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Social Support, Flexible Resources, and Health Care Navigation

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Abstract

Recent research has focused attention on the role of patients' and clinicians' cultural skills and values in generating inequalities in health care experiences. Yet, examination of how social structural factors shape people's abilities to build, refine, and leverage strategies for navigating the health care system have received less attention. In this paper I place focus on one such social structural factor, social support, and examine how social support operates as a flexible resource that helps people navigate the health care system. Using the case of families navigating pediatric cancer care this study combines in-depth interviews with parents of pediatric cancer patients ($N=80$), direct observation of clinical interactions between families and physicians ($N=73$), and in-depth interviews with pediatric oncologists ($N=8$). Findings show that physicians assess parental visibility in the hospital, medical vigilance, and adherence to their child's treatment and use these judgments to shape clinical decision-making. Parents who had help from their personal networks had more agility in balancing competing demands, and this allowed parents to more effectively meet institutional expectations for appropriate parental involvement in the child's health care. In this way, social support served as a flexible resource for some families that allowed parents to more quickly adapt to the demands of caring for a child with cancer, foster productive interpersonal relationships with health care providers, and play a more active role in their child's health care.

Keywords

United States; social support; patient-provider interactions; health communication; culture

When confronting a serious illness, people must learn how to navigate the complicated system of health care delivery in the United States. Patients and their caregivers must act as liaisons between teams of physicians, synthesize medical information from multiple sources, and accommodate the logistical demands of appointments, medical procedures, and at-home treatment administration. Theoretical approaches to understanding differences in health outcomes and health care experiences emphasize the importance of flexible resources that some people leverage to gain health advantage (Link & Phelan, 1995; Shim, 2010). These

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flexible resources – such as social support, beneficial social network connections, money, knowledge, power, influence, and interpersonal resources – afford people more agility and skill in navigating the health care system and achieving higher quality medical care. The differential distribution of such flexible resources has been proposed to be a fundamental cause of health inequities because the pathways that connect possession of such resources and health are fluid and multifactorial (Link & Phelan, 1995). Therefore, such resources may contribute to inequalities across a range of health outcomes and across the illness continuum (Link & Phelan, 1995). For example, social support may shape a person's health through a broad range of mechanisms, such as health-related advice as a person is making sense of new symptoms, assistance paying bills so a person does not forgo medical care, or encouragement to engage in health promoting behaviors. In this way, the relationship between a person's receipt of social support and their health is flexible in that the specific mechanisms through which social support shapes health vary throughout a person's life (Link & Phelan, 1995). Cultural health capital theory places focus on how such flexible resources contribute to differences in health care experiences and proposes that the effective deployment of flexible resources is dependent upon both a person's possession of such resources, and the health care system's rewarding of some characteristics and skills over others (Shim, 2010). Cultural health capital theory emphasizes the importance of the health care system as an institution that prioritizes certain approaches to one's own health, such as the knowledge of medical terms and medically relevant information, communication and interpersonal skills, a sense of control over one's health, and the ability to communicate social privilege (Shim, 2010; Chang et al., 2016; Dubbin et al., 2013). Therefore, the cultural health capital framework highlights the importance of both patient attributes, and also how those attributes are perceived and differentially rewarded within health care interactions as playing a critical role in contributing to differences in health care experiences (Shim, 2010). Building upon conceptual innovations advanced by cultural health capital theory (Shim, 2010) recent research has focused attention on the role of patients' and clinicians' cultural skills and values in generating inequalities in health care experiences (Chang, Dubbin & Shim, 2016; Dubbin, Chang & Shim, 2013; Gengler, 2014; Gage-Bouchard, 2017). Yet, examination of how social structural factors shape people's abilities to build, refine, and leverage strategies for navigating the health care system have received less attention. These social structural factors (such as social networks, labor market characteristics, economic resources and family composition) shape people's abilities to meet institutional expectations for patient and caregiver involvement in health care. In this paper I place focus on one such social structural factor, social support, and examine how social support operates as a flexible resource that helps people navigate the health care system. Using the case of families navigating pediatric cancer care this study combines in-depth interviews with parents of pediatric cancer patients, direct observation of clinical interactions between families and physicians, and in-depth interviews with pediatric oncologists to examine: (1) physicians' expectations for parental involvement in the child's medical care, (2) the role of social support in shaping parents' abilities to meet these institutional expectations, and (3) implications for clinical decision-making and health care experiences.

