Understanding the Organizational and Institutional Origins of
Social Support in a Cancer Support Center

A dissertation submitted to the College of Communication and Information
of Kent State University in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

by
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August, 2016
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Acknowledgements

Many individuals have contributed to and supported me in the completion of this dissertation and my doctorate. I would like to acknowledge some of people who have been my support system throughout this process.

First, I would like to thank my dissertation committee: Drs. Rebecca Cline, George Cheney, Janet Meyer, and Alicia Crowe. My advisor, Rebecca Cline, has been a constant source of support to me. She has guided me through this long and rewarding journey. I am extremely thankful to her for being my mentor. Additionally, I am grateful to George Cheney for his willingness to look at early versions and offer valuable insights into the conceptualization and realization of this study. I would also like to thank Janet Meyer for her comments on this work and her help with the logistics of finishing a dissertation. Finally, I am sincerely grateful to Alicia Crowe for her help with developing the methodology for the present study. I would also like to convey my thanks to the College of Communication and Information and its staff for their ongoing support.

This study would not have been possible without the support of the staff and clients at the Cancer Support Center on which it is focused. In particular, I am very thankful to the Program Coordinator at the Center for her help with recruiting and scheduling interviews. Her kindness and understanding helped to make this project a realization. I am also grateful to the other staff members and volunteers who helped me to coordinate participants and were always helpful. It goes without saying (but I still would like to say it), I am immensely grateful to the individuals who took the time to participate in this study. Their experiences and stories were illuminating and provided rich insights into the nature of social support in healthcare.
Finally, I would like to thank the many colleagues, friends, and family members who have been my support system. Although these individuals are too numerous to name all here, I would like to make sure I thank some of you individually. Thank you to my fellow doctoral students in the CCI Ph.D. program and especially, Maja, Will, and Shawn. You have all been a huge help to me. Thank you to my close friends Laura and Chelsea for your continued friendship and support. I am extremely grateful to my loving and caring family. Thank you to my grandparents, Sebastian, Ruth, Judy, and Dick, for being there to cheer me up on cloudy days. To my brother, Brent, and sister, Jordan, I would like to say how grateful I am to have both of you in my life. Thank you to my wonderful parents, Rick and Laura. Both of my parents have always inspired me to keep working hard and have made me the person I am today. Last, but certainly not least, I am thankful to my awesome husband, Brian. Brian picks me up when I am down, helps me to keep things in perspective, and always, always makes sure that dinner is ready when I’m too preoccupied – thank you!
Chapter I

Introduction

The present study explored how, from the perspective of clients,\(^1\) the communication of social support is institutionalized in healthcare settings. Although researchers previously have examined social support communicated by healthcare professionals in the context of provider-client relationships (e.g., Street, Makoul, Arora, & Epstein, 2009), very little research has examined the roles of healthcare organizations and the healthcare institution in facilitating or obstructing the opportunities for and abilities of healthcare providers to communicate social support to their clients (Ansmann et al., 2014; Stone, 2013).

This study was guided by the overarching research question: *What is the nature of social support that clients experience and perceive as institutionalized in healthcare organizations?*

Specifically, this study explored how people diagnosed with cancer (i.e., clients) perceive social support communicated within the context of a Cancer Support Center and, more broadly, within the healthcare institution. The following chapter (a) provides the rationale for the study; (b) presents a case exemplar, a Cancer Support Center, as the focal organization for the study; (c) presents a brief argument for benefits of the use of a case exemplar; and (d) provides an overview for the remainder of the study.

Rationale

Researchers have not previously conducted research that focuses on how social support is institutionalized or comes to be perceived as institutionalized in healthcare settings; thus, this area of study represents a gap in the extant literature. The examination of communication in a

\(^1\) The term “client(s)” is used in the present study in lieu of the term “patients.” The term “patient” can be disempowering and stigmatizing (e.g., Mathieson & Stam, 1995). Further, it may imply that a person who has been diagnosed with cancer is “sick” or in treatment (Harwood & Sparks, 2003). In order to prevent stigmatizing and/or mislabeling individuals, the present study used the term “client(s)” rather than “patient(s).
cancer support organization magnified the processes that may indicate the institutionalization of social support, because these organizations have the mission to provide support to people diagnosed with cancer and their families. Thus, investigating the perceived institutionalization of social support in this context made potential institutionalizing processes more apparent and more readily observable. Furthermore, cancer support organizations have been neglected as a context for in-depth examination in the arena of organizational health communication research. Together the Cancer Support Center and, more broadly, the healthcare context, provided a rich area for the exploration of the perceived institutionalization of social support. Additionally, social support is relevant both practically and theoretically when considering the health-related needs of people diagnosed with cancer. Specifically, investigating the ways in which social support leads to better health outcomes advances scholarly understandings of supportive communication in an institutional context and provides practical insight for healthcare organizations on how their supportive behaviors are beneficial to clients.

**Institutional approaches to examining health communication.** The present study expands institutional approaches to understanding health communication. Specifically, the present research considered clients’ perceptions of organizational and institutional levels of influence on social support they experienced within healthcare organizations and in the healthcare institution at large. As such, the present study applied institutional theory and organizational culture conceptualizations to provider-client contexts.

Early in the study of health communication, researchers realized the need to focus on how healthcare organizations shape the communication that occurs between healthcare providers and clients (e.g., Costello & Pettigrew, 1979; Nussbaum, 1989). However, as the study of healthcare communication grew, the investigation of institutional and organizational influences
became secondary to the study of the interpersonal dimensions of the provider-client relationship (Street, 2003). Some health communication researchers have argued that the provider-client relationship, in an interpersonal sense, is the most important subject of study for health communication researchers (Duggan & Thompson, 2011). Yet, such arguments often neglect to acknowledge how healthcare organizations and, more broadly the healthcare institution, shape provider-client communication (Real, 2010; Real & Street, 2009).

The present research focused on how organizational and institutional norms influence provider-client communication, and more specifically supportive communication. Provider-client communication occurs within organizational and institutional settings (Real, 2010; Real & Street, 2009). Organizations, and the institutions to which they belong, have a very real influence on how organizational members (e.g., physicians, nurses, social workers) communicate with each other and individuals who they may encounter as part of their work (e.g., clients) (Lammers & Barbour, 2006; Lammers & Lambert, 2016). Healthcare asserts itself as an institution designed to provide healing and care (e.g., Lammers, Duggan, & Barbour, 2003; Miller & Considine, 2009; Shi & Singh, 2012). However, whether healthcare organizations and healthcare as an institution truly exhibit a caring persona through the communication of social support to clients has been unclear; the present study attempted to understand this social phenomenon.

Organizational communication scholars have not considered whether social support can be institutionalized in the same ways that other organizational processes (e.g., rules, practices) are institutionalized. The present study investigated communication processes that indicate the institutionalization of social support. Within sociology, social support has been examined as a byproduct of institutionalism (i.e., organizational members who adhere to the same institutionalized norms and behaviors also provide social support to each other; Oliver, 1991).
Further, researchers recently have found that social support offered to clients by healthcare providers can be facilitated and/or impeded by organizational and institutional rules and conditions (Ansmann et al., 2014; Stone, 2013). However, understanding if, how, and to what extent social support is institutionalized or is perceived to be institutionalized in healthcare represents a current gap in the literature.

Researchers have examined social support mostly in personal relationships, such as family and friends. Perceptions of social support in professional relationships (e.g., provider-client) have not received the same degree of attention. This is not to say that communication researchers have entirely ignored the fact that healthcare providers actively use supportive communication when interacting with clients. Research has demonstrated that social support does take place in the healthcare institution between providers and clients (e.g., Neuling & Winefield, 1988; Sloan & Knowles, 2013). However, research has not specifically considered the role(s) that organizations and institutions play in healthcare professionals’ abilities and opportunities to provide social support to clients. Further, researchers have not considered whether clients perceive and experience social support as emanating from – or on behalf of – organizations and the institution, rather than being perceived solely as the products of interpersonal interactions with individual providers.

**Social support and better health.** For more than four decades researchers have studied the associations between social support and positive health outcomes (e.g., Goldsmith & Albrecht, 2011; Roy, 2011; Uchino, 2004). In the context of the present study, social support is critically important for people diagnosed with cancer. People diagnosed with cancer are in need of social support to help them manage the stress that accompanies cancer experiences (e.g., Dunkel-Schetter, 1984; Helgeson & Cohen, 1996; Uchino, 2004). Research has shown that social
helps to buffer the stressors associated with health crises and, thereby, leads to better health outcomes (e.g., Cohen & Wills, 1985; Uchino, 2004).

The present research considered whether clients perceive benefits due to social support experienced within institutional contexts. Specifically, the present study investigated what benefits (social, health, other) clients perceived to result from social support they experienced in a healthcare organization (specifically a cancer support center) and within the healthcare institution at large.

**Cancer as a context.** The present study examined cancer as the particular healthcare context. Within the U.S., the magnitude of cancer makes it one of the most pervasive types of diseases. More than one million people are diagnosed with cancer each year in the U.S. (National Cancer Institute, 2015a). In 2014, more than half a million Americans died of cancer, making it the second leading cause of death in the U.S. (American Cancer Society, 2014a; Centers for Disease Control and Prevention, 2014a). Additionally, more than one third of all U.S. citizens will have cancer at some point in their lives (National Cancer Institute, 2015a). As such, almost everyone is affected, either by being diagnosed and/or knowing someone who is diagnosed with cancer (Mukherjee, 2010). Moreover, because so many individuals are affected by cancer, the support needs of this population are quite large, making the cancer care context important for the present research.

The magnitude of cancer within the U.S. carries with it enormous societal costs. According to the Centers for Disease Control and Prevention (2015), in 2010, financial costs associated with cancer care in the U.S. totaled $157 billion. Historically, treating and finding a cure (or cures) for cancer has been one of the largest health initiatives in U.S. history (Mukherjee, 2010). However, the societal investment in research and treatment does not
outweigh the personal costs that individuals who are dealing with cancer incur.

Experiencing cancer can be physically, emotionally, and financially straining for both people diagnosed with cancer and their families (American Cancer Society, 2014b). As such, they often are in need of social support throughout treatment and beyond.

Cancer treatment is physically demanding, if not painful, and often affects the ability to live a normal life. However, research has shown that receiving adequate social support is associated with better physiological health among people diagnosed with cancer (e.g., Neuling & Winefield, 1988; Zaza & Baine, 2002). Cancer diagnosis and treatment also can be emotionally painful experiences and can place mental health at risk. Most people experience cancer-related issues that affect their psychological adjustment (e.g., depression, anxiety) at some time following their diagnosis (American Cancer Society, 2013). As a result, people diagnosed with cancer may require counseling or other support resources to help them with the emotional and mental side effects of cancer. Research suggests that having access to adequate social support has beneficial mental health consequences (e.g., Hegleson & Cohen, 1996; Uchino, 2004).

Finally, cancer treatment in the U.S. is expensive. People diagnosed with cancer and their families often face the dual daunting tasks of navigating the complex U.S. healthcare system, in order to receive needed medical treatment (Quillin et al., 2009), and paying for that treatment. Although personal financial costs of cancer vary widely, based on the type of cancer, duration of the treatment, and quality of medical insurance, cancer treatment constitutes some of the most expensive healthcare services available (American Cancer Society, 2014a). Further, because of the physical strains and time spent on treatment, people diagnosed with cancer often lose productivity (e.g., ability to work) (Centers for Disease Control and Prevention, 2014b). Sloan and Knowles (2013) have argued that because people diagnosed with cancer face many financial
challenges, and the cost of cancer treatment is so high, healthcare providers have an ethical responsibility to help them gain access to the information and resources (i.e., social support) needed to manage these concerns and related stress.

**Challenges in obtaining social support faced by people diagnosed with cancer.** People diagnosed with cancer experience many challenges when it comes to meeting their medical and psychosocial needs. Specifically, their social support needs (e.g., needs for adequate information, empathy, financial counseling) often go unmet (e.g., Hegleson & Cohen, 1996; Sloan & Knowles, 2013). Hegleson and Cohen’s (1996) review of literature examined the support needs of people diagnosed with cancer and found that they often experience barriers to receiving adequate support. Specifically, people diagnosed with cancer often have physical limitations that may make interacting with others more difficult. Further, they may experience stigma related to their disease, which may cause them to retreat from others socially – or – others to retreat from them (e.g., Mathieson & Stam, 1995). Additionally, because cancer is an isolating disease, they may experience loss of their sense of normalcy and their identity (Charmaz, 1983, 1995; Mathieson & Stam, 1995). These factors all make obtaining social support challenging for people diagnosed with cancer, which is particularly problematic because social support is critical to the effectiveness of their coping processes.

Healthcare organizations and the healthcare institution may be in a unique position to help meet the social support needs of people diagnosed with cancer that otherwise would be under- or unfulfilled. Specifically, healthcare organizations may be able to offer social support (e.g., information, empathy) that other social ties (e.g., family members, friends) may be unprepared – or unable – to provide. Further, people diagnosed with cancer spend an inordinate amount of time in healthcare organizations and the healthcare institution after they are diagnosed.
with the illness (e.g., visiting with physicians; having surgical procedures, chemotherapy and radiation treatments). As a result, they often are specifically in need of support resources to help them navigate the healthcare system (Quillin et al., 2009; Sloan & Knowles, 2013), as well as to manage the emotional and physical strain that often goes along with diagnosis and treatment (e.g., Helgeson & Cohen, 1996).

**Cancer support initiatives in healthcare.** Providing adequate support to people diagnosed with cancer throughout their treatment and beyond is an integral component of effective cancer treatment. In 2012, the American College of Surgeons’ (ACS) Commission on Cancer (CoC) released the most recent version of their *Cancer Program Standards* (2012) The ACS is an accrediting body for cancer programs within the U.S. and Puerto Rico. Historically, the ACS was the first accrediting body for cancer programs in the U.S. and has continued to evaluate diagnostic and cancer treatment services

The *Cancer Program Standards* specify cancer care requirements for U.S. healthcare organizations that have an affiliation with the ACS. Programs that do not meet the ACS standards lose their accreditation. In the U.S., more than 70% of the healthcare organizations that provide cancer care hold ACS accreditation, making the ACS standards the benchmark for cancer care.

The ACS standards specify the types of support services that affiliated healthcare organizations must provide to people diagnosed with cancer, either directly or by creating partnerships with other organizations (e.g., cancer support organizations) that will, in turn, provide the requisite support. In the 2012 edition of the standards, the ACS added three standards related specifically to support services. These support services all focus on psychosocial needs. Further, the ACS required accredited organizations to phase in these particular support services
The first standard focuses on the client navigation process. Organizations that provide cancer treatment are required to provide clients with the resources (i.e., access to medical care, access to psychosocial care) necessary to effectively navigate the healthcare system. Further, the ACS recognizes that clients often encounter barriers to care (e.g., socioeconomic barriers). As such, standards related to the client navigation process were designed to help clients navigate the healthcare system in a manner that helps them to overcome such barriers. The second standard focuses on providing clients with screening for psychosocial distress (i.e., “psychological, social, financial, and behavioral issues that can interfere with treatment” (ACS, 2012, p. 76)). Screening methods can vary by organization (i.e., the ACS standards do not stipulate a required assessment mode (e.g., clinical assessment, self-report/questionnaire)). This screening process effectively should determine if the client’s psychosocial needs are being met. When clients are identified via the screening process as having psychological distress, the standards indicate that the organization should refer the client to psychosocial care (e.g., counseling services). The final standard requires that organizations that provide cancer treatment provide their clients with a survivorship care plan (i.e., a comprehensive summary of the client’s treatment that serves as an informational resource). The purpose of the plan is to keep a detailed record of care that may “otherwise get lost in transitions from the care they received during treatment through the phases of their life or stages of their disease course” (p. 78).

Accredited cancer care organizations must meet the ACS standards directly, by offering these services within their organization, or indirectly, by partnering with a cancer support organization that can offer services otherwise unavailable within the cancer care organization. Meeting the standards identified by the ACS currently is not achievable in all healthcare
organizations (e.g., due to limited resources). Many healthcare organizations are not currently equipped to meet the support needs of clients that are required by the standards. However, when healthcare organizations (e.g., hospitals, clinics) are unable to meet those needs, they can partner with cancer support organizations (see Cancer support organizations below) (Matthews, Baker, & Spillers, 2002).

**Cancer support organizations.** Cancer support organizations are a unique organizational context because their explicit mission is to provide support to people diagnosed with cancer (Rosenbaum & Smallwood, 2013). Thus, logically, one can expect social support processes to be amplified, or more obvious and readily observable in an organizational and institutional sense, in cancer support organizations than in other healthcare organizations. Further, health communication researchers have not examined the social support processes within cancer support organizations. This type of organization is likely to grow in numbers due to the ACS standards and increases in cancer diagnoses. Thus, the potential increase in the need for cancer support organizations, in conjunction with a limited understanding of this healthcare context, creates a unique opportunity for research.

Cancer support organizations are relatively common organizations across the U.S. (National Cancer Institute, 2015b). Although some cancer support organizations operate independently, others are part of national and local chains (e.g., Cancer Support Community; Gilda Club). Unlike many healthcare organizations (e.g., hospitals, clinics), cancer support organizations often offer free services and resources to people diagnosed with cancer during their cancer experience. To date, a centralized accreditation or professional organization for cancer support organizations does not exist. However, some national organizations provide resources and act as professional bodies for educational and training purposes (e.g., Cancer Patient
Education Network, American Cancer Society). For many individuals with cancer and their families, cancer support organizations are a beneficial source of support (Matthews et al., 2002; Rosenbaum & Smallwood, 2013).

**Summary of rationale.** In summary, the rationale for the present study has multiple components. First, very little research has investigated institutional and organizational influences on social support. Second, social support is associated with positive health outcomes. Thus, the healthcare institution’s and healthcare organizations’ facilitation or obstruction of social support may be associated with individuals’ health outcomes. Third, in the U.S., cancer represents one of the most pressing health concerns. Families who experience cancer are in need of social support resources to manage the stressors of the cancer experience. Finally, many healthcare organizations now have a recently identified institutional imperative to provide support to people diagnosed with cancer. Cancer support organizations can play a significant role in fulfilling these social support needs. However, researchers have not previously investigated social support in the context of cancer support organizations.

**The Specific Case: A Cancer Support Center**

The present research focused on the experiences of clients at a local Cancer Support Center. That Center served as a case exemplar. The Center has the mission to be a source of support for people diagnosed with cancer and their families. Thus, the local Cancer Support Center presented an organizational context where, logically, the institutionalization of social support would be amplified, making its observation and analysis more accessible. This amplification allowed the researcher to more readily capture the relevant phenomena via in-depth description.

The Cancer Support Center is a small, community-based cancer wellness center serving
people diagnosed with cancer and their families. It has the goal of helping people diagnosed with cancer and their families by providing psychosocial (e.g., counseling, peer support groups), physical (e.g., massage, medication counseling), and financial support (e.g., debt management, insurance counseling) (see also Chapter IV, Description of the Case: The Cancer Support Center). The Center offers more than 50 programs and services free of charge to people diagnosed with cancer, their caregivers, and other family members. The Center’s programs include counseling services, integrative services, financial consultations, wig programs, support groups, health and wellness activities (e.g., yoga classes), and workshops and other social activities (see also Chapter IV, Description of the Organizational Context at the Cancer Support Center).

A local family founded the Cancer Support Center in honor of a family member who died from cancer. Their experience taught them that people diagnosed with cancer and their families need support and “there is more to cancer than chemotherapy and surgery.” Thus, they founded the Cancer Support Center in an effort to provide support to people diagnosed with cancer and their families.

The Cancer Support Center is a non-profit organization. It operates through resources provided by an endowment established by a local family, from community donations, and from the organization’s fund-raisers. The Center employs a small staff ($n = 9$) of full-time and part-time team members. The Center also operates with the help of more than 200 volunteers and a Board of Directors.

Examinining a case exemplar. The present study centered on and was immersed in a specific case exemplar. According to Flyvbjerg (2001), an exemplar case gives social scientists the opportunity to examine a social phenomenon acutely, where nuance can be uncovered.
Furthermore, using an exemplar case allowed the researcher to uncover and explain complex social phenomena by using rich narrative. Critics of qualitative research, especially qualitative research that examines a specific case with a limited number of participants, often comment on the lack of generalizability of such work (Flyvbjerg, 2001). However, an exemplar case that provides rich narrative can have applicability to other similar contexts (Flyvbjerg, 2001). Specifically, the knowledge obtained from this particular exemplar case may be applicable to other cancer support organizations and to hospital or clinical settings that offer cancer support services in-house.

**Social construction and qualitative research.** The present study drew on social constructionism as both a meta-theoretical framework for the key concepts being examined (e.g., institutions, social support) and as a foundation for exploring the exemplar case. As a meta-theoretical framework, social constructionism is based on the idea that, through symbolic interaction, individuals attribute and share meaning about reality (Tracy, 2013). Specifically, social constructionism is a framework for understanding how individuals come to share and agree upon the meanings of social phenomena (e.g., institutions, social support). Further, social constructivism lays the foundation for constructivist grounded theory, which, as a form of interpretative qualitative research, allows researchers to acknowledge the socially constructed nature of the research context (Charmaz, 2014). Constructivist grounded theory was a particularly appropriate approach for the present study because it involved an in-depth examination of a specific social context (i.e., the Cancer Support Center). Further, the present research used qualitative research methodology, thus, the research context is also socially constructed (Charmaz, 2014).

Scholars differ widely in their approaches to constructivism (Allen, 2005). Some hold a
constructivist approach that assumes that all reality is socially constructed, whereas other researchers accept that certain material aspects of the world are not social constructions (Allen, 2005). Allen (2005) discusses the issue of materiality when applying social constructivism. That is, Allen explains that some social constructivists claim that “everything is socially constructed” (p. 39). The present research was built on a social constructivist approach that assumes that social processes not only influence our understandings of reality, but actually create some types of reality (what everyone knows; Berger & Luckmann, 1966). However, the approach that was used in the present research also acknowledges that some other types of reality (e.g., objects, human bodies), or what might be termed a material reality, exist independently of social interaction (e.g., disease has materiality in the context of the present research). The present research applied this approach to examine particular social processes (e.g., social support) and the organizational and institutional influences on these processes (e.g., organizational and institutional norms). Thus, this approach was consistent with the view that organizations and institutions are socially constructed (Berger & Luckmann, 1966). Researchers continue to investigate the communicative processes through which institutions are created and maintained (e.g., Lammers, 2011; Lammers & Barbour, 2006; Lammers & Garcia, 2014). Social support also is subject to social construction (Lakey & Cohen, 2000). That is, social support, both in terms of the functions it serves, and the social ties through which it is provided, is created through shared understandings of responsibility and providing care to others, especially when they are ill.

**Overview of the Study**

Chapter one provides an overview of the study and its rationale. The present research was designed to fill a gap in the literature: an understanding of how social support is experienced and
perceived as institutionalized within a cancer support organization and, more broadly, within the healthcare institution. The present research is valuable because it explored whether and how healthcare organizations can facilitate and impede offering social support to people diagnosed with cancer.

Chapter two provides a review of relevant literature that guided the present study. Two specific bodies of literature informed the present research: (a) institutional theory and its connections within organizational culture, and (b) social support and its associations to health. First, chapter two reviews the role of organizational culture in creating the norms, practices, and values of organizations, and discusses organizational culture within the healthcare context. Second, the literature review examines institutional theory, and how institutional beliefs, structures, and institutionalization processes are constructed through communication. Third, chapter two focuses on the background, contemporary understandings, and significance of social support. The review examines relevant literature on the associations between social support and health outcomes, specifically in the cancer context. The chapter ends with a discussion of the study specific research questions.

Chapter three describes the methodology of the present study, which used a constructivist grounded theory approach to qualitative research. The chapter begins with an explanation of constructivist grounded theory and then details the procedures used in conducting the research, including data collection and analysis.

Chapter four presents the study’s results. Relevant themes are identified, evidence to support the themes is presented, and results are analyzed within the appropriate context (i.e., the Cancer Support Center or healthcare institution at large). In particular, themes related to (a) the nature of social support in healthcare contexts, (b) sources of social support in healthcare
contexts, and (c) benefits of social support experienced in healthcare contexts are identified, supported, and discussed.

Chapter five begins by providing an overview of the study. Results are summarized in the form of specific themes that emerged regarding perceptions of social support at the Cancer Support Center and in healthcare in general. Study findings are integrated and discussed in order to provide answers to the three specific research questions. A proposed model, based on study findings related to the nature of social support that clients experience and perceive to be institutionalized in healthcare organizations, is then presented and discussed. Next, the chapter discusses the conceptual contributions and practical implications of the study. The chapter concludes by acknowledging limitations of the study and suggesting directions for future research.
Chapter II

Review of Literature

This research examined the origins of social support in healthcare organizations, and more specifically, within the context of a Cancer Support Center. This study was guided by the overarching research question: *What is the nature of social support that clients experience and perceive as institutionalized in healthcare organizations?* Specifically, this study examined clients’ experiences and perceptions of social support at a Cancer Support Center and, more broadly, within the healthcare institution. The following chapter reviews relevant organizational processes, institutional theory, and social support literature as a foundation for this research.

The terms *institution* and *institutionalize* are central to addressing the present research question. *Institution* is a term that has many meanings in the research literature. For example, institution can refer to a large organizational body (e.g., university, hospital), to a collection of organizations (e.g., U.S. government), or to social conventions (e.g., marriage) (Lammers & Barbour, 2006; W. R. Scott, 2014). Importantly, the term institution also may reference entities solidly established over time (e.g., fixtures in social life, such as pastimes; W. R. Scott, 2014). In the context of the present investigation, *institution* refers to overarching belief systems to which similar organizational bodies adhere (Lammers & Barbour, 2006). Specifically, the healthcare institution refers to healthcare organizations (e.g., hospitals, hospice) that share the same institutional beliefs (e.g., take care of the sick, “do no harm”). Institutions shape and are shaped by broader socio-cultural norms and beliefs (W. R. Scott, 2014). That is, institutions very much influence and are influenced by the wider cultural norms of a society (e.g., helping out another person if she or he becomes ill is normalized in many cultures as part of social life).

The concepts of institution and organization both overlap and differ, in colloquial and
academic usages. Indeed, one often finds them used interchangeably. However, for purposes of this study, the term *organization* refers to individual structures that are characterized by their members, who work together to achieve specific goals (Miller, 2009). *Institutionalize*, in this study, refers to the processes through which certain behaviors are established and routinely practiced as normative in organizations and/or within the broader institution (Zucker, 1977). Institutionalizing, as such, is a process through which institutional beliefs and norms are created and maintained within organizations and also a process through which the beliefs and norms of the broader institution can be subject to change over time (W. R. Scott, 2014). Institutional norms, beliefs, and practices are established through communication processes.

