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Social networks of experientially similar others: Formation, activation, and consequences of network ties on the health care experience

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Abstract

Research documents that interactions among experientially similar others (individuals facing a common stressor) shape health care behavior and ultimately health outcomes. However, we have little understanding of how ties among experientially similar others are formed, what resources and information flows through these networks, and how network embeddedness shapes health care behavior. This paper uses in-depth interviews with 76 parents of pediatric cancer patients to examine network ties among experientially similar others after a serious medical diagnosis. Interviews were conducted between August 2009 and May 2011. Findings demonstrate that many parents formed ties with other families experiencing pediatric cancer, and that information and resources were exchanged during the everyday activities associated with their child's care. Network flows contained emotional support, caregiving strategies, information about second opinions, health-related knowledge, and strategies for navigating the health care system. Diffusion of information, resources, and support occurred through explicit processes (direct information and support exchanges) and implicit processes (parents learning through observing other families). Network flows among parents shaped parents' perceptions of the health care experience and their role in their child's care. These findings contribute to the social networks and social support literatures by elucidating the mechanisms through which network ties among experientially similar others influence health care behavior and experiences.

Keywords

United States; Social networks; Social support; Health care behavior; Child health; Social determinants

Introduction

After receiving a serious medical diagnosis patients must quickly acquire skills in communicating with physicians, coordinating care across numerous clinicians, and navigating complex health care and insurance organizations. Most patients do not enter the health care system with these skills, but rather they must be learned and refined (Liu, King, & Bearman, 2010). It is thought that social networks play an important role in this social learning through shaping the activities individuals engage in to cope with a serious medical diagnosis, and influencing how individuals navigate their health care (Pescosolido & Levy, 2002). Previous research on social networks in health has shed considerable light on the role

that pre-existing social networks play in shaping health behavior and health care experiences. This paper builds upon recent advances in the social networks and social support literatures, and examines the ties individuals form with others experiencing similar illnesses (experientially similar others). Through in-depth interviews with 76 parents of pediatric cancer patients in one hospital setting, this paper examines the relationships parents form with each other while undertaking the daily tasks associated with their child's care. This allows examination of the network ties patients form throughout the everyday routines associated with their child's care – in hospital hallways and waiting rooms – and the influence these network ties have on the health care experience. Building on the robust finding in previous research that social networks influence health care behavior, this paper places focus on the micro processes through which ties among individuals confronting similar illnesses are formed, activated, and used. In doing so, it examines how network ties among parents of pediatric cancer patients shape parents' perceptions of the health care experience, their role in their child's care, and the activities they engage in throughout their child's cancer treatment.

Theory and background

The health care environment

The changing health care landscape has fostered an environment in which patient networking has become an important part of the health care experience. During the late twentieth century a shift occurred in the relationship between patients and physicians that was marked by a decline in the perceived authority of the physician and an increase in patient consumerism (Heritage & Maynard, 2006; Potter & McKinlay, 2005; Rosich & Hankin, 2010; Timmermans & Oh, 2010). As health care delivery became more commercialized and clinical encounters less personal throughout the 20th century, research has shown a decline in patients' trust in their physicians (Boyer & Lutfey, 2010; Lipset & Schneider, 1982; Pescosolido, Tuch, & Martin, 2001; Potter & McKinlay, 2005; Reeder, 1972; Timmermans & Oh, 2010). As the physician-as-expert view of clinical encounters eroded, a new sociocultural emphasis of patients-as-consumers emerged. Today, patients encounter cultural messages to be empowered self-advocates, question the authority of physicians, participate in health care decisions, and take an active role in their own health care (Stacey, Henderson, MacArthur, & Dohan, 2009). This health care landscape serves as a backdrop for patient health care navigation and the role of social networks in shaping the health care experience. Social networks, especially those between patients, may play a role in shaping individuals' conceptions of their role in their own care, and their perceptions of health care experiences. Similarly, as the clinical encounter has become shorter and less personalized, patients may rely more on their social networks for health-related information, advice and resources.

Social networks and health care behavior

Scholars have articulated multiple definitions of social networks, but social networks can be broadly conceptualized as “the web of social relationships that surround an individual and the characteristics of those ties” (Berkman, Glass, Brissette, & Seeman, 2000: 847). Research has documented that individuals' social networks influence their ability to cope with illness and the types of medical services they use (House, Landis, & Umberson, 1988; Pescosolido, 1992; Pescosolido, 1996; Thoits, 1982, 1995, 2010). Social networks diffuse health-related resources, including information, strategies for managing care, emotional sustenance, and logistical support (Berkman et al., 2000; Borgatti, Mehra, Brass, & Labianca, 2009; Pescosolido, 2006; Smith & Christakis, 2008; Thoits, 2011). In addition to health-related information and resources, social networks may diffuse norms, values, pressures, and attitudes that shape individuals' health care behavior and experiences