Navigating Pediatric Cancer Care

Having a child diagnosed with a serious illness is a traumatic experience for families, marked by grief, confusion, and fear (Kagawa-Singer, 2011). In order to secure optimal treatment for their children, parents must adjust to the logistical and emotional demands of caring for a seriously sick child while also learning how to navigate the complex health care system (Sobo, Seid, & Gelhard, 2006). As caregivers of seriously ill children, parents must navigate their child's health care which includes communicating with clinicians, coordinating their child's care across numerous physicians, managing treatment outside of the clinical setting, and making decisions on behalf of their children (Markides, 2011; Sobo et al., 2006).

Treatment for pediatric cancer can extend for months or years, and commonly includes chemotherapy, radiation therapy, surgical removal of the tumor, or stem cell transplant. These treatment regimens are intensive, and successful treatment requires collaboration between parents and physicians (Sobo et al., 2006). Physicians train parents to oversee their child's treatment outside of the clinical environment, including administering oral or IV medication; observing and communicating relevant health-related information; monitoring for fevers or other signs of infections; and ensuring compliance with the dietary and activity limitations of their child's treatment protocol (Landier, 2011; Tebbi, 1993). The success of this collaboration to deliver the child's cancer therapy is shaped by parents' relationships with the physicians that care for their children. These relationships are fostered through frequent doctors appointments and in-patient hospital stays, and productive parent-physician relationships play an important role in ensuring that the child receives optimal cancer treatment (Markides, 2011; Sobo et al., 2006). However, this requires parents to have the flexibility and skills to adjust their pre-existing commitments to work and family to accommodate the demands of their child's health care.

The Influence of Social Support on Health Care Experiences

A large body of research on social support and health documents that emotional, logistical, informational, and financial support from personal networks enhances the coping options available to people as they manage a serious illness (Berkman, Glass, Brissette, & Seeman, 2000; House, Landis & Umberson 1988; Pescosolido, 2006; Smith & Christakis, 2008; Thoits, 2011). Support from personal networks (such as financial assistance, transportation, childcare, and emotional support) may reduce non-medical life strains for families, thereby allowing parents to focus more of their attention on their child's health care. Personal networks may also offer informational support that helps families connect with health-related resources, learn strategies for communicating with health care providers, understand medical terminology, and learn about the institutional structure of health care delivery (Berkman et al., 2000; Borgatti, Mehra, Brass, & Labianca, 2009; Hurlbert, Haines, & Beggs, 2000; Smith & Christakis, 2008).

Much of the research on social support and pediatric health care has focused on psychological adaptation and family resilience (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1999, 2001; Rini et al., 2008; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers 2005).

Access to social support is an important factor that helps parents cope with the psychological distress associated with having a child diagnosed with a serious illness (Wijnberg-Williams et al., 2005). For example, access to social support has been found to buffer psychological adjustment for parents of children diagnosed with pediatric cancer (Hoekstra-Weebers et al., 1999, 2001; Rini et al., 2008). Other research has examined the role of social support in improving family resilience to pediatric cancer. Access to help with childcare, transportation, and emotional support helps parents cope with the daily strains of caring for a seriously ill child (Granek et al., 2012; McCubbin, Balling, Possin, Freierdich, & Bryne, 2002).

Building upon research that identifies access to social support as important in shaping parents' coping and adaptation to pediatric cancer caregiving, in this paper I examine how social support shapes parents' strategies for navigating pediatric cancer care. Specifically, I examine the role of social support as a flexible resource that shapes parents' abilities to meet physician expectations for parental involvement in their child's health care. Examination of these processes fills an important gap in the understanding of the factors that contribute to differences in health care experiences. Understanding the factors that help or hinder parents as they adapt to the demands of caring for a seriously ill child is critical for developing strategies to improve health care delivery.

