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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.

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#### 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 indepth interviews with 76 parents of pediatric cancer patients in one hospital setting, this paper examines the relationships parents form

#### 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

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.

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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

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