(Berkman et al., 2000; Borgatti et al., 2009; Pescosolido, 2006; Smith & Christakis, 2008). This diffusion of norms, knowledge, and resources occurs through both explicit and implicit processes. Social networks may explicitly shape health care experiences through the direct sharing of emotional, logistical, informational, and financial support. Individuals' social networks may contain beneficial social connections that help them gain access to health-related information, advice from a specialist, information about treatment options, connections to second opinions, or institutions that offer illness-related support. In addition to the explicit exchange of information and resources, social networks may influence health care behavior through implicit processes such as social comparison. Social networks may afford patients the opportunity to observe and compare their health care behavior and experiences to the experiences of their network members (Thoits, 2011). For example, an individual may observe a network member's style of interacting with clinicians and appraise their own behavior against their perception of another person's experience. Therefore, as individuals observe others they may gain information, resources, support, and ways of thinking about their own health care experiences. Through these explicit and implicit processes, after a serious medical diagnosis individuals' embeddedness in certain networks may influence the information and resources they are able to leverage to help navigate their health care. Social networks may also influence individuals' beliefs about their role in their own care, attitudes about their clinicians, and the activities they engage in throughout their health care.

Networks of experientially similar others

Networks of patients experiencing the same illness, or experientially similar others, represent one network sector that may play an important role in shaping an individual's health care experience. This paper examines networks of experientially similar others, or individuals who have first hand experience with the same life crisis or stress, rather than individuals who are similar because of common social structural or demographic characteristics, such as age, race or gender (Suitor & Pillemer, 2000; Suitor, Pillemer, & Keeton, 1995). Due to having a shared experience, experientially similar others are thought to offer specialized support that differs from the support available in an individual's network of significant others (Suitor & Pillemer, 2000; Suitor et al., 1995; Thoits, 2011). Experientially similar others may offer tailored emotional support that is more helpful than the emotional support available from significant others. Research on support from existing networks of significant others has found that, "well intentioned supporters sometimes give unwanted advice, expect and encourage recovery too soon, minimize the crisis, force cheerfulness, discourage open expression of feelings, and say 'I know how you feel' when they do not" (Thoits, Hohmann, Harvey, & Fletcher, 2000: 264). In contrast, because they have first hand knowledge of the experience of coping with a particular life event, experientially similar others can offer empathy and tailored emotional support (Suitor & Pillemer, 2000). Due to their shared experience, similar others may be able to validate emotions and concerns, and offer safe outlets to ventilate feelings (Thoits, 2011).

Networks of experientially similar others may also afford the opportunity for social comparison (Thoits, 2011). Individuals may compare their emotional reactions and coping styles to others who have faced a similar life stress (Thoits et al., 2000). Individuals may observe similar others who they perceive to be coping well, and strive to emulate them. In contrast, individuals may compare themselves against less fortunate similar others, and re-appraise their perception of their own status (Taylor & Lobel, 1989). Similar others are also thought to offer tailored active coping assistance, through exchange of information, ideas, resources, and strategies for getting the most out of their health care (Thoits, 2011). Due to this tailored support offered, network connections with experientially similar others have the

potential to offer specialized dimensions of support that may shape the health care experience.

Researchers who have examined the role of networks of experientially similar others have found these networks to play an important role in shaping illness and the health care experience. In a study of men undergoing coronary artery bypass surgery, Thoits et al. (2000) found that patients who talked to other cardiac patients while in the hospital had improved physical and emotional well-being. Talking with other cardiac patients in the hospital was positively associated with perceived health, health satisfaction, fewer activity limitations, lower depression and lower psychological distress post-surgery (Thoits et al., 2000). These findings show the value of informal exchange among experientially similar others, and highlight the importance of the information and support exchanged within these networks. Interestingly, when study participants had discussions with acquaintances that had previously experienced coronary artery bypass surgery before their own procedure, these conversations outside of the hospital setting were not associated with improvements in physical or mental health outcomes post-surgery (Thoits et al., 2000). This distinction between interactions with different types of experientially similar others highlights the importance of the timing of the shared stressor, and suggests that experientially similar others who are collectively experiencing a common stressor may offer more effective support than network members whose similar experience is in the past.

Research has also documented the role of networks of experientially similar others in shaping collective experience of contested illnesses (Barker, 2008; Zavestoski et al., 2004). In a study of an electronic support group for fibromyalgia sufferers, Barker (2008) found that participation in the electronic support group shaped participants' perceptions of medical expertise, illness experiences, and the role of lay knowledge. However, we have little understanding of interactions among similar others that occur throughout routine, everyday activities. While some individuals seek out opportunities to interact with experientially similar others online, others may be uninterested in, or avoid, such interactions (Gage & Panagakis, 2012). To date, much of our understanding of networks of similar others focuses on networks constrained by participation in a certain domain (for example participation in an internet chat group or in-person support group). Due to this, we know very little about similar others in individuals' natural networks of everyday contacts. Yet, most exchanges of social support occur in these informal daily interactions, not in support groups. The nature and content of support exchanged through natural networks may vary from similar other interactions in settings focused on providing support. This paper examines the network ties formed among parents of pediatric cancer patients amid the everyday routines associated with their child's care. In doing this, it enhances our understanding of how network ties are formed and used, and how networks of experientially similar others shape the health care experience. Examining network experiences among parents of pediatric cancer patients in one hospital setting allows analysis of the explicit and implicit diffusion of information, resources, and support through the network. This paper examines network flows of explicit support through the direct sharing of information, resources, and emotional support. It also examines the implicit support that diffuses through the network as parents observe other families and learn through watching other families' experiences.