*The present study examines a specific, bounded organization – a Cancer Support Center – to learn about the processes by which social support comes to be perceived as institutionalized in this setting.* Cancer support centers are designed to assist people diagnosed with cancer and their families by offering an array of services, such as counseling, physical therapies, and peer support groups. Cancer support organizations are healthcare organizations, in that they provide services to support the health (i.e., physical, mental, and social wellbeing; see often-cited World Health Organization definition of health, 1948) of people experiencing cancer. Thus, Lammers, Duggan, and Barbour (2003) would characterize cancer support organizations as part of the larger healthcare institution or sector.²

*Healthcare,* as used throughout this review, describes the institution, and organizations within the institution, that provide health and medical services to the public (Lammers et al., 2003). Organizations that fall into the healthcare institution (or sector) are diverse. They include, but are not limited to hospitals, physician practices, clinics, nursing homes, hospice, and

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² The term *healthcare* also is commonly referred to as a “sector.” The term “sector” captures the interrelatedness of the healthcare community and its involvement in the U.S. economy, politics, and social matters (e.g., Lammers et al., 2003). In the context of this study, healthcare is referred to as an institution.
healthcare financing organizations, such as insurance companies and government programs (e.g., Medicare, Medicaid; Lammers et al., 2003). Because this study focuses on healthcare, the bulk of examples used to illustrate relevant concepts in this chapter are derived from that context. However, some examples from other organizational and institutional domains also are employed.

The literature review examines literatures related to investigating beliefs and values in the healthcare institution and social support in healthcare organizations. For instance, relevant literature on healthcare culture, the healthcare institution, social support, and supportive client-provider communication (also referred to commonly as provider-patient communication) are discussed. To ground this investigation, the following literatures were broadly consulted and reviewed: organizational culture, institutional theory, and social support.

The areas of literature explored emerge mainly from the sub-fields of organizational communication and health communication. Organizational communication examines interactions and messages used to accomplish both individual and collective goals within organizational and institutional bodies (Tompkins & Wanca-Thibault, 2001). Health communication examines the construction and meanings of messages that occur in both formal and informal communication contexts and influence health and risk, and related behaviors, and outcomes, (Cline, 2014). This chapter addresses how organizational communication research has studied organizational culture and institutionalizing processes, how social support is conceptualized in health communication, and the relationship of social support to health outcomes, and how social support is communicated in healthcare contexts.

This chapter first reviews related literature on organizational culture in order to address how values, beliefs, and norms are constructed in organizational contexts. Next, the literature review concentrates on the institutional theory literature in order to address the process of
institutionalization and how institutions inform everyday organizational interactions. The organizational culture and institutional theory literatures are integrated to explore institutionalizing processes holistically. Because organizational culture and institutional theory developed, and are generally examined, as two independent conceptual perspectives (Pedersen & Dobbin, 2006), integrating them is useful to researchers who are interested in how organizational processes influence communication between healthcare providers and clients. For example, an institutional belief within the healthcare institution may influence the organizational culture in individual healthcare organizations and ultimately may influence provider-client communication. Finally, this review considers the literature on social support, conceptualized as communication; and the health benefits of social support, specifically in cancer, or oncology, contexts; and institutional and organizational influences on social support processes.

For each body of literature, the review provides relevant historical background, key concepts, and a synthesis of research that is pertinent to the present study. The review begins with an examination of the organizational culture literature and its key concepts, which is integrated with institutional theory.

**Organizational Culture**

Organizational culture research focuses on the culture of individual organizations and the larger cultural contexts that inform organizational culture. The term *culture* has diverse meanings and definitions (Carey, 1992; Cheney, Christensen, Zorn, & Ganesh, 2011). In lay understanding, culture can refer to arts and entertainment (i.e., “popular culture”), as well as to the beliefs and customs of a group within society (e.g., Carey, 1992; Cheney et al., 2011). However, in the social sciences, scholars of different disciplines (e.g., anthropology, sociology, communication) offer multiple definitions of culture (e.g., Mohan, 1993). In the academic
literatures, the following common meanings and usages of the term occur: (a) a system of beliefs that guide behaviors; (b) shared understandings; and (c) centralized structures (Mohan, 1993).

Kroeber and Kluckhohn (1952) provide a foundational definition of culture. They define culture as “explicit and implicit patterns of historically derived and selected ideas and their embodiment in institutions, practices, and artifacts” (p. 357). Geertz (1973) extended Kroeber and Kluckhohn’s definition of culture to include “socially established structures of meaning” (p. 12). Thus, culture is patterned over time, is understood through social constructions of meaning, and is embodied through institutions, social practices, and artifacts. One definition of culture that is especially pertinent to this study is from Lederach (1995). Lederach defines *culture* as “the shared knowledge and schemes created by a set of people for perceiving, interpreting, expressing, and responding to the social realities around them” (p. 9). Lederach’s definition of culture casts culture as collective understandings, or schemas, that are socially constructed and emerge through communication processes. However, culture has a reflexive relationship with communication. That is, culture *both* is influenced by communication processes and simultaneously influences communication.

Organizational communication researchers have used cultural approaches to investigate *belief systems* in organizational contexts (e.g., Chiles & Zorn, 1995; Keyton, 2011, 2014). Organizational culture research generally has focused on how values and belief systems emerge and become institutionalized within individual organizations to result in unique organizational practices (Pedersen & Dobbin, 2006). Organizational culture highlights the values and practices that organizations create, which makes them differ from other organizations in their environment. In contrast to scholars who use an organizational culture approach, institutionalists

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3 Cheney (1991) said, “*Environments* [emphasis added] include aspects internal to the organization and aspects outside of it, though the boundaries are often unclear (as is the case for many service organizations [e.g., hospitals,
emphasize that similarities exist among organizational structures and belief systems that essentially legitimize (i.e., recognize as correct) organizational practices (e.g., Greenwood, Oliver, Sahlin, & Suddaby, 2008; Lammers & Barbour, 2006). That is, institutionalists examine the similarity of belief systems and rules to which comparable organizations (e.g., healthcare organizations, schools) adhere to ensure that they are legitimate. Thus, a contrast exists between organizational culture scholarship, which tends to examine organizations for their distinctive qualities, and institutional theory, which tends to examine the similarities among organizations that legitimize them (Pedersen & Dobbin, 2006). As such, scholarship on organizational culture tends to focus on the uniqueness of particular organizations, that is, on how and why certain organizations come to understand organizational life in particular ways; whereas, institutional theory scholarship tends to focus on the ways in which organizations follow substantially similar rules and structures as a result of institutionalizing processes.

Organizational culture analyses typically are more narrowly drawn than institutional analyses. Thus, researchers analyzing organizational culture often cannot explain institutionalizing processes that are shared across organizational boundaries. However, organizational culture approaches are quite useful for identifying value and belief systems within organizations. By integrating organizational culture and institutional approaches, researchers can better understand the reciprocal relationship between organizational culture and broader institutionalizing processes (Pedersen & Dobbin, 2006).

The present research used an institutional perspective. However, the organizational culture literature defines many key concepts (e.g., beliefs, values, practices) that are useful for explaining institutionalizing processes. Further, organizational culture can be informed by cancer support organizations’ values. Thus, environment can be understood as the internal and external influences of the setting in which an organization carries out its work.
institutional influences and likewise informs the beliefs and norms of the institution.

The following section: (a) examines organizational culture in the scope of the present research; (b) defines the key terms and ideas used in organizational culture research that specifically inform institutional theory; (c) examines organizational culture research in healthcare; and (d) discusses the similarities and differences between organizational culture and institutional theory research, and why institutional theory, versus using an organizational culture approach alone, is particularly applicable as an approach to conducting the present research.

**Defining organizational culture.** The investigation of organizational culture in communication studies examines the norms and traditions that are socially constructed in organizations. According to Alvesson (2004), research in organizational culture examines “systems of meanings and symbolism involving taken-for-granted elements in need of deciphering” (p. 317). As such, organizational culture often is something inferred by participants within or those who are examining organizations. Keyton (2011) defines organizational culture as “the set(s) of artifacts, values, and assumptions that emerges from the interactions of organizational members” (p. 28). Thus, in the present study, organizational culture is understood as the collections of knowledge that are developed and shared through communication among organizational members.

Organizational culture within emerges in the form of norms, practices, and/or values that are developed and shared through communication among organizational members. A reflexive relationship exists between organizational culture and communication within organizations. That is, organizational culture and communication among organizational members simultaneously influence each other. Organizational interactions allow organizational members to both construct and interpret shared understandings of organizational artifacts, values, and assumptions.
Artifacts, values/beliefs, and assumptions. According to Schein (1985, 2004), organizational culture can be conceptualized and observed concentrically. That is, culture is openly noticeable at the most outer organizational levels and recognized in deep-seated understandings at the most inner levels within organizations. Artifacts, values and beliefs, and assumptions represent three levels, or degrees, at which organizational culture is observable (Schein, 1985, 2004). For example, artifacts, such as dress and furniture, are at a surface level of organizational culture and are readily observable, whereas assumptions about organizational work are at a deeper level of shared meaning among organizational members, and not as readily discernable.

Artifacts are at the most visible and outer level of organizational culture (Schein, 1985, 2004). Organizational artifacts are the tangible materials and/or practices that are evident in and around organizations and across institutions. Artifacts can be both the materials used in organizations and the organizational routines that structure activity; this can make their exact purposes perplexing to the outside world (Schein, 2004). For example, in healthcare, a material artifact that easily identifies the organizational culture is the white lab coat worn by healthcare professionals (e.g., physicians, pharmacists). Those outside of the healthcare institution can easily recognize the lab coat as the attire of healthcare professionals; however, without cultural understanding, one may not know that the lab coats represent cleanliness (Hochberg, 2007).

Schein’s (1985, 2004) second level of organizational culture is values and beliefs. Values and beliefs encompass the philosophy adapted by organizations and/or institutions. Thus, organizational and/or institutional practices are guided by values and beliefs. Organizational members are sensitized to organizational values. Cheney et al. (2011) explain that organizational members often have difficulty articulating the values of their organization and why
organizational members follow those values. The abstract and complex nature of organizational values makes their observation and understanding somewhat difficult from an outside perspective. Although organizational members understand the meaning behind their values, they may not know how to explain this meaning to those who have not experienced their organizational life. For example, a cancer support organization may exhibit welcoming behaviors and warmness toward clients that reflect valuing inclusiveness (i.e., welcoming everyone affected by cancer regardless of type of experience or severity of cancer).

Organizational members use the organization’s values and belief systems to determine if organizational actions are ethical. For example, in a healthcare organization, organizational members strongly value, first and foremost, the concept “do no harm” (Oath of Hippocrates, 1910). As a value, “do no harm” aids healthcare providers in determining if their actions toward clients meet the ethical standards of the healthcare institution. This example serves as a reminder of the degree of formalization, or how organizational behaviors are guided by values and rules (Cheney et al., 2011), involved in organizational and institutional practices. Specifically, formalization is indicative of the organizational and institutional influences on organizational behaviors, such as decision-making.

Schein’s (1985, 2004) third level of organizational culture is assumptions. Assumptions are at the most central, or core, level of organizational culture. Assumptions are “unconscious, taken-for-granted beliefs, perceptions, thoughts, and feelings” (Schein, 2004, p. 26). Generally, the assumptions of an organization are implicit ideas about why organizational culture is the way it is. Thus, assumptions sometimes are difficult, even for members within the organization, to describe and explain (Cheney et al., 2011). Assumptions directly influence organizational behaviors (Schein, 2004).
An example of how assumptions operate in healthcare organizations is found among healthcare professionals in a cancer support center. They assume that they are compassionate, caring individuals. Healthcare providers generally are regarded as caring, or helping, professionals (Miller & Considine, 2009). Thus, in a cancer support center, the organizational members are guided by the assumption that their professional work has the goal of helping clients. Durkheim (1893/1964, 1900/1996) explained that professionalism is both an aspect of an individual’s identity (e.g., the “calling” to be a healer) and a performance by which an individual meets the needs of an organization, institution, and society. That is, professionals both adhere to their own individual identity within a given profession (e.g., medical doctor) and assume that their work serves the greater good (e.g., helping others). The concept of a “caring” profession carries with it the assumption that providers, also commonly referred to as “caregivers,” are motivated by internal compassion towards those in need of their help (i.e., clients) within their healthcare organization (McGaghie, Mytoko, Brown & Cameron, 2002). Assumptions, such as being a “caring professional,” are indicative of how organizational culture is informed by and informs institutional influences.

**Institutional understandings of organizational culture.** Organizational culture and institutions are inherently related through their ability to establish organizational legitimacy (Pedersen & Dobbin, 2006). “Legitimacy” refers to the acceptance that an organization meets institutional standards. The concepts “institution,” “culture,” and even “communication” can be somewhat ambiguous. That is, these concepts have multiple interpretations and even conflicting meanings (e.g., “institution” can refer to both an organization and a body of organizations; “culture” can refer to both societal and organizational patterns of behavior; “communication” can refer to the transactional process through which individuals together create and interpret
messages, to the messages themselves, to the interpretations themselves). Clear definitions are critical in order to apply to them in the context of the present study.

In the present study, the term “institution,” when used alongside the term “culture,” refers to similar organizational bodies that adhere to the same overarching belief system (Lammers & Barbour, 2006). Likewise, in the present study, “culture” refers to the specific values and understandings that emerge from and are shared among organizational members within the same organization (Keyton, 2014). Culture and institutional beliefs are both constructed and enacted through communication processes. “Communication” also is defined in numerous ways in the literature. In the present study, “communication” is understood as a social, behavioral, and interpretive process. That is, communication processes occur transactionally when meaning is constructed and assigned to messages (e.g., behaviors, actions) and interactions (e.g., negotiating the nature of a relationship).

Although analyses of organizational culture often examine distinct organizational practices and norms, and institutional examinations often consider similarities across organizations that create and indicate legitimacy, organizational culture and institutions are both products of and enacted through social processes, such as institutionalizing. For example, a teaching hospital may institutionalize interviewing family caregivers to see if their support needs and the support needs of their family member are being met, but also will follow the institutional rules (e.g., Health Insurance Portability and Accountability Act (i.e., “HIPAA”)) designed to guarantee the legitimacy of their work. Thus, the institution and organizational culture are constructed, enacted through, and influenced by the everyday communication (i.e., organizational members interviewing family caregivers) occurring within the organization.

The cultures of individual organizations generally are structured to fit within broader
societal and institutional ideologies (e.g., sexism, classism, capitalism; Carlone & Taylor, 1998). As such, organizations and their cultures serve as “nodes” where societal and institutional influences are constructed and enacted (Carlone & Taylor, 1998, p. 341). That is, within organizations, culture is influenced both by societal norms (e.g., gender roles, socioeconomic status) and by institutional norms (e.g., professional prestige, legitimacy). The inverse is also true; the communication that occurs within organizations may also influence broader societal and institutional norms. For example, in early healthcare clinics, physician autonomy and professional status developed through provider interactions with clients within healthcare organizations (Foucault, 1963/1994). Foucault argued that the norms that developed within these early clinics eventually led to wider societal reverence toward physicians.

The relationship between organizational culture and institutional influences is perceptible in internal-external relationships. Internal-external relationships in organizations include the everyday communication that occurs between organizational members (i.e., internal) and organizational participants (i.e., external; e.g., in healthcare, provider-client relationships; in business, supplier-consumer relationships; Cheney et al., 2011). Organizational culture and institutional influences are both socially constructed and enacted through internal-external relationships (Cheney et al., 2011). Together, organizational culture and institutional beliefs may establish how internal-external relationships are conducted by organizations (e.g., valuing customer satisfaction, in business; valuing doing no harm to clients, in healthcare). However, internal-external relationships also may influence organizational culture and institutional beliefs. For example, in a healthcare organization, clients’ expectations for support may influence how much the healthcare organization values providers’ enactment of supportive behaviors (i.e., if clients expect support, the organization will ensure that organizational members provide support
A reflexive relationship exists between organizational culture and internal-external relationships. That is, organizational culture and internal-external relationships influence one another. For example, within the healthcare institution a healthcare organization may value the role of client opinions in treatment decisions and thus may have practices in place whereby healthcare providers solicit clients’ questions and preferences; the organization also may display artifacts (e.g., signs, handouts) that encourage clients to communicate with their providers. The clients of that healthcare organization also may simultaneously appreciate and expect to have their opinions and preferences solicited. In this example, soliciting clients’ questions and preferences are organizational practices that influence the client-provider relationship and the clients’ expectations simultaneously influence the reinforcement of this organizational practice.

Trujillo’s (1992) ethnographic investigation of American baseball illustrates the processes whereby organizational culture, society, and institutions influence internal-external relationships in organizations. Trujillo investigated the nature of baseball culture, as an institution in the U.S., and how organizational culture is enacted through communication processes. He argued that components of American culture (i.e., capitalism, community, entertainment) are evident in the baseball institution. Trujillo examined internal-external relationships in the baseball institution through the relationship between organizational members (e.g., baseball players, announcers, stadium workers) and fans.

Trujillo (1992) concluded that baseball is foremost a capitalistic endeavor. Baseball is a commodity that is sold as a product. Fans have a consumerist relationship with baseball organizations, where the organizational culture focuses on revenue (e.g., ticket sales, food sales) and fans want to be entertained. Trujillo (1992) also concluded that baseball creates community.
Communing through baseball is symbolic of greater American culture, where Americans from all over the country are unified through shared beliefs and values. Finally, Trujillo (1992) concluded that baseball is an entertainment medium, much like theatre, where organizational members are performing for fans. As such, all organizational members within the baseball institution are working to make the baseball experience as entertaining as possible for fans.

The case of baseball is relevant for the present discussion because, like healthcare organizations, U.S. baseball teams share a similar organizational culture throughout their institution but also are individually unique, with their own individual organizational cultures. For example, in healthcare, individual organizations like the Cleveland Clinic and University Hospitals are both healthcare organizations with the same overarching institutional values, norms, and practices. However, their organizations also have unique organizational cultures (e.g., the Cleveland Clinic values specialization in their service offerings; Cleveland Clinic, 2014; and University Hospitals values diversity in healthcare providers’ backgrounds; University Hospitals, 2015).

Trujillo’s (1992) study also shows how societal norms, institutional beliefs and practices, and organizational culture can influence communication within organizations that are characterized by internal-external relationships (i.e., baseball’s internal-external relationships between organizational members and fans; healthcare’s internal-external relationships between healthcare providers and clients). Healthcare in the U.S., like the baseball institution, is characterized by economic and societal concerns (e.g., capitalistic endeavors), institutional norms (e.g., professional standards), and individual organizational cultures (e.g., organizational identity).

In summary, organizational culture creates and reinforces socially and institutionally
constructed norms. Organizational culture also is perceptible through internal-external relationships and healthcare is a prime example of how organizational culture is perceived in internal-external relationships.

**Organizational culture in healthcare.** Researchers have specifically investigated the organizational culture of both individual and groups of healthcare organizations (e.g., Kirschbaum & Fortner, 2012; Klingle, Burgoon, Afifi, & Callister, 1995; Lammers et al., 2003; Stevenson & Baker, 2005). Although a larger body of research has investigated organizational culture in healthcare, two studies by Kirschbaum and Fortner (2012) and Klingle et al. (1995) specifically capture commonalities among the cultures of healthcare organizations at an institutional level in the U.S. Thus, these studies illuminate cultural and institutional influences in healthcare.

Kirschbaum and Fortner’s (2012) and Klingle et al.’s (1995) research was conducted in the U.S. Numerous studies focusing on organizational culture in healthcare have been conducted outside of the U.S. (e.g., Alharbi, Ekman, Olsson, Dudas, & Carlström, 2012; Khokher, Bourgeault, & Sainsaulieu, 2009; Stevenson & Baker, 2005). However, the U.S. healthcare system differs from the remainder of the developed world in economic, political, and organizational and institutional respects (e.g., structure of healthcare system, payment system, necessary accreditations). Because the present research focused on U.S. healthcare, the literature review was limited to research conducted on the U.S. healthcare system.

Kirschbaum and Fortner (2012) argued that understanding medical culture could provide health communication researchers with a cultural understanding of how physicians communicate with one another, other healthcare professionals (e.g., nurses), and their clients. Kirschbaum and Fortner (2012) defined medical culture as, “a heightened sense of individualism, professional
pride, invulnerability, and a denied susceptibility to stress” (p. 182). This definition emphasizes the physician’s perspective (i.e., autonomous, professional, and detached). It also describes how clients and other healthcare professionals perceive physicians. That is, medical culture represents the professional authority that is awarded to physicians inside and external to healthcare organizations (Foucault, 1963/1994; Freidson, 1970). Traditionally, physicians were respected with a “god-like” reverence, because they were perceived to have power over the body (Foucault, 1963/1994). Specifically, clients and other healthcare professionals regard physicians as having knowledge necessary to provide care and, thus, the power to help the sick and injured.

Kirschbaum and Fortner’s definition of medical culture also is inherently institutional in nature. It refers to a culture that spans organizational boundaries. That is, the definition captures characteristics of health and medical organizations in general.

Klingel et al. (1995) examined organizational culture and internal-external relationships in healthcare. Klingel et al. (1995) were interested in the beliefs, values, and assumptions of healthcare organizations and how they influence communication among organizational members and participants. They studied physician, nurse, and client understandings of organizational culture in healthcare. The inclusion of clients in this study implies that clients can develop an in-depth understanding of the healthcare culture, despite their internal-external relationship with healthcare providers (i.e., clients can be relative “outsiders” in healthcare contexts). Klingel et al. found that clients’ perceptions of organizational culture within healthcare organizations were similar to those of nurses and physicians. Specifically, the study found that clients, nurses, and physicians shared understandings of physician authority, hospital mission/goals, and physician and nurse communication behaviors (e.g., organizational expectations about listening to clients and providing clear explanations).
Kirschbaum and Fortner’s (2012) and Klingel et al.’s (1995) examinations of U.S. healthcare represent investigations of organizational culture at an institutional level. However, organizational culture analyses often are too narrow with respect to context (typically, one organization) for drawing institution-level conclusions. As such, analyses of organizational culture typically do not explain wider institutionalizing processes within the institution at large.

**Organizational culture and institutional theory.** Organizational culture and institutional theory developed independently as approaches to understanding social constructions of organizational behavior (Pedersen & Dobbin, 2006). Investigations of organizational culture generally are more micro-level in design and application than studies based on institutional theory. More often than not, the former focus on the development of organizational culture in specific organizations (Keyton, 2014). In contrast, institutional theory typically offers macro-level explanations for shared beliefs, practices, and assumptions across organizational boundaries (Lammers & Barbour, 2006; Lammers & Garcia, 2014). Institutional theory also examines institutionalizing processes that occur across organizations.

For the purposes of the present research, I consider micro-level studies to be those that examine the behaviors of an individual organizational member, organizational group, or organization (Bamberger, 2008). In contrast, I consider macro-level approaches to be those that examine suprastructures in society, such as institutions or fields of study (Bamberger, 2008). Zucker (1977) argued that the “macro-level and micro-level are inextricably intertwined” (p. 728). For example, organizational and institutional policies can affect how organizational members communicate with one another (e.g., openness versus restraint) and also are influenced by how organizational members communicate with one another. Chiles and Zorn (1995) argue that organizational values are intrinsically linked to how organizational members interact one-
on-one (e.g., competitive versus collaborative). As a result, everyday interactions often, but not always, influence and are influenced by institutional norms.

Examining organizational culture in the context of the present study is useful because it clarifies how organizational and institutional value and belief systems influence and are influenced by everyday interactions. An example of how organizational and institutional value and belief systems influence everyday interactions can be seen in how healthcare providers interact with clients (Real, 2010; Real & Street, 2009). Specifically, healthcare providers are likely to follow both organizational values (e.g., making sure clients have the opportunity to ask questions) and institutional beliefs (e.g., “do no harm”) when interacting with clients.

Despite the relationship between organizational culture and institutional theory, analyses of organizational culture often do not attempt to explain the macro-level formation of belief systems and institutionalization of organizational behaviors across organizational boundaries (Lammers & Barbour, 2006; Zucker, 1977). For example, an organizational culture analysis typically focuses on organizational members’ perceptions of organizational values and beliefs instead of their perceptions of why these values and beliefs legitimize their organization as part of the institution at large. That is, organizational culture scholars generally are more interested in the values that are developed within organizations instead of how these values legitimize the organization within the wider institution. Analyses of organizational culture tend to capture rules, values, beliefs, and assumptions that are followed within a specified organization or cultural context. However, analyses of organizational culture generally do not examine the institutionalization of rules, values, beliefs, and assumptions across organizational boundaries. Analyses of organizational culture also tend not to explain the processes whereby organizations are legitimized, but analyses using institutional theory often do. Using institutional theory can...
help researchers to explain how institutions socially construct organizational operations and why institutions continue to determine organizational legitimacy. However, few scholars have attempted to clarify and integrate an organizational culture approach with an institutional theory approach (e.g., Pedersen & Dobbin, 2006). In the context of the present research, integrating these two approaches clarifies how both institutionalizing processes and an individual organization’s culture affect client perceptions of social support in healthcare.

Institutional Theory

A key premise of the present study was that institutional norms influence everyday interactions in organizations. Research based on institutional theory examines how micro-level interactions are influenced by in the macro-level institutional norms. Institutional theory considers the taken-for-granted organizational rules, beliefs, norms, and structures in and across organizations that legitimize the organization, and makes sense them of them by analyzing organizational interactions and behaviors (Lammers & Barbour, 2006; Lammers & Garcia, 2014).

Institutional theory in organizational communication research developed out of the earlier sociological use of institutional theory (Lammers & Barbour, 2006). Although, the sociological and communication uses of institutional theory are similar in many ways, some marked differences also exist. For example, institutional theory in sociology generally focuses on how institutions shape and inform societal norms and structures (Suddaby, 2011). In contrast, institutional theory from a communication vantage point tends to focus on how institutions are communicatively constituted. That is, from the latter perspective, institutions are developed and established through communication processes (Lammers & Barbour, 2006). The present research applied institutional theory from the communication perspective. Specifically, this study built on
the perspective that institutions and institutionalizing processes occur through communication processes that occur both within and across organizations.

**History of institutional theory.** The foundations of institutional theory date back to the works of Weber (e.g., 1906-1924/1968) at the turn of the 20th century. Later sociologically-leaning scholars, working in the 1970s and 1980s, developed institutional theory. Some of their key concepts are *institutions, institutionalization, isomorphism, and rational myths*. Since then, researchers across disciplines have applied institutional theory to different contexts (e.g., politics, economics, communication) to examine how institutions influence and are influenced by social (and therefore, communicative) processes.

Institutional theory grew out of Weber’s (1906-1924/1968) explanations of authority, rationality, and bureaucracy in the modern world. Weber explained that bureaucracies are rational structures in which institutions operate. Bureaucracies use a merit-based, or rational, system to structure their work. That is, the more qualified an individual is for a position, the more likely that individual is to hold the position (Perrow, 1986). Bureaucracies are sustained through strict adherence to bureaucratic rules and practices, such as organizational hierarchies (Cheney et al., 2011). As bureaucratization and hierarchical structures spread across sectors and organizations, sociologists came to understand that institutions were being established based on organizational rules and structures.

For Weber, deeply embedded and widely promoted values and beliefs manifest themselves in institutional arrangements which, in turn, help to shape the beliefs of subsequent generations of organizations. At the same time, some of the values, beliefs and practices become routinized and taken for granted. Indeed, the tension between reflective expressions and implementations of certain organizational features, and partially mindless – or at least
unexamined – ones, was central to Weber’s predictions for and concerns about modernity.