Method

In-Depth Interviews with Parents of Pediatric Cancer Patients

Parents were recruited in the Department of Pediatric Hematology/Oncology at one hospital in the Northeast US. To protect patient confidentiality the psychologist or social worker approached parents, described that researchers were conducting a study on how families cope with pediatric cancer, and asked parents' permission to have their contact information forwarded to the researchers. Eighty-six parents agreed to learn more about the study, however six of these parents did not participate in the study because they either later declined to participate or we were unable to reach them to schedule an appointment for an interview.

Two research assistants and I conducted in-depth interviews with 80 parents of children who were undergoing treatment for cancer between August 2009 and August 2011. The interviewer asked respondents to choose a location convenient to them, and conducted interviews in respondents' homes, coffee shops, and the hospital. The study was IRB approved, and respondents provided written informed consent. A semi-structured interview guide organized each interview, which included questions focused on parents' experiences with social support, personal networks, balancing pre-existing commitments with their child's care, interacting with clinicians, and experiences navigating their child's health care. Interviews lasted between 30 minutes and 2 hours. All interviews were audio recorded and transcribed verbatim.

Clinical Observations and Interviews with Physicians

From October 2013 to January 2014 I conducted clinical observations and interviews with physicians who worked in the same Department of Pediatric Hematology/Oncology. All eight of the pediatric oncologists on the clinical team agreed to participate. On the first day observing each physician I obtained physicians' written informed consent. I asked each physician to give me a short briefing on the patient before each appointment. I did not use an interview guide to structure these conversations (Daly, 2007). Instead, I sought to capture what the physician deemed to be the important information to report on each family. After each clinical observation I briefly interviewed the physician, asking targeted questions about their impression of the family, the family's ability to manage the child's care, factors that shaped clinical decision making, and clarification questions on what I observed throughout the clinical interaction.

When the physician and I entered each exam room the oncologist explained to the child and caregiver(s) present that I was a researcher interested in understanding more about medical interactions and asked for their verbal consent to participate in the study. I observed 73 clinical interactions with 52 different families, and all families invited agreed to participate. I took detailed notes during clinical interactions and physician interviews, and recorded the conversations verbatim when possible. After observations I extracted family demographic information from medical records. There was no overlap between parents in the in-depth interview sample and parents in the clinical observation sample.

Data Analysis

Throughout data collection I read all interview transcripts and observation notes and identified salient aspects of each respondent's experience. After data collection was complete two graduate research assistants and I independently read all interview transcripts and free coded the data, allowing codes to emerge from the data (Charmaz, 2006). The two research assistants and I wrote coding memos that reflected on the codes, patterns among the codes, and early ideas about themes in the data (Charmaz, 2006). At peer debriefing meetings we reviewed and discussed points identified in coding memos (Weis & Fine, 2000). I then developed a codebook to systematically code all data. We used a multiple coder strategy to increase the reliability of data analysis, and one of the graduate student research assistants and I independently analyzed the data (Weis & Fine, 2000). We used the qualitative data analysis software NVivo 8 to assist in managing and sorting the data (Weis & Fine, 2000). I used coded data to sort and compare cases. For example, I grouped families into categories representing high and low levels of social support and systematically compared experiences navigating their child's cancer care. I also sorted and compared physicians' descriptions of families, with one group of cases where physicians perceived the family to be effectively managing their child's care and another group of cases where physicians perceived the family to be struggling to manage their child's care. Though an iterative process of reviewing the data early ideas identified in coding memos became more focused and refined, and patterns in families' experiences emerged. I examined key themes across the three data sources and compared data from the multiple vantage points to increase the credibility of themes (Giacomini et al. 2000). Respondent quotes have been edited to remove potentially identifying information and all names are pseudonyms. In some cases

family characteristics, such as child gender or details of their disease, have been changed to protect the confidentiality of respondents.

Results

Sample Characteristics

Of the 80 parents who participated in the in-depth interviews, 51 were women and 29 were men. Sixty-three parents were white and 16 were black. Sixteen parents were never married, 55 were married, and 9 were divorced. Thirty-seven of the parents had a high school degree or less, 8 had an associates degree, and thirty-five had a bachelors degree or more. Nineteen of the families reported a total household income below the federal poverty line, 20 families fell between the federal poverty line and 299% of the poverty line, and 41 families were above 300% of the federal poverty line. The mean time since child's cancer diagnosis was 2.4 years. All of the children in the study had health insurance. In the state where data were collected all low-income children diagnosed with cancer are eligible for Medicaid. The hospital works with uninsured families to assist with the process of applying for Medicaid coverage.

