



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.

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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 and Phelan, 1995; Shim, 2010). These 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 and Phelan, 1995). Therefore, such resources may contribute to inequalities

across a range of health outcomes and across the illness continuum (Link and 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 and 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

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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 et al., 2016; Dubbin et al., 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.

1. 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 et al., 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, 1992). 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.

2. 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 et al., 2000; House et al., 1988; Pescosolido, 2006; Smith and 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 et al., 2009; Hurlbert et al., 2000; Smith and Christakis, 2008).

Much of the research on social support and pediatric health care has focused on psychological adaptation and family resilience (Hoekstra-Weebers et al., 1999, 2001; Rini et al., 2008; Wijnberg-Williams et al., 2006). 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., 2006). 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 et al., 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.

3. Method

3.1. 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

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