Institutional theory was developed in the field of sociology in the 1970s and 1980s as a means to consider how institutions are created and sustained through “widespread social understandings” (Greenwood et al., 2008, p. 3). Specifically, through institutionalizing processes, institutions are socially constructed and accepted as the norm. For example, healthcare organizations are understood socially as places to receive medical care when one is sick or injured. These understandings developed over time as the medical profession was institutionalized and clinics were developed (Foucault, 1973/1994).

Foundational articles related to institutional theory include Meyer and Rowan (1977), Zucker (1977), and DiMaggio and Powell (1983). Meyer and Rowan argued that institutions are rational entities. Zucker explained that institutions are socially constructed through institutionalizing processes. DiMaggio and Powell later argued that institutions are structured similarly because of shared social understandings of what an institution should look like (e.g., hierarchical structures). Together, these core articles laid the groundwork for the key premises of institutional theory. Each of these articles are explained in depth later in this review (see below, Key concepts in institutional theory).

Early explorations of institutions and institutionalization in sociology informed later research on institutional theory in both sociology and other fields. Organizational researchers examined institutions through the perspectives of the political science (e.g., Nardulli, 1991), economics (e.g., Furubotn & Richter, 1997), and communication (e.g., Lammers & Barbour, 2006) disciplines. In the context of the present research, reference to institutional influences in political science and economics warrants acknowledgement, because the U.S. healthcare institution often is influenced by political concerns (e.g., The Patient Protection and Affordable
Care Act) and economic conditions and arrangements (e.g., managed care). Although different disciplines vary in their applications of institutional theory, in general, their conceptual bases for the study of institutions and institutionalizing processes generally are similar.

**Key concepts in institutional theory.** Organizational communication researchers who apply institutional theory in their scholarship build on concepts explicitly related to communication processes. Although these concepts originally were not cast in terms of communication, each of them can be profitably examined using a communication perspective. Key concepts that inform institutional theory include: institution, rational myth, isomorphism, institutionalization, and institutional messages.

**Institutions.** The term *institution* is used frequently in everyday speech and in the academic literature. However, the concept within institutional theory is distinct. The term *institution* is used in several ways, including as a supraorganizational entity (i.e., governing bodies), professional field (e.g., medicine as an institution), and as a synonym for the term “organization” itself (Lammers & Barbour, 2006). The concept of *institution* in the context of institutional theory is distinct from the typical usages of the term *organization*. An institution captures a much larger system of beliefs and practices that spans organizational boundaries (Lammers & Barbour, 2006). Thus, in the case of U.S. healthcare, *institution* embodies healthcare organizations that operate in substantially similar ways by following the same beliefs, practices, and rules (e.g., “do no harm”).

Lammers and Barbour (2006) define *institutions* as, “constellations of established practices guided by enduring, formalized, rational beliefs that transcend particular organizations and situations” (p. 357). This definition emphasizes that institutions are boundary-spanning entities. That is, institutions are comprised of many organizations that adhere to shared
institutional practices and belief systems. In the context of the present study, an institution is understood as the wider system of beliefs, norms, and rules to which similar organizational bodies adhere in order to remain legitimate.

The term *institution* can be traced back to Weber (1906-1924/1968). Weber focused on how institutions are able to persevere, or endure, over time. Weber explained that membership in institutions was “compulsory” versus “voluntary,” where organizations and their members were obligated to stay in an institution in order to be recognized as legitimate. Institutional membership and rationality give institutions the ability to last long beyond the lifespan of a typical organization (i.e., organizations follow a fixed lifecycle with a “birth” and “death,” whereas institutions endure).

Institutions are socially constructed, or brought about by shared norms that are developed over time within social systems (Berger & Luckman, 1966; Zucker, 1977). Casting institutions as social constructions allows for the examination of both the emergence and the enactment of institutions through social processes. That is, institutional beliefs, rules, and norms both emerge and are enacted through communication among institutional members. Although institutions are established and maintained through interactions among institutional members, they also are influenced by – and also often influence – wider societal norms. A relationship exists between institutions and societal norms whereby what is considered normative within an institution may become normalized within wider society and, in turn, what is considered normalized within wider society may become institutionalized within the institution.

Etzioni’s (1961) typology of organizational work is helpful in classifying institutional practices and norms. Etzioni’s typology clarifies how institutional motivations (e.g., organizations within an institution being motivated to advance societal wellbeing) are manifested
through practices and norms enacted by institutional members. Etzioni considered the motivations for organizational work. Specifically, Etzioni argued that organizations and institutions serve both utilitarian (i.e., organizations motivated by financial incentives) and normative (i.e., organizations motivated by societal wellbeing) roles. Etzioni’s typology of organizational work classifies healthcare organizations as motivated by both financial and social concerns. That is, healthcare organizations render services for a profit, but they also are established to help with the public’s wellbeing. Therefore, healthcare organizations have an inherent tension in their institutional work; on the one hand they are providing services (e.g., fixing a broken leg) that result in monetary gains, and on the other hand they are caring for clients’ wellbeing.

**Rational myth.** Rational myths capture how institutions achieve rationality. Rationality can be understood as organizational logics that seem *reasonable* within certain contexts and for certain groups (Cheney et al., 2011). For example, in healthcare it is rational to employ healthcare providers with the appropriate educational background (e.g., MD, RN, DO). Doing so helps to ensure the quality of healthcare and thus the health of the organization. Thus, rationality is a means to a specific end (Lammers & Barbour, 2006).

Meyer and Rowan (1977) coined the term “rational myth” to refer to the institutional beliefs that lend legitimacy to the institution. Rational myths are understood as the enduring beliefs of an institution that will allow the organization to be considered legitimate by others in the institution and the public. The term “myth” is used in this context to refer to the story and ideology that surround an institution’s rationality (e.g., Frye, 1990). For example, in healthcare, for an organization to be recognized within the institution as legitimate, it must be deemed rational by adhering to institutional norms. Examples of institutional norms in the healthcare
institution include accreditation (something formalized) and employing providers with appropriate educational backgrounds (something expected and also to an extent formalized) (e.g., MDs, DOs, RNs). Further, healthcare practices are constrained by legal requirements. Healthcare is regulated by federal statutes (e.g., Affordable Care and Patient Protection Act). Following these statutes is important for ensuring that healthcare organizations are operating in a lawful manner, and, in turn, are legitimate and rational.

Rational myths and legitimacy separate organizations in the institution from organizations that an institution does not recognize. For example, for a hospital to be recognized as rational and legitimate it must have appropriate accreditations and employ healthcare providers with proper educational backgrounds. Thus, rational myths guide organizational practices across institutions, creating similarities, or isomorphism, among institutional forms.

**Isomorphism.** According to DiMaggio and Powell (1983), organizations are isomorphic, or similar, because of institutional patterns and influences. The term *isomorphism* refers to the similarity among organizational structures within institutions (e.g., hospitals are organized similarly). DiMaggio and Powell argued that organizations are structured similarly not because of efficiency, but because organizations follow institutional standards in order to remain legitimate. Such patterns are found in a variety of sectors, including healthcare, business, education, etc. DiMaggio and Powell contended that if organizations operated only for economic or organizational efficiency, they would not replicate institutional forms, or be isomorphic, because isomorphism can result in organizational wastefulness (e.g., investing in departments that do not contribute to organizational gains). For example, in healthcare, many hospitals have emergency rooms in order to be isomorphic, even though these departments can be a massive strain on the hospital’s financial and staffing resources (Kavilanz, 2009).
DiMaggio and Powell recognized three types of institutional isomorphism: coercive, mimetic, and normative. Coercive isomorphism is achieved through legal authority. Legal authorities define how organizations must operate in order to adhere to federal, state, and local laws. An example of coercive isomorphism in healthcare is the federal Health Insurance Portability and Accountability Act (i.e., “HIPAA”). HIPAA regulates what information healthcare organizations can share with whom about clients (U.S. Department of Health & Human Services, 2015a). In healthcare, HIPAA remains a source of coercive isomorphism, because all healthcare organizations must follow its policies for keeping client information private.

Mimetic isomorphism results from organizations imitating other previously successful organizations that reside within the same institution. An example of mimetic isomorphism in healthcare is the early use electronic health records. Currie (2012) argued that hospitals initially switched from the traditional paper-based medical records to electronic medical records because of mimetic isomorphism. That is, healthcare organizations began to recognize electronic medical recording keeping as an institutional norm and, thus, needed to adhere to that norm in order to conform to the institution. Successful hospitals used electronic records early on. They provided an example of rationality for other healthcare organizations to follow. As electronic medical record keeping became the institutional norm, it became required by governmental mandates and became a source of coercive isomorphism (U.S. Department of Health & Human Services, 2015b).

Normative isomorphism occurs when organizational members establish their legitimacy by linking themselves to professional fields. That is, organizations and their members must verify their relationships with the institution through professional ties, such as appropriate
degrees (e.g., MDs) and affiliations (e.g., American Medical Academy; AMA). Scholars regard healthcare as a model for establishing professionalization (Freidson, 1970; Lammers et al., 2003). That is, physicians are regarded as being one of the first professionals (Foucault, 1973/1994; Freidson, 1970). Lammers et al. (2003) discuss the role that accreditation organizations play in healthcare. In healthcare, accreditation gives both healthcare organizations and organizational members legitimacy to practice. Specifically, accreditation by the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) affirms that a given healthcare organization “meets certain formal and professional standards” (Lammers et al., 2003, p. 324).

In summary, institutional isomorphism explains why varied organizations within an institution are structured similarly. In the context of the present research all three types of institutional isomorphism are relevant. Coercive isomorphism captures the inherent legalities involved in establishing legitimacy as a healthcare organization. Mimetic isomorphism illustrates why healthcare organizations (e.g., clinics, hospitals) are structured so similarly. Finally, normative isomorphism demonstrates the relationships between the healthcare institution and healthcare professions (e.g., MDs, RNs, DOs). However, institutions influence organizations beyond their structures. Institutionalizing is a key process by which institutions are developed and maintained and accounts for similarities among organizations.

**Institutionalization.** Institutionalizing is the core process through which overarching beliefs and norms are created and maintained within organizational bodies. Zucker (1977) defines institutionalization as, “the process by which individual actors transmit what is socially defined as real and at the same time, at any point in the process, the meaning of an act can be defined as more or less a taken-for-granted part of this social reality” (p. 728). Therefore, when
organizations and their members communicate, they *simultaneously construct and reinforce* social and institutional norms. Social and institutional norms are the “taken-for-granted” aspects of institutional life. Organizations and their members socially construct what is “natural” based on institutional and social norms. Meyer and Rowan (1977) define institutionalization as “the processes by which social processes, obligations, or actualities come to take on a rule-like status in social thought and action” (p. 341). Meyer and Rowan’s definition casts institutionalizing as the process of creating and adhering to institutional rules, and/or norms, that are recognized by organizations and their members as natural or as meeting institutional standards. For example, institutionalizing processes in healthcare are evident when nurses do not question physicians because physician authority is a taken-for-granted assumption (e.g., Eisenberg et al., 2005).

Although scholars often use the terms institutionalizing and institutionalization interchangeably, in the context of the present study, institutionalizing is treated as the dynamic processes through which beliefs and norms are transmitted and institutionalization is understood as the outcome of those processes.

Through institutionalizing processes, organizations and their members construct and reinforce shared understandings of institutional norms, beliefs, and rules. Berger and Luckmann (1966) explain that “institutionalization occurs whenever there is a reciprocal typification of habitualized actions by types of actors. Put a bit differently, any such typification is an institution” (p. 51). Through the common enactment of certain behaviors by institutional members, those behaviors may come to be institutionalized (Berger & Luckman, 1966). That is, behaviors are institutionalized when they function to enact the standards and habits that typify the institution. For example, caring behaviors toward clients may function to enact the standards and habits of (e.g., providers are caregivers to the sick) of the healthcare institution.
Institutionalizing processes are evident in healthcare organizations (Barbour & Lammers, 2007; Lammers & Barbour, 2009; Lammers et al., 2003). The healthcare field is highly institutionalized in that provider behaviors are habitualized and typified. For example, physicians use habitualized question-and-answer sessions when engaging with clients (e.g., Street et al., 2009). Further, healthcare organizations constantly are replicating and reinforcing institutional norms through communication. For example, healthcare organizations require healthcare providers to follow organizational and institutional rules (e.g., privacy standards, HIPAA) when interacting with clients. Thus, within healthcare organizations, institutional understandings are manifested, maintained, and reinforced through communication processes.

**Institutional messages.** Institutional messages connect everyday communication behaviors to the institution by articulating institutional norms, beliefs, and practices. Institutional messages are communicative processes through which institutional members enact institutional beliefs. Lammers (2011) defines institutional messages as, “collations of thoughts that are intentional, enduring, have a wide reach, and encumber organizational participants to engage in certain behaviors or to take performative responses” (p. 154). Although Lammers’s definition casts institutional messages as “thoughts,” in actuality these “messages” are the everyday communication (e.g., messages, interactions, behaviors) that occur within organizations. Thus, institutional messages occur as everyday communication that replicates and reinforces the institution’s existence within organizations.

Institutional messages are instances of formal communication (i.e., function to meet formal organizational needs; Jablin, 2001) in which institutional influences are evident. Formal communication, or formalization, is “the degree to which interactions in the organization are characterized by rules, regulations, and norms” and therefore tend to be focused on
organizationally sanctioned and required tasks (Cheney et al., 2011, p. 23). That is, within organizations, formal communication is composed of interactions that adhere to institutional standards. Formal communication functions to advance organizational goals (e.g., complete organizational work). An example of formal communication in healthcare is when physicians communicate with clients about illness or injury and options for treatment. When physicians discuss illness and injury with clients, they are required to follow organizational and institutional standards and norms, which may include notifying clients of insurance restrictions or options. In contrast, informal communication also occurs within organizations and can be thought of as “the grapevine” (Davis, 1978, p. 112). Informal communication generally is conceptualized as communication within organizations that does not function meet organizational tasks (Barnard, 1968). Although informal communication is sometimes conceptualized as gossip, it serves many purposes in organizations, such as increasing cohesion among organizational members (Barnard, 1968).

**Summary of key concepts.** Institution, rational myth, isomorphism, institutionalization, and institutional messages, are key concepts that form the building blocks of institutional theory. Institutions are boundary-spanning entities that perpetuate specific belief systems. Those belief systems can be understood as rational myths. Organizations must be isomorphic to remain institutionally legitimate and meet institutional expectations. Institutionalizing processes allow individuals to understand what is real and rational within institutions. Finally, institutional messages are instances of institutional communication in action and are formal in nature.

To illustrate these key concepts together, consider the example of the healthcare institution: Healthcare is situated as an institution in nature as it is comprised of many healthcare organizations following the same belief system (e.g., providing care for those who are injured or
ill; “do no harm”). Beliefs within the healthcare institution serve as rational myths. The example of “do no harm” is based on the ideology that physicians and healthcare providers put the client’s well-being first. Healthcare organizations also are isomorphic, in that they follow laws governing how they are structured and operate, they follow similar structures to appear legitimate, and they partner with professional fields that share and help to normalize their values and beliefs.

Healthcare also is institutionalized in that healthcare professionals follow institutional practices and rules in their daily behaviors (e.g., physician authority). Finally, the healthcare institution is shared through institutional messages. Institutional messages are formal forms of communication, such as discussions with clients about their health, in which institutional rules and practices are reinforced.

**Propositions of institutional theory in organizational communication.** Lammers and Barbour (2006) delineate five propositions, or primary statements, about the nature of institutional theory in organizational communication.

**Communication sustains institutions.** The first proposition of institutional theory is that “communication sustains institutions” (Lammers & Barbour, 2006, p. 364). Institutions are not one organization, but are “communicatively constituted” (p. 364) among isomorphic organizations. Institutions are created through and maintained by communication across and among organizations within a given institution. A reflexive relationship exists between institutions and communication processes, whereby an institution both influences and is influenced by the communication processes that occur across and among organizations within that institution’s purview.

In the healthcare institution, the medical profession is sustained, or reinforced, through communication. That is, through communication within an institution, work is formalized and
considered “professional” (Cheney, Lair, Ritz, & Kendall, 2010). Medical doctors are an exemplar of the professional; they conform to social and institutional standards, and follow a strict ethical code (Cheney et al., 2010). At the institutional level, the medical profession is sustained through the recognition of specialized knowledge (i.e., doctor of medicine degree, MD; see Freidson, 1970). At the organizational level, organizations and their members adhere to the institution by employing providers with an MD. Employing organizational members with the requisite credentials both adheres to institutional beliefs and sustains institutional norms. At the interpersonal level, the institution is sustained through formal communication that reaffirms the institution. This includes references to providers’ credentials (i.e., MD). Physicians usually introduce themselves by saying “I’m Dr. ______,” instead of using their first names alone. Referring to physician credentials in interpersonal interactions calls attention to adherence to institutional standards. Thus, the institution is present and sustained through institutional, organizational, and interpersonal communication.

**Communication aligns organizing with institutions.** The second proposition of institutional theory is that “communication aligns organizing with institutions” (Lammers & Barbour, 2006, p. 365). Weick (1969) explained organizing as the process through which organizational members work together to perform organizational activities, make sense of the work being done, and reduce uncertainties. As such, communication serves as the process through which organizing occurs (e.g., Kreps, 2009). However, Lammers and Barbour’s second proposition is somewhat circular. Specifically, the phrasing “communication aligns organizing” reads as a tautology because “organizing” is inherently a communicative process.

Examples of organizing include adhering to organizational practices and creating organizational rules. Organizing in institutions occurs when organizations adhere to institutional
standards (i.e., norms, values, beliefs, rules). Organizing is a communication process in which organizations and their members follow “institutional rules” formulated by its values and beliefs (Lammers & Barbour, 2006, p. 365). Lammers and Barbour illustrate this proposition with the example of the Hippocratic Oath. That Oath embraces the concept of “do no harm” (Oath of Hippocrates, 1910). Thus, the Hippocratic Oath represents an institutional value that is communicated throughout healthcare, where organizing aligns with institutional standards in healthcare (i.e., operating healthcare organizations with the mission to first, do no harm).

**Institutions operate in organizing through formal communication.** The third proposition of institutional theory is that “institutions operate in organizing through formal communication” (Lammers & Barbour, 2006, p. 365). This proposition stipulates that institutional communication is formal and typically recorded through organizing processes. Unlike informal communication, that fosters relationships among organizational members (e.g., “water cooler” conversations, gossip), formal communication is used for the sole purpose of conducting the operations of the organization as a whole.

One example of formal communication in healthcare is client records or charts. These may be in paper or electronic form or both. These formal messages reflect institutional beliefs and rules. Client records are formulaic in nature and impart information about the client (e.g., symptoms, test results, history, prescribed medications). As formal communication, client records have the organizational objective of using the provider’s knowledge, obtained through formal education, to communicate to others within the organization and institution about what is going on with the client. This formal communication simultaneously shows others within the institution that the provider has followed institutional rules (e.g., “do no harm”).
The success of boundary-spanning communication depends on the presence of institutions. The fourth proposition of institutional theory is that “the success of boundary-spanning communication depends on the presence of institutions” (Lammers & Barbour, 2006, p. 366). Organizations and their members communicate with other organizations and members within their institution. The act of communicating beyond one’s own organization is termed “boundary-spanning.” An example of boundary-spanning occurs when one organization distributes its press releases to other organizations within the institution. Press releases are formal messages written by public relations professionals. Press releases often are used by healthcare organizations to communicate with other healthcare organizations and the public. Press releases may include references to institutional rules, such as its institutional accolades (e.g., yearly rankings of hospitals in *U.S. News and World Reports Top Hospitals*). Institutions are maintained and reinforced through communication that spans organizational boundaries.

Institutional hierarchy is manifested in organizing. The final proposition of institutional theory is “institutional hierarchy is manifested in organizing” (Lammers & Barbour, 2006, p. 367). This proposition argues that organizations are hierarchical in nature and that power is distributed unevenly. In institutions, those with the greatest amounts of power within organizations are situated at the top of the organization’s hierarchy. Lammers and Barbour (2006) argue that institutional rules are observed with different stringency based on where an individual ranks in the organizational hierarchy.

An example of this proposition comes from research by Noland and Carl (2006). They studied medical residents’ sensemaking surrounding malpractice lawsuits. The researchers interviewed medical residents about the communication strategies they used when confronted with potential malpractice lawsuits. The study’s findings indicated that the residents felt that they
were not afforded enough hierarchical power (i.e., residents are lower hierarchically than attending physicians) to be held directly accountable for malpractice claims. They saw themselves as being in contrast to attending physicians, who were regarded as higher in the organizational hierarchy. As such, residents expected attending physicians to follow institutional rules, but also to make sure that their subordinates (including the residents themselves) were also following institutional rules (i.e., attending physicians were essentially viewed as responsible for residents’ practices). Thereby, residents viewed themselves as immune from responsibility for malpractice and, in this manner, protected by the organizational hierarchy.

**Strengths and limitations of institutional theory in communication.** Institutional theory in communication presents unique opportunities for the development of organizational communication scholarship (Lammers & Garcia, 2014). However, institutional theory in communication also has received some criticism (Suddaby, 2011).

Institutional theory in communication has several strengths in its applications. I highlight these with an eye toward the healthcare context. Lammers and Barbour (2006) argue that institutional theory is a response to the criticism that most organizational communication research focuses on micro-level interpersonal phenomena (e.g., superior-subordinate communication) and does not link those to the larger systemic practices in organizations. Thus, a major strength of using institutional theory to examine communication in organizations is that it aims to capture how institutions influence communication both within and among organizations. Institutional theory guides the examination of organizational communication phenomena holistically (Lammers & Garcia, 2014). Lammers and Barbour (2006) explain that institutional theory captures the “macro” level in organizational research and explains how the institution influences everyday organizational interactions. For instance, in the healthcare institution,
organizational policies and practices, such as managed care, influence how organizational members and participants, such as providers and clients, communicate with one another (e.g., managed care plans may prevent a physician from ordering certain tests).

A second strength of institutional theory is that it is useful in explaining organizational communication “diachronically” (see also Barley & Tolbert, 1997). That is, it can explain organizational communication as a dynamic over time (Lammers & Barbour, 2006, p. 370). Research in organizational communication research often has captured snapshots of organizational phenomena (e.g., specific instances of superior-subordinate communication, peer conflict). However, using an institutional approach offers the possibility for understanding why widespread beliefs and assumptions *endure*. The ability to examine institutional issues over periods of time is particularly useful in healthcare, because significant healthcare values, such as The Hippocratic Oath and its associated beliefs, have endured.4

A third strength of institutional theory is that it gives researchers the ability to reevaluate how different organizational levels (e.g., individual, group, organization) are analyzed (Lammers & Barbour, 2006). That is, institutional theory examines how messages are situated within multiple levels of interaction, such as institutional, organizational, and interpersonal. For example, in healthcare, at the institutional level, healthcare providers are expected to take care of their clients, but this caretaking actually is observable at an interpersonal level. Rather than focusing within one level of organizational communication, institutional theory is useful in clarifying how various levels of organizational communication are connected to and influence one another. Through the examination of multiple levels of analysis, researchers are able to explore the reciprocal influence among organizational levels (e.g., individual, group,

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4 Healthcare practices often change rapidly with regard to new technology and innovation. However, organizational beliefs and values are slower to change and tend to endure.
organization, etc.).

The primary critic of institutional theory in organizational communication is Suddaby (2011). Suddaby argues that institutional theory cannot provide a universal explanation for organizational outcomes. He asserts that not all organizational activities can be explained through the institution. In addition to Suddaby’s critiques, I add that Lammers’ and associates use of the term “institution” is overly expansive. That is, Lammers and associates’ work tends to cast all organizational processes as the outcomes of institutionalizing. Lammers and associates often fail to recognize that many factors influence organizing processes (e.g., socio-cultural norms, power) and instead they explain all organizational outcomes as the result of institutional beliefs, norms, and rules. Thus, Lammers and associates apply the term “institution” almost as a blanket concept to capture all organizational processes instead of acknowledging the complexity and nuances of institutions and institutionalizing processes.

Suddaby (2011) poses three main criticisms of Lammers and associates’ institutional theory in organizational communication: (a) the explanation of institutional theory is too narrow; (b) it overlooks neo-institutionalism; and (c) it subordinates communication to institutionalization. First, Suddaby argues that using institutional theory tends to remove agency from organizations and individuals. By “agency,” Suddaby means the ability of organizational members to act independently within organizations and institutions. Thus, Suddaby argues that institutional theory does not consider the fact that individuals and individual organizations do make decisions outside of institutional logics (e.g., when organizations make an effort to go against the institutional norm). However, institutional theory does not necessarily need to be applied in communication in the way that Suddaby argues. When communication scholars are open to both institutional and individual/organizational explanations of communication
phenomena, the role of the institution does not underestimate the power of other interactional processes (e.g., informal communication) in organizations. Instead institutional theory can elaborate on how both institutionalization influences everyday communication among organizational members and how organizational members have the agency to construct norms through other interactional processes.

Second, Suddaby (2011) criticizes Lammers and associates’ theory for neglecting neo-institutionalism (i.e., the concept that institutions interact with and affect society). Suddaby argues that Lammers does not address the sociological issue of how institutions influence societal norms. He contends that using a rhetorical approach can help to correct this oversight, because rhetorical approaches can examine how institutions and society communicate and the meanings of this communication. Since Suddaby voiced this criticism, Lammers and Garcia (2014) have discussed institutional rhetoric as an avenue for exploring neo-institutionalism. They contend that institutions respond to social and political influences through their rhetoric. For instance, businesses within the U.S. voiced their opinions against The Affordable Care and Patient Protection Act; they specifically cited the additional costs that businesses would incur in order to cover employee health insurance that the law required.

Third, Suddaby (2011) argues that researchers should not subordinate communication processes to institutionalization. By this, he means that communication processes should not be cast as a secondary process to institutionalizing. The issue here is that communication is not just a conduit of institutions, but instead is the very process through which institutionalization occurs. Suddaby questions Lammers’s (2011) explanation of the “institutional message,” arguing that it is often difficult to ascertain the source of institutional messages. Lammers (2011), however, explains that institutional messages are the product of institutional norms, practices, rules, and
beliefs.

Despite these criticisms, Suddaby (2011) agrees that incorporating institutional theory into communication studies is valuable. Further, he contends that institutional messages and communication processes can help fill one of “institutional theory’s biggest voids – that is, the absence of any mechanism that explains how institutional reproduction occurs” (p. 183). Thus, Suddaby ultimately agrees that institutional theory is specifically valuable in communication research. This value is evident with respect to its applications in healthcare. Specifically, healthcare is highly institutionalized and, thus, institutionalization can be examined in the communication that occurs within healthcare organizations.

**Institutional theory in communication and healthcare research.** Institutional theory can be applied to numerous types of institutions (e.g., education, government). The healthcare institution is one such application. Healthcare has been the most widely studied institutional phenomenon from a communication perspective (see Barbour, 2010; Barbour & Lammers, 2007; Lammers & Barbour, 2009; Lammers et al., 2003; Lammers & Lambert, 2016). However, institutional theory has been applied in other institutional contexts as well (e.g., veterinary medicine, Lammers & Garcia, 2009; non-profit organizations, Zorn, Flanagan, & Shoham, 2010).