Ninety-four percent of families in the clinical observation sample were white, 4% were African American, and 2% were multiple races. Seventy-three percent of parents in families observed were married, 19% were divorced, and 2% were never married. Fifty-eight percent of children in the families were insured through private insurance plans and 42% were on Medicaid or Child Health Plus. The mean time since diagnosis was 3.7 years. The 8 physicians observed included both men and women, with a range of practice experience spanning 1 year to over 25 years.

Parental Visibility and Physicians' Impressions of Families—A parent's ability to be present for medical appointments or when the child was admitted to the hospital was an important factor in shaping clinicians' impressions of the family. Physicians used parental visibility in the hospital as a short cut for making judgments about the quality of care the child was receiving at home, treatment adherence, and the family's prioritization of the child's medical care. Physicians relied on parental involvement for treatment adherence and continuity of the child's medical care, and one of the ways that physicians assessed parental involvement in their child's care was parental visibility in the hospital. Physicians expected parents to be present when their child was admitted to the hospital, despite potential competing commitments to work and family. For example, Angela and Charles Jones' thirteen-year-old son was diagnosed with cancer two years earlier. Charles and Angela Jones are married and have four children. Throughout the most intensive parts of their son's cancer treatment Charles managed the care of the children at home which allowed Angela to always be at the hospital with their son. In an interview Dr. Franklin noted Angela's presence in the hospital despite having other children at home. Dr. Franklin said,

I really like them. [Mom] is always here, even though there are [other] kids. At the time of diagnosis the youngest was 1 year old. The dad took care of the baby so that mom could be at the hospital.

As Dr. Franklin explained, physicians expected parents to stay with their children when admitted to the hospital even if they had competing demands, for example having other children. These perceptions of parental involvement shaped Dr. Franklin's assessment of the family as being committed to their child's cancer care and contributed to her "really liking" this family.

Physicians relied on parents to be partners in delivering treatment and monitoring the child's condition, and this partnership was complicated when parents were not present for clinical interactions. This was illustrated during one clinical observation of the Ward family. Kate and Tom Ward's 14-year-old daughter Emily had a bone marrow transplant and was in the intensive care unit due to complications. Emily was on a highly restricted diet that the physicians believed she was not following. Prior to her transfer to the intensive care unit Emily had given differing descriptions of what she had been eating to the nutritionist and nurses, and the physicians were concerned that her parents were not present to provide accurate information. Dr. Sussman, Emily's primary oncologist discussed the case with Dr. Russo, who had been on call over the weekend,

Dr. Sussman: What did mom say?

Dr. Russo: She wasn't here. She was at work.

Dr. Sussman: She went to work?

Dr. Russo: I think she has already used all of her Family Medical Leave and sick time.

Dr. Sussman: But she has a kid in the ICU.

As this conversation among physicians shows, physicians expected parents to be present in the hospital. While acknowledging the need to balance competing commitments, Dr. Sussman believed that the child's mother should be present when her daughter was in the Intensive Care Unit.

Physicians also used parental visibility in the hospital as a signifier of the quality of care the child was receiving when at home. Amy Henderson is a single mother and at the time of observation her fourteen-year-old son John had been undergoing therapy for bone cancer for a year and had finished his initial treatment. When John was admitted to the hospital throughout his cancer treatment Amy did not stay in the hospital with her son. Dr. Sussman explained,

Mom seldom came when [John] was on therapy. Mom would drop [John] off and then we would see her again when she picked [John] up. I get the sense that there isn't much oversight at home. I mean if mom isn't ever here, how much can she be around at home?

Dr. Sussman's perception of parental involvement shaped her judgment of the quality of care John received while at home. Parental visibility in the hospital shaped physicians' perceptions of adherence to treatment protocols, the quality of care the child was receiving at home, and parents' involvement in their child's cancer care.