Methods

The case: pediatric cancer

Pediatric cancer is the number one cause of death by disease for children in the United States (Jemal et al., 2005). Pediatric cancer includes a range of diagnoses, which are commonly categorized into solid tumor cancers and blood cancers. Treatment for pediatric cancer can include chemotherapy, radiation therapy, surgical removal of the tumor, and bone

marrow transplant. Treatment protocols can extend over months and years. This paper focuses on parents' network experiences after their child has been diagnosed with pediatric cancer and begun treatment. Due to its relatively low incidence, treatment for pediatric cancer is centered at one National Cancer Institute (NCI)-designated comprehensive cancer center in the study area. Due to statewide policies, all uninsured children in the study area are eligible for Medicaid enrollment due to their cancer diagnosis. Therefore the study site is the only pediatric cancer treatment facility in the study area, and socio-demographic characteristics do not determine either where children with cancer are treated or whether they have insurance.

Participant recruitment

This study used a mixed-methods design to examine the experiences of parents of pediatric cancer patients, and included observation, in-depth interview and survey components. The first phase of the study involved ethnographic observations of six families of pediatric cancer patients, which occurred from February 2007 to August 2007 (for description, see Gage, 2010). Data from observations revealed the important role that parent networks played in families' experiences throughout their child's care, and informed the focus on social network processes in the second phase of the study. Data for this paper are from the second phase of the study, which included in-depth interviews and surveys with 76 parents of children diagnosed with cancer. Data were collected from August 2009 to May 2011. Participants were recruited through one NCI-designated comprehensive cancer center in the Northeastern United States. Due to patient privacy concerns, researchers did not approach families directly. Instead, the study team partnered with a social worker and psychologist at the recruitment site to facilitate participant recruitment. These representatives approached patients' parents, introduced the study and asked parents' permission to have their contact information forwarded to the study team. All parents of pediatric cancer patients on active therapy at the time of data collection were invited to participate. However, parents of children who had stage four cancers were not approached, due to sensitivity for the severity of their child's illness and because we believed that experiences would likely vary among parents caring for children in the end of life. In an effort to increase the representation of African American families in the study, one African American family whose child was in remission at the time of data collection was recruited. All parents who were approached agreed to be contacted by the study team. A member of the study team then contacted each parent and scheduled a time to administer a survey and in-depth interview. Eighty-two parents agreed to have their contact information forwarded to the study team. Six of these potential respondents were not enrolled due to scheduling difficulties or later declined to participate. Seventy-six parents (93% of those approached) were enrolled in the study.

Procedures

Study team members met parents at a location convenient to each respondent, which included coffee shops, the hospital, and family homes. The study was IRB approved, and each respondent signed a written informed consent. A sociologist led the study team, and none of the interviewers had a clinical background. The study team was based at a university, and parents were assured that their responses would not be shared with their child's health care team. There were three interviewers on the study team. Respondents were asked to complete a standardized survey questionnaire, which included the MacArthur Foundation Research Network on Socioeconomic Status and Health socio-demographic questionnaire (Singh-Manoux, Adler, & Marmot, 2003). Respondents also completed a semi-structured in-depth interview. Interview questions focused on the story of their child's diagnosis, family routines pre- and post-diagnosis, social support, social networks, experiences interacting with clinicians, and experiences managing their child's care. To gather detailed social network data, respondents were asked to describe their experiences

interacting with other parents of pediatric cancer patients, participating in pediatric cancer charities and activities, social networking online, and social support experiences with family, friends, and coworkers. We also asked questions about specific health care experiences respondents may have had (for example, “Have you had to make a difficult decision related to your child’s care?”). Many respondents described interactions with other families of pediatric cancer patients in their responses to these questions, and when they did, the interviewer followed up with questions aimed to get detailed information on these social network experiences.

Interviews lasted between 30 minutes and 2 hours. All interviews were audio recorded and transcribed verbatim. Interviewers wrote detailed observation notes on the interview scheduling process, experiences with the respondent before and after the recorded interview, and non-verbal aspects of the interview. Observation notes were added to interview transcripts to form complete data files.