In the *Handbook of Health Communication*, Lammers, Duggan, and Barbour (2003) provided a typology of healthcare organizations (e.g., hospitals, hospice, nursing homes). They argued for institutional theory as a useful framework for identifying and investigating organizational forms of healthcare. They explained that healthcare organizations are “societal sectors where decision-making rights tend to be hierarchically distributed” (p. 321). The hierarchy of healthcare provides an environment for observing institutional influences on healthcare providers’ decision-making processes. That is, hierarchical structures in healthcare
organizations follow institutional influences, where those with more experience and knowledge more closely follow institutional norms. In healthcare, decision-making is guided by institutional values such as “do no harm.” When clients receive healthcare from a given organization (e.g., hospital, clinic), their care is constructed and communicated based on institutional beliefs held by the healthcare institution.


Barbour and Lammers found that the number of managed care contracts and the amount of communication physicians had with managed care administrators both were negatively associated with physician satisfaction. These findings are similar to other research (e.g., Lammers & Duggan, 2002), which found physician dissatisfaction with managed care. Barbour and Lammers also found that physicians’ institutional beliefs (e.g., knowledge affording them autonomy, best interests of the client at heart) were related to their dissatisfaction with managed care. That is, physicians who had strong institutional beliefs about their role in healthcare also were dissatisfied with the changes that managed care made to the institution of healthcare (e.g., managed care’s influence over physician authority to prescribe medications and order tests). Lammers and Barbour also indicated that physicians who hold strong institutional beliefs (e.g., physician knowledge and authority) tend to dislike managed care’s influence on physician
decision-making abilities.

Most of the research in healthcare contexts that used institutional theory from a communication perspective examined physician practices. Related research findings have supported the ability of institutional theory to capture and address institutional-level beliefs, practices, and norms.

**Summary of institutional theory.** *Institutional theory is one of the few organizational theories available to communication researchers to use in examining how micro-level interactions are influenced by in the macro-level institution.* Institutional theory provides a framework for understanding similarities among organizational bodies. Institutional theory grew out of scholarship that examined the concept of “institution” as a boundary-spanning entity through which belief systems, norms, and rules are created and maintained. Specifically, scholars noted that organizational structures often are similar even though adhering to similar organizational structures can lead to inefficiencies.

Institutional theory proposes that organizations become isomorphic (i.e., structured similarly) in order to be accepted as meeting institutional standards (i.e., legitimate). Within organizational communication scholarship, institutional theory proposes that through institutional messages (i.e., institutional beliefs enacted through formal communication) institutions are sustained. Further, the communication of institutional messages influences organizing processes within and across (i.e., boundary-spanning) organizations. Finally, institutional theory proposes that through institutionalizing processes that institutions are created and maintained.

Institutional theory is used to examine institutionalizing processes within and across organizations. Understanding institutionalizing processes is helpful for explaining how and why
institutional beliefs, norms, and rules are accepted and adhered to within and across organizations. Although institutional theory is useful for explaining how activities are normalized across similar organizational bodies, the concepts of “institutions” and “institutionalizing” cannot explain all organizational processes and should be used carefully and in a specified manner so as not to attribute all organizational behaviors to institutional beliefs, norms, and rules.

Institutional theory fits well within the context of the present study because it provides a framework for identifying how norms, beliefs, and rules within institutional contexts (i.e., macro-level) influence everyday interpersonal communication, such as social support (i.e., micro-level). Further, investigating how larger belief systems influence everyday interpersonal interactions provides a framework for researchers to interpret patterned behaviors enacted by institutional members and, potentially, identify the origins (e.g., institutional norms, rules) of these behaviors. Institutional theory is useful in examining healthcare contexts because especially, it can explain why and how similar behaviors are used in carrying out organizational work across the healthcare institution. Specifically, in the healthcare institution it is useful to understand how members of the institution go about interacting with clients in ways that are beneficial to clients’ health and wellbeing. Currently, researchers have not used institutional theory to study social support processes in healthcare settings (Lammers & Lambert, 2016). The present study was designed to investigate this gap in the literature.

Social Support

The communication of caring among individuals is captured in the study of phenomena labeled social support (Burleson, Albrecht, Goldsmith, & Sarason, 1994). Substantial research indicates the health benefits associated with social support (e.g., Cohen & Wills, 1985; Roy,
2011; Uchino, 2004). Specifically, evidence shows that social support helps individuals limit and/or manage their stress and, thereby, improves health (Albrecht & Goldsmith, 2003). The following section: (a) reviews the history of the concept of social support, which dates back to early work on social relationships; (b) discusses varied conceptualizations of social support, with an emphasis on those conceptualizing social support as communication phenomena; and (c) discusses how social support influences health outcomes, with particular attention to cancer-related contexts.

**History of research on social support.** The social support literature grew out of early sociological work on social relationships (Durkheim, 1897/1951) and developed throughout the 1970s and 1980s with an emphasis on investigating relationships between social support and health (e.g., Caplan, 1974; Cassel, 1976; Cobb, 1976; Cohen & Wills, 1985; Moss, 1973). The following section reviews Durkheim’s (1897/1951) work on social relationships; it laid the groundwork for what later developed into the study of social support. Next, the section reviews early literature from the 1970s and 1980s on social support. Specifically, the section discusses the development of the concept of social support and research that established its association with health benefits. Finally, the section ends with a discussion of contemporary directions in research on social support.

**Early study of social relationships.** The contemporary study of social support can be traced back to 19th century sociological research on social relationships. Durkheim’s (1897/1951) research explored associations between the presence of social relationships and suicide rates. In, *Suicide: A Study in Sociology*, Durkheim (1897/1951) examined whether social structures, such as marriage and parenthood, are associated with individuals’ likelihood of committing suicide. Durkheim found that unmarried individuals were more likely to commit
suicide than those who were married. He also found that individuals who had children were less likely to commit suicide than those who did not have children. Thus, Durkheim concluded that the presence of social relationships affects the likelihood of committing suicide.

Social support researchers continue to cite early sociological work as the foundation for modern conceptualizations of social support (e.g., Uchino, 2004). Uchino (2004) explained that Durkheim’s findings were radical at the time, because they indicated that the social environment affects mortality. This conclusion was in opposition to the conventional wisdom of the time that physical characteristics, or attributes, were the sole explanations of health. Durkheim’s research attracted the interest of later scholars who investigated relationships between the social environment and health outcomes.

The development of social support literature. The study of what the contemporary literature refers to as social support began in the 1970s. Sociologist Gordon Moss (1973) offered one of the first examinations of social support and health (1973). In his book, *Illness, Immunity, & Social Interaction*, Moss discussed the relationships between stress and communication processes in social networks. Specifically, Moss examined the relationships among social interactions, stress, and disease susceptibility. Moss argued that social relationships help to create an environment where stress is reduced and, as a result, adequately supported individuals are less susceptible to disease.

Near the end of his book, Moss introduced the term “social support” to refer to the phenomenon of social relationships that help individuals to reduce or manage stress. Moss (1973) defined social support as “information that led to the subjective feeling of belonging, of being accepted or being loved, of being needed all for oneself and for what one can do” (p. 237). This early definition cast social support as an outcome rather than a process. That is, Moss used
the term social support to refer to the feeling of belonging that is a result, or an outcome, of social interactions.

Shortly after Moss’s book was published, psychiatrist Gerald Caplan published a book titled, *Support Systems and Community Mental Health* (1974). In his work, Caplan examined how social relationships can aid in recovery from mental illness. Specifically, Caplan argued that the *existence* of social support networks can facilitate an individual’s recovery from mental illness and, in some cases, serve to prevent negative mental health outcomes (e.g., prevent suicide). Throughout his book, Caplan explained that having a social network (i.e., relationships through which individuals can receive support) of family and friends provides a safe place for individuals to recuperate from mental illness. That is, he cast social networks as spaces or environments in which individuals feel comfortable and safe and, therefore, are better able to recover from mental illness.

As research on the role of social support in health outcomes grew, researchers began to evaluate the developing body of literature. Cobb’s (1976) seminal review of literature on the social environment and health examined how social support moderates stress. Cobb referred to *social support* as information that “led the subject to believe that he/she 1) is cared for and loved; 2) is esteemed and valued; and 3) belongs to a network of communication and mutual obligation” (p. 300). Cobb’s definition implied that social support occurred by providing information that resulted in the outcomes of feeling cared for and belonging. He argued that these emotional and social outcomes alleviate stress and, thereby, result in better health outcomes.

Cobb’s review that focused on research regarding the relationships between the social environment and health outcomes addressed several health issues. These included low birth
weight, arthritis, depression, and alcoholism, among others. Based on his review of literature, Cobb concluded that social support, both in the forms of information and access to social networks, moderated stress and, as a result, clients experienced better health outcomes (e.g., higher birth weight, reports of less pain).

Whereas Cobb viewed social support as a moderating factor that reduced stress, including stress associated with health problems, an alternative position, in terms of social support’s influence on health, began to emerge. That position, as expressed by John Cassel (1976), suggested that social support might directly influence susceptibility to disease itself. In his address to the American Public Health Association in 1976, Cassel, an epidemiologist, argued that social support helps individuals to resist disease (Cassel, 1976). Cassel explained that certain individuals are more susceptible to disease because of stress in their social environment. That is, aspects of the social environment (i.e., stressful social situations, such as financial concerns or relational conflict) could expose individuals to greater stress and, thus, lead to worsened health outcomes (e.g., heart disease; stroke).

Cassel viewed a supportive social environment as protecting individuals from experiencing stress and, thereby protecting them from illness, whereas Cobb conceptualized social support as a sense of belonging that helps reduce and, thus, ameliorates stress. Cobb’s and Cassel’s different conceptualizations of social support offered opposing explanations of social support and its role in alleviating the potentially harmful effects of stress and, thereby, protecting individuals from disease. Cobb argued that social support served as a stress moderator, or buffer, whereby individuals’ stress was more easily managed when social support was available and, thus, brought about better health outcomes as a result of reduced stress. However, Cassel argued that the existence of social support itself (e.g., social networks) directly influenced health
outcomes (e.g., susceptibility to heart disease) by reducing individuals’ exposure to stress that otherwise would negatively affect health outcomes.

As research on social support continued, scholars increasingly aligned themselves with either Cobb’s or Cassel’s positions. Cobb’s and Cassel’s work constituted the early development of what later were described as two models explaining the associations among social support, stress, and, thus, health: the stress buffering model and the direct effects model (Cohen & Wills, 1985). Although Cobb and Cassel did not use the terms “stress buffering” or “direct effects,” essentially they argued that social support was beneficial to health through one of these two processes. Specifically, Cobb argued that social support moderates the stress that comes with experiencing a health issue (i.e., an explanation that was the basis for what was later called the stress buffering model). However, Cassel argued that the presence of extant support (i.e., a supportive network) made individuals less susceptible to experiencing stress and, thus, less susceptible to illness or disease (i.e., an explanation that was later called the direct, or main, effects model).

Into the 1980s, researchers examined the specific processes suggested by the two models to explain how social support is related to health outcomes. For example, researchers sought to understand how social support ultimately influenced the use of healthcare services. Wallston, Alagna, DeVellis, and DeVellis (1983) reviewed literature on social support, illness, stress, and the use of healthcare services. They found wide variations in the conceptual and operational definitions of social support (e.g., breadth of the term, measurement issues, such as some studies measuring quality of social support, such as benefits, and others focusing on quantity of social support, such as number of social ties). However, Wallston et al. concluded that most definitions conceptualize social support in one of three ways: as a process of providing particular
resources (e.g., information, listening; Pinneau, 1975), as the amount of social support received through social networks (e.g., frequency of support; Donald, Ware, Brook, & Davies-Avery, 1978), or in terms of the perceived adequacy of available social support (e.g., quality or quantity of social support; Donald et al., 1978).

Although Wallston et al. found differing definitional approaches to social support in the literature, they concluded that a positive relationship exists between frequency of interaction within one’s family support network⁵ and the likelihood of individuals seeking healthcare when ill (e.g., visiting a doctor). Wallston et al. argued that social support’s relationship with using healthcare services is important, because individuals who seek healthcare services are more likely to receive the treatment they need and to have more positive health outcomes as a result.

Cohen and Wills’ (1985) comprehensive review contributed to the literature, in part, by offering more precise explanations for the relationships among stress, social support, and health outcomes. They defined stress as, “feelings of helplessness and the possible loss of self-esteem” (p. 312). From this perspective, stress is the outcome of personal perceptions about one’s self and efficacy. Cohen and Wills also clarified the mechanisms whereby stress may adversely affect health and described two relatively distinct approaches to understanding and observing social support.

Cohen and Wills identified two models to explain relationships among stress, social support and health outcomes: the direct effects model and the stress-buffering model. They explained that the direct effects model of social support is based on the premise that social networks provide individuals with social support that creates stability and, thus, protects individuals from stress, which leads to better health. They explained the stress-buffering model

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⁵ Due to the early nature of Wallston et al.’s review, the researchers were not specific in summarizing particular social network variables (e.g., density, homogeneity) that were analyzed across research studies.
of social support as: “a process of support protecting persons from potentially adverse effects of stressful events” (p. 310). That is, individuals who experience social support are less likely to experience the otherwise often negative health outcomes that result from experiencing that stress. Experiencing social support, typically from others who recognize that a stressor is occurring, reduces the potentially negative impact of stress.

Cohen and Wills also explained two mechanisms whereby stress itself plays a role in health. First, stress leads to disruptions in immune or neuroendocrine systems. Second, individuals often respond to experiencing stress by engaging in unhealthy personal behaviors (e.g., poor diet, alcohol use). Therefore, experiencing social support can influence health by either (a) reducing the likelihood of actually experiencing stress that disrupts specific physiological systems, and thereby reducing the likelihood of disease, or by (b) buffering stress, that is, by reducing the otherwise negative health impact of stress that is experienced, and thereby reducing the likelihood that the experienced stress will cause or exacerbate a health problem.

Finally, the Cohen and Wills (1985) review contributed to the literature by identifying and clarifying two relatively distinct approaches that had emerged in prior research for understanding, observing, and measuring social support. They referred to these as functional support and structural support. Cohen and Wills defined functional support as specific resources that are provided through social support processes. These resources include information, material aid (e.g., loans), encouragement, and empathy. In contrast, they defined structural support in terms of the relational ties that embed one in a social network (i.e., create one’s social integration). Social networks are the composite organization of the links among relational ties in which one is socially integrated (e.g., families, friends).
Research reviewed by Cohen and Wills supported the conclusion that functional support, (i.e., receiving support resources) helps individuals to reduce and/or manage stress, including stress brought on by health problems. That is, receiving supportive resources can buffer or protect individuals against the otherwise additional negative effects of stress on their health, thereby resulting in better health outcomes. For example, when an individual who is experiencing significant health issues feels valued and accepted, as a result of being provided encouragement, his or her stress may be reduced. Thus, giving encouragement is one functional mechanism or means of providing resources. Others include offering information and providing material and behavioral aid (see Chapter II, Structural and functional approaches to analyzing social support).

Cohen and Wills also explored the mechanisms whereby structural support directly serves to prevent health problems and, thus, leads to better health outcomes. By structural support, they meant social networks that are characterized by providing support. For example, people who have a supportive social network may be less likely to actually have stress brought about by the financial issues associated with an illness; thus, their health will not be further compromised by that stress (i.e., they will be healthier than individuals who do not have a supportive social network and are forced to manage financial concerns on their own). That is, being part of a supportive social network means that individuals may never actually experience some stressors that otherwise could occur and thereby create health problems (see Chapter II, Structural and functional approaches to analyzing social support).

Cohen and Wills’ work more clearly and explicitly articulated mechanisms to explain the role of social support in health outcomes (i.e., stress buffering and direct effects) that were only loosely described in the early work of Cobb and Cassel. Cohen and Wills’ review also provided
At the time, researchers had a better understanding of the mechanisms whereby specific social support processes (i.e., functional versus structural) resulted in better health outcomes.

**Contemporary directions in the social support literature.** Today, many social support researchers focus on investigating health outcomes associated with social support (e.g., see reviews by Roy, 2011; Uchino, 2004). Researchers are interested in a variety of social support processes (e.g., resources provided, amount of social support) and their relationships to varied health outcomes (e.g., pain, recovery rates; e.g., Goldsmith & Albrecht, 2011; Thoits, 2011a; Uchino, 2006). As a result, researchers have examined social support in a variety of health contexts, including mental health (e.g., Turner & Brown, 2010), cardiovascular health (e.g., Uchino, 2009), and cancer (e.g., Nausheen, Gidron, Peveler, & Moss-Morris, 2009; Zaza & Baine, 2002).

As social support research developed and grew throughout the past four decades, researchers have investigated new and/or previously unstudied sources of social support. For example, historically, researchers studied social support groups that met face to face (see Cline, 1999; Helgeson & Gottlieb, 2000 reviews). But in more recent years, a substantial volume of research has investigated online social support groups (e.g., Mo, Malik, & Coulson, 2009; Rains & Young, 2009). Although numerous descriptive studies of online support groups have been conducted (e.g., Campbell et al., 2001; Tanis, 2008), the more important issue for researchers is understanding the relative psychological and physiological benefits of participation in online social support groups, particularly in comparison to traditional face-to-face support groups (for a review of online support groups, see Wright, Johnson, Bernard, & Averbeck, 2011).

As the social support literature continues to develop, scholars have identified the needs for future research to examine previously un- and under-explored social support processes and
contexts. These include social support provided by healthcare professionals (e.g., Goldsmith & Albrecht, 2011; Lammers & Lambert, 2016).

**Definitions of social support.** Scholars have defined social support in numerous ways that often vary by disciplinary perspective and by the specific social processes addressed (e.g., Albrecht & Goldsmith, 2003; Burleson et al., 1994; Cohen & Wills, 1985). Although definitions of social support emanate from varied disciplinary perspectives (e.g., sociology, psychology), *most scholars from diverse disciplines define social support in ways that state or imply that social support is communicative in nature.* For example, psychologists’ definitions of social support often focus on individuals’ perceptions of others’ behaviors (which can be understood as messages) that communicate social support or the availability of social support (e.g., see Sarason, Pierce, & Sarason, 1990). That is, they tend to focus on the individual’s perceptions regarding social support experiences (e.g., meanings or interpretations that result from being supported, such as feeling valued, cared for; Burleson et al., 1994). In contrast, sociologists generally focus on the social structures (e.g., social networks) whereby individuals are tied or connected to one another (see Gottlieb, 1981). These structures are understood as the pathways whereby support occurs (Burleson et al., 1994). Thus, varied communicative phenomena (e.g., messages, interactions, social networks) are central to the, albeit diverse, conceptualizations of social support emanating from different disciplinary perspectives (e.g., Albrecht & Goldsmith, 2003; Burleson et al., 1994; Goldsmith, 2004).

Some of the earliest definitions of social support came from the sociologists Moss (1973) and Cobb (1976). Moss defined social support as, “*information* [italics added] that led to the subjective feeling of belonging, of being accepted or being loved, of being needed all for oneself and for what one can do” (p. 237). Cobb defined social support as *information* that, “led the
subject to believe that he/she 1) is cared for and loved; 2) is esteemed and valued; and 3) belongs to a network of communication and mutual obligation” (p. 300). Both Moss’ and Cobb’s definitions focus on the informational nature of social support. They both explained social support in terms of a commonly cited component of messages, that is, information or what could be understood as message content. Information is provided via messages. Thus, even early definitions of social support emphasized some aspect of the communicative nature of social support.

Other early definitions of social support emphasized individuals’ actions or behaviors as supportive in an interactional context, but sometimes implied rather than stated the interactional nature of social support. For example, Tolsdorf (1976) was one of the first researchers to define social support in a manner that implied an interactional context. Tolsdorf defined social support as “any action or behavior that functions to assist the focal person in meeting his [sic] personal goals or in dealing with the demands of any particular situation” (p. 410). His definition implied that the actions or behaviors are interpreted by another as meeting his or her needs. That is, those actions may be understood as communicative phenomena, specifically as messages within social interaction.

Definitions that focused on social support from an explicitly communication, or interactional perspective, began to emerge in the late 1980s. For example, Hobfoll (1988) defined social support as “social interactions or relationships that provide individuals with actual assistance or that embed individuals within a social system believed to provide love, caring, or sense of attachment to a valued social group or dyad” (p. 121). Hobfoll’s definition conceptualized social support as a communicative process that, tangibly or symbolically, provides assistance. Thus, Hobfoll’s definition offered an interactional view of social support as
communication, or the idea that social support as communication occurs *between individuals* rather than resides in individuals’ behaviors. Hobfoll further situates social support within social systems in which an individual is experiencing needs (e.g., care, attachment) that can be met communicatively.

Albrecht and associates (Albrecht & Adelman, 1987) were some of the first scholars from the communication discipline to define social support. Albrecht and Adelman (1987) initially defined social support as “verbal and nonverbal communication between recipients and providers that helps *reduce* [italics added] uncertainty about the situation, the self, the other or the relationship and functions to enhance a perception of personal control in one’s life experience” (p. 19). Albrecht and Adelman’s original definition posited that social support *reduces* uncertainty. Uncertainty is the ambiguity that one experiences when one is lacking information (e.g., Brashers, 2001). For example, many unknowns are encountered when one is dealing with a health crisis (e.g., duration of illness, outcome of illness; e.g., Politi & Street, 2011) that can create feelings of uncertainty about numerous aspects of the situation. Albrecht and Adelman explained that uncertainty in health crises leads to stress. They contended that when social support *reduces* uncertainty, social support also *reduces* stress. Thus, Albrecht and associates initially argued that social support benefited health by reducing stress.

However, Albrecht and Goldsmith (2003) later revised the original Albrecht and Adelman (1987) definition of social support by proposing that social support helps individuals to *manage* rather than to *reduce* uncertainty. Albrecht and Goldsmith recognized that uncertainty is not necessarily a negatively valenced experience. Although uncertainty often is experienced negatively (e.g., concerns over one’s ability to pay medical expenses or one’s ability to manage side effects of treatment), uncertainty also can be a positive experience if it allows an individual
to feel hopeful or optimistic. For example, when someone is diagnosed with an advanced stage cancer, that individual likely will experience much uncertainty in terms of the future (e.g., regarding length of life, treatment options, quality of life). That uncertainty may actually permit the individual to be optimistic about his or her longevity. Thus, receiving social support can facilitate managing (not just reducing) uncertainty, and thereby uncertainty can function to create motivation and hope, not just stress or possible despair.

MacGeorge, Feng, and Burleson (2011) provided an alternative term for social support. They offered the term *supportive communication* and defined it as “verbal and nonverbal behavior produced with the intention of providing assistance to others perceived as needing that aid” (p. 317). MacGeorge et al.’s definition conceptualized social support as messages that are created with the intention of providing help to others. Supportive messages can include actions. For example, supportive messages may offer reassurance (e.g., encouragement) or they may give others the opportunity to vent pent-up frustration (e.g., listening behaviors; Albrecht & Goldsmith, 2003). Whereas Albrecht and associates’ definitions focused on the function of the supportive communication (i.e., to manage uncertainty), MacGeorge et al.’s definition identifies social support based on intended impact rather than functional impact. That is, they understood social support as communication that is provided in an effort to help another person. However, despite the positive intent of an individual to communicate social support, scholars have indicated that recipients of communication that is intended to be supportive may actually find it unhelpful (and sometimes harmful or hurtful) (e.g., Goldsmith, 2004). For example, a friend may intend to convey empathy by saying, “I know how you feel.” However, the recipient may find the comment baseless and unhelpful, or disingenuous, because the friend cannot know for certain what the recipient feels.
In summary, the literature offers numerous definitions of social support. However, despite their diversity, and differences in disciplinary perspective, most definitions imply or explicitly recognize the communicative nature of social support.

Social support as communication. For the purposes of the present research, social support is defined as, verbal and nonverbal communication that provides individuals with actual assistance or the perception that assistance is available within their social relationships, and thereby helps the individual to manage uncertainty. This definition is valuable in the context of the present research because it explicitly captures the communicative nature of social support. By recognizing that social support is inherently a communicative process that occurs via messages and through interactions, and results in the construction of social networks, this definition provides a unifying approach for understanding and integrating the social support literature. Further, this definition focuses on the functions that the communication of social support serves from the recipient’s perspective. It does not consider the intentions of the person attempting to provide social support. In the context of the present research, potential support providers’ intentions typically cannot be known. (Although, individuals occasionally may engage in explicit metacommunication by saying something like, “I meant to be helpful,” after seeing that the recipient did not recognize the person’s intentions; see Wilmot, 1980). Burleson et al. (1994) argue that, “communication remains a central (if implicit) mechanism through which support is conveyed” (p. xvii). As such, messages, interactions, and social networks all function as units of analysis for researchers interested in examining social support as communication processes (see Burleson et al., 1994).

Messages. One approach to investigating social support from a communicative perspective is to focus on supportive messages. Researchers who have explicitly approached
social support from this perspective have explained that supportive messages are communication behaviors or actions that are helpful in function (i.e., from the recipient’s perspective) (Albrecht & Adelman, 1987; Albrecht & Goldsmith, 2003; Dakof & Taylor, 1990). Others have focused more narrowly on the content or informational component of verbal and nonverbal messages as the source of help (e.g., Cobb, 1976; MacGeorge et al., 2011; Moss, 1973). For example, providing referrals for care or giving advice are primarily informational in nature. But a message’s supportive value could come from metacommunication (i.e., “communication about communication;” Wilmot, 1980, p. 61) as well as from message content. For example, the statement “You can do this,” when expressed in an encouraging tone of voice could be interpreted as helpful. Beyond verbalized messages, supportive messages also can include nonverbal actions that are interpreted as helpful (e.g., providing food or money).

Some researchers have investigated social support in terms of identifying the types of messages that are understood as helpful in the experience of recipients (e.g., among people who have been diagnosed with cancer; Dakof & Taylor, 1990; Ford, Babrow, & Stohl, 1996). For example, Dakof and Taylor explored the nature of messages received by people diagnosed with cancer from seven groups of people in their social networks: spouse/partner, other family members, friends, support group members or others who had been diagnosed with cancer, acquaintances, physicians, and nurses. The goal of the research was to identify categories of messages that the people diagnosed with cancer perceived as helpful or as unhelpful. The categories of messages identified by the researchers were summarized in terms of the typical typology of support functions commonly found in the literature: esteem/emotional support, informational support, and tangible support.

Although Dakof and Taylor found some types of messages generally were perceived as
helpful or unhelpful regardless of the network source, patterns of what was assessed as helpful or unhelpful varied by source. For example, in Dakof and Taylor’s research, people diagnosed with cancer generally viewed having others expressing concern and affection as helpful. In contrast, minimizing their concerns, criticism, and expressing too much pessimism generally were seen as unhelpful. However, the most commonly identified helpful responses varied somewhat by source. The most helpful responses from partners were “being there” (presence) and expressing concern and affection; the latter was most commonly cited as helpful for other family members and friends. In contrast, providing information generally was absent in those closer relationships but was commonly identified as helpful, especially when coming from physicians but also from other people who have been diagnosed with cancer and nurses. In general, these research participants indicated that messages of emotional support were the most helpful; and the absence of such messages was perceived as unhelpful. Although the researchers concluded that the perceived helpfulness of specific kinds of messages partially depended on source, they also noted relatively few cases in which one individual labeled a behavior as helpful and another labeled that same behavior as unhelpful.