The Role of Social Support in Shaping Parents' Visibility in the Hospital—

One of the common experiences among parents was struggling with the logistics of time commitments to their jobs, caring for their other children, and adapting to the demands of caring for a child with cancer. Parents who had support from their personal networks had more coping options available to them to help them balance these competing demands and spend more time at the hospital when their child was admitted or receiving treatment. For example, Marie Hay is a single mother and after her daughter's cancer diagnosis she needed to develop new strategies to balance her commitments to work with the new demands associated with her daughter's medical care. Throughout this time she relied on support from her family members. She explained, "My son came and sat with [my daughter] because I never left her [at the hospital] unless somebody else was here. He sat with her so I could go to work. I was only getting 20 hours at work, because I was at the hospital all of the time." Some parents also had network members who could stay at the hospital when the parent could not be there. For example, Mary McCann had family members who cared for her daughter while she was at work. She explained,

My aunt will take [my daughter] a lot when she doesn't feel well and I have to go to work...She is a great help to me as far as transportation and following through, getting [my daughter] to take her medicine, getting hydrated, relieving me so I don't have to be stressed out about working all of the time and how am I gonna leave [my daughter] at the hospital by herself while I work... I'm the only one working now and I have to work otherwise we won't have a place to live.

As Mary McCann explained, some parents had social network members who offered support to enhance parents' abilities to be at the hospital (such as providing transportation) or stayed at the hospital with the child when the parent could not be there ensuring that the child was not left alone in the hospital. Another mother described how social network members helped her get to and from the hospital, "I lost my job...that is when I heard about [my son's] diagnosis. Two months later I had to get rid of my car. I didn't have transportation. [My sister] is helping me get back and forth to the doctor."

In addition to this logistical support, some families received financial assistance from their personal networks. This financial support helped some parents make the decision to leave their jobs to care for their child with cancer. Susan Grove explains, "I quit working...We were lucky; we had a lot of support. My dad came to me and said 'If you ever need money, don't ask me, just tell me. Just tell me and I will give it to you.'" As Susan Grove describes, having support from personal networks in the form of financial support eased the demands on some parents as they renegotiated their household responsibilities to manage their child's cancer care.

Personal networks were also a source of health-related information and resources for some parents. This information helped familiarize parents with medical terminology and procedures, and allowed them to have a better understanding of their child's treatment. Alicia Stewart explained,

We have a couple of registered nurses in the family, so everyone was on the computer trying to find out about [her diagnosis]...My sister in law who is a nurse

had read her paperwork for me and said ‘oh yeah, did they tell you it is in her bone?’ And I’m like, ‘no, they said bone marrow. Nobody ever told me it was in her bone.’ And my sister in law said, ‘well that is how it is worded here in her file, be careful, watch for these things.’

Like this mother, some parents had people within their personal networks who shared medical knowledge that helped parents understand their child’s treatment. These network members were able to translate the highly specialized medical terminology, treatment protocols, and health care procedures for parents. This informational support helped some parents more quickly adapt to their child’s cancer care and have more productive interactions with clinicians.

Other parents lacked support from their personal networks, making it difficult to always be present for medical interactions. For example, Robert Williamson is a single father and works in construction. Throughout his son’s cancer therapy Robert experienced difficulty balancing the new demands associated with his child’s cancer care. He explained, “[It has been hard] getting the work schedule and come to the hospital and trying to find some type of way to watch my other son, just trying to go to work and keep paying my rent and bills.” As Robert Williamson described, parents with little social support expressed difficulty maintaining commitments to work, caring for their well children, and being at the hospital. Another mother explained,

My family says they will do this, or they will do that, but when it comes down to it we’ve got to ask them and sometimes they give us a hard time. Like they know we come [to the hospital] every Monday and Tuesday, and we have another younger son. You would think somebody would just say, ‘okay, every time you guys have to go to the hospital we’ll watch [your younger son]. But every week we’ve got to hunt somebody down.

Due to demands of balancing work and other household responsibilities, some parents who lacked network support were not able to stay with their child when they were admitted to the hospital, or accompany their children to medical appointments. Parents who had help from their network members were given more agility in balancing these competing demands, and this allowed parents to take on a role in their child’s care that was more visible to clinicians.