Participants

We made purposeful efforts to recruit both mothers and fathers, and the final sample was made up of 64% women and 36% men. As Table 1 shows, 21% of respondents were black, while the majority of respondents (79%) were white. Income data was converted to percent of the US federal poverty line, accounting for the number of family members in the household. Twenty-two percent of the sample had a total household income below the federal poverty line, while 50% of respondents reported a total household income 300% of the federal poverty line or more. Forty-three percent of respondents had a high school degree or less, while 22% held a bachelor’s degree and 20% had an advanced degree. Seventy percent of respondents were married, 12% were divorced, and 18% never married. As for child characteristics, 46% of the sample was caring for a male child diagnosed with cancer, while 54% had a female child diagnosed with cancer. The mean child’s age at diagnosis for this sample was 7.9 years, and the mean child’s age at the time of data collection was 10.2 years old. Therefore, the mean time since diagnosis for families in this sample was 2.3 years. Thirty-six percent of the respondents were caring for a child diagnosed with a solid tumor (or organ tumor) cancer, for example Osteosarcoma and Ewing’s Sarcoma. Fifty nine percent of the sample was caring for a child diagnosed with a liquid tumor (blood cancer) such as Acute Lymphoblastic Leukemia (ALL).

Data analysis

An initial list of codes was developed based upon the interview guide, major research questions, and a review of the literature. Three members of the research team also carefully read each interview transcript and made notes on major concepts that emerged from the data. This process yielded 44 broad data-driven codes (such as “support from immediate family” and “interactions with other families of pediatric cancer patients”). Three members of the research team then re-read each data file and coded the data. Team members brought their coded data to coding meetings, where each team member discussed their coding. Inter-coder reliability was extremely high (Fleiss’ kappa for specific items ranged from .91 to 1), and any discrepancies were discussed and resolved at coding meetings (Fleiss, 1971).

Egocentric network maps were created for each respondent. Interview data was used to code the nature of the dyadic relationship between each respondent (ego) and the individual members of their network (alters). Each dyadic relationship was coded according to three qualities: the nature of the social relation (for example: mother, co-worker), the nature of their interactions (for example: talked to, helped) and flows (for example: emotional support, information, resources) (Borgatti et al., 2009). The analyses for this paper focus on dyadic relationships between parents of pediatric cancer patients. Therefore, social relations

with other network members were not included in these analyses. Themes were developed based upon similarities and variations in the nature of interactions and the flows within dyadic relationships. Two members of the research team independently conducted a second round of analysis where codes were categorized, and themes identified (Guest, MacQueen, & Namet, 2012). Thematic analysis was conducted and attention was paid to code frequency, code co-occurrence, and the context and meaning of codes for groups of respondents (Guest et al., 2012). Themes among codes were discussed and refined at team meetings, where patterns in the data were identified and conceptually linked to themes identified in the literature review.

Findings

Tie formation

The parents in the sample described their child's cancer diagnosis as a great emotional shock, and a disruption to their family routines. After their child's diagnosis, parents had to negotiate their child's many cancer-related appointments, re-arrange schedules to accommodate their child's treatment demands, and adapt to the logistical and emotional demands of their child's care. Parents also described the monotony and boredom that filled the vast amount of the time spent at the hospital. Depending upon their child's treatment protocol, some families spent hours in the outpatient chemo infusion clinic, others "moved in" to the hospital for weeks while their child was admitted for treatment. As one father explained during an interview while his daughter was admitted to the hospital "around here time goes backwards." This waiting that constituted much of the time spent in the hospital afforded parents opportunities to interact.

Many parents did not actively seek out connections with other families of pediatric cancer patients. These parents met other families casually, while in the hospital waiting rooms, or in the kitchen on the pediatric in-patient floor. One mother explained,

I met [her] in the ER...So [her son] had the same diagnosis, and [our kids] started chemo together...At times she could stay with both the kids while I took a shower or I could stay with both the kids while she got something to eat. Or, [I could ask her] "Is this happening? Is this normal?" Someone to ask questions to and bounce things off. [*R52; 12 years since diagnosis*]

The parents in the sample described these ties as important aspects of their experience coping with pediatric cancer. Parents referred to their "hospital friends" and fellow in-patients as "neighbors" and behaved in neighborly ways. One mother describes, "This family right next door [to my daughter's hospital room] is starting out new and I go over there and talk to them." [*R24; 5 months since diagnosis*] Like these mothers, many parents connected with each other throughout the daily routine associated with their child's care.