Interactions. A second approach for investigating social support from a communicative perspective is to focus on interactions. Burleson et al. (1994) define supportive interactions, or social episodes, as “interactions in which supportive messages are produced and interpreted” (p. xviii). Research that focuses on supportive interactions can include the analysis of conversations through which social support is provided and/or solicited.

A study by Pistrang, Barker, and Rutter (1997) provides an example of social support research that focuses on examining interactions. The researchers studied audio-recorded interactions between three women diagnosed with breast cancer and their spouses. Pistrang et al.
examined the women’s perceptions of those interactions, in order to identify the nature of the communication they interpreted as helpful and empathic. In the conversations, the couples followed a semi-structured communication task that was designed to encourage help-intended interaction. The researchers interviewed the women participants after the conversations, using tape-assisted recall, in order to assess the husband’s intentions behind his responses (i.e., what he was trying to do to be helpful) and the women’s interpretations of the degree to which she felt helped and understood as a result of her husband’s responses. Using this method allowed the researchers to better understand both effective and ineffective attempts at supportive interaction.

The researchers concluded that the meanings of the interactions to the research participants were not always apparent or obvious without the tape-assisted commentaries. That is, spouses understood and interpreted the interactions to some extent based on personal and idiosyncratic meanings. Thus, what is perceived as supportive interaction may be subject to relational complexities (e.g., relationship-specific rules, patterned yet unique understandings of meanings associated with behaviors) not readily accessible to outside observers. At the same time, the researchers noted “there may also be patterns of helpful and unhelpful communication which are not unique to each couple” (p. 780). In fact, a review of the cited transcripts shows that the husband’s changing the focus or topic of the conversation, attempts at lightening the conversation or adding humor, reassuring, and/or minimizing the wife’s concerns were assessed as unhelpful by the women in multiple cases. In contrast, the women viewed interaction that centered on feelings as helpful. That occurred when the husband initiated discussion of feelings, or when he acknowledged, validated and/or accepted his wife’s feelings.

Social networks. A third approach for investigating social support from a communicative perspective is to focus on social networks. Social networks are comprised of the social ties
shared with and/or among numerous individuals (Thoits, 2011a). According to Thoits (2011a), the term *social ties* refers to “connections and contacts with other people through membership in primary and secondary groups” (p. 146). Thoits explained that primary groups often are informal and intimate relationships (e.g., family members, friends). In contrast, secondary groups are larger and often less personal groups with which individuals are associated (e.g., colleagues).

Research by Ashida, Palmquist, Basen-Engquist, Singletary, and Koehly’s (2009) provides an example of investigating social support in terms of social networks. Ashida et al. investigated whether social networks change over time among women diagnosed with breast cancer. The researchers surveyed women diagnosed with breast cancer in order to measure the size of their social networks (i.e., the number people in an individual’s social network) at the beginning and end of a six-month period shortly after diagnosis. At baseline and six months later, the researchers asked the women to identify members of their social networks to whom they go for emotional support. At baseline, for each identified network member, the research participant indicated gender and if the person was a family member. In order to assess the emotional support provided by each member, each woman also rated (on a four-point scale from “never” to “always”) how often she sought emotional support from that person during a minor crisis and during a major crisis. They also rated the degree of friendship of each member (on a four-point scale from “not friends” to “very good friends”).

The researchers found that among women diagnosed with breast cancer, initially, younger women (50 years old or younger) reported having larger networks than did the older women (51 years old or older). In contrast, the older women reported relatively more family members and stronger friendships in their networks. However, over the six-month period, the size of the social networks among the younger women was more likely to decrease, compared to
the size of the social networks of the older women (i.e., network size remained more stable among the older women). That is, at six months, the younger women were more likely to “drop” names from their previously identified lists of network members, whereas older women were more likely to “retain” previously identified network members. In general (but especially among the younger women), network members who provided support more frequently were less likely to be dropped from networks over time, as were those who frequently provided support in networks characterized by relatively higher proportions of family members. The researchers hypothesized that older women likely were more embedded in their networks, and before their diagnoses already may have had networks members who provided the kinds of support they tend to need. In contrast, the younger women may have had network members who were less experienced with providing support for people who are experiencing serious health problems. Among younger women, network members may have been dropped because they were unable to provide the kinds of support these women needed as a result of their recent diagnosis. The researchers noted that, among the younger women, the decrease in network size was associated with a decrease in mood disturbances (i.e., they may have adapted better psychologically by eliminating attempts to seek support from people who could not meet their needs). Thus, it is clear that the structural aspects of social networks may be subject to change over time, as life stressors change, and that a larger social network may not necessarily be better than a smaller one.

Summary. In summary, social support can be investigated as communicative in nature from numerous perspectives. These include focusing on attributions of meanings associated with communicative behaviors (messages), the communicative behaviors that constitute messages, and patterns of communicative behaviors found in interactions or conversations, as well as the
structure of potentially supportive social ties (i.e., social networks) that are created by communication. By defining and examining social support as communicative phenomena, researchers may gain insight into the processes by which social support occurs, how social support functions, and the conditions under which communication has helpful or beneficial outcomes versus unhelpful and possibly harmful outcomes.

Advantages of studying social support as communication phenomena. Social support has been studied using a variety of disciplinary perspectives (e.g., communication, psychological, sociological). Burleson et al. (1994) have argued that defining and studying social support as communicative phenomena has marked advantages.

First, the study of social support from a communication approach offers a more comprehensive approach than do psychological or sociological approaches. Specifically, investigating social support as communication permits researchers to capture support processes (i.e., supportive messages and interactions) by which support is provided. As a result, researchers can better understand how social support is perceived, enacted, and made available through social ties. A communication perspective recognizes the roles of both behaviors (messages) and interpretations (meanings) in supportive communication processes. Thus, examining social support as communication allows researchers to observe and understand how social support processes actually occur and what specific social processes are perceived or experienced as helpful versus unhelpful.

In contrast, psychological perspectives often rely solely on the recipients’ perceptions of support rather than examining both the perceptions and the actual behavioral processes and patterns (e.g., messages, behaviors, interactions) that elicit those perceptions of supportiveness or lack of supportiveness. Burleson et al. (1994) contend that psychological approaches to social
support tend to conceptualize social support as the “subjective sense of being supported” (p. xvi). That is, psychological approaches to social support focus on individual interpretations of social support. As such, Burleson et al. argue that the psychological approach to social support does not consider the interactions and actual experiences (e.g., messages and conversations) that lead an individual to feel supported and, thus, does not fully capture the processual nature of social support (e.g., Burleson et al., 1994; Gottlieb, 1985). By examining social support as communicative phenomena, researchers can examine the communicative phenomena (e.g., messages, behaviors, interactions) that lead to recipients’ perceptions of support being helpful.

The second advantage to studying social support as communicative phenomena is that, by examining supportive communication processes, researchers can investigate the social construction of social support (Burleson et al., 1994; Lakey & Cohen, 2000). This is important because understanding the social construction of social support can provide insight into how and why social support is motivated (or discouraged), enacted (or withheld), and expected (or not) in particular social situations or contexts, or particular social systems. Specifically, as individuals interact within their social environments they develop beliefs about the social support appropriate to that environment (Burleson et al., 1994). Thus, within families, organizations, and other social contexts, perceptions and expectations of social support are socially constructed.

In contrast, sociological approaches to social support generally have focused on the structural features of communication networks (e.g., size, density; Burleson et al., 1994) and the implications of these structures for support (e.g., size of network may imply relatively more or fewer available sources of support). However, examining social support in terms of structural features does not consider the content of, or meaning attributed to, messages or interactional processes through which social networks and social ties are created and maintained (Burleson et
al., 1994). Thus, structural approaches do not explain how expectations and processes of social support are socially constructed within social systems.

Finally, Burleson et al. (1994) argue that examining social support as communicative phenomena has pragmatic value. Specifically, social support research conducted from a communication perspective can lead to a better understanding of how and under what circumstances communication is helpful. This knowledge can provide the basis for interventions to improve the availability, quality, and effectiveness of communication that functions as help or support. That is, the study of supportive messages can help researchers to determine what makes particular messages helpful and thereby beneficial in terms of health-related outcomes (e.g., Goldsmith, 2004). In turn, they can create interventions to encourage those conditions.

**Key concepts in the study of social support.** Two key sets of distinctions regarding the nature of social support have emerged in the literature that are important to investigating social support, in general, as communication, but also are specifically relevant for the present research. These distinctions have important implications for how researchers go about observing and/or measuring social support. The two sets of key concepts are *perceived* and *received* social support, and *structural* and *functional* approaches to social support.

**Perceived and received social support.** Researchers, in their conceptualization and measurement of social support, often distinguish between perceived and received support (e.g., Goldsmith, 2004; Wills & Shinar, 2000). Wills and Shinar explain how these terms differ. They define *perceived support* as the belief that support is available to an individual if he or she should need it at a given time. In contrast, Wills and Shinar explain that *received support*, or *enacted support* (a term offered by Goldsmith, 2004), is comprised of the actual actions or behaviors that provide support.
Researchers have compared the associations between perceived social support and received social support and beneficial outcomes (e.g., Helgeson & Cohen, 1996; Hobfoll, 2009; Uchino, 2009). Their goal was to determine whether perceived or received support was more predictive of positive outcomes. For example, Uchino’s (2009) review examined studies that assessed whether perceptions of available support or actual support received (based on self-reports), was more strongly associated with health outcomes. Differences between received and perceived support became a focal point of discussion among scholars because evidence indicated that received support is more strongly associated with health outcomes (e.g., recovery time and reports of pain and other symptoms) than is perceived support (e.g., Goldsmith, 2004; Hobfoll, 2009). That is, researchers found evidence that reports of perceived availability of support (e.g., Wills & Shinar, 2000; Uchino, 2009) were more strongly associated with beneficial health outcomes than were reports of actual acts of received support (e.g., taking someone to the doctor, listening). However, research that has examined differences in the impact of perceived and received support relies on self-report measures for both aspects of support; that is, both are based on personal perceptions. (Note that although received support can be assessed by coding observed behaviors, studies that compare perceived and received support rarely, if ever, observe actual support behaviors or supportive communication; see Reis and Collins, 2000 for a review of studies that observed social support directly). Logically, then both involve perceptions of support, whether the perceptions are about availability (i.e., what typically is termed perceived support) or about experiences (what typically is termed received support).

Hobfoll (2009) further addresses why the common distinction between perceived and received support may be misleading. He argued that the perception of support being available is informed by real life events, including one’s history of experiencing or observing support within
given relationships and circumstances. In other words, a person’s perceptions about available support are informed by support that was provided in the past to that individual or that the individual observed under similar circumstances. Thus, an individual who perceives that support is available often holds that expectation that support is available because of previous experience. For example, an individual who is diagnosed with cancer may believe that support is available from his or her family members to help that individual through the illness. However, that belief (i.e., that one’s family will be supportive while dealing with a cancer diagnosis) likely is based on previous experiences with family members who were supportive when the person experienced other stressors, or because the person had observed family members being supportive of another family member who had an illness. Conversely, an individual diagnosed with cancer may believe that support is not available from his or her family members if those family members were not very supportive of that person or of other family members in the past.

In the context of the present study, both what the literature described as perceived and received support was examined as found in participants’ reports regarding social support available and/or received (e.g., from a cancer support organization and the healthcare institution). That is, participants described both actual support received (or not received) and their perceptions of available support. Thus, as is typical of other studies that examine perceived and received support, this research considered participants’ perceptions of both dimensions of support rather than observing actual interactions. A second distinction regarding the nature and observation of social support that is important to this research relates to structural and functional approaches to social support.

*Structural and functional approaches to understanding and analyzing social support.*

Social support often is analyzed as either structural support or functional support (e.g., Cohen &
Wills, 1985; House, Umberson, & Landis, 1988; Wills & Shinar, 2000). **Structural support** is defined as the social relationships available to an individual through direct or indirect ties (pathways) within one’s social network (Cohen & Wills, 1985). **Functional support** is defined as the nature of the resource (e.g., informational, emotional, instrumental) that is offered via social support (Cohen & Wills, 1985). The following section reviews the distinction between structural and functional support and focuses on how each informs the observation and assessment of social support. The section ends with a discussion of the relevance of structural and functional support for the present research.

**Structural support.** Research on structural support examines social networks, or systems of personal relationships, within which social support may (or is assumed to) occur (e.g., Albrecht & Goldsmith, 2003; Cohen & Wills, 1985; House et al., 1988). Social networks are the patterns of social ties or social links among a set of individuals (e.g., Albrecht & Goldsmith, 2003; Thoits, 2011a). Thus, social networks are created through communication that creates ties or relationships among individuals. The study of social networks tends to focus on variables that capture the structural features of the network (i.e., network size, density, complexity, homogeneity, reciprocity, and formality).

**Network size** refers to the total number of individuals (or social ties) within the network (Albrecht & Goldsmith, 2003). For example, one’s network size is the number of family members or friends one has.

**Network density** refers to “the extent to which network members are connected to one another, usually expressed as a ratio of the number of actual ties to the number of theoretically possible ties” (Albrecht & Goldsmith, 2003, p. 268). Specifically, a network is denser when a relatively higher concentration of actual links exists among the individuals who comprise the
Network complexity refers the number of roles individuals hold within a social network (Albrecht & Goldsmith, 2003; Heaney & Isreal, 2008). Specifically, in this context, one’s role refers to the relationship that individuals have with one another, such as friend or neighbor. To the extent that a network is characterized by individuals having multiple roles within the same network, or with the same person (e.g., a person could be both a friend and neighbor), the network is characterized as complex.

Network homogeneity refers to the degree of similarity among individuals within a network (Heaney & Isreal, 2008). For example, individuals from a given neighborhood may have a similar socioeconomic status (e.g., upper-middle class), education, or cultural background. To the extent that a network is characterized by individuals who are similar to one another, the network is more homogeneous.

Network reciprocity refers to the degree to which support is exchanged in a reciprocal manner within the social network. Social support often follows relational rules of mutuality, whereby individuals exchange social support equitably (e.g., Albrecht & Goldsmith, 2003). For example, if an individual who is ill receives social support from a friend, he or she is likely to provide social support to that friend if the friend becomes ill.

Network formality refers to the degree to which social networks develop within formal contexts, such as organizations or institutions, versus in informal contexts, such as among family or friends (Heaney & Isreal, 2008). More formal social networks may develop in organizational and institutional contexts, including at work, in community organizations (e.g., volunteer groups), and in religious organizations. Thoits (2011a) explains that social networks with high degrees of formality are influenced by organizational and institutional rules, practices, and
structures. For example, coworker relationships occur within institutional and organizational contexts where the organization and institution influence how social support takes place.

In summary, structural support refers to social ties that create a social network. Structural social support variables generally are examined quantitatively. However, they are relevant in the context of the present qualitative study because participants discussed aspects of their social networks (e.g., the number of people in their social networks, the formality of their networks, similarities or differences between themselves and others in their networks) in describing their experiences with a support organization or in comparing support from the organization with support from other (i.e., informal) sources.

Functions of social support. Functions of social support have been studied since the early examinations of social support (e.g., Cassel, 1976; Cobb, 1976; Foa, 1971; Kaplan, Cassel, & Gore, 1977). For example, Cobb (1976) explained that social support can provide resources (e.g., information, material aid, encouragement) that help individuals to moderate their stress.

Barrera and Ainlay’s (1983) literature review created a typology of six support functions based on literature at the time (i.e., material aid, behavioral assistance, intimate interaction, guidance, feedback, positive social interaction, p. 134). Today, researchers often focus on three functions of social support: informational, emotional, and instrumental support (e.g., Goldsmith, 2004). However, other functions (e.g., esteem, network, spiritual) of social support can be found in the literature (e.g., Cutrona & Suhr, 1992; Levine, Vong, & Yoo, 2015). Specifically, recent research has acknowledged and investigated the spiritual function of support (e.g., Levine et al., 2015). The three most commonly observed functions of social support, as well as spiritual support, are examined in this literature review.

Foa (1971) was one of the first researchers to discuss informational support. Foa referred
to informational support as the guidance that individuals provide to one another. A more typical explanation of informational support is “the provision of advice, suggestions, and information that a person can use to address problems” (Heaney & Isreal, 2008, p. 190).

Cobb (1976) was one of the first researchers to discuss emotional support. Cobb explained that emotional support is rooted in close interactions with others that create a sense of feeling cared for. Emotional support can also consist of providing encouragement (similar to most conceptions of what sometimes is called esteem support; e.g., Heaney & Isreal, 2008; Helgeson & Cohen, 1996). Specifically, Helgeson and Cohen explain that emotional support can function to help restore self-esteem and, thus, emotional and esteem support are not clearly distinguishable. Emotional support can be understood as “the provision of empathy, love, trust, and caring” (Heaney & Isreal, 2008, p. 190). Emotional support encourages a sense of belonging (e.g., Albrecht & Adelman, 1984; Goldsmith, 2004). Individuals provide emotional support to one another by listening and by being available to provide encouragement when needed.

Foa (1971) explained that instrumental support occurs by providing money or goods and other types of “active” support or services (e.g., driving someone to the doctor). Instrumental support includes tangible or material support (Barrera & Ainlay, 1983; Heaney & Isreal, 2008). Examples of instrumental support include helping someone with their daily activities (e.g., driving, shopping, cleaning) and providing someone with tangible resources (e.g., loaning money).

People diagnosed with cancer often reevaluate their spirituality and their expression of it (Vachon, 2008). Prior research indicates that members of the healthcare institution sometimes provide support by addressing the spiritual needs of people who have cancer (Surbone & Baider, 2010). In the context of the present study, because of the Center’s spiritual resources (e.g.,
spirituality support group, consultations with chaplain; see also Chapter IV, Description of the Organizational Context at the Cancer Support Center) participants could receive spiritual support in that context. Although relatively few studies have explicitly investigated “spiritual support” (e.g., Levine et al., 2015), the concept has received attention in recent years. Spiritual support, as defined in the present study, encompasses the closely related concepts of spirituality and religion. Both concepts address transcendent meaning (Koenig, 2012; Vachon, 2008).

Spirituality is “that which allows a person to experience transcendent meaning in life” (Puchalski & Romer, 2000, p. 129). It focuses on the values that give a person a sense of meaning and purpose in life. Religion may be the source of spirituality, but so too can nature, music, art, and social relationships. In contrast, religion is organized and formalized. It is “an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the transcendent,” where the transcendent is God, a higher power, or ultimate truth or reality (Koenig, 2012, p. 2), and is connected to a faith-related community and/or organization.

Summary. Taken together, the terms structural and functional support provide two relatively distinct approaches to how social support can be understood, observed, and measured (i.e., a focus on structure of social networks versus a focus on functions of messages). Specifically, social networks identify the structure of – and relationships among – potential sources of support. In contrast, understanding varied support functions can facilitate understanding both the nature of specific support needs (e.g., advice versus empathy) and the extent to which those support needs are met via providing particular resources from varied support sources. Although a social network analysis was not conducted in this study, understanding participants’ references to social networks and their characteristics was helpful for analyzing their reported experiences with regard to social support and its sources (e.g., family
versus organizational sources).

In the context of the present study, understanding varied functions of social support was critical in identifying and interpreting the supportive processes participants’ experience within organizational and institutional contexts versus what they experience in other interpersonal contexts (e.g., family, friends). For example, participants were asked to identify and explain any specific support needs fulfilled by the Cancer Support Center and healthcare institution. They also were asked about the impact (including potential health benefits) of that support. In that context, assessing and understanding the literature on the associations between social support and health outcomes also requires an understanding of both structural and functional support. Studies have addressed the roles of both structural and functional support in investigating relationships between health outcomes and social support.

**Associations between health and social support.** Researchers explain that social support and its relationship to the reduction and/or management of stress and, thereby to the enhancement of health, is a key reason for studying and understanding social support processes (e.g., Bloom, 1990; Cohen & Wills, 1985; Uchino, 2004). To a large degree, the significance of social support, and thus of related research, lies in evidence of associations between social support and health outcomes. Evidence of these associations provides a foundation for conducting research that is designed to identify, and develop interventions to promote, the specific social support processes that lead to better health and wellbeing. In the context of the present study, reviewing the relationship between social support and health outcomes provides (a) a framework for understanding the potential importance of social support processes in the context of cancer, and (b) identifies gaps in the current body of research that are related to the present study; namely, that little research has investigated social support in organizational and
institutional contexts and, in particular, its associations with health outcomes (Goldsmith & Albrecht, 2011).

**History.** Since the early work on social support, researchers have hypothesized that social support ameliorates stress and, thereby, has health benefits for those who receive it (e.g., Cassel, 1976; Cobb, 1976; Cohen & Wills, 1985). Research continues to support this early premise (i.e., that social support has significant health benefits; see reviews by Uchino, 2006, 2009). Although research has examined social support in a variety of health contexts (e.g., cancer, cardiovascular health), major literature reviews across varied health contexts have drawn similar conclusions regarding the physiological/physical and mental health benefits of social support (Roy, 2011; Uchino, 2004).

Cobb’s (1976) first review of literature on social relationships and life stress concluded that social relationships moderate stress. Specifically, Cobb found that when individuals were supported (e.g., given correct information, cared for) they required less medication, had faster recovery rates, and were able to better adhere to medical directives. Later, the House et al. (1988) review of literature also concluded that social support leads to better health outcomes, specifically by reducing social isolation. House et al. found that the number of social ties – or network size – is inversely related to mortality rates. They reported that social isolation among men led to worse health and higher mortality rates, whereas having a greater number of social relationships protected individuals from social isolation and, thus, helped to ameliorate stress.

**Physiological health.** Substantial research has focused on the relationship between social support and physiological health. Uchino, Cacioppo, and Kiecolt-Glaser (1996) reviewed literature on social support’s relationship to physiological processes. Specifically, their review of 81 research studies concluded that experiencing social support was related to better functioning
of the cardiovascular, endocrine, and immune systems. According to Uchino et al., social support influences physiological systems by reducing stress and, thus, the amount of cortisol released. Cortisol is commonly referred to as the “stress hormone;” it is released in greater amounts when the body is experiencing stress (E. Scott, 2014). Cortisol helps the body metabolize glucose, regulate blood pressure, release insulin to maintain blood pressure, regulate immune functions, and regulate inflammatory responses (E. Scott, 2014). Thus, increases in cortisol influence cardiovascular functioning (e.g., increased blood pressure), the endocrine system (e.g., decreased metabolism), and immune responses. Uchino et al. concluded that social support helps to buffer against stress and, thus, against higher cortisol rates, and thereby leads to better health outcomes. Moreover, cortisol levels play a specific role in physical healing. Stress influences the body’s ability to heal after trauma specifically because increased cortisol levels prevent the body from healing (Walburn, Vedhara, Hankins, Rixon, & Weinman, 2009). Walburn et al.’s review of literature concluded that social support’s capacity for reducing stress and cortisol levels results in quicker healing of wounds (e.g., following surgery).

More recently, Uchino (2006) reviewed epidemiology literature on social support and its relationship to diseases associated with the cardiovascular (e.g., heart disease) and immune systems (e.g., autoimmune diseases). Specifically, Uchino explained that strong biological associations exist between social support and cardiovascular (e.g., lower blood pressure) and immune (e.g., decreased risk of cancer cells developing) functioning. That is, social support is associated with better cardiovascular and immune health and, thus, a decreased risk for comorbidity and mortality.

Researchers also have examined the association between social support and adherence to treatment recommendations, which is predictive of health outcomes (DiMatteo, 2004). DiMatteo
conducted a meta-analysis of 122 research studies examining structural or functional social support and adherence to recommended medical treatments (e.g., taking medications as prescribed). The analysis indicated positive associations between social support variables (e.g., social ties, emotional support) and adherence. Specifically, individuals with closer social ties were relatively more likely to adhere to recommended medical treatments; individuals who did not receive emotional support were relatively less likely to adhere.

In summary, stress has significant influences on physiological processes. Therefore, decreasing stress through social support can facilitate better physiological functioning and, thus, better physical health.

*Psychological health.* Social support has positive influences on psychological health as well as physical health. Caplan (1974) was one of the first researchers to argue that social support, specifically in the form of social relationships, could help individuals recover from mental health disorders (e.g., depression and anxiety). He argued that having access to individuals in one’s social network (e.g., living in a household with other people, or cohabiting) gives individuals a better sense of security and the ability to better manage their mental health.

Substantial research has examined the relationship between social support and psychological health (e.g., Barrera, 1986; Cohen & Wills, 1985; Kawachi & Berkman, 2001; Santini, Koyanagi, Tyrovolas, Mason, & Haro, 2015; Thoits, 2011a, 2011b). For example, in their review of literature, Kawachi and Berkman considered how social ties are related to mental health, specifically by examining research that focuses on relationships between social support and mental health in urban populations. Kawachi and Berkman concluded that social support helps to reduce stress reactions, increase psychological well-being, and decrease psychological distress (e.g., reports of depression and anxiety). They found evidence to support both the stress
buffering and direct effects models to explain relationships between social support and psychological health. However, Kawachi and Berkman also explained that the psychological benefits of social support are not equally supported across urban populations. For example, individuals in lower socioeconomic classes may not experience the same psychological benefits associated with social support as individuals in higher socioeconomic classes.

Other research has examined the relationship between social support and specific psychological conditions, such as depression. Santini et al.’s (2015) systematic review analyzed 51 studies that focused on associations between social support and depression. The review concluded that individuals’ perceptions of experiencing emotional support and instrumental support, and large social networks, were associated with lower levels of depression.

Research on social support and psychological health also has examined the associations between social support and the likelihood of using mental health services (Thoits, 2011a, 2011b). Thoits (2011b) used data from the National Comorbidity Survey to investigate (a) the relationship between perceived social support and the likelihood of seeking mental health care, and (b) whether that relationship varies based on severity of mental disorders. Perceived social support was measured by asking respondents to rate (on a four-point scale from “a lot” to “not at all”) how much they can rely on specific friends or relatives (with whom they do not live) when they have a serious problem, and how much they “open up” to those individuals when they need to talk about their worries. Severity of mental illness was assessed in two ways: (a) the number of disorders experienced in the previous 12 months; and (b) the presence or absence of a serious mental illness, based on applying an established diagnostic cut-point to responses to the K6 scale (Kessler et al., 2003), a measure that accurately distinguishes between serious and non-serious mental health issues.
As expected, Thoits found that the more disorders a person had in the past 12 months, the more likely the individual was to use mental health services. Thoits hypothesized that, in general, individuals with larger social networks had adequate social support to manage their mental health issues without the help of professionals. However, Thoits predicted that those with more serious mental health problems would be relatively more likely to use mental health services if they had larger social networks. She reasoned that individuals with more serious mental health issues, who have larger social networks, would be more likely to have social ties who pressure, encourage and/or help individuals to obtain professional treatment. Results supported her hypotheses. In general, the more support respondents perceived to be available, the less likely they were to seek mental health treatment in the previous 12 months. However, among those with three or more mental health disorders, high levels of perceived support was associated with an increased probability of seeking mental health services.

