancer is a stressful experience for parents. Paediatric cancer is a severe and potentially life-threatening diagnosis, and parents must quickly adapt to the demands of navigating their child's health care (Jemal *et al.* 2005). Paediatric cancer therapy is physically taxing on patients, which can cause emotional stress for their parents as they observe their child's suffering (Fletcher 2011, Greening and Stoppelbein 2007). Treatment protocols are often confusing and extend over long periods, requiring physical and emotional endurance for both patients and their parents (Trask *et al.* 2003). Due to the demands of paediatric cancer care, throughout their child's treatment parents must

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renegotiate their competing commitments to find a new balance that allows them to manage their child's care (Trask *et al.* 2003). Consistent with the broader coping literature, research has documented that social support can buffer the negative consequences of the stressful life event of a child being diagnosed with cancer (Rini *et al.* 2008). Studies have found that parents who have social support are able to better cope with their child's cancer and have improved psychosocial outcomes (Fletcher 2011, Rini *et al.* 2008, Manne *et al.* 2000, Hoekstra-Weebers *et al.* 2001, Trask *et al.* 2003, Wijnberg-Williams *et al.* 2006). While research has documented the benefits of having a supportive network to help cope with paediatric cancer, recently scholars have highlighted the interpersonal complexities of these social support exchanges.

While the benefits of social support in buffering the effects of stress have been well documented, the intricacies of social support exchanges have received less attention (Wellman and Wortley 1990). The questions of how individuals request, manage, and perceive offers of support remain largely unanswered (Winkeler *et al.* 2006). As Winkeler and colleagues note, ‘social support…should not be considered as a resource more or less available per se, but rather must be mobilized actively from network members’ (Winkeler *et al.* 2006: 248). Few studies have examined how social support is mobilized and interpersonally managed for families of paediatric cancer patients. Yet, social support exchanges involve nuanced interpersonal dynamics, boundary maintenance, and network mobilization. If a network member extends support to a family whose child has been diagnosed with cancer, both the support recipient and the support provider must overcome these interpersonal obstacles. From the perspective of support providers, social network members may not want to intrude, may not know how to help, or may not want to become overly involved in another person's struggle (Rini *et al.* 2008, Winkler *et al.* 2006, Chesler and Barbarin 1984). Conversely, a person experiencing a stressful life event may want to maintain privacy, may not know how to effectively request the support they need, or may not want to appear demanding (Chesler and Barbarin 1984).

Building on the robust finding that social support helps buffer the effects of stressful life events, this paper uses data from 76 parents of paediatric cancer patients to examine the micro-interactional processes through which individuals interpret, marshal, and manage social support. First, it examines the interpersonal complexities parents face while coordinating support. Second, this paper examines the conditions under which support was most helpful for parents. These findings offer insight into the mechanics under which support is offered, negotiated, organized, and executed after a major life event, and contributes theoretical insight on the conditions under which support efforts are most effective.

Background

Social scientists have long recognized the important role that social support plays in buffering the effects of stressful life events on individuals and families (Thoits 1982, Thoits 1995, Thoits 2010, House *et al.* 1988, Wethington and Kessler 1986). Social support has been examined as a source of emotional, informational, and instrumental assistance that can help people weather periods of stress or change in their lives. Broadly, social support has been conceptualized as ‘a social ‘fund’ from which people may draw when handling stressors’ (Thoits 1995: 64). An extensive literature has identified social support as an important variable in understanding how individuals cope with stress, examined differences in the relationship between exposure to stress and numerous physical and mental health outcomes, and described the parameters of the relationship between stress, social support (both perceived and received), and well-being (Thoits 1982, Thoits 1995, Thoits 2010, House *et al.* 1988). This association between social support and well-being has been repeatedly found in studies of parents of paediatric cancer patients (Fletcher 2011, Rini *et al.* 2008, Manne *et al.* 2000, Hoekstra-Weebers *et al.* 2001, Trask *et al.* 2003, Wijnberg-Williams *et al.* 2006).