Parents of newly diagnosed children often formed ties to parents who had been caring for a child with cancer for several months or more. One father explains,

You understand that when you're there you're not there alone; you're with other families. On our very first day of chemo, you know we're in there all white as ghosts, shaking like a leaf and you might bump into somebody in the little kitchen up on [the pediatrics floor] that is a six month veteran. And the parents start talking. [*R61; 2 years since diagnosis*]

Many parents described interactions with "veteran" parents when their child was newly diagnosed with cancer. Similarly, several parents whose child had been in treatment for several months or more tried to help other parents whose child was recently diagnosed, or

were struggling with their child's illness. One father describes how he deliberately connected with other parents of pediatric cancer patients,

Since my daughter's been doing better I've been trying to reach out and meet other people. There's a young lady that I've been kinda holding her dad's hand for a couple months now...so he and I speak at least daily, whether its email or phone.
[R55; 2 years since diagnosis]

Like this father, as parents became immersed in the their child's cancer care, some purposefully sought to build ties among parents confronting pediatric cancer. These connections allowed them to share the highly specialized knowledge they accrued throughout their child's care with other families. More experienced parents often acted as ambassadors to the world of pediatric cancer, helping parents understand the hospital structure, the intricacies of cancer therapy, and medical jargon. Parents also appreciated the learning curve associated with becoming a savvy health care consumer, and respected the opinions of "veterans." Both families who had informal interactions with other families and those who courted close and persistent relationships discussed these networks as formative aspects of their health care experience.

Explicit network flows through direct sharing

Emotional sustenance

Many parents received emotional support through direct sharing with other parents of pediatric cancer patients who intimately understood their experience. The experience of caring for a child with cancer brought challenges and struggles that many parents felt members of their existing networks could not adequately appreciate. In contrast, other parents of pediatric cancer patients offered an outlet to share experiences, emotions, or concerns with someone parents felt understood what they were going through. One father explains,

Just to be able to talk to somebody, because you had something in common. You try to explain to somebody who doesn't know what you've got to go through and they're like, "Yeah, yeah, I know what you're saying" but they really didn't know.
[R76; 8 years since diagnosis]

Like this father, many parents felt that their pre-existing friends and family did not truly understand what they were going through. Parents felt that other families experiencing pediatric cancer could relate to their struggles, understand their concerns, and know how to respond to their feelings. Parents could openly share their struggles and frustrations with each other, and felt like they were not alone. One mother describes,

Being in the hospital with [our children] and they would be having really bad days and their mood was awful. [This other mother] and I would help each other through that. [R40; 8 months since diagnosis]

As this mother describes, many parents felt that they could be open about their emotional reactions to their child's illness with others who had shared similar experiences and ventilate their feelings. A connection with other parents was a coping resource for parents, and helped them deal with the stress associated with being a caregiver for a child with cancer.

Active coping assistance

Caregiving strategies—Relationships with other parents of pediatric cancer patients also provided informal exchange of strategies for coping with the day-to-day struggles of parenting a sick child that parents felt were not addressed by clinicians. For example, parents exchanged strategies for teaching their toddlers to swallow pills, and tricks to calm

their children when they had blood drawn. Parents also exchanged strategies for complying with the rigorous demands associated with their child's treatment. For example, one mother explains,

It lets you know that you're not alone. Like [my son] being so picky about food, I was getting really frustrated and then a lot of the other parents I talked to said, "oh no, [my child is] just as bad, if not worse." You can open up with the other parents more than the doctors. [*R35; 6 months since diagnosis*]

Relationships with other families provided parents instrumental support though equipping them with tips and strategies to overcome obstacles associated with their children's care. They also offered emotional support through giving parents an outlet to vent these frustrations, and know they were not alone. Ties to other parents coping with pediatric cancer offered a space to discuss difficulties associated with their child's care that were considered outside of the purview of physicians. In this way, networks of parents of cancer patients filled an important void for families. They had specialized knowledge and experiences so they understood more than other social network members, and parents felt comfortable venting frustrations that they thought were too mundane for physicians.

Tailored medical information

Many parents in the sample also exchanged sophisticated medical information with other parents in the network. Parents used this information to connect with alternative treatment options, check the recommendations of their child's physicians, and compare the protocols being used across the country. One mother explains,

We called the Leukemia/Lymphoma Society and they put us in touch with several families that have children that have also been diagnosed with CML (Chronic Myeloid Leukemia) around the country. We've been chatting with them so we get not only what our doctors [at this hospital] have but we hear from them about what their physicians are recommending. [*R69; 1 month since diagnosis*]

As this mother describes, many parents exchanged medical information related to their children's care. Parents often placed a large amount of credibility in information and advice that flowed through networks of parents of cancer patients.

Many parents used connections with experientially similar others to compare the recommendations of their child's physicians with other families within and outside of their geographic area. For many parents, this information served as a form of seeking a second opinion. Checking their child's treatment protocol against another child's gave them reassurance that they were receiving good care. One father explains,

We've talked with other families about the treatment options that we've been presented with but we have not gotten a second opinion on the diagnosis. It's more of a chatting with them about, this is what our physicians are suggesting and recommending as the planned treatment and hearing from them what their physicians are saying. [*R4; 1 year since diagnosis*]

These connections provided reassurance to parents without having to go through the logistically and emotionally demanding process of seeking a second opinion from a physician. Parents took each other's recommendations very seriously, and due to the unique struggle of caring for a child with cancer, ascribed an expert status to other parents of pediatric cancer patients.