In conclusion, researchers have investigated the relationships between social support and both physiological and psychological health. Although some of this literature has focused on more general populations, much of this literature is context specific (i.e., focused on a limited population, by medical condition or socio-demographic characteristics). Research specifically examining relationships between social support and physiological and psychological health outcomes for people who have been diagnosed with cancer is particularly relevant to the present study.

**Social support and health outcomes for people who have been diagnosed with cancer.**
Over the past three decades, researchers have investigated the associations between social support and health outcomes in the context of cancer (e.g., Cobb & Erbe, 1978; Dunkel-Schetter, 1984). The following section reviews how social support is associated with health outcomes,
both physiological and psychological, among people who have been diagnosed with cancer. Cancer is largely a disease of adults, and specifically older adults. The present study focused on the experiences of adults who have been diagnosed with cancer (i.e., over 18 years old).

*Social support and physiological health outcomes among people who have been diagnosed with cancer.* The literature focusing on associations between physiological health and social support among people who have been diagnosed with cancer is not as well developed as the literature for some other disease contexts (e.g., cardiovascular health). However, a relatively small body of research focuses on the associations between social support and physiological health (e.g., pain, recovery rates) among people who have been diagnosed with cancer. The findings have significant health implications, including for experiences with pain and pain management and recovery time (Uchino, 2004).

Research has investigated the associations between social support and pain management. Pain management has important implications for people diagnosed with cancer in terms of quality of life (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Zaza and Baine (2002) conducted a critical review of literature on pain associated with cancer treatment and the availability of social support through social networks. They concluded that higher levels of pain were associated with smaller social networks (i.e., fewer social relationships). Zaza and Baine explained that social support helps to decrease psychological stress, which, in turn, decreases physiological effects (i.e., pain) that result from arousal in the nervous system and muscle tension. A recent study supports Zaza and Baine’s conclusion. Hughes et al. (2014) conducted a longitudinal study in order to investigate the association between size of social network (i.e., numbers of family and friends) and levels of pain among women diagnosed with breast cancer. They found that larger social networks were associated with lower levels of pain. Specifically,
women with larger social networks and, thus, presumably greater access to social support, experienced lower levels of pain.

Similarly, Cormie, Turner, Kaczmarek, Drake, and Chambers (2015) examined the association between social support and reported pain among men with prostate cancer who were enrolled in supervised exercise programs. Research has found exercise to be effective for counteracting side effects (e.g., pain, sexual dysfunction) associated with prostate cancer treatment. They found that greater peer support (i.e., support from other men in the exercise programs) was associated with experiencing fewer side effects of treatment, including pain.

A second area of research on social support and physiological health in the context of cancer focuses on recovery time from surgery (e.g., Malicka, Kozłowska, Woźniakiewicz, Rymaszewska, & Szwepańska-Gieracha, 2015; Neuling & Winefield, 1988). The immune systems of people diagnosed with cancer often are comprised; thus they cannot fight infection well (Grant, Bloch, Hamilton, & Thomson, 2010). As a result, recovery time from surgery is a crucial concern for people who have been diagnosed with cancer whose surgery wounds often are relatively more susceptible to infection than individuals with a healthy immune system. Neuling and Winefield (1988) conducted a longitudinal study in order to examine the relationship between recovery time following surgery and functional support (e.g., informational, emotional). They used the Multi-Dimensional Support Scale to assess functional support received by women diagnosed with breast cancer from family, friends, and physicians. The researchers found that recovery from surgery was quicker among people diagnosed with cancer who reported receiving relatively greater amounts of emotional and informational support from their family, friends, and surgeons.

A third area of research addressing physiological health and social support among people
who have been diagnosed with cancer examines cancer progression (or how quickly cancer spreads/worsens). Nausheen, Gidron, Peveler, and Moss-Morris (2009) conducted a systematic review of literature specifically focused on the relationship between social support and cancer progression (i.e., how quickly cancer spreads). They concluded that the findings are mixed. The review evaluated 31 studies, the majority of which (i.e., 16 studies) investigated women diagnosed with breast cancer. They concluded that characteristics of social networks (e.g., greater size, density) were associated with slower cancer progression among these women. However, this conclusion is controversial, because cancer type, stage, and treatment options often are more indicative of cancer progression than is social support. The authors acknowledge substantial methodological limitations in the literature (including regarding measurement of cancer progression). Moreover, the conclusion may be questionable because much of the reviewed literature related to breast cancer and the definition of what constitutes breast cancer (relative to previous definitions) currently is a matter of some debate (see Esserman, Thompson, & Reid, 2013). This debate is particularly relevant to understanding research that has found associations between experiencing social support and disease progression and/or mortality among people who have been diagnosed with early stage breast cancer. Thus, extant research does not support an association between greater social support and slower cancer progression.

Finally, some research has examined the associations between social support and cancer progression. A position emerging in the medical community in response to the problem of over-diagnosis, and thus, overtreatment of some cancers, is that the taxonomy that determines which types of lesions should be labeled “cancer” should be revised (Esserman et al., 2013). One “cancer” specifically at issue is ductal carcinoma in situ. This condition is considered to be a precancerous or premalignant condition and currently is identified as “stage 0 breast cancer;” those diagnosed with the condition generally receive treatment (e.g., surgery; National Cancer Institute, 2015c). A working group, convened by the National Cancer Institute to address strategies for improving cancer screening, specifically recommended limiting the use of the term “cancer” to those “lesions with a reasonable likelihood of lethal progression if left untreated” (Esserman et al., 2013, p. 797). The panel argued that “ideal screening focuses on detection of disease that will ultimately cause harm” (p. 797). Further, “premalignant conditions (e.g., ductal carcinoma in situ . . .) should not be labeled as cancers or neoplasia, nor should the word “cancer” be in the name” (p. 797).
mortality rates. Although social support can have beneficial physiological outcomes for people who have been diagnosed with cancer, the associations between social support and physiological health outcomes are influenced by the type and stage of cancer. Ell, Nishimoto, Mediansky, Mantell, and Hamovitch’s (1992) study investigated the association between numerous potential protective factors and mortality among people diagnosed with cancer. In addition to social support, the researchers examined marital status, size of social network, and emotional support as potential protective factors. In a sample of 294 participants, 57% had breast cancer, 26% had colorectal cancer, and 17% had lung cancer. Ell et al. found that among those with localized disease, socioeconomic status and perceived adequacy of emotional support were the only significant predictors of survival. However, among those with advanced stage disease, only the stage of disease predicted survival. When data were analyzed by cancer site, emotional support was the only factor that predicted survival among those with breast cancer (i.e., support did not predict survival among those with lung and colorectal cancer). Although emotional support appeared beneficial to the survival of those who have localized disease, that benefit varied by cancer type and disease stage. Further, the caveat regarding the debate about what constitutes breast cancer (Esserman et al., 2013), and the preponderance of cases of breast cancer in the sample, raise questions about the actual role of social support in cancer survival.

In summary, social support clearly is associated with some specific physiological health outcomes associated with treatment for cancer (e.g., pain, recovery time). However, evidence does not support conclusions regarding benefits of social support for disease progression and longevity. These latter outcomes are highly dependent on the type and stage of the cancer. However, the associations between social support and mental health outcomes among people who have been diagnosed with cancer are relatively clear.
Associations between social support and psychological health among people who have been diagnosed with cancer. Researchers have examined social support and its associations with psychological adjustment, including depression, anxiety, and coping, among people diagnosed with cancer (e.g., Blanchard, Albrecht, Ruckdeschel, Grant, & Hemmick, 1995; Hann et al., 1995, 2002; Helgeson & Cohen, 1996; Rodin et al., 2007). Threats to the psychological health of people diagnosed with cancer are a common concern (American Cancer Society, 2013).

Psychological adjustment is an umbrella term used in the mental health literature to refer to an array of mental health issues including coping, depression, and anxiety, among others (Helgeson & Cohen, 1996). Helgeson and Cohen reviewed studies that focused on investigating the relationships between social support functions and psychological health outcomes among people diagnosed with cancer. They found that people diagnosed with cancer reported a greater desire for emotional support from their family and friends, compared to their desire for informational or instrumental support from these sources. Research participants tended to assess informational support from personal contacts as unhelpful. Further, Helgeson and Cohen found that informational support was more helpful (and more strongly associated with health outcomes) when it was obtained from healthcare professionals than from personal contacts. They also noted that no association existed between instrumental support and health outcomes. Helgeson and Cohen concluded that emotional support was particularly helpful for psychological adjustment. Specifically, they argued that receiving emotional support from family and friends may help with managing the stress and uncertainty that accompanies cancer diagnosis and treatment. However, Helgeson and Cohen also indicated that certain attempted or intended expressions of emotional support (e.g., forced happiness, minimizing the experience of stress) could be unhelpful and thereby could have a negative impact on psychological adjustment.
Depression is one of the most common mental health issues among people who have been diagnosed with cancer (e.g., McDaniel, Musselman, Porter, Reed, & Nemeroff, 1995; Williams & Dale, 2006). One in four people diagnosed with cancer also are diagnosed with clinical depression, (i.e., characterized by a depressed mood that interferes with everyday life; National Institute of Mental Health, 2015) and many others likely have episodic or subclinical depression (American Cancer Society, 2013). The associations between social support and symptoms of depression are well established in the literature. Research has found both larger social networks (e.g., Oxman & Berkman, 1990) and higher perceived adequacy of social support (e.g., Barrera & Ainlay, 1983; Hann et al, 1995) to be inversely associated with numbers of depressive symptoms or severity of depression. For example, Hann et al. (1995) examined the association between depressive symptoms and perceived adequacy of social support from family, friends, and significant others. Hann et al.’s study included people over age 55 and who represented more than 20 different types of metastatic cancer, including lung, breast, and colon cancers, and lymphoma. The researchers employed the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988) to assess perceived adequacy of social support from their significant others, family, and friends. The MSPSS asked respondents to indicate the extent to which social support is available from each of those sources. Hann et al. (1995) found that greater total perceived adequacy of social support, as well as adequacy of support from each of the support sources, were all inversely associated with number of depressive symptoms.

Hann et al. (2002) investigated potential age and gender differences in the influence of social support on depression among people diagnosed with metastatic disease. Although perceived adequacy of social support was significantly and negatively associated with depressive
symptoms, the researchers found no significant age or gender differences in those associations. That is, regardless of age or gender, reports of greater perceived adequacy of social support and satisfaction with family functioning were associated with less severe depression. Although the association between size of social network and depression was not statistically significant, a trend occurred whereby females and younger individuals (but not males and older individuals) with larger social networks had less severe depression.

Research by Rodin et al. (2007) examined the roles of perceived social support (e.g., informational, emotional) and attachment security (i.e., security in the emotional bond between individuals), in depressive symptoms among people with advanced stage gastrointestinal or lung cancer. The researchers used the Medical Outcomes Study Social Support Survey (MOS-SSS; Sherbourne, & Stewart, 1991) to assess perceived availability of various domains of social support (i.e., functions; emotional, informational, instrumental) from close family and friends. The MOS-SSS asks respondents to identify the number of family and friends they feel close to and to assess availability of various types of social support. The researchers found that severity of depressive symptoms was inversely related to all dimensions of perceived availability of support and positively associated with attachment anxiety and avoidance. The authors concluded that factors associated with attachment security and social support offer independent protection from depression symptoms.

A second common psychological adjustment issue among people who have been diagnosed with cancer is anxiety (American Cancer Society, 2013). People diagnosed with cancer commonly experience fear or anxiety related to treatments, doctor visits, and test results, among other sources. Not surprising then, according to the American Cancer Society (2013), most people have anxiety at some point after receiving a cancer diagnosis. Research on the
associations between anxiety and social support for people diagnosed with cancer is not as well developed as the literature on social support and depression (Jarrett et al., 2013).

Applebaum et al. (2014) examined whether optimism was a moderator in the associations between functional social support and anxiety, depression, hopelessness, and quality of life among people with advanced-stage cancer. Research participants had been diagnosed with advanced stage (III or IV) solid tumor cancers or non-Hodgkin’s lymphoma. They completed the Duke-UNC Functional Social Support Questionnaire (DUFSS; Broadhead, Gehlbach, du Gruy, & Kaplan, 1988), a measure that assesses functional social support in general. The DUFSS asked respondents about their satisfaction with functional support provided by their family and friends. The researchers found that optimism moderated the relationship between functional social support (support provided that represented a number of functions) and the number of reported anxiety symptoms. Specifically, a strong negative relationship existed between functional social support and anxiety among those who reported low optimism (but not for those who reported high optimism).

Limitations of research on the associations between social support and health outcomes among people who have been diagnosed with cancer. Research examining the associations between social support and health outcomes among people who have been diagnosed with cancer is characterized by some important limitations.

First, much of the research is based on cross-sectional surveys (e.g., Applebaum et al., 2014; Bigatti et al., 2010; Ell et al., 1992; Hann et al., 1995, 2002; Rodin et al., 2007). Conducting longitudinal research with populations of people diagnosed with cancer often is difficult because of health constraints (e.g., ability to participate in research throughout the study, duration of cancer experience, death of research participants). As a result, the literature is based
largely on snapshots of social support and reported health outcomes at a given point in time. Thus, the research largely has failed to address how social support processes and associated health outcomes develop over time.

A second potential limitation in the literature is that studies often focus on one type of cancer (e.g., breast cancer; Bigatti et al., 2010; Hughes et al., 2014; Neuling & Winefield, 1988). Individuals’ social support needs may be affected by cancer type, as well as stage. Cancers vary widely in projected longevity, pain associated with the cancer itself, difficulty associated with treatment regimen, and availability of efficacious treatments (Mukherjee, 2010). Alternatively, some studies are limited because, although they include participants representing various types and stages of cancer, they draw conclusions based on the composite sample, without assessing the impact of cancer type and stage (e.g., Ell et al., 1992; Hann et al., 1995). Cancer is not one disease, but instead is more than 200 different diseases (National Cancer Institute, 2015d). Thus, research based on treating different cancers at different stages (Mukherjee, 2010) in monolithic fashion may be misleading.

**Summary of social support.** The social support literature has developed significantly over the last three decades. Definitions of social support are characterized by the implicit or explicit acknowledgment of the communicative nature of social support. Further, the conceptualization of social support is typified by important distinctions, specifically perceived versus received support, and functional versus structural support. A large body of research on social support has investigated the associations between social support and health-related outcomes. Much of that literature supports positive associations between various aspects of social support and positive health outcomes (e.g., Cohen & Wills, 1985; Uchino, 2004, 2006), including research conducted in the context of cancer (e.g., Applebaum et al., 2014; Helgeson &
Cohen, 1996). Most of the research on social support, in general as well as with regard to health outcomes, has examined support in the context of family, friends, and other close relationships. Thus, social support in healthcare contexts, that is, between healthcare providers and their clients, has received relatively little attention and represents a gap in the literature (Goldsmith & Albrecht, 2011).

Social Support in Healthcare Contexts

Social support generally has been studied in close and informal interpersonal relationships (e.g., family, friends; Goldsmith & Albrecht, 2011). However, social support often takes place in weak ties (i.e., the “wide range of potential supporters” within the community “who lie beyond the primary network of family and friends”; Adelman, Parks, & Albrecht, 1987, p. 127) and in formal relationships, including in the context of an organization’s internal-external relationships (e.g., healthcare providers and clients) within institutions (e.g., healthcare; Goldsmith & Albrecht, 2011; MacGeorge et al., 2011). Research indicates that professional caregivers (e.g., nurses, physicians) often do offer social support to their clients in order to help manage uncertainty and to buffer stress (e.g., Stone, 2013). Although clients indicate the need for social support from their healthcare providers (e.g., Helgeson & Cohen, 1996; Neuling & Winefield, 1988; Rose, 1990), very little is known about the roles that organizations and institutions may play in affecting healthcare providers’ abilities or opportunities to offer social support to their clients. That is, researchers generally have not addressed how individual healthcare organizations and, more broadly, the healthcare institution may facilitate or impede providers’ abilities or opportunities to meet the social support needs of their clients. For example, research has not explored how healthcare organizations may facilitate, or institutionalize, healthcare providers’ behaviors that may function to provide social support to clients. Because
social support has documented health benefits (see Chapter II, The associations between health and social support), factors that facilitate or encourage, or conversely obstruct or impede, social support provided within healthcare organizations and the healthcare institution may ultimately influence health outcomes, which is the very mission of healthcare organizations and the healthcare institution. The present study addresses this gap in the literature.

The following section distinguishes between informal (e.g., family, friends) and formal (e.g., healthcare providers) sources of social support. Second, the section discusses healthcare providers and their formal roles within organizations and the healthcare institution. These roles are subject to organizational and institutional policies, procedures, rules, and beliefs and likely influence providers’ supportive communication with their clients. Finally, this section reviews research regarding the social support that takes place between healthcare providers and clients.

**Informal and formal sources of social support.** MacGeorge et al. (2011) explain that social support occurs in both formal (e.g., organizational internal-external relationships, relationships between clergy and their congregants) and informal (e.g., family members, friends) relationships. Communication that takes place between providers and clients, or in internal-external relationships, can function to fulfill clients’ social support needs, such as their needs for informational support (e.g., Brashers, Neidig, & Goldsmith, 2004; Neuling & Winefield, 1988) and emotional support (e.g., Anker, Akey, & Feeley, 2013). Healthcare providers often are sources of social support for clients (Goldsmith & Albrecht, 2011; Rickwood et al., 2005). Rickwood et al. (2005) explain that potential formal sources of social support are individuals, acting in their professional roles (e.g., counselors, physicians, government employees, clergy), who can provide advice and other forms of help. Rickwood et al.’s explanation of formal sources of support captures the formalized *role* of individuals in organizational and/or institutional
positions. Examples of such potential formal sources of support include healthcare providers, clergy, counselors, and government employees (Rickwood et al., 2005).

**Formal roles in healthcare.** The term *role* is conceptualized in a variety of ways across the health and organizational communication literatures. Roles generally are understood as the responsibilities, or expectations, associated with certain positions (Katz & Kahn, 1978). That is, roles are contextualized in that the specific expectations depend on the particular position held within a social unit. For example, the role of caregiver is associated within multiple contexts (e.g., healthcare, family), with different expectations in each context.

Mead (1934) described the process of role taking as following expectations in a given social situation. Mead’s explanation of role taking assumes that when individuals take on a given role, others make certain attributions and form expectations about that role. For example, taking on the role of healthcare provider often is associated with the attribution that the healthcare provider has knowledge about healthcare and with the expectation that the healthcare provider is willing to take care of others. Thus, the role is connected to a specific social context or social situation. As such, one’s *role* arises from the social situation (Blumer, 1969). That is, within a given social situation, expectations associated with the roles taken on are socially constructed through shared meanings and understandings of the particular context. Thus, roles are socially constructed.

Katz and Kahn (1978) defined roles as “specific forms of behavior associated with given positions” (p. 43). Role behaviors, or how individuals act when they are within a given institutional role, are outcomes of formal and informal expectations and experiences within an organization (Graen, 1976). For example, in healthcare, a physician’s role is that of healer. Clients, healthcare organizations, and the healthcare institution may also expect physicians to
help those who are sick or injured and to be caring and considerate by offering social support to clients (e.g., Sloan & Knowles, 2013; Street et al., 2009).

Healthcare providers’ roles are comprised of a variety of expectations created by their clients, their organization, and even their institution. Further, healthcare providers also must adhere to certain legalities that, in turn, function as expectations. An example of the many expectations placed on healthcare providers can be seen in physicians’ work with clients. Physicians have the responsibility to take care of their clients, in terms of assisting clients with their injuries or illness and often are expected to do so in a way that provides support. They also have the responsibility to follow their organization’s rules and policies. Finally, they have a responsibility to the healthcare institution to do their work ethically, in accordance with institutional beliefs and laws. Because physicians have many expectations imposed upon them in their formal roles, determining how social support is or can be integrated into organizational and institutional expectations can be difficult. However, it is clear that social support offered by healthcare providers’ has important implications.

**Social support in provider-client relationships.** Research has shown that clients commonly receive and/or expect to receive social support from healthcare providers (e.g., Goldsmith & Albrecht, 2011; Neuling & Winefield, 1988; Sloan & Knowles, 2013). Further, healthcare providers commonly provide social support to clients in accordance with their roles and their other organizational and institutional duties.

Early social support scholars argued that healthcare providers had an ethical obligation to provide social support to clients who lacked the personal sources (e.g., family) to access sufficient or effective social support (e.g., Caplan, 1974; Cassel, 1976). Caplan (1974) was one of the first social support scholars to recognize the importance of distinguishing between formal
and informal sources of support. Caplan argued that informal support, coming from family members, was an ideal support system; he viewed this source as offering the greatest degree of comfort to the person in need. Thus, Caplan viewed families as support systems where individuals could feel safe to recover from an illness. However, Caplan also recognized that family support systems were changing (i.e., more individuals are living in urban environments and thus geographically removed them from potential sources of family support). As a result, many individuals lack the availability of family members as potential support sources. Caplan argued that, as individuals have smaller informal support systems available, the government and other social institutions (e.g., healthcare institution) should supplement the social support that traditionally was assumed to be available and obtained from family members.

Although Caplan argued that healthcare providers need to supplement social support for clients, other researchers argued that social support was not a professional expectation (e.g., Cobb, 1976). In contrast to Caplan, Cobb (1976) contended that professional services rendered in healthcare, such as tending to a broken leg, were not the same as social support. Cobb argued that supporting a client to make the client feel cared for was not the same as providing healthcare services to the client. He indicated that, unlike most services that are rendered and paid for in healthcare, social support could not be measured objectively and thus could not have its value assessed monetarily. That is, Cobb believed social support was not a billable service. He considered the acts of healing, such as mending a broken leg, to be the types of services that clients pay for in their exchanges with healthcare providers. As a result, Cobb did not believe that social support was a professional responsibility. However, Cobb indicated that social support could occur in healthcare contexts when a nurse’s or physician’s responses make clients feel a sense of belonging and/or comfort, while in that provider’s care. That is, although Cobb did not
believe that social support was a specified responsibility of healthcare providers, he agreed that healthcare providers often do provide social support to clients in accordance with their other job responsibilities.

In contrast to Cobb, Cassel (1976) argued that healthcare providers have an *ethical responsibility for ensuring that clients have adequate social support*. Specifically, he believed that providers should identify clients who lack social support and find alternative sources of support (versus family members and others in clients’ social networks) for such clients. In his 1976 address to the American Public Health Association Cassel explained:

> With advancing knowledge, it is perhaps not too far-reaching to imagine a preventive health service in which professionals are involved largely in the diagnostic aspects—identifying families and groups at high risk by virtue of their lack of fit with their social milieu and determining the particular nature and form of the social supports that can and should be strengthened if such people are to be protected from disease outcomes. (p. 121)

Like Caplan, Cassel emphasized that healthcare providers need to identify ways to provide social support to individuals who lack sufficient informal social support systems (e.g., family).

More recently, researchers have made arguments similar to those of Caplan and Cassel. Mookadam and Arthur (2004) argued that healthcare providers should assess clients’ available informal social support to better identify clients who are socially isolated. They argued that informal social support has a strong association with clients’ adherence to prescribed medical regimens, decisions (willingness) to undergo treatment and ultimately, recovery. Thus, clients without – or with insufficient – informal social support may have worsened health outcomes. Mookadam and Arthur contended that healthcare providers need to identify clients who are socially isolated so that those clients can be referred to alternative or additional sources of
support, including formal sources (e.g., counselors, physicians).

Similar to Mookadam and Arthur (2004), Street et al. (2009) argued that physicians should identify clients who lack sufficient or effective informal sources of social support (e.g., family) and help them to manage these deficiencies by providing alternative or additional formal social support resources (e.g., counseling, physicians). Street et al. explained that although physicians do provide social support (mostly informational support) to clients, providing social support is not their primary responsibility.

Although very little literature has addressed relationships between social support offered in the context of provider-client relationships and health outcomes, that limited volume of research points to probable health benefits of such support. Mills and Sullivan (1999) reviewed literature regarding relationships between informational support offered by nurses to people diagnosed with cancer and those clients’ health outcomes. Mills and Sullivan found that informational support provided by nurses was associated with reduced client anxiety, clients’ enhanced sense of personal control, greater client compliance with suggested medical regimens, and clients’ feelings of greater security.

Other research has examined the relationship between social support received by clients from healthcare providers and the clients’ health behaviors. For example, Robinson, Turner, Levine, and Tian (2011) conducted a content analysis of online interactions between clients with diabetes and their healthcare providers to assess associations between provider support and clients’ health behaviors related to disease self-management (e.g., clients monitoring their blood glucose levels, watching diet). They found that the frequency of messages from providers to individuals was positively associated with the frequency of clients’ blood glucose monitoring. Specifically, informational and instrumental support messages from providers were positively
associated with better client self-management health behaviors.

Research on provider-client communication also has investigated the nature of clients’ social support needs. Krishnasamy (1996) reviewed research on social support for people diagnosed with cancer and considered the implications for nursing practice. Krishnasamy noted the challenges this population faces in gaining effective social support from family and friends at the same time they face uncertainty, and often fear, and the need to make complex decisions. Further, people diagnosed with cancer often experience stigma and isolation as a result of their diagnosis, which makes accessing social support more difficult (e.g., Mathieson & Stam, 1995).

People who have been diagnosed with cancer often consider physicians to be a potential source of social support, particularly informational support (e.g., Street et al., 2009). For example, Neuling and Winefield examined social support from family and friends (i.e., informal sources) and from doctors (specifically surgeons, i.e., formal sources) among women diagnosed with breast cancer recovering from surgery. The researchers found that the women indicated that they had greater needs for informational support from their surgeons than from their family and friends. Thus, these women regard physicians as a necessary source of support, at least for support that is rooted in knowledge and expertise (i.e., informational support). The study also found that the women who were more satisfied with social support from their surgeons had less anxiety than women who were less satisfied with social support from their surgeons. A similar pattern emerged for depression (i.e., those more satisfied with social support from their surgeons had relatively lower levels of depression).

Rose (1990) also investigated the relative desires for specific types or functions of social support (i.e., emotional, instrumental) from family, friends, and healthcare professionals among people diagnosed with cancer. Results indicated, with regard to emotional support, that the
research participants desired reassurance and esteem support from all sources. However, they had greater preferences for opportunities for intimacy and to ventilate from family and friends compared to healthcare providers. The research participants also desired greater clarification and open communication from their healthcare providers (i.e., they wanted clearer and more open communication than they received). With regard to instrumental support, research participants desired advocacy and guidance from all three sources. However, they preferred that instrumental support come from family members more than from the other two sources. In contrast, research participants wanted relatively greater clarification (likely an indicator of health/medical informational support) from healthcare providers than from the other sources.