Parental Visibility, Physician Decision Making, and Health Care Experiences—

Throughout clinical interactions physicians assessed how much health-related responsibility they could place on parents. Physicians used these assessments of parental competence to make family-specific determinations of what aspects of the child’s care could be managed at home, and what needed to be administered by clinicians. For example, while preparing to examine a patient an oncology resident reviewed the patient’s medical record and recent lab results. After reading the medical record the resident asked Dr. Clough, an attending physician,

Resident: Do we send kids home to finish therapy for fever and neutropenia if afebrile for 24 hours and culture negative for 48 hours?

Dr. Clough: It depends, you have to assess if the family can handle that.

As Dr. Clough described to the resident, physicians believed that families were differentially equipped to manage their child's treatment outside of the clinical setting. These assessments of what families "can handle" influenced physicians' treatment decision making. Physicians used clinical interactions with parents as a means of making judgements of parents' motivation and aptitude to comply with treatment guidelines while at home. The amount of time parents spent with their children in the hospital was an important variable in shaping parents' abilities to build relationships with clinicians and foster the impression that they were highly motivated regarding their child's care.

When parents were able to spend more time at the hospital they developed closer relationships with clinicians who got to know their family more intimately. These closer relationships often fostered trust and more open communication between parents and clinicians. For example, Nancy Marty is a single mother whose 9-year-old son had been undergoing treatment for cancer for 2 years. After her son was diagnosed with cancer Nancy's extended family cared for her one-year-old daughter, which allowed her to spend more time in the hospital with her sick son. She explained,

I live with my aunts right now, so they are a big help...I felt okay going home. Because I have a one year old, so we couldn't stay up [at the hospital] every night. But I felt comfortable leaving him with the staff and I knew that if anything happened, they would be calling. When I would come in right after work they were telling me everything that was going on, so I felt comfortable.

As Nancy Marty described, support from network members allowed some parents to form close relationships with their child's health care providers. Help with household tasks and childcare from her aunts allowed Nancy Marty to spend more time in the hospital with her sick child while also remaining in the paid workforce. This network support helped Nancy balance care of her other child, work responsibilities, and her child's cancer care. As a result, Nancy felt that she was able to build trusting and productive relationships with the nurses and physicians caring for her child with cancer.

Parents' difficulty in meeting clinicians' expectations to not leave their child alone in the hospital sometimes led to a breakdown in the relationship between parents and health care providers. Jennifer Cleary is a divorced mother of four children and throughout her son's cancer therapy Jennifer struggled to manage her work hours, care for her other children, and her son's cancer care. She explained,

I went to work while he was in the hospital, it was pretty hard for me, being a single mom and doing it all on my own. But I've got to work; I've got to pay my bills. Once they did a biopsy, and I didn't hear anything, and the results should have been in. So I called [the hospital], I was working, and they said 'No nothing yet.' I waited a little while and I called later and they said 'oh yeah, he is going in for [a procedure].' I was like, what? No phone call, no nothing?' I was at work and they said I could go, so I took the bus [to the hospital]. I got there at 6pm, but it ended up that he went in for [the procedure] at 5 o'clock.

Like Jennifer Cleary, parents sometimes felt they were excluded from health care decisions because they were not at the hospital when decisions were being made. As Jennifer

describes “doing it all on my own,” parents who lacked network support had limited options in how they could balance competing demands to their jobs, household responsibilities, caring for their well children, and their child’s cancer care.

Support from personal networks also shaped parents’ abilities to meet the demands associated with the rigorous treatment protocols for pediatric cancer. The child’s treatment often required frequent medical appointments and long stays in the hospital, many of which occurred on short notice as their child’s health fluctuated throughout treatment. Parents who did not have support from their personal networks had increased difficulty adapting to these shifts in their child’s health and treatment. For example, Bridget O’Shey is a single mother of three children, and described her difficulty keeping up with the demands of her daughter’s care on her own,

One of the biggest problems I have with the staff is in regards to getting to appointments on time. They do not give me enough time to get to the hospital, since I have to get my [other] children on the bus. When I have been late the receptionist on the pediatrics floor has been rude to me, and told me that they can’t get any of the tests done that were scheduled because we were late. They always blame me.

As Bridget O’Shey described, some parents struggled to keep up with the demands, and often shifting needs, of their children’s cancer treatment. Bridget O’Shey perceived that clinicians had expectations for how she should manage her child’s cancer care, and describes feeling that “they always blame” her for not being able to get to appointments on time. However, she also notes her limited options and struggle to balance her pre-existing commitments while also learning to manage her daughter’s complicated health care needs.