Implicit network flows through social comparison

Emotional sustenance

Connections among experientially similar others allowed parents to observe other families and appraise their own experiences with their child's cancer. Several parents reflected that these relationships made their families appreciate their own circumstances more. Parents described these social comparisons in relation to coping with the logistical demands of treatment, their child's prognosis compared to other children, and accepting the side effects and long-term effects of treatment for their children. Being able to compare their child's treatment protocol to others brought comfort to some parents who observed that compared to other children, their child required fewer hospitalizations, or had fewer side effects from medication. One mother describes, "We're fortunate because some people have to stay a month or longer [in the hospital]." [R24; 5 months since diagnosis] Like this mother, some parents found encouragement in comparing their own experiences against other children who had more logistically demanding treatment protocols.

Comparison to other families of pediatric cancer patients also offered hope and encouragement for many parents. Families came into contact with other patients and families who had positive outcomes. Interactions with children entering remission, or who were long-term survivors, offered a foundation for parents' hope that their child would survive their cancer. One father explains, "My wife talked to one guy...his son had the same thing. He had it when he was 8 and he's just getting ready to go to college." [R30; 1 year since diagnosis] Several parents reflected on similar stories of positive outcomes that helped them emotionally cope throughout their child's care.

Active coping assistance

Caregiving strategies—Parents also learned strategies for managing their child's care through observing other families. As parents watched other families through the daily routines associated with pediatric cancer care they obtained knowledge and tricks that made parenting a child who has cancer easier. One mother explains,

My daughter learned to swallow pills at five years old because the liquid medicines were so terrible tasting. We'd put the tablet into a spoon of pudding... We got the idea because we saw another family having their child practice with tic tacs, and put them in applesauce or yogurt [R75; 5 years since diagnosis].

As this mother describes, families learned strategies for managing their child's care through observing other families. Since many interactions among parents occurred while they were in the hospital, or in the chemo-infusion clinic, parents had the opportunity to observe and learn from other families' approaches to caring for their sick child.

Negative aspects of social comparison

While stories of positive outcomes offered hope to many parents, parents also reflected on the difficulty of comparing their own child's prognosis and experience to other children in their network. One mother describes,

You're always comparing your child to their child. You think, "[my daughter] has the same tumor as that girl and [my daughter] can't even move, she's paralyzed and this girl is up running around the halls, why is that?" But then that child passes away a month later, which actually happened. And then you're like, okay, well at least [my daughter] is still alive. [R57; 6 years since diagnosis]

As this mother expresses, social comparison sometimes led to mixed emotional reactions as parents observed children's changing health and prognosis. Direct comparisons to children who had the same diagnosis, or were undergoing parallel treatment, allowed parents to compare their child's condition with other children. As this mother describes, comparisons to children who seemed to be responding better to treatment could be emotionally difficult for parents.

Some parents also formed close ties with families who lost a child to cancer. Frequent exposure to children who experienced negative side effects of treatment, or passed away, was one of the difficult aspects of having ties to other families experiencing pediatric cancer. One mother explains, "A lot of times I would get scared and nervous for [my daughter] thinking 'oh my God, what if that happened to her?' You're hearing other people's situations and it could be quite frightening." [R17; 2 years since diagnosis] While comparison to children who survived their cancer offered hope and encouragement, one of the negative consequences of interactions with other pediatric cancer patients was seeing children who did not survive their cancer. One father reflects, "We got to know the families living around us, living in the hospital room next to us. Too many funerals. [Pause, crying] Too many kids." [R54; 3 years since diagnosis]

Influence on health care behavior

Interactions with other parents of pediatric cancer patients shaped parents' views of clinicians and the hospital, as well as their own role in their child's care. Stories and observations of other families' experiences diffused through the network and shaped parents' attitudes and behavior. One of the themes in the information that parents exchanged among each other was stories of medical errors, and perceived inadequacies in the care some families experienced. Parents shared these stories that affirmed many parents' belief in the necessity of parental advocacy. One mother explains,

We know a family; their little girl was misdiagnosed with having rheumatoid arthritis because of the pain in her legs for six months. For six months she was treated for arthritis and she had leukemia. What they went through, that was really frustrating for them. It was frustrating for me, too. [R74; 9 months since diagnosis]

Stories like this spread quickly among parents, and bolstered their belief that they needed to check the recommendations of their child's physicians. As this mother describes, many parents were emotionally impacted by their observations of other families' struggles and these experiences influenced their interpretation of their own child's care. Due to this, parental networks helped to shape parents' conceptions of their role in their child's care. Another mother explains,

I know families who have gone to other hospitals...they didn't even deal with [this hospital]. I heard of a kid not getting a certain type of chemo...[this hospital] wasn't allowing it, and this was this kid's last hope and, you know, [the parents] didn't let up...I think that you just have to go in, at least in my opinion, and just don't take [what the doctors say] at one hundred percent all the time. [R72; 5 years since diagnosis]

Like this mother, many parents watched other families struggle, and insights from other families' experiences informed their own approach to advocating for their child. Parents cited other families' negative experiences with the hospital as evidence of the importance of parental advocacy.