While the benefits of having supportive social networks to fall back on after a child is diagnosed with cancer are well established in the literature, (e.g. McCubbin *et al.* 2002) researchers have highlighted the complexity of social support, noting the importance of the interpersonal context in which support changes occur (Rini *et al.* 2008, Winkeler, *et al.* 2006). This research places focus on the importance of both the broader context surrounding social support exchanges, as well as the nature of interpersonal dynamics on the ultimate utility of social support. Recently, scholars have noted that social networks are not always helpful, and network members do not universally offer assistance in times of need (Rini *et al.* 2008, Harknett and Hartnett 2011). This provides valuable insight into debunking a ‘romanticized version of support networks [where] network members are altruistic and willing to help in response to need’ (Harknett and Hartnett 2011: 861), and enhancing understanding of the complex relationship between exposure to stress, coping styles, and levels of social support. It also highlights a potential disparity in perceived and received support by the individual experiencing the life stress. An individual may take for granted the ‘fund’ for social support in the absence of having to use it, however, when experiencing the life stress may be surprised by the realistic availability of support from his or her networks. These findings emphasize the conceptual distinctions between an individual feeling supported (perceived support) and actually having to mobilize support in times of need (received support).

Research examining this disparity has highlighted the nuanced interpersonal dynamics of social support exchanges. First, requests for help from one's network can be interpersonally difficult to manage. From the perspective of the support provider, members of an individuals' network may want to help, but not know what to do (Winkeler *et al.* 2006). Conversely, other network members may want to protect themselves from becoming emotionally entangled in another person's distress (Winkeler *et al.* 2006). In an experimental study, Winkeler and colleagues (2006) found that when participants were presented with vignettes about an interaction with a cancer patient, participants were more likely to offer support if the vignette included a direct request for support. These results suggest explicit requests for support may reduce the interpersonal difficulties in support exchanges. They also highlight the complexity in marshalling support, and suggest that there are conditions under which beneficial social support is requested, coordinated, and managed.

Scholars have also documented a cyclical nature of social support, where individuals receive the most support surrounding an acute stressor, but support erodes over the course of a chronic stressor (Thoits 1995). Studies of families of paediatric cancer patients have also documented a life cycle of social support. In a longitudinal study of parents of paediatric cancer patients, Wijnberg-Williams and colleagues (2006) find that social support significantly decreased over time. Research has shown that parents receive the most social support during the acute crisis surrounding their child's cancer diagnosis, and this support dissipates after the crisis of the diagnosis (Hoekstra-Weebers *et al.* 2001). However, the stress associated with paediatric cancer can last years beyond the diagnosis phase (Chesler and Barbarin 1984). Therefore, understanding parents' experiences marshalling sustained support throughout the course of their child's treatment is of particular relevance for this population.

While previous research suggests that the processes of requesting and sustaining support are interpersonally complicated, we have an incomplete understanding of how parents marshal effective support after a child is diagnosed with cancer (Winkeler *et al.* 2006, Vangelisti 2009, Thoits 1995). In addition to adding to the scholarly understanding of social support processes, a more nuanced understanding of the mechanics of social support has relevance for planning and implementation of programs designed to help families cope with stress. It has specific relevance for informing evidence based practice, and translating findings of the importance of social support into programs designed to help individuals leverage social support as a coping and health resource.

Methods

Participant Recruitment

Data come from a mixed-methods study of parents of paediatric cancer patients, which included survey, in-depth interview, and ethnographic observation components. Data were collected from August 2009 to July 2011. The data for these analyses are from the in-depth interview component of the study. Participants were recruited through a National Cancer Institute (NCI) designated comprehensive cancer centre in the North-eastern United States. To maintain patient privacy, the study team partnered with clinicians at the cancer centre who had established relationships with families, and these individuals introduced the study to families. Parents signed a contact consent form that allowed the cancer centre to release their contact information to the study team. Eighty-two parents signed contact consent forms, and seventy-six were enrolled in the study (93% of those approached). Six parents who agreed to be contacted by the study team were not enrolled to the study due to scheduling difficulties or later declined to participate. The study team was led by a sociologist, and did not include any members with a clinical background. During the informed consent process all parents were informed that the study team was from an academic setting, and not associated with their child's health care team.

Procedures

Interviewers met parents wherever they preferred: at their homes, workplaces, coffee shops, or in the hospital if their child was admitted. After completing the written Institutional Review Board (IRB) informed consent, each parent completed a survey questionnaire. The questionnaire included several validated scales of family processes and health care experiences, and the MacArthur Foundation Research Network on Socioeconomic Status and Health socio-demographic questionnaire, which is the source of demographic information for this paper (Singh-Manoux *et al.* 2003, Singh-Manoux *et al.* 2005).