Given the limited amount of research that has investigated social support in provider-client relationships, researchers recently have called for more investigation of social support offered by healthcare providers (e.g., Goldsmith & Albrecht, 2011; Mookadam & Arthur, 2004; Sloan & Knowles, 2013; Stone, 2013; Street et al., 2009). Specifically, researchers have argued that the investigation of social support provided by healthcare professionals to their clients is an important area for research growth, (a) because social support has been studied primarily in the context of informal relationships (i.e., family and friends), and (b) social support often is associated with health outcomes. Thus, the social support offered by healthcare providers may have particularly important implications (Goldsmith & Albrecht, 2011). Sloan and Knowles (2013) argued that healthcare providers should be a source of social support for people diagnosed with cancer. Sloan and Knowles argued that people diagnosed with cancer often are in need of social support from formal sources because they may be unable to provide for all their support needs on their own. Specifically, they may need information, empathy, and tangible resources that only healthcare providers may be able to offer.
Although scholars have called for greater research attention to social support in provider-client relationships, few have noted that the communication of social support by healthcare providers to clients can be facilitated (Ansmann et al., 2014) or inhibited by organizational and institutional policies (Stone, 2013) and by the organizational culture of individual healthcare organizations (Ansmann et al., 2014). Ansmann et al. examined how systemic factors, such as work environment in the hospital setting (e.g., hospital structures, job demands), influence the ability of physicians to offer social support (i.e., emotional, instrumental) to people diagnosed with cancer. The researchers compared data from physicians and clients who were recruited from 35 different German hospitals. They found that clients perceived that more social support was available in hospitals where physicians had less physical strain (fewer physical demands associated with their work) and greater job security. The study also found that clients’ perceived availability of support was positively associated with an element of organizational culture: social capital. Specifically, the higher social capital (i.e., mutual trust, common values, and a sense of community in the work environment), as reported by the physicians, was associated clients’ perceptions of greater availability of social support in the hospital. The researchers argued that organizational culture influenced physicians’ abilities to provide social support to clients. This study is particularly relevant to the present research as it underscores the influence that healthcare organizations and the healthcare institution have on provider-client communication.

Similarly, in her study of professional caregivers’ communication with people diagnosed with Alzheimer’s disease and their families, Stone (2013) found that the social support provided by professional caregivers (e.g., registered nurses, care assistants, licensed practical nurses) is influenced by organizational and institutional policies. This influence constrained providers’ ability to provide support. Stone found that healthcare professionals experience a dilemma
regarding being able to provide social support (i.e., informational support) to family caregivers due to institutional policies (e.g., HIPAA, organizational rules). For example, they are unable to provide informational support to caregivers if providing that support conflicts with institutional privacy policies. Stone (2013) advises that institutions should be “actively connecting familial caregivers with the institution” (p. 13) in order to explain why support cannot be provided in given circumstances. Thus, the formal nature of healthcare providers’ institutional role can either facilitate or inhibit the ability of healthcare providers to offer social support to their clients.

Research Questions

Evidence indicates that people who have been diagnosed with cancer view healthcare providers as a potential source of social support (e.g., Sloan & Knowles, 2013; Street, 2009). Further, healthcare providers may be motivated to want to provide social support to clients and may find that their organizations facilitate their opportunity to provide social support (Ansmann et al., 2014). However, healthcare providers may also encounter organizational and institutional rules that inhibit their ability or opportunity to provide social support (Lammers & Lambert, 2016; Stone, 2013).

Research on social support in healthcare contexts generally has investigated interpersonal interactions between providers and clients. Studies have been bounded largely by the interpersonal relationships, that is, they have considered primarily, if not solely, interpersonal influences on social support. As such, studies rarely have considered organizational or institutional influences on supportive interactions between providers and their clients. Confining social support analyses to the interpersonal boundaries of provider-client interactions largely ignores the influences that organizations and the healthcare institution inevitably must have on these interactions (e.g., Real, 2010; Real & Street, 2009).
As Real and Street (2009) argue, provider-client communication “does not occur in a vacuum” (p. 84). That is, healthcare organizations and the healthcare institution necessarily influence the communication between providers and their clients. This influence includes potentially facilitating or impeding healthcare providers’ abilities and opportunities to supportively communicate with their clients. For example, healthcare organizations that have an organizational culture that values providing support and caring may encourage or facilitate healthcare providers’ motivations and/or abilities to communicate social support (Ansmann et al., 2014). Further, clients in such an organizational environment may also believe that social support is an institutional norm in healthcare; that is, they may believe that the healthcare institution is a place of healing and caring and, thus, may expect to receive social support. In contrast, a healthcare organization that does not facilitate the communication of social support between providers and clients may be perceived by its clients as obstructing their support needs.

In summary, research on social support in healthcare contexts largely has been limited by treating social support as a purely interpersonal phenomenon between providers and clients. Logically, both organizational and institutional factors must influence social support processes between providers and clients in the healthcare context. Because client health and wellbeing is the primary goal of healthcare organizations and of the healthcare institution, understanding how clients perceive the support processes that occur – or fail to occur – within these organizations and the healthcare institution may provide insight into how healthcare organizations and the healthcare institution can provide more effective care in the forms of social support.

The present study focused on addressing this gap in the literature by examining client perceptions of social support in a Cancer Support Center. This study is guided by the following overarching research question: What is the nature of social support that clients experience and
perceive as institutionalized in healthcare organizations? The nature of social support refers to the variety of experiences that clients may have with supportive communication. For example, clients’ reports regarding their experiences or perceptions of support in the context of a healthcare organization may include some of the array of factors suggested by the larger support literature, such as: extent of support available or received, types or forms of support or resources provided (i.e., functions), characteristics of supportive interactions and processes, perceived value of support experienced (i.e., benefits), and variations in sources of support. Further, this question considers the extent to which social support experienced or perceived in healthcare organizations is viewed by clients as institutionalized (i.e., typified), as well as the nature of that institutionalized support.

The present investigation addressed three specific research questions. The first research question focuses on clients’ actual perceptions and experiences of social support in healthcare contexts. Because social support is characterized by structural dimensions, functions (i.e., types of support or support resources), and variations in availability (extent of perceived and experienced social support) (see Chapter II, Key concepts in the study of social support), this research question attempted to capture dimensions of social support that clients identify within healthcare organizations. The first research question asked:

RQ1: What are clients’ perceptions regarding the structural nature, functions, and availability of social support they have experienced in healthcare?

RQ1a: What are clients’ perceptions regarding the structural nature, functions, and availability of social support they have experienced in the Cancer Support Center?

RQ1b: What are clients’ perceptions regarding the structural nature, functions,
and availability of social support they have experienced in the healthcare institution?

The second research question addressed clients’ perceptions regarding the sources of social support in healthcare. Specifically, the question sought to understand the specific sources to which clients attribute social support. These could be individual healthcare providers, healthcare organizations, such as the Cancer Support Center, and/or the healthcare institution itself (i.e., their experiences in healthcare settings). Thus, the second research question asked:

RQ2: What attributions do clients make regarding the sources (e.g., individual, organizational, institutional, other) of social support that they perceive, experienced, or expect to receive in healthcare?

The third research question addressed the potential benefits (or absence thereof) of social support perceived or received by clients in healthcare organizations, both in the Cancer Support Center of interest to this study and more generally within the healthcare institution. Research has shown that social support often is strongly associated with significant beneficial health outcomes (see Chapter II, Associations between health and social support). Thus, clients may perceive the social support they have experienced (or not experienced) as having benefits or potential benefits (e.g., personal, social, health, or other benefits). The third research question asked:

RQ3: What are clients’ experiences and perceptions of the benefits or potential benefits, if any, that they associate with social support in their healthcare experiences?

RQ3a: What are clients’ experiences and perceptions of the benefits or potential benefits, if any, that they associate with social support in the Cancer Support Center?

RQ3b: What are clients’ experiences and perceptions of the benefits or potential
benefits, if any, that they associate with social support in the healthcare institution?
Chapter III

Methodology

The goal of the present research was to understand cancer patients’ experiences and perceptions of social support within a healthcare organization (i.e., a cancer support center) and, more broadly, within the healthcare institution. The study used a constructivist grounded theory approach (e.g., Bryant & Charmaz, 2007; Charmaz, 2000, 2006, 2014) in order to investigate participant experiences and perceptions of social support and to answer specific research questions. The following section: (a) reviews the meta-theoretical framework that underpins a constructivist grounded theory approach; (b) explains the procedures used in conducting the study; (c) describes the data analysis; and (d) discusses issues of trustworthiness relevant to the analyses and results.

Constructivist Grounded Theory

A constructivist grounded theory approach, a qualitative research method of inquiry, was employed in this study. According to Tracy (2013), qualitative research methods allow researchers to examine the meanings of social complexities through rich description and in-depth analyses. Qualitative research methods are appropriate for an in-depth understanding of social phenomena (e.g., in the present study, institutionalization of social support) from the participants’ perspective. Tracy explains that qualitative research also is useful for examining areas of social phenomena where little is known about the subject. Thus, qualitative methods were appropriate in the present study due to the absence of previous research that considers the role of healthcare organizations and the healthcare institution in the social support processes that occur in the context of cancer.

Constructivist grounded theory is an interpretive approach to research (Charmaz, 2014).
Constructivist grounded theory is based on conducting systematic, yet flexible, analysis of qualitative data through comparative methods (i.e., inductive processes whereby data are compared with other data within the same dataset; Charmaz, 2011). Constructivist grounded theory acknowledges the researcher’s construction and interpretation of data (Charmaz, 2014). That is, the approach recognizes the researcher’s role in creating the research context and data (e.g., via conducting interviews, observations) and in interpreting data. As Tracy (2013) explains:

From an interpretive point of view – which is also termed constructivist or constructionist – reality is not something “out there,” which a researcher can clearly explain, describe, or translate into a research report. Rather, both reality and knowledge are constructed and reproduced through communication, interaction, and practice. Knowledge about reality is therefore always mediated through the researcher. (p. 40)

From this perspective, the researcher is the intermediary in the construction of knowledge about reality. That is, the researcher interprets socially constructed reality. Resulting knowledge is based on the researcher’s interpretation.

In the context of the present study, employing a constructivist grounded theory approach allowed the researcher to study a socially constructed communication phenomenon (i.e., institutionalization of social support), while acknowledging the socially constructed nature of the research and the interpretive lens through which the data were analyzed.

**Why employing constructivist grounded theory was valuable for this study.** Using a constructivist grounded theory approach to conducting the present research offered two key advantages. The first major advantage is that constructivist grounded theory provided an epistemological framework for understanding the social construction of and meanings attributed
to the social phenomena under investigation. Specifically, constructivist grounded theory draws on symbolic interactionism (Charmaz, 2014). Charmaz (2014) explains symbolic interactionism as “a dynamic theoretical perspective that views human actions as constructing self, situation, and society. It assumes that language and symbols play a crucial role in forming and sharing our meanings and actions” (p. 262). Thus, symbolic interactionism casts communication as the social and interpretive processes through which individuals construct and share meaning. Symbolic interactionism is the underlying framework through which data were interpreted in the present study.

A second advantage is that constructivist grounded theory approach allowed the researcher to examine multiple levels at which social phenomena (e.g., social support) occur and their mutual influence. Constructivist grounded theory draws on Strauss and Corbin’s (1990) logics to capture action and meaning, which includes the conditional matrix (Figure 1). Strauss and Corbin (1990) explain the conditional matrix as a metaphor for qualitative researchers to use in understanding how different levels of interaction conditionally influence social phenomena relative to each another. Strauss and Corbin’s conditional matrix is a set of concentric circles that represents how varied levels of communication phenomena (e.g., interpersonal, organizational, institutional) are conditional to one another (see Figure 1). Strauss and Corbin argue, “Regardless of the level within which a phenomenon is located, that phenomenon will stand in conditional relationship to levels above and below it, as well as within the level itself” (p. 162). Thus, through qualitative research, investigators can observe the varied levels of communication (e.g., interpersonal, organizational, institutional) that occur and their influence in terms of affecting social processes (e.g., social support within the healthcare institution). In previous studies, researchers interested in institutional and organizational influences on everyday
communication have successfully used grounded theory methods for identifying and interpreting multiple levels of interaction (e.g., see Lammers and Garcia, 2009; Stone, 2013). Using the conditional matrix as a framework for interpreting different levels of interaction in the present study allowed the researcher to consider relationships among interpersonal, organizational, and institutional dynamics within the context of healthcare.

*Figure 1. Conditional Matrix, adapted from Strauss and Corbin (1990, p. 163).*

The application of relevant literature in constructivist grounded theory. A common debate among researchers who rely on grounded theory approaches to research relates to the role of using extant literature while constructing new theories based on the data at hand (Strübing, 2007). Some grounded theory researchers argue that studies using grounded theory should attempt to understand social phenomena independently, as they emerge in the data, without relying on previous research to inform the findings (e.g., Glaser, 1992; Stern, 1995). In contrast, Tracy (2013) argues for an *iterative approach* to the role of extant research when conducting qualitative research in general, and more specifically in research that employs a grounded theory approach. Tracy describes the iterative approach as alternating “between considering existing
theories and research interests on the one hand, and emergent qualitative data on the other” (p. 8). In other words, in the iterative approach, researchers locate and integrate their findings with previous literature and theory. Thus, the decision to employ a constructivist grounded theory approach does not mean that the researcher cannot employ existing knowledge in the pursuit of new understanding. Instead, the researcher is responsible for identifying how existing research fits into emerging themes within the data. In the context of the present research, extant research was critical to enabling the researcher to inductively identify and understand the nature of key support processes (e.g., support functions, perceptions of available support) and their sources (e.g., individuals, organizations, institutions).

In summary, using a constructivist grounded theory approach to conduct the present study allowed the researcher to simultaneously discern the participants’ social constructions of reality while acknowledging the researcher’s role in the construction and interpretation of the data. This approach was particularly valuable because it allowed the researcher to capture abstract understandings of social phenomena within specific conditions and to connect these understandings to extant literature.

**Procedures**

Semi-structured in-depth interviews were conducted with clients of the Cancer Support Center who had been diagnosed with cancer, and who *regularly used* the Center. Interviews focused on clients’ experiences and perceptions of social support and, more specifically on social support received at the Cancer Support Center and within healthcare. The research protocol was approved by Kent State University’s Institutional Review Board prior to implementing recruitment and data collection procedures.
Participant recruitment. With permission from the Cancer Support Center (see Appendix A), clients were recruited for the study in cooperation with the Center: (a) using a recruitment letter from the Center (Appendix B); (b) through personal contact at the Center, using a recruitment script (Appendix C); and (c) via flyers posted and distributed at the Center (Appendix D). The Center mailed the recruitment letter (Appendix B) to all potential participants who met the study’s inclusion criteria. In addition, the researcher attended several group activities at the Center (e.g., breast cancer support group, spirituality support group, lung cancer support group, yoga class, gardening workshop), gave a short presentation about participation in the study (see Appendix C for recruitment script), and provided a sign-up sheet to potential participants. Finally, the researcher created a flyer (see Appendix D) that was available at the Center’s front desk or provided to participants by the Program Coordinator when they were at the Center. Interested participants called, emailed, or texted the researcher using the contact information provided on the letter and flyer to schedule an interview. The researcher then contacted participants, who had provided their contact information via the sign-up sheet, and scheduled the interviews. The majority of study participants made the initial contact with the researcher after receiving the recruitment letter.

Participants. The researcher conducted interviews with adults who had been diagnosed with diverse types of cancer and who regularly used the Cancer Support Center. In order to effectively answer the study questions, participants needed to be experienced with the Cancer Support Center. Therefore, only cancer patients who regularly used the Center were recruited. Regular use of the Cancer Support Center was operationalized as having participated in programs and/or services at the Center at least four times in the four months prior to the
interview. Individuals who had used the Center more than four months prior to the interview may not have had current understandings of the Center relevant to the interview. Further, having used resources at the Center at least four times (although most participants well exceeded this number) meant that participants had multiple experiences with the organization and were likely to have formed perspectives about the Center’s organizational culture.

As of June 2015, 416 clients had used the Center at least once within the previous year. Clients included people who had been diagnosed with cancer, caregivers of people who have cancer, and family members of people who have cancer, including children and grandchildren. According to the Center’s statistics, about three-quarters of the Center’s client population (75.9%) self-identified as female and 24.1% identified as male. More than half (60.6%) self-identified as white, 33.7% chose not disclose ethnicity, 5.5% self-identified as Black. About one-quarter (23.6%) of the Center clients are ages 55-64; 19.5% are 65-74, and 10.3% are 45-54. Almost a third (29.6%) of the Center clients chose not to disclose their age. The remainder of the Center clients are ages 75 or older (7.2%), 35-44 (4.3%), 25-34 (2.4%), 6-13 (1.9%), or 14-17 (1.2%).

The inclusion criteria for the study were regular use of the Center (i.e., used the Center’s resources four times in the past four months) and being at least 18 years of age. One-hundred of the Center clients met these criteria.

Three men and 28 women participated in the study. They ranged in age from 34 to 82 years ($M = 59.2, SD = 9.19$). Twenty-eight participants self-identified as White (not of Hispanic origin), two participants self-identified as American Indian/White, and one participant self-identified as Black.

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7 The definition of “regular use” was determined after consultation with the Program Coordinator at the Cancer Support Center.
8 Only 18 of the 100 clients who met the inclusion criteria for the study were male.
The Cancer Support Center serves clients who have been diagnosed with cancer. All participants had been diagnosed with cancer; some were currently in treatment; others had completed treatment. The Center serves clients with all types of cancer diagnoses. Participants’ cancer diagnosis and cancer stage varied. Twenty participants were diagnosed with breast cancer, four with gynecological cancer, two with colorectal cancer, two with brain cancer, two with prostate cancer,\(^9\) and one with throat cancer.

The researcher conducted a total of 37 interviews with the Center’s clients during the data collection phase. However, in the process of collecting data, the researcher learned that five \((n = 5)\) participants also were regular volunteers at the Cancer Support Center (e.g., front desk volunteers, support group facilitator, Reiki volunteer). Although these volunteers met the study’s initial inclusion criteria, the researcher and the director of the dissertation concluded that, because volunteers played a formal organizational role, they had potentially different organizational perspectives and more formal organizational knowledge than other clients. In order to maintain a focus on client perceptions and experiences, the interviews with volunteers were excluded from present analyses. Further, initially the researcher had planned on interviewing clients who are caregivers to people with cancer as well as people diagnosed with cancer. However, only two \((n = 2)\) caregivers\(^{10}\) volunteered for the study and one of the caregivers was also a volunteer at the Center. Interviews with caregivers were excluded from present analyses. (They will serve as pilot data for future research.) The final data analyzed in the present study was derived from interviews with thirty-one \((n = 31)\) participants.

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\(^9\) One participant self-identified as in remission from throat cancer; however, he also had been diagnosed with prostate cancer at the time of the interview.

\(^{10}\) Some participants in the study had both personal experiences with cancer (i.e., were diagnosed with cancer) and had had the experience of being a caregiver for another person diagnosed with cancer (e.g., spouse, child, sibling, parent). In some of these cases, these participants discussed their caregiving experiences in addition to their personal experiences with cancer; however, their personal experiences with cancer were the focus of the present analysis.
**Data collection procedures.** The researcher conducted semi-structured in-depth individual interviews with the Center’s clients who agreed to participate in the study following completion of informed consent procedures. Interviews were conducted at the Cancer Support Center in the counselor’s office, support group room, or conference room, depending on availability of space. Conducting interviews in the Center’s space ensured both privacy and maximum comfort for participants (i.e., clients knew the location of the Center, parking was easily accessible, and the spaces used were private, quiet, and free of outside distractions).

The researcher implemented an informed consent process with all participants prior to the interviews. This general consent process included addressing potential risks and benefits of the study and informing participants that their participation in the study would not affect their relationship with the Cancer Support Center (see Appendix E for the consent form). In addition, a separate process gained participants’ consent to be audio-recorded (see Appendix F for the audio-recording consent form). Following completion of informed consent procedures, participants completed a demographic questionnaire (Appendix G).

All interviews were audio-recorded for transcription purposes and the transcripts served as the data for the study. Interviews ranged in length from 32 minutes to 118 minutes ($M = 58.9$ minutes; $SD = 15.92$). They were guided by an interview protocol (Appendix H). The interview protocol was organized into seven sections: (a) introduction to the study; (b) getting to know the participant; (c) participant’s support experiences with family and friends; (d) participant’s support experiences with the Cancer Support Center; (e) participant’s support experiences in the healthcare institution and perceptions of the responsibilities of healthcare organizations; and (f) closing thoughts. Following the interview all participants were presented with a $20 gift card to a local grocery store as compensation for their participation.
Transcription procedures. All audio-recordings were encrypted and sent to a transcription service. The transcription service ensured ninety-nine percent accuracy of all audio-recorded data. After receiving the initial transcripts from the transcription service, the researcher verified and de-identified all transcripts. The researcher listened to audio-recordings and used transcripts to check accuracy of transcription. All personally identifying information (e.g., names, places) was removed from the transcripts. During the de-identification of the transcripts, participant names were replaced with pseudonyms. Final transcripts ranged in length from 11 to 48 single-spaced pages \((M = 22.5\) pages; \(SD = 9.11\)) formatted in Calibri 12-point font. Following transcription, verification, and de-identification of the transcripts, the audio-recordings of the interviews were erased. Electronic copies of transcripts were stored on the researcher’s password-protected computer.

Analysis

All data were analyzed using Charmaz’s (2014) five steps for implementing a constructivist grounded theory approach: (a) initial coding; (b) focused coding; (c) memo-writing; (d) theoretical sampling; and (e) writing findings and related implications.

NVivo for Mac facilitated data analysis (NVivo 10, 2010). NVivo is computer software designed to assist qualitative researchers in organizing and analyzing qualitative data (QSR International, 2016). Using NVivo facilitates the researcher’s ability to organize codes assigned to units of data (e.g., line of text), to sort those codes into meaningful categories, and to search what has been coded and categorized. For example, the researcher can identify all of the data (i.e., specific lines of text) that have been assigned a specific code or category (i.e., codes that contain similar data). Researchers can also use NVivo to write and store memos. The researcher found it useful to write the memos in NVivo because she was able to alternate between coding
and memo-writing without using multiple software programs.

The researcher imported all de-identified final versions of transcripts into NVivo. Using the software, the researcher coded data (i.e., initial line-by-line coding), organized codes into categories (i.e., focused coding), and wrote memos.

**Coding.** Coding is the process of making sense of the data and finding meaningful connections among the codes and themes (Charmaz, 2014). The researcher used short codes (i.e., words and phrases) to describe phenomena within the data. Data were compared with other data from the present research, ensuring constant comparison throughout the analysis. This process occurred through sorting, comparing, and synthesizing the data.

*Initial coding.* In the present study, initial codes were created during line-by-line coding (Charmaz, 2006). Initial codes are “provisional, comparative, and grounded in the data” (Charmaz, 2014, p. 117). Each code was descriptive in nature (Tracy, 2013). That is, the assigned code described what was occurring in that line or piece of data.

The researcher developed initial codes to describe individual datum. The line or lines of text that were assigned individual codes constituted the unit of analysis in the present study. She examined each line of text and assigned a code to that line or lines that in order to describe the key idea in that text. Breaking the data into smaller pieces through line-by-line coding kept the researcher focused on individual datum. For example, the researcher used the code “grateful to healthcare” for the following line, “But I appreciate my medical team, the hospital and everything they’re doing for me.” If a participant’s idea occurred over the course of multiple lines, all lines focusing on the same idea were coded as one unit, or idea. For example, the researcher assigned the initial code “feeling isolated” to the lines, “Especially those drab winter months, you know? When there’s nothing to do and nowhere to go, it’s like, ‘Woe is me.’ I feel
like I’m the only one. I feel like I’m alone.” Additional examples of initial codes include:
“compassion for the patient,” “being seen as a person not a number, healthcare,” “feeling like healthcare is an assembly line,” “distancing in personal network,” “no one to talk to about cancer,” “just feeling better from Center activity,” “Reiki relieving health problem,” “releasing stress through yoga at Center,” “Center helping to deal with stress,” “feeling isolated,” “number of programs at Cancer Support Center,” and “importance of free services.” Throughout the coding process, multiple initial codes often were assigned to the same unit when multiple ideas were evident. As a result, the same unit sometimes was relevant to multiple themes.

**Focused coding.** The second step in coding was *focused coding*. According to Charmaz (2014):

> Focused coding means using the most significant and/or frequent earlier codes to sift through and analyze large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize . . . data incisively and completely. It also can involve coding . . . initial codes. (p. 138)

In the present study, the process of focused coding consisted of organizing initial codes that were related to the same concept into categories.

The researcher conducted focused coding simultaneously with much of the initial coding. As the researcher created initial codes, she began to group those related to the same concept into categories. For example, the focused code “value of support at the Center” was the category developed to encompass the following initial codes: “importance of support at Center,” “thankful for Center,” “grateful for volunteers at Center,” “value of Center,” “need more places like Center,” “Center understands the cancer experience,” “Center is a positive experience,” and “receiving support from Center.” The researcher also practiced *theoretical sensitivity* while
coding. Charmaz (2014) describes theoretical sensitivity as the researcher’s “ability to understand and define phenomena in abstract terms and to demonstrate abstract relationships between studied phenomena” (p. 161). Specifically, the researcher used her understanding of terms and concepts from the literature to describe themes that emerged. For example, in identifying the nature of perceived support experienced at the Cancer Support Center, the researcher used the focused code “Perceived Support at Cancer Support Center.” This focused code represented a category that included three initial codes, all of which focused on perceptions of available support: “number of programs,” “following-up [Cancer Support Center],” and “available support at Center.” As the researcher coded, she found that all new initial codes identified in the last nine transcripts fit into the extant categories that had emerged during focused coding of the previous transcripts. Thus, the coding process had achieved theoretical saturation, or the point at which no new themes emerge from the data (Charmaz, 2014).

**Memo-writing and theoretical sampling.** During data analysis, the researcher engaged in memo-writing. Miles and Huberman (1994) explain that memos are conceptual work; they do not function as reports, but instead they function as a way to record the sense-making process. In the present analysis, the researcher wrote memos to explain her thought processes and interpretations while conducting the analysis. When writing memos, the researcher practiced specific steps in order to stay organized and clearly show how she reached conceptual understandings within the data. First, all memos were typed. Typing memos helped to keep them neat and organized to avoid the risk of losing hand-written memos. Second, all memos were dated and included a title that explained the subject of the memo. Third, the researcher incorporated raw data into the memo, so that examples were clearly present and easily

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11 Although some memos were initially written on paper or a white board, all were ultimately converted to electronic formats to ensure they were kept neat and organized.
identifiable.

All memos focused on the key themes and meanings that emerged from the data set. For example, as the researcher analyzed data, she noticed that participants did not believe that their social networks provided adequate support to meet their needs. The researcher described her interpretation of this in a memo:

Memo Title: “Personal Network not Sufficient Source of Social Support”
Written on October 8, 2015

Tara explains that she needs to talk to others who understand the cancer experience. Further, she doesn’t see her family as being able to give her sufficient support. Similarly, Audrey explains that her family was not there enough for her. Elaine pointed out that people who don’t have cancer have not been in those “shoes.” This isn't perhaps surprising for a support group setting, but I think it gets more to the isolating experience of cancer and the need for healthcare to address that need and create places where individuals can find others who also have experiences with cancer and can provide support.