Some families in the sample adapted their style of interacting with clinicians based on experiences observing and interacting with similar others. One mother describes,

I [have learned to] voice certain things with her treatment...I will request more than what they're gonna give and they'll listen to me...I learned that from a woman that lost her daughter to leukemia. That even though they were taking blood tests from this little girl, it didn't show up in the blood work but it was in her bones and nobody knew. She said to me "you know, just to be safe why don't you have it checked with her next spinal tap." [R10; 18 months since diagnosis]

As this mother's experience illustrates, many parents who had ties to similar others credited these ties with helping them gain knowledge and confidence that helped them manage their child's care. Connections with other families shaped parents' view that they needed to actively participate in their child's care. These networks also offered strategies on how to cope with the demands of their child's care. Another mother describes,

But the parents, they'll let you know what to expect and stuff, the doctors know you're going to come [to the hospital] if she gets a fever. The parents are going to say "Don't freak out, this is gonna happen," and they're more likely to tell you what's gonna happen and what to expect in a different way than a doctor is. [R56; 11 months since diagnosis]

As this mother describes, many parents felt that the candid nature of relationships among parents allowed more meaningful communication of how to cope with their child's care. Many parents described feeling that physicians were too experienced to appreciate the fear and uncertainty parents felt throughout their child's care. Parents described learning these strategies from similar others, and over time gaining the confidence and skills that allowed them to become more savvy health care consumers and advocates for their children.

Parents used the knowledge and resources derived from network ties to advocate for their children. Parents felt confident enough in each other's advice, that some approached their child's clinicians with recommendations of other parents. One father explains,

At that time, I was communicating with several families that had gone through the same thing and basically from them, I let [our son's doctor] know that these families all say that the best course of treatment is to keep him on [this protocol] as long as possible and indefinitely if possible. [R3; 1 year since diagnosis]

Like this father, many parents relied on the information they received from other parents to guide their advocacy for their child's care. Rather than conducting direct medical research in academic journals, the information that flowed through networks of similar others offered synthesized information in a format that was easy for parents of diverse backgrounds to understand.

In some cases, parents also used network connections to collectively advocate for their children. As parents exchanged frustrations and struggles with each other, there were occasions where they came together to approach physicians with their concerns. As a group, they were able to advocate for the needs that arose throughout their children's care. One mother describes a time where parents came together to collectively approach the physicians,

We just started...a program...where the parents get to talk to the doctors and bring up some issues...The last one we had the doctor was really in the hot seat and people were really coming at him with some really [tough questions], Parents said "this is what we deal with, these are the challenges that we have, what do we do about it?" [R54; 3 years since diagnosis]

As this mother describes, parents had challenges associated with their child's care that they felt were not adequately addressed by the hospital and clinicians. This collective advocacy

allowed them to bring these concerns to the physicians in a way that they felt was more difficult for the physicians to dismiss.

Discussion

Research has documented the important role that social networks play in influencing health care behavior and health outcomes (House et al., 1988; Pescosolido, 1996; Thoits, 1982, 1995, 2010). However, as Pescosolido and Levy argue, “at this point in time, we know much more about the empirical finding that having social networks matter than how or why they operate, where they come from, how they are activated or how they are meshed with psychological, biological or clinical factors” (Pescosolido & Levy, 2002: 5). This current study places focus on the network ties formed by individuals experiencing a similar diagnosis who come into contact with each other through the routines associated with their health care. The network ties individuals form with others experiencing a similar illness have received little attention in previous research, yet these findings document that these new network ties to other families experiencing pediatric cancer played an important role in the health care experience. Building upon previous studies which have focused on patient’s participation in illness-related support groups (Barker, 2008), these current findings reveal that parents formed ties with other families experiencing pediatric cancer throughout the everyday routines associated with their child’s care. While many parents did not deliberately foster ties with other parents of pediatric cancer patients, they described brief interactions in waiting rooms and the hospital hallways that influenced their coping processes, access to information, attitudes about the health care community, and advocacy for their child’s health care.

These findings build upon Thoits’ (2011) theoretical argument that individuals who have experienced a similar life stress can offer specialized emotional sustenance and active coping assistance (Thoits, 2011). Parents in the sample exchanged health-related information, caregiving strategies, and strategies for interacting with health care providers. Parents served as role models for each other, and afforded parents the opportunity to observe and compare their experiences to those of other families (Suitor & Pillemer, 2000). This social comparison offered hope, encouragement, emotional support, health-related information and knowledge. There were also negative aspects to comparison with other families experiencing pediatric cancer. Parents experienced distress when they observed the grief of other families who lost a child to cancer.