The expectation that parents play a visible role in their children’s cancer care shaped physicians’ impressions of families and framed clinical interactions. For example, when describing Andrew, one of his patients, Dr. Rockwell noted that Andrew’s mother was often absent throughout her son’s care. Dr. Rockwell described the family,

[Andrew] came by bus because mom works at a [restaurant] and was afraid she would loose her job. She comes across as kind of ambivalent. When I told them the prognosis was bad she didn’t show any emotion. In fact she left.

Andrew’s mothers’ lack of visibility at the hospital shaped Dr. Rockwell’s impression of her approach to her son’s care, which he interpreted as ambivalence about her son’s cancer treatment. While expressing his empathy for this mother’s need to balance the demands of work and her child’s medical care, the mother’s absence from the hospital also shaped Dr. Rockwell’s impressions her prioritization of the child’s medical care. Later, during a clinic appointment Andrew’s mother asked Dr. Rockwell questions that revealed that she did not understand the medications her son was on.

Dr. Rockwell to Andrew: So you are still on Bactrim?

Mom: What is Bactrim?

Dr. Rockwell: It is a medication for a certain kind of infection.

Mom: IV?

Dr. Rockwell: No, it is a pill.

When Andrew's mother revealed confusion over her son's medications Dr. Rockwell attributed her confusion to not being present throughout her son's care. After the appointment Dr. Rockwell explained, "When Andrew's mom asked about Bactrim that is because he takes charge of all of his medication. He takes control of all of this care." In this way, parental visibility in the hospital was an important factor in shaping how physicians interpreted the family's dispositions towards the child's cancer care, parents' questions, styles of interaction, and ability to manage their children's cancer care.

Discussion

Theoretical approaches to understanding differences in health outcomes and health care experiences emphasize the importance of flexible resources that some people leverage to gain health advantage (Link & Phelan, 1995; Shim, 2010). Findings from this study improve understanding of the mechanisms that underlie the development and deployment of strategies for navigating the health care system and highlight the role of social support as a flexible resource that helps people meet institutional expectations for appropriate involvement in health care. Findings show that parents who had support from their personal networks had more coping options available to them, which allowed them to find their own way to balance work, finances, household responsibilities, and their child's cancer treatment. Parents who had help from their network members were given more agility in balancing their competing demands, and this allowed parents to take on a role in their child's care that was more visible to clinicians. This fostered trust and more effective communication between clinicians and parents. In this way, social support served as a flexible resource for some families that allowed parents to more quickly adapt to the demands of caring for a child with cancer, learn about the highly specialized oncology care, foster productive interpersonal relationships with health care providers, and play a more active role in their child's health care.

Cultural health capital theory highlights the implicit institutional norms and expectations regarding appropriate strategies for navigating health care that advantage patients who display more cultural health capital (Shim, 2010). Patients who have more cultural health capital have cultural skills, knowledge, styles of interaction, and health related attitudes that are aligned with the values and preferences of clinicians (Shim, 2010). Building upon conceptual innovations advanced by cultural health capital theory (Shim, 2010) recent research has focused attention on the role of patients' and clinicians' cultural skills and values in generating inequalities in health care experiences (Chang, Dubbin & Shim, 2016; Dubbin, Chang & Shim, 2013; Gengler, 2014; Gage-Bouchard, 2017). These studies show that patients who display relevant medical knowledge, communication skills, a proactive stance towards health, self-discipline, and future orientation are able to leverage these attributes to have more optimal health care encounters (Gengler 2014; Chang et al. 2016; Dubbin et al. 2013; Lutfey & Freese 2005; Gage-Bouchard, 2017). Yet, a fundamental component of developing, refining, and using these resources is having the ability to devote time and attention to clinical encounters. Findings from this study document the role of

social network support as a flexible resource that can shape people's abilities to build, refine, and leverage cultural strategies for navigating the health care system.