Each participant also completed a qualitative in-depth interview that focused on the story of their child's diagnosis, their experiences with social support, their experiences balancing their child's care with other family and work commitments, parenting, and social networks. All interviews were digitally recorded and transcribed verbatim. Interviewers also wrote detailed observation notes on their experiences scheduling the interview, the physical environment in which the interview occurred, nonverbal elements of the interview, and their interaction with the respondent. The demographic information from the MacArthur questionnaire, observation notes, and interview transcript were compiled to form complete data files used for this analysis.

Sample Characteristics

The sample included seventy-six respondents. Sixty-four per cent of the sample were women, and seventy-nine per cent identified as non-Hispanic white. Seventy per cent of the sample were married, while nineteen per cent were never married, and twelve per cent were divorced. Twenty-six per cent of the sample had a total household income of $24,999 or less, while forty-two per cent reported a combined household income of $75,000 or more. Fifty-one per cent of the sample had an educational attainment less than a bachelor's degree, while forty-nine per cent had a bachelor's degree or more.

Data Analysis

Three members of the research team read each data file. Data analysis began with a meeting of the research team to discuss impressions from field experiences and prominent themes within the data files. Forty-four broad codes (such as ‘support from co-workers’ and ‘support from immediate family’) were developed based upon these initial conversations, a review of the literature, and the interview guide. Three members of the research team then coded each data file, and any coding discrepancies were discussed and resolved at team meetings. Inter-coder reliability was high, and Fleiss' kappa for specific items ranged from .91 to 1 (Fleiss 1971). Discrepancies between coders were discussed and resolved at team meetings.

Thematic analysis was conducted, and two team members conducted a second round of data analysis to categorize codes and identify themes (Guest *et al.* 2012). Themes were identified based upon frequency of codes, code patterns and the context and meaning of codes for groups of respondents (Guest *et al.* 2012). These themes were further explored using the qualitative analysis program NVivo. Themes were discussed and refined at team meetings.

Results

Interpersonal Dynamics of Marshalling Support

Translating offers into action—The parents in this sample described receiving frequent offers of help immediately after their child was diagnosed with cancer. While parents were appreciative of the displays of support, they also commonly did not interpret these offers as genuine. Feeling that they were more expressions of sympathy than tangible offers of assistance, parents described these generic offers of help as interpersonally difficult to manage. A theme among respondents was not knowing how to act on offers of support. One mother explains,

> We don't have any family around us unfortunately. [My husband]'s family is the closest because they're in [nearby state], so occasionally his mom offers to come and help. Its hard, from the very beginning people were always offering, ‘If there is anything I can do’ and I totally appreciate the fact that they make that offer, but its hard, there's nothing anybody can do. You know? It would be helpful if somebody did my grocery shopping [laughs] cause there are times when you just can't get to the store, that kind of thing. [Respondent 53]

Like this mother, many respondents reflected on the difficulty of managing offers of support. Numerous parents expressed feeling unsure of how to act upon these offers. Parents found it difficult to distinguish genuine offers from efforts to be polite or express concern. As this mother articulates, many parents described not knowing how to ask for the real help they needed. They often reflected on the interpersonal difficulty of asking people to help with the specific daily chores that would have been most helpful. Parents described feeling uncomfortable asking for help with the mundane everyday life activities that they struggled to keep up with.

People don't know what to do—Many parents interpreted these broad offers, or the absence of any offers of support, as people not knowing how to respond. They sympathized with the difficult position that many members of their social networks found themselves in, that network members didn't know how to offer support. One mother describes,

> People don't really know what to do. Initially, I would say for the first three months, we got a lot of stuff. A lot of gift cards and food and presents. Both of the kids got a lot of presents. People were just not knowing really what to say or what to do. [Respondent 44]

As this mother describes, many parents received monetary support and gifts that were meaningful symbols of being in people's thoughts and financially helpful. What parents found most difficult was asking for the other logistical help that they needed. Parents reflected on the awkwardness of transitioning this monetary support into the logistical support that became increasingly needed as their child's illness progressed. While many parents needed help with childcare and household chores, these were the tasks that they found most uncomfortable directly asking for support with.