These findings highlight the importance of the timing of the shared experience among similar others. In previous research, Thoits et al. (2000) found that interactions with similar others who were currently facing a shared stressor improved health outcomes, yet, interactions with similar others whose shared experience was in the past did not change individuals’ health outcomes. Findings from this study highlight the important function of ties to similar others who are collectively experiencing a shared stressor. Findings also reveal the importance of the context in which patients receive their health care for structuring interactions among similar others. In this study, the hospital provided a space where parents interacted while undergoing the routines associated with their children’s care. Due to this, interactions with similar others occurred naturally while parents were actively engaged in managing their children’s health care. This context fostered network flows through both explicit and implicit processes, and parents learned through direct sharing as well as from watching other families actively engaged in their child’s health care. The hospital also afforded parents the opportunity to interact with other families who had differing levels of experience navigating their child’s health care. Parents whose child was recently diagnosed often connected with and heeded the advice of “veterans” who had more experience navigating pediatric cancer care.

Given the changing health care landscape that has been documented in previous research (Heritage & Maynard, 2006; Potter & McKinlay, 2005; Rosich & Hankin, 2010; Timmermans & Oh, 2010), this study shows that networks of experientially similar others play a role in shaping network members' perceptions of the health care experience and their role as patients. Parents in this sample relied on these social networks for health-related information, advice and resources. Findings also show that networks of experientially similar others served an important function by bridging lay and expert knowledge (Barker, 2008). Information derived from network contacts contained sophisticated medical knowledge, which was synthesized into an accessible format that parents could understand. In certain contexts parents were more comfortable being candid with each other than with physicians, and also trusted the information gained through network contacts.

While this research contributes to our understanding of parental networking, there are limitations to note when interpreting findings. These findings support and build upon Thoits' (2011) theoretical argument of the support offered by experientially similar others. However, they do not allow comparison of the differential roles of similar others and significant others. Future research which offers contrast of the support offered by similar others versus significant others would enhance the understanding of these processes in important ways.

Pediatric cancer serves as an interesting case to study parental networking because of the severity of the diagnosis, the rigor of treatment protocols and the immersion into a complicated health care setting. However, unlike some other pediatric diagnoses there is not a large amount of uncertainty surrounding pediatric cancer diagnosis, there are typically clear treatment protocols children begin upon diagnosis, and it is not a contested illness. These factors may create important distinctions between how parents form and use networks when dealing with pediatric cancer versus other pediatric illnesses that should be examined in future research.

Another limitation of this data is that it is egocentric, not sociocentric. Not having whole network data limits the study in several ways. First, data only offer each respondent's (ego) point of view. We did not recruit alters to participate in the study, and therefore do not have data on their perspectives of the tie and network exchanges. Second, data do not permit analysis of network position. An important direction for future research would be to examine how network position impacts network flows and network structures. Finally, these data do not permit analysis of how network ties evolve over time. It may be that as parents are integrated into the network the flows between network members change. Network processes may also change over the course of a child's treatment. Future studies that use longitudinal designs to examine network structure and processes over time would enhance our understanding of networks of experientially similar others in important ways.

These findings show that the natural network of individuals experiencing a common illness meaningfully shaped the health care experience. The parents of pediatric cancer patients in the sample received information, resources, and emotional support through their everyday interactions with other families experiencing pediatric cancer. While the types of support exchanged through this natural network of experientially similar others was similar to the kinds of support documented in in-person and online support groups, this study shows that interactions with other families experiencing pediatric cancer was a central part of the health care experience, and not restricted to parents who sought out these interactions. That is, these networks may have a wider reach than previously documented, and findings suggest that the influence of the network extends to parents who did not seek out connections to other families experiencing pediatric cancer. These network interactions often occurred real time as events were unfolding, which allowed both explicit influences on health care

experiences through direct sharing, as well implicit processes as parents observed other families' and through these observations derived information, beliefs, resources, and emotional sustenance. These implicit network processes made it possible for parents to obtain information, resources, and support through observing other families, and benefit from resources derived from the network without having formal interaction with other network members.

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Table 1

Demographic characteristics of sample.

	% (n) or <i>M</i> ± <i>SD</i> <i>N</i> = 76
Caregiver characteristics	
Gender	
Female	64% (49)
Male	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)
Percent of federal poverty guideline	
Below the federal poverty guideline	22% (17)
100% of the Federal poverty guideline	12% (9)
200% of the Federal poverty guideline	8% (6)
300% of the Federal poverty guideline or more	50% (38)
Don't know/no response	8% (6)
Total	100% (76)
Child characteristics	
Gender	
Male	46% (35)
Female	54% (41)
Total	100% (76)
Diagnosis	
Solid tumor	36% (27)
Liquid tumor	59% (45)
Don't know/no response	5% (4)

	% (n) or $M \pm SD$ $N = 76$
Total	100% (76)
Age at diagnosis ($M \pm SD$)	7.9 \pm 4.7 yrs
Current age ($M \pm SD$)	10.2 \pm 4.8 yrs
Time since diagnosis ($M \pm SD$)	2.3 \pm 4.3 yrs