Previous research documents that some people have life experiences that equip them with more understanding of "the rules of the game" when interacting with societal institutions such as the health care system (Lareau, 2015:1). Patients and caregivers with more cultural health capital may be more aware of clinical expectations that parents be visible and display active engagement in the child's health care delivery. These families may therefore direct social network support to help facilitate the parents' meeting of such institutional expectations. Other families may have social network support, but less cultural health capital, and therefore direct social network support to help the family in ways that are less valued by clinicians (for example, to enable the child attend a soccer game). These findings highlight the important interplay between structural factors and cultural knowledge. One important direction for future research is to examine the relationship between cultural health capital and the differential deployment of social network resources.

Previous research documents that in addition to social support patient characteristics such as race, social class, and gender play important roles in influencing physicians' assessments of patients, clinical interactions, and treatment decision-making (Joseph & Dohan, 2009; Lutfey et al., 2008; Lutfey & McKinlay, 2009; Lutfey Spence & Grace, 2016; Tritter, Lutfey & McKinlay, 2014; van Ryn & Burke, 2000). An important future direction is to understand how family characteristics, such as parental marital status, gender, race, and SES shape differences in the social network resources available to parents, how parents use social network support, and how clinicians perceive these network resources. Specifically, research should examine how social support interacts with other parent characteristics, such as the parent's communication style and self-presentation, to shape relationships with clinicians. For example, a social network member may offer informational support by sharing cancer-related treatment information. However, the physicians' assessment of the relevance and reliability of the information, the patient's interactional style, and the nature of the patient-physician relationship in past encounters may shape the influence this social support has on clinical interactions. Understanding how social characteristics shape both access to specific kinds of health-related social support from network ties, and how specific types of network resources are evaluated and perceived by physicians is an important direction for future research. Related to this, understanding the relative importance of different kinds of social support in shaping health care experiences is important for designing targeted clinical interventions. Nuanced understanding of the influence of different kinds of social support (such as informational, emotional, and logistical support) on health care experiences is critical for understanding which kinds of support services are most needed for parents that are not able to access particular types of support through personal networks.

While these findings extend the understanding of the role of social support in shaping families' health care experiences, some data limitations should be noted when interpreting findings. While the data offers nuanced understanding of families' experiences, the design does not allow disentanglement of personal network experiences from other family characteristics. Parents who have compounding difficulties may have both less support and more difficulty navigating institutions such as health care. While I was able to account for

many family characteristics in the analyses, I cannot fully disentangle these family experiences. One important direction for future research is to examine how social support experiences vary across race, class, and gender. All data for these analyses were collected in one hospital dedicated to cancer care, and all parents were caring for a child diagnosed with cancer. Future research should build upon these findings to examine whether the availability and nature of support from personal networks varies among families coping with different types of illness, or other kinds of acute stress. The extended nature of cancer therapy may place unique demands on parents to manage their child's medical care and amplify the importance of parent-physician relationships. An important direction for future research is to examine these processes in other health care delivery contexts, such as emergency care and routine medical care.

The passage of the Affordable Care Act has highlighted a national priority to increase access to health care in the United States. Yet, access to health care is often thought of as synonymous with people's ability to pay for medical care. These findings highlight the many barriers to health care, beyond health insurance status, some patients face in the US. Findings from this study show that within the current system of health care delivery in the United States the burdens associated with caring for a seriously ill child fall on parents and families' social networks. This makes access to social support an additional mechanism of disadvantage for some families. These findings highlight the need for policy and interventions that focus on assisting parents in balancing the demands associated with caring for a seriously ill child, which include maintaining family finances, caring for their other children, and managing their sick child's medical care. Policy and intervention aimed at reducing the burden of these competing responsibilities would increase parents' abilities to meet institutional expectations, build productive relationships with physicians, and manage their child's treatment outside of the clinical setting. Policy that offers extended job protection and financial support would allow parents to take time off of work to meet the intensive demands associated with caring for a seriously ill child. Additionally, programs that offer daily in-home medical support would reduce the amount of medical responsibility being placed on parents to oversee the child's medical care outside of the clinical environment. Efforts to improve access to high quality health care need to account for parents' differential abilities to manage their children's medical care on their own.

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Highlights

- Social support helps people meet institutional expectations of caregivers.
- Parents who had support from their personal networks had more coping options.
- Social support helped parents balance competing demands (i.e. work, childcare).
- This allowed parents to make their caregiving roles more visible to clinicians.
- This fostered trust and effective communication between clinicians and parents.