Difficulty sustaining support—Many parents described receiving initial support that quickly faded after their child's diagnosis. One father describes feeling like people were avoiding his family's situation,

> People tend to stay away from me because they don't want to share your grief. Strangers, I think, have been more outpouring with wanting to help you out. Family… they help as much as they can but still everybody's busy. [Respondent 9]

Other parents reiterated this experience of not having support they would have expected. While they received generic offers of support, these expressions of sympathy were often not translated into mobilized support. Parents expressed uncertainty of how to interpret vague offers of support, and what kinds of support they could request. They also discussed feeling uncomfortable directly requesting help, fearing that they would appear to be dwelling on their child's cancer diagnosis. These interpersonal dilemmas contributed to parents receiving less support than they would have anticipated. This uncertainty also made it difficult to sustain support over time, and the support parents did receive often dissipated after the immediate crisis of their child's diagnosis was over. Another father describes,

> Family, I don't know … yeah, there was support you know they'd come see you in the hospital and stuff. Just like anything, like when there's a death or something, everybody's there for a couple weeks and then they kind of get sick of hearing about it. [My daughter has] such a long road. [Respondent 10]

Like this father, many respondents felt that they lacked support after their child's initial diagnosis. Parents described feeling alone because their support systems did not rally around them throughout the most difficult aspects of their child's illness, which often occurred long after the initial diagnosis. Another mother describes,

> Everybody was there with you at the beginning; everybody's falling all over you at the beginning. Now it's like more forgotten. We used to get lots of phone calls. People were bringing meals all the time. Cards were coming. People were sending multiple cards. Now it's almost, you know it's only been three months, and I think it's just that everybody's busy in their own lives. They know we're handling it and you just kind of forget. [It feels like] we've been forgotten. [Respondent 44]

As this mother's experience illustrates, many parents felt that the support they received dissipated after the initial crisis of their child's diagnosis was over. Like this mother, parents described feeling ‘forgotten’ when members of their social networks stopped offering support. In this way, the interpersonal dynamics of support exchanges compounded to increase parents' difficulty in marshalling sustained support. Parents felt that their network members did not know what to do, and conversely parents did not know how to ask for the help they needed or how translate offers of support into action. The consequences of these interpersonal uncertainties became most visible over the course of their child's illness as support faded, and parents were uncomfortable directly requesting the support they continued to need.

Mobilizing Effective Support Exchanges

Marshalling Logistical Support—When parents talked about the most helpful support they received throughout their child's illness, they emphasized the importance of the nature of their relationships with support providers before their child's illness. One theme among effective support efforts was that they were consistent with the boundaries of the relationship between the support recipient and provider before the paediatric cancer diagnosis. Therefore, parents reported that different types of support were most effectively provided from network members they had different kinds of relationships with. Some social support involved logistical assistance with day-to-day family life, such as help with childcare, preparing meals, providing transportation to appointments, and helping with housework. These tasks necessitated that the support provider become involved in the family's private life, and required extensive coordination with the parents. Due to this, parents found support with these kinds of tasks was most effective when the support provider was a close network member. One father explains,

> That first summer was very rough. Again, one of the reasons why we're fine financially is because my in-laws after a couple weeks looked after both [of our children] so that we could handle all the…medical expenses. So without having to pay for day care, we were fine… So we're probably running through $700-800 a month. Like I said, with my in-laws watching the kids, then we were fine. [Respondent 3]

As this father describes, receiving support from close friends and family members on the daily activities of family life reduced many of the interpersonal dilemmas parents faced while marshalling support. Parents reported being more comfortable sharing personal information (such as details of their financial problems) with these network members whom they already had close relationships with. This support was also often easier for parents to coordinate when the support providers were close network members that the parents did not feel uncomfortable asking for help.

Parents reported the most interpersonal uncertainty requesting help with chores and help with household day-to-day tasks. However, these dilemmas were reduced when close network members provided this support. Helping with childcare was difficult for parents to request because they knew it was a demanding task for their network members. Parents also needed this support from someone reliable that they knew they could depend upon. As such, logistical support was most effective when provided by a close network member. One mother explains,

> My mother had just retired from her job as a teacher so she actually helped out and took a lot of the day shifts so that my husband and I could continue to work. She would come over and be here in the mornings to get him up and off to school. She would be here for him if he needed to come home early during the day. She helped with a lot of the running around to various appointments. [Respondent 4]

As this mother describes, parents found it most effective when this labour intensive support was provided from someone they had a pre-existing close relationship with. Knowing the demanding nature of the tasks, parents felt more comfortable receiving support from a close friend or family member. It was also easier for parents to manage this support when someone whom they already had a trusting relationship with provided it. They could rely on their pre-existing patterns of communication and interactions to manage the support after their child's cancer diagnosis.