While writing memos, the researcher practiced theoretical sampling. *Theoretical sampling* is the process of “seeking pertinent data to develop . . . emerging theory” (Charmaz, 2014, p. 193). Through memo-writing, the theoretical and conceptual connections in the data became clear to the researcher; based on these, she began to write the study’s findings. The study’s findings were organized around the research questions and were reported in the forms of key themes that related to specific research questions.

**Trustworthiness and the Writing Process**

Trustworthiness in qualitative research is defined as the confidence that study results are
valid, are applicable to other contexts, could be replicated, and are not based on the biases of the researcher (Lincoln & Guba, 1985). To ensure the trustworthiness of the results, the researcher took several steps to ensure confidence in the validity, accuracy, applicability, consistency, and neutrality of the results.

First, the researcher demonstrated trustworthiness and validity of the findings through careful documentation of the research process and reporting of results. The researcher explained in detail how data were gathered and analyzed. Further, the researcher was careful to make connections between data and findings in writing the results.

Second, the researcher demonstrated trustworthiness through using member-checking to ensure that the findings of the study were not based on the researcher’s biases. Specifically, the Program Coordinator at the Cancer Support Center served as the member-check, or representative of parties included in the study, to assess the validity of the study’s findings (Lincoln & Guba, 1985). The researcher discussed findings with the Program Coordinator at the Center to ensure that the researcher’s interpretations were valid. The Program Coordinator (a cancer survivor herself) had detailed knowledge of the Cancer Support Center and had personal experience with cancer. Further, the Program Coordinator’s expertise in the context of the Cancer Support Center was useful to help clarify ambiguous participant comments or to provide otherwise incomplete information about the Center’s activities and/or processes. For example, the Program Coordinator explained how participants actually use the resource library at the Center because participants’ comments did not clarify that process.

Finally, the researcher demonstrated trustworthiness by consulting an external source (i.e., an individual who has an outside perspective) to aid in the research process and further interrogate the data and the findings (Miles & Huberman, 1994). The researcher’s advisor played
this role. Together, they examined data and codes and discussed the accuracy, applicability, and consistency (i.e., reliability) of the study findings.

**Summary**

In summary, semi-structured interviews with 31 people diagnosed with cancer, who regularly used the Cancer Support Center, constituted the data for the present study. Data were analyzed using constructivist grounded theory techniques (i.e., initial coding, focused coding, memo-writing, theoretical sampling). Finally, to ensure the trustworthiness of the findings, the researcher engaged in member-checking procedures and consulted with an external source.
Chapter IV

Results

This chapter presents the results of a study that addresses the following overarching research question: *What is the nature of social support that clients experience and perceive as institutionalized in healthcare organizations?* Using constructivist grounded theory the researcher identified themes related to participants’ experiences and perceptions of social support at the Cancer Support Center and in the healthcare institution at large in order to understand the ways in which organizations and the institution facilitate and/or impede the communication of social support. The following chapter identifies themes related to: (a) the nature of social support experienced at the Cancer Support Center and in the healthcare institution at large, (b) the sources of social support in the Cancer Support Center and the healthcare institution at large, and (c) the benefits of social support experienced at the Cancer Support Center and in the healthcare institution at large. The results are situated within participants’ experiences in healthcare related to their experiences with cancer. First, this section describes the Cancer Support Center in order provide readers with an understanding of the organization. Next, this section addresses each research question by identifying, supporting, and discussing relevant themes that emerged in the data.

Description of the Organizational Context at the Cancer Support Center

An understanding of the Cancer Support Center’s purpose and organization, and how participants use it, provides the context for interpreting results related to the Center. The following description is based on information obtained from documents published by the Center (i.e., newsletter, website), Center staff members, and observations the researcher made during data collection.
**Center mission.** The Cancer Support Center was founded to be a source of support for individuals who are experiencing cancer. The Center’s explicit mission is “to provide a caring, relaxed environment offering supportive services and programs for individuals and families on their cancer journey.” The Center offers an array of services, programs, resources, and activities to support wellness. Individuals diagnosed with cancer, caregivers to individuals diagnosed with cancer, and children or other family members of individuals diagnosed with cancer, use the Center free of charge.

**Non-profit status.** The Cancer Support Center is a non-profit healthcare organization. It is funded by an endowment from a local family who founded the Center, donations made directly to the Center, and two major annual fund-raisers.

**Center organization and staff.** The Center’s staff is comprised of six full-time and three part-time employees who manage the organization’s day-to-day operations. The full-time staff members are: the Executive Director, the Director of Development, the Program Coordinator, the Office Manager, the Children’s Program Coordinator, and the Marketing Coordinator. The Executive Director manages facility operations and serves as a liaison to the Center’s Board of Directors. The Director of Development oversees the Center’s grant development and special events, including fundraising events. The Program Coordinator develops and maintains services offered by the Center and ensures that clients receive appropriate care. The Office Manager makes appointments for clients and carries out other administrative tasks. The Children’s Program Coordinator leads all children’s activities and assists with other administrative work at the Center. The Marketing Coordinator manages the Center’s promotional activities, including the Center’s website and social media presence.

The part-time employees are: the Human Resources and Volunteer Coordinator, the
Counselor, and the Housekeeper. The Human Resources and Volunteer Coordinator coordinates the Center volunteers and other personnel. The Center Counselor provides individual, marital, family, and group counseling and facilitates some of the support groups. The Housekeeper cleans the facility and assists with the logistics of some Center events.

In addition to paid staff, the Center relies heavily on volunteers from the community. Volunteers facilitate most of the Center’s services, programs, and activities. For example, financial advisors, yoga instructors, and massage therapists, and other individuals with varied expertise, volunteer their time and expertise to the Center. Volunteers also staff the reception desk and greet clients when they arrive. Reception desk volunteers work in two or three hour shifts.

The Center also has a Board of Directors that meets bi-monthly. The Board of Directors evaluates the Center’s overall direction and works with the Executive Director to conduct the Center’s strategic planning. The Board creates both short-term and longer-term (i.e., up to three years) goals for the Center and develops tactics that can be used to meet those goals.

Center location, design, and décor. The Cancer Support Center is located in a suburban area of northeast Ohio. It is relatively secluded from passing foot and vehicular traffic, which helps to ensure the privacy of its clients and activities.

The front of the Center is lined with a long row of windows. Immediately outside of the windows is the Center’s Butterfly Garden (the Center’s logo is a butterfly). The Butterfly Garden features flowers, a short walkway, a seating area, and a trellis. The walkway in the garden includes pavers engraved with donors’ names. Clients often use the Butterfly Garden during activities (e.g., gardening class, lunch socials) or as a place to relax before or after appointments.

Clients enter the Center through a lobby area. The lobby has a reception desk, a seating
area, and a video monitor that plays a continuous slide show that features Center events and information. Each time a client enters, a doorbell sounds. The reception desk is staffed by one of the Center’s volunteers who greet clients when they enter the Center. These volunteers check in clients, offer them something to drink, and show them to the appropriate rooms for activities.

The Center lobby is positioned at the end of a long hallway that has various activity rooms and staff offices along both sides. Several large canvas prints, featuring Center clients (e.g., children’s group photo from the summer camp, clients talking to each other during a support group meeting), decorate the lobby and hallway. Activity rooms include a large multipurpose room, where meditation, physical activities (e.g., yoga), and other events generally are held; a wig room; a resource library; a conference room; a support group room; a children’s room; a healing arts suite with two private rooms for integrative services (e.g., massage, Reiki); and a private counseling room. The support group room is furnished with overstuffed couches and chairs. The Center also has a small kitchen area located near the lobby.

**Cancer Support Center services, programs, and resources.** The Cancer Support Center offers a variety of services, programs, resources, and activities. Those include: integrative services, workshops and other short-term events, support groups, health and wellness consultations and programs, counseling, a resource library, wigs and beauty services, financial and legal consultations, and children’s activities. Use of services and programs varied widely among participants in the present study. Some participants were active only in an individual service (e.g., healing touch) or in one support group (e.g., spirituality support group), while other participants had participated in most activities offered by the Center. The following sections describe services, programs, resources, and activities offered by the Center.
**Integrative services.** The Cancer Support Center offers a variety of integrative services, including: Reiki, massage therapy, lymphatic massage, foot reflexology, aromatherapy, healing touch, and color and sound wave therapy. Integrative services “involve bringing conventional and complementary approaches together in a coordinated way” (National Center for Complementary and Integrative Health (NCCIH), 2016). Volunteers who perform integrative services (e.g., Reiki practitioners, massage therapists) provide these services. Most study participants used integrative services at the Center ($n = 21$). Of these, massage was the most commonly used ($n = 12$), followed by Reiki ($n = 10$).

**Workshops and other short-term events.** Although many of the Cancer Support Center’s programs are regularly-scheduled ongoing activities with monthly or weekly meetings, some programs are offered periodically, such as workshops (e.g., Meditation Workshop, Herb and Gardening Workshop), or are one-time events (e.g., guest speaker events). Nineteen study participants ($n = 19$) reported having attended a workshop or one-time event at the Center.

**Support groups.** The Cancer Support Center offers support groups that focus on specific types of cancer (e.g., breast cancer, lung cancer, gynecological cancers, and prostate cancer) or on a common theme (e.g., coping with cancer, spirituality and cancer). Center staff or volunteers facilitate support groups. Seventeen ($n = 17$) study participants reported having participated in support groups.

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12. Reiki is an integrative therapy used to manipulate the energy flow within the body to facilitate the body’s natural healing (NCCIH, 2016).
13. According to the Center, lymphatic massage is a technique designed to help ease pain associated with lymphedema. Lymphedema, swelling in the area of lymph nodes or where lymph nodes have been removed, is a common side-effect of surgery and/or radiation therapy (National Cancer Institute, 2015e). Lymphedema may cause psychosocial as well as physical problems (National Cancer Institute, 2015e).
14. The Center describes foot reflexology as the use of “pressure applied to reflex points on the feet, which correspond with various body parts and helps to stimulate the body’s self-healing powers.”
15. The Center describes aromatherapy as “simple hand techniques with the use of essential oils to help reduce stress and strengthen immunity.”
16. The Center describes healing touch as “compassionate energy therapy where practitioners use their hands to promote healing and to assess [the client’s] energy system.”
17. The Center describes color and sound wave therapy as the use of “sound vibrations of tuning forks to restore healthy vibration of the body and clear the blockages that impede the body’s natural energy flow.”
one or more of the support groups. Of these, the spirituality and cancer support group was the most common \((n = 8)\), followed by the breast cancer support group \((n = 6)\). Three participants \((n = 3)\) reported participating in the gynecological cancers support group, two participants \((n = 2)\) reported participating in the prostate cancer support group, and one participant \((n = 1)\) reported participating in the grief and loss support group.

**Health and wellness consultations and programs.** The Cancer Support Center offers health and wellness services and programs staffed by volunteers. These include health and wellness activities (i.e., yoga, gentle strength bodywork, tai chi, walking club), medication consultations with a licensed pharmacist, nutrition consultations with a nutritionist, and spiritual care sessions with a chaplain. Fourteen study participants \((n = 14)\) reported engaging in Center health and wellness activities.

**Counseling.** The Cancer Support Center offers short-term counseling services with the staff’s licensed counselor. Available counseling services include individual counseling, marital and family counseling, and group counseling. Eight study participants \((n = 8)\) participated in the Center’s counseling services.

**Resource library.** The Cancer Support Center has a resource library that features books, CDs, and other resources on cancer treatment, coping with cancer, and spirituality. Eight study participants \((n = 8)\) reported using the resource library.

**Wigs and beauty services.** The Cancer Support Center offers free wigs, toupees, hats, and scarves to individuals who experience hair loss during cancer treatment. The wig room features wigs with a variety of cuts and colors, as well as hats and scarves. The Center also provides wig styling, as well as a “Look Good, Feel Better” workshop (designed to teach cosmetic use and skin care techniques to women in cancer treatment). Seven participants \((n = 7)\) reported receiving
wigs and/or hats from the Center during treatment. Many of those who had completed treatment donated their wigs back to the Center. Six study participants ($n = 6$) indicated they had attended a beauty workshop.

**Financial and legal consultations.** The Cancer Support Center offers financial and legal consultations. Volunteers who are financial advisors and lawyers provide these services. Consultations offered at the Center include: debt management, financial planning, health insurance, social security and disability, and wills, trusts, and estate planning. Four study participants ($n = 4$) had consulted with the Center’s financial advisors or lawyers.

**Children’s activities.** The Cancer Support Centers offers activities for children and grandchildren of individuals who have been diagnosed with cancer. (The Center does not serve children diagnosed with cancer.) Activities for children include a summer camp and movie nights. One study participant ($n = 1$) enrolled her son in children’s activities at the Center.

In summary, the Center is a non-profit organization that provides support services, free of charge, to people who have been diagnosed with cancer and their families. A small staff and volunteers offer and facilitate a wide array of services and activities.

**Structural Nature, Functions, and Availability of Social Support in Healthcare**

The present study investigates clients’ experience and perceptions of the nature of social support in healthcare contexts. Research question 1 (RQ1) asked, “What are clients' perceptions regarding the structural nature, functions, and availability of social support they have experienced in healthcare?” Previous research examined: (a) the structure of support, or the networks of social ties that connect individuals to support (e.g., Cohen & Wills, 1985); (b) the functions that support serves (e.g., informational, emotional, instrumental, spiritual; e.g., Cobb, 1976; Foa, 1971); and (c) the perceived availability of support, or belief that social support is
available if or when needed (e.g., Donald et al., 1978). The following section identifies and discusses themes within clients’ perceptions that relate to structural support, functions of social support, and perceived availability of support in healthcare settings. Research question 1a (RQ1a) addresses the nature of social support at the Cancer Support Center, whereas Research question 1b (RQ1b) addresses the nature of social support in the healthcare institution at large.

**Nature of social support experienced at the Cancer Support Center.** RQ1a asked: “What are clients' perceptions regarding the structural nature, functions, and availability of social support they have experienced in the Cancer Support Center?" Themes emerged in clients’ perceptions of (a) access to supportive social ties through the Cancer Support Center; (b) informational, emotional, instrumental, and spiritual support functions served by support experienced at the Cancer Support Center; and (c) social support that clients perceived as available due to the resources offered by the Cancer Support Center.

**Nature of structural support at the Cancer Support Center.** Structural support is defined as the social networks, or systems of personal relationships, through which social support occurs or is perceived to occur (e.g., Albrecht & Goldsmith, 2003; Cohen & Wills, 1985; House et al., 1988). Social support occurs within social networks that are manifested in the communication patterns among individuals’ social ties (Albrecht & Goldsmith, 2003). Clients’ perceptions of new social ties (e.g., other clients, staff) that were developed via the Cancer Support Center are indicative of the Center’s impact on structural support.

Most participants reported receiving some support from close social ties in their existing personal networks (e.g., family members, friends) following their cancer diagnoses. The amount and quality of the support received varied considerably among participants. But even many of those who reported experiencing substantial support also reported diminished support (or less
support than expected) from some social ties, including close ties. As a result, many participants arrived at the Center having experienced inadequate social support in their extant social networks. Two themes emerged related to clients’ perceptions of the role of the Cancer Support Center in their structural support.

The first theme relates to structural support at the Cancer Support Center: Many clients experienced diminished structural support following cancer diagnosis. Many clients came to the Center with the experience of diminished social support from extant close social ties (e.g., family members, friends). Numerous participants indicated that previously existing support networks did not meet the support needs they had developed following their cancer diagnosis. Clients had expected their close ties to “be there” (Maggie) and “step up” (Elaine) for them as a strong source of support. For example, Tabitha said that her family members were not around as much as she expected. She said, “I always thought people would gather around you [when you are diagnosed with cancer]. . . . [That] didn't happen.” Similarly, Audrey thought her brother would be a source of support to her after she was diagnosed. However, he did not help her move when she needed him and she was “disappoint[ed].” Julia said that her husband did not “pick up the slack” around the house, which made her feel like she “had the wrong expectation[s]” of support.

Many participants reported that, prior to being diagnosed with cancer, they had believed they had strong social relationships with family and friends. For example, participants said that they had a “close family” (Nora), that in their families they “love each other dearly” (Sandra), and that family and friends had been their “rock” (Melanie, Maggie, Elaine). However, numerous participants experienced distancing and social isolation in their relationships with these close ties following their diagnosis. Participants’ encounters with close personal ties sometimes made evident the inadequacy of their personal support networks. This inadequacy
was made visible in interpersonal dynamics such as distancing, avoiding, and abandonment. For example, Maggie said that she and her daughter “used to be very close,” but Maggie perceived that, after her diagnosis, her daughter “doesn’t show much concern.” She said, “I mean I guess the bottom line for me is, you would think she’d want to spend more time with me, not less.” Similarly, Tara talked about previously helping her sister through a health crisis, only to find that her sister did not come over or check in on her when she was in treatment. Lindsay reported that her sister just stopped calling her and did not “explain” the reason for her avoidance.

Participants found that some friends with whom they had been close for years avoided them. For example, Tamra said:

> When I told some of my friends, they ran away [starts to cry]. . . . They are starting to talk to me again, some of them, but I think, in my own personal opinion, I think they thought I was going to pass and they figured if they just quit talking to me it wouldn't hurt as bad when I went. . . . My one friend, she's been my friend for like 30 years, she just quit talking to me.

Similarly, Holly said “Nobody [high school friends] got back with me anymore.” Carmen had “expect[ed]” her friends “to call and say, ‘Hey Carmen, how are you doing?’” but she found that her friends did not contact her. Melanie said that it became “too much work to stay close to” friends after she was diagnosed because they did not check in. Participants who experienced family and friends avoiding and/or distancing remarked that it “hurt” (Tamra) and “broke my heart” (Lindsay).

Two participants reported abandonment by their romantic partners. When Taylor was diagnosed with cancer her romantic partner of several years ended their relationship. She said, “[Romantic partner and his mother are] very redneck. . . . I bet you they thought they were going
to catch cancer. . . . Yeah, [breaking up] was due to ignorance in a way.” Similarly, Ginny reported that her fiancé essentially considered abandoning her. He “considered not marrying” her because of her cancer diagnosis.

Over time, many clients experienced diminished support from their close ties. For example, in the initial period following her diagnosis, Lindsey’s friends accompanied her to doctors’ appointments and helped her with housework. However, as her disease progressed, she found that her friends “drifted away.” Some participants explained that family members offered support only to back out later when actually asked for help. For example, Whitney’s nephew said, “If you need anything, just let me know and I’ll help you.” However, when she called him to mow her lawn one day he said, “Oh, I can't do that.” Whitney said that she “never” asked him for help again. Tara perceived that support from her family was inconsistent. She said she wanted help to be “automatic” and instead she found that she needed to ask her family members for help, whereas in the beginning they just “stepped up.” Thus, in contrast to their expectations, participants perceived that their friends and family members could not be counted on to be sources of support.

Clients’ interpersonal dynamics with close social ties often included abandonment, distancing, and avoidance. These interpersonal dynamics effectively functioned to alter their structural support. Specifically, it decreased the size of their support networks (i.e., number of supportive social ties available; Albrecht & Goldsmith, 2003) and the strength (i.e., amount of support resources provided through social ties; Hall & Wellman, 1985) of those social ties. These findings are consistent with previous research, which indicates that people diagnosed with cancer commonly lose social ties, including some close ties, following diagnosis (e.g., Dunkel-Schetter, 1984). Clients of the Cancer Support Center discovered, unexpectedly, that they could not rely
on their existing support networks. This discovery may have triggered their arrival at the Center. Indeed, in contrast, the Cancer Support Center provided access to supportive social ties and thereby facilitated increased structural support.

The second theme related to structural support at the Cancer Support Center is: *Structural support is facilitated through social ties developed at the Center.* Clients’ support networks were enhanced via experiences at the Cancer Support Center. First, the Center provided clients with new social ties that could compensate, at least in part, for inadequacies in their previously existing support networks. Second, via the Center, clients incorporated new social ties, who also had experience with cancer, into their support networks. In effect, experiences at the Cancer Support Center both enhanced participants’ support network size and added relevant homogeneity to their networks.

The first way that the Cancer Support Center enhanced clients’ structural support was by compensating for diminished access to close supportive ties in their previously existing social networks. For example, Nora said, “You definitely need a lot of support. No matter if it’s family or if it’s something like [the Cancer Support Center].” Similarly, Terri said, “People that don’t have the support in their families, [the Cancer Support Center] is a lifesaver for.” Ginny said, “I would say . . . [the Cancer Support Center] is where I got my support.” Connor also reported that the social ties he developed at the Cancer Support Center were his “prime” source of support.

Clients characterized the Cancer Support Center as providing access to a “support system.” For example, Holly said, “[The Cancer Support Center is] just a wonderful *support system* [emphasis added] that your newly-diagnosed could really use.” Similarly, Howard said, “[The Cancer Support Center is] a huge *support system* [emphasis added].” Participants indicated that the Cancer Support Center enhanced their existing support networks by facilitating access to
additional supportive ties. Julia said that the Cancer Support Center provides support to clients’ “above and beyond” as an “extension” to their “support system [emphasis added].” Maggie explained that the Cancer Support Center was a “piece” of her support network. Similarly, Elaine clarified that the Cancer Support Center was an “adjunct” to her support network. Tamra talked about receiving support through a “combination” of the Cancer Support Center, her oncologist, and her family. Likewise, Tabitha listed the Cancer Support Center, her family, her church group, her surgeon, her general practitioner, the secretaries at her doctors’ offices, and even the healthcare staff at the emergency room as all being part of her support network. Thus, participants viewed the Cancer Support Center as facilitating the development of new social “connections” (Riley, Lena). These connections functioned as additional sources of structural support.

A second way that the Cancer Support Center enhanced clients’ structural support was by connecting clients to other people who have been diagnosed with cancer. Participants explained that they wanted to “meet” (Dale, Lindsay) and “connect” (Holly, Ginny) with other people who had been diagnosed with cancer. For example, Tara said, “I didn't know anybody. I had a few acquaintances in the past that had breast cancer, but not close enough for me to call them.” Elaine also believed that creating social ties with other people diagnosed with cancer was particularly supportive because they could relatively better understand her experience. She said, “You don't know until you've walked in those shoes, so I think it's important to be able to talk to people that have been there.” Taylor said that the most beneficial part of coming to the Cancer Support Center was that the activities gave clients the opportunity to “talk to other people that have cancer.” Carmen and Tabitha both said that it was helpful to talk to other women who also had gynecological cancers. Connor expressed that he “want[ed]” to meet other men diagnosed
with cancer because he perceived that they could “grow together” and “share” their experiences beyond what men can share with women. Thus, participants perceived that other clients who have been diagnosed with cancer are especially supportive because they more readily understand the participants’ experiences than do close ties in their personal networks who had not had cancer.

Participants’ perceptions can be understood as indicating that the Center enhanced their structural support in two specific ways. First, through the Cancer Support Center, participants’ support networks increased in size due to the addition of new social ties. Participants who had experienced diminished structural support in their previously existing social network may have been able to compensate, at least in part, for these reductions via increased network size due to the new social ties developed at the Cancer Support Center. Second, through the Center, participants connected specifically with social ties who have been diagnosed with cancer. Having new social ties who also have experience with cancer, effectively increased relevant homogeneity in participants’ social networks. Network homogeneity is defined as the degree of similarity among ties (e.g., Hall & Wellman, 1985) within a support network. For many people diagnosed with cancer, the most relevant aspect of support network homogeneity is having social ties with people who also have been diagnosed with cancer. Prior research indicates that people diagnosed with cancer often find that others who also have been diagnosed with cancer are a strong source of support because they are perceived as relatively more understanding than people who have not had cancer (e.g., Ussher, Kristen, Butow, & Sandoval, 2006). Present findings inform and demonstrate the significant role that healthcare organizations (for example a support organization) can play in facilitating the development of new sources of structural support for people who have been diagnosed with cancer. Specifically, healthcare organizations can
facilitate both increased support network size and increased relevant network homogeneity. In addition, healthcare organizations can provide access to functional support.

*Nature of social support functions at the Cancer Support Center.* Participants receive social support from the Cancer Support Center that functions to meet varied needs. Social support functions are conceptualized in terms of the varied types of needs that the support addresses (Barrera & Ainlay, 1983). Researchers have identified numerous social support functions. These include informational, emotional, instrumental, and spiritual functions (e.g., Albrecht & Adelman, 1984; Cutrona & Suhr, 1992; Foa, 1971; Levine et al., 2015). Themes related to all four of these functions emerged in discussions of support at the Cancer Support Center. The most dominant functions that emerged were emotional and informational support. However, policies related to instrumental support and opportunities for spiritual support also emerged as important for meeting participants’ needs.

*Emotional support at the Cancer Support Center.* Emotional support is defined as the communication of caring, encouragement, and empathy, which creates feelings of belonging (e.g., Albrecht & Adelman, 1984; Cobb, 1976; Cutrona & Suhr, 1992). Researchers have conceptualized emotionally-supportive behaviors as including: expressing caring and concern (Lehman & Hemphill, 1990); showing kindness, pleasantness, and friendliness (Dakof & Taylor, 1990); and demonstrating understanding and empathy (Burleson, 1994; Dakof & Taylor, 1990).

Participants perceive that the Cancer Support Center is a source of emotional support. In fact, participants explicitly reported that the Center provides “emotional support” (Millie, Carmen, Tabitha). Three themes emerged related to experiencing emotional support at the Center.

The first theme related to emotional support is: *Center staff and volunteers are genuinely*
caring and friendly. Several clients explicitly used the term “caring” (Melanie, Lena, Nora, Lindsay, Howard) to characterize the staff, including volunteers, at the Cancer Support Center. Lucy said that “[staff and volunteers at the Center] care [emphasis added] about what I'm going through.” Similarly, Melanie referred to the staff and volunteers as “caring.” Tamra reported, “[The staff and volunteers] care [emphasis added] so much for you as a person and your sickness . . . It's like when you are walking in [to the Center], you are walking home [emphasis added] . . . You feel comfortable [emphasis added] here.” Lindsay reported that the Housekeeper always “asks how you're doing, how you're feeling.”

Participants perceive the Center staff and volunteers as friendly and kind. Several participants used the terms “friendly” (Paige, Dolores, Julia, Alyssa, Terri, Carmen) and “nice” (Alyssa, Carmen, Riley, Tabitha, Lena) to describe staff members and volunteers at the Center. Paige said that “everybody” at the Center “is super friendly.” Likewise, Alyssa said, “The staff are just so nice and friendly.” Carmen said, “[The Center staff and volunteers are] always friendly, and they're always nice, and they always ask how you're doing, so they carry a positive energy.” Tabitha said that the counselor was “very nice and open.” Lena said that the Program Coordinator at the Center was “nice” and “as cooperative as can be.” Vanessa described the Program Coordinator as “very kind.” Millie said, “The staff is unbelievable. Even the cleaning lady. . . . She knows us all. She comes and says, ‘Hi.’” Only one exception to the pattern of participants perceiving caring, friendly, and kind staff at the Center occurred. One participant characterized a volunteer as “rude” because she interfered with clients’ providing emotional support to one another during an activity.

Participants overwhelmingly perceive organizational members at the Center as caring, friendly, and kind. That is, collectively, the Center’s organizational members exhibit behaviors
that function to meet emotional needs. The often-repeated use of terms specifically related to caring