Having a close pre-existing relationship also allowed parents to be honest about the help they really needed. Asking for support often placed parents in an emotionally vulnerable position. Parents described difficulty when telling their network members that they needed a break from their caregiving role. One mother describes how her family helped her throughout her son's care,

> My Grandma helped out watching him and my Uncle, he used to take me back and forth [to the hospital]. Then he gave me a car to get back and forth over there… we were at the hospital a lot so the days where I was just exhausted from being up there, my mom or my dad would stay up there with him and I would be able to come home and go get [my other son]. We would come home, clean up and do grocery shopping and I'd be able to stay the night at home with him. [Respondent 33]

As this mother's experience illustrates, requesting support also required parents to share personal information about their own coping reaction to their child's cancer diagnosis. Parents sometimes felt uncomfortable admitting that they needed respite from caring for their child, or were having financial problems. Support from close network members reduced the interpersonal burden in making honest requests for support because of the pre-existing trust in the relationship. For many parents, close network members filled these roles without being asked, which further reduced the interpersonal difficulty parents experienced while marshalling this support.

Marshalling Financial and Symbolic Support—Parents found that effective support from extended network members was often support that did not need to be requested by the family, was non-intrusive in their private lives, and was coordinated with little interaction with the support recipients. Members of their extended networks could rally this support on the family's behalf with little intrusion to their already hectic lives. One mother describes the extensive financial support she received from friends, co-workers, and extended family throughout her son's illness, ‘Everybody wants to give you money. I keep thinking - do they know something I don't?’ [Respondent 21]

Most respondents in the sample described receiving some kind of financial support from their extended networks. Not knowing what to do, or not wanting to be intrusive, friends, neighbours, co-workers and members of their school communities often showed their support by giving money. This ranged from gift cards to local restaurants to fundraisers, that in one family's case raised over $40,000. Financial support was easy for members of extended networks to coordinate, and often did not need to be marshalled by the parent. In addition to being financially helpful, these efforts also served an important symbolic role for parents. They were tangible reflections of being in people's thoughts, while requiring little involvement of the support recipient to coordinate.

Interpersonal dilemmas were also reduced when receiving support from extended network members in situations where someone other than the cancer patient's parents marshalled the support. This allowed parents to avoid feeling uncomfortable asking for support from extended network members. Many parents had someone, or groups of people, who marshalled support on their behalf. One mother describes,

> [My husband's] co-workers actually got together, took up a collection at work and they did the ramp, they did it in one day. Because [my son] needs to be in a wheelchair because he's not supposed to put any weight on his one leg. They donated all the funds for the wood and everything, which was great. [Respondent 22]

In addition to providing financial assistance, this helped parents cope emotionally by making them feel supported without requiring much effort from parents to marshal the support. Members of families' extended social networks also connected parents with resources that helped them bear the financial burden of their child's care. One mother describes how her daughter's teacher connected them with charity support,

> We were trying to get our house fixed and one of my daughter's fourth grade teachers is on the board for Habitat for Humanity and they were about to decide on which house to fix and somebody nominated our name and then they voted and they agreed to take on our house. [Respondent 34]

Like this mother, many parents had members of their extended networks organize fundraisers for their family, send cards and messages of support, or participate in a charity event in their child's honour. This support had important distinctions from extended network members' attempts at logistical support (like bringing over meals and helping with household chores) that parents described as less helpful. Financial and symbolic support required little to no coordination by the parents, allowed extended friends and family to unobtrusively offer support, and allowed parents to decide how to use the support offered.

Direct Requests for Support—Another way families overcame interpersonal difficulties in support exchanges was through directly requesting the support they needed. This allowed support providers to know exactly what the family needed, and how much the family wanted network members involved in their day-to-day lives. One father describes the effort involved in coordinating support,

> While we've been [in the hospital] for the last 30 days, I contacted one of my brothers and said, ‘Okay, organize a dinner committee’ and I gave him the names of people that said they'd do anything for us, all family members. Everyday Monday through Friday we had dinner delivered to us. We were at the hospital rotating people all the way through which worked out really, really well for us and for them. We got to see them, they got to see us, they got to see [my sick son]. It was good for everybody. [Respondent 27]

As this father's experience demonstrates, requesting and coordinating social support often took a great deal of time and coordination. Marshalling support was also easier when there was a specific task to accomplish. Some parents had a member of their extended family or close friend who filled this role. Parents who had explicitly requested support from their social networks were able to circumvent issues of their network members not knowing what to do, or not wanting to intrude. They were also able to ensure that they received support that met their evolving needs throughout their child's cancer care.

Discussion

A large body of research has repeatedly shown that social support helps buffer the negative effects of stressful life events on individuals. Within the paediatric oncology literature, studies have shown that parents who have social support have reduced negative psychosocial outcomes (Fletcher 2011, Rini *et al.* 2008, Manne *et al.* 2000, Hoekstra-Weebers *et al.* 2001, Trask *et al.* 2003, Wijnberg-Williams *et al.* 2006). Due to these findings of the significance of social support, it is important to understand the mechanics of effective social support exchanges so the benefits of social support can be leveraged for more families. In this study, parents' experiences reveal that there were conditions under which support was most helpful. These experiences emphasize the importance of the quality of pre-existing relationships between the support recipient and provider, as well as the interactions throughout the period of support. Parents found logistical support with daily activities most effective when it came from someone with whom they had a pre-existing close relationship. This reduced the amount of communication and coordination required by parents, and parents felt comfortable having these support providers involved in the most private aspects of their lives. Help from close friends and family members continued an established relationship that was formed and negotiated before the paediatric cancer diagnosis (Chesler and Barbarin 1984). This support was effective in part because interpersonal dilemmas were reduced. Parents felt comfortable asking for the real help they needed, and did not feel awkward placing this increased burden on a trusted family member or close friend. Support from extended networks was effective when it was unobtrusive and required little marshalling by parents. Friends, co-workers and neighbours often gave financial support without having been asked, and with little communication and coordination from the parents of the sick child.

Implications for Theory and Future Research

While the social support literature has made vast gains in understanding how social support influences individual's coping processes, researchers have also suggested that the processes through which support is negotiated are likely complicated and highly variable experiences for families (Uehara 1990). In their research examining social support processes, Wellman and Wortley (1990) found that relationship characteristics were an important indicator of the kinds of social support offered, and the nature of these relationships was more important than characteristics of network members themselves. Wellman and Wortley find that ‘most relationships provide specialized support’ (Wellman and Wortley 1990: 558). Data from this study of parents of paediatric cancer patients show that the pre-existing relationships parents had with support providers was an important variable in determining the utility of the support relationship. The most helpful logistical support (most often help with childcare and household chores) came from the strong ties within their social networks. These support providers already had intimate relationships with families, and parents felt comfortable breaching norms of privacy and politeness due to the already close nature of the relationship. When members of extended networks attempted to fill these roles the support quickly dropped off, in part due to difficulties sustaining this kind of support with more distant pre-existing relationships with parents.

In a study of mothers' access to social support, Harknett and Hartnett's (2011) found that families who had numerous personal disadvantages were less likely to perceive available housing and child care support, however they were not less likely to have access to financial support. Harknett and Hartnett (2011) suggest that this may reflect the differential burden in providing logistical versus financial support. They contend, ‘The onus of providing support may be an underappreciated influence in support relationships’ (Harknett and Hartnett 2011: 872). Findings from this paper provide further insight into the difference between logistic and financial support, revealing that help with childcare and household chores was difficult for parents to request, organize, and sustain. This was especially true when attempting to marshal logistical support from extended network members. Parents cited financial assistance as effective support from extended network members because it required the least coordination and was unobtrusive into families' private lives. Findings from this paper suggest that individuals with fewer close networks members may have increased difficulty marshalling logistical support.

While this research contributes to a richer understanding of the mechanics of social support after a major life event, there are several limitations. As is a common limitation in social support research, this design does not permit disentangling parents' personalities from their experiences with social support. It may be the case that parents' reports of their experiences with social support are influenced by their personality characteristics. For example, parents with extroverted personalities, positive affect, or good leadership skills may perceive more positive experiences with social support. In this way, respondents' perceptions of social support may systematically vary across personality characteristics, and respondents' interpretations of social support may be different than their actual experiences. Second, while these findings highlight the complicated nature of negotiating social support, these processes are likely further complicated by the dynamics between the support recipient and their relationships with their social networks. For example, some parents may have already exhausted their social support in other circumstances and therefore have less available throughout their child's illness. These data do not allow examination of these processes. One important direction for future research is to examine how previous investments in social networks impact receipt of social support after a serious life event.

These data only permit reflection on experiences with social support from parents' perspectives. Data from members of families' social networks would enhance our understanding of these processes, and would add to our understanding of the mechanisms through which social support is negotiated. It would also allow some disentanglement of individual personality characteristics from broader network dynamics. Future research that integrated data from multiple individuals within social networks would provide valuable insight into the intricate processes through which social support is perceived, negotiated, and experienced.

This study was conducted in the United States, and some of the findings may be particular to the healthcare delivery context in the US. First, while all families in this sample had health insurance that covered their child's cancer treatment, the levels of coverage varied. Some families had large medical expenses related to their child's cancer treatment. Therefore, the financial ramifications of their child's cancer diagnosis may not be the experience of families in countries with different healthcare delivery structures. Similarly, many parents in this sample discussed the large monthly expense of paying for childcare. The experience of balancing the cost of childcare and medical expenses may not generalize to parents in other countries. While the financial experiences of parents experiencing paediatric cancer may vary across countries, parents likely experience similar interpersonal dynamics when requesting and managing social support. One direction for future research is to use a crossnational design to compare these interpersonal dynamics of marshalling social support in different cultural and healthcare delivery contexts.

Implications for Practice

While research has repeatedly found the beneficial effects of social support, the methods of translating these findings to clinical practice are less transparent. Building on previous research, this paper shows that these translational difficulties may be in part due to the complexities in social support exchanges, and the nuanced interpersonal dynamics involved in effectively mobilizing social support. Findings from this paper have implications for programs designed to help parents mobilize social support. First, these parents' experiences reveal that individuals experiencing stress may not know how to ask for the help they need, may not know what kinds of help to ask for, and may fear appearing needy if they directly request help. Previous research shows that direct requests for support are most effective at mobilizing support (Winkeler *et al.* 2006). One opportunity for programs designed to increase social support is to improve parents' efficacy in identifying their support needs and making explicit requests for support.

Second, findings show that the nature of the pre-existing relationship between support providers and recipients influenced the types of support that were effectively exchanged. Support efforts that necessitated coordination with the parent and involvement in the families' daily activities were most effective when the support provider had a pre-established close relationship with the support recipient. Conversely, less personal support efforts (such as financial help) could be effectively offered from more socially distant network members because they required little interaction with the support recipient, and respected privacy boundaries of the family of the cancer patient. It may be fruitful to design programs that counsel parents to identify support needs, and potential support providers with these distinctions in mind. This may help parents mobilize sustained support throughout their child's illness by actively identifying their support needs, and reflecting upon the members of their networks who are best suited to provide assistance with specific tasks.

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Table 1

Demographic Characteristics of Sample

	Percentage of Total Sample N in Parenthesis
Gender	
Women	64% (49)
Men	36% (27)
Total	100% (76)
Race/Ethnicity	
Non-Hispanic White	79% (60)
Non-Hispanic Black	21% (16)
Total	100% (76)
Marital Status	
Never married	18% (14)
Married	70% (53)
Divorced	12% (9)
Total	100% (76)
Education	
Less than high school diploma	2% (2)
High school diploma or equivalency (GED)	41% (31)
Associate degree (junior college)	11% (8)
Bachelor's degree	22% (17)
Master's degree	19% (14)
Doctorate or advanced professional degree	1% (1)
No Response	4% (3)
Total	100% (76)
Total Household Income	
Less than $5,000	5% (4)
$5,000 through $11,999	8% (6)
$12,000 through $15,999	4% (3)
$16,000 through $24,999	9% (7)
$25,000 through $34,999	3% (2)
$35,000 through $49,999	12% (9)
$50,000 through $74,999	13% (10)
$75,000 through $99,999	12% (9)
$100,000 and greater	29% (22)
Don't Know/No Response	5% (4)
Total	100% (76)

	Percentage of Total Sample N in Parenthesis
Employment Status	
Working full time	53% (40)
Working part time	14% (11)
Unemployed or laid off	8% (6)
Keeping house or raising children full time	14% (11)
Retired	3% (2)
Other	7% (5)
No response	1% (1)
Total	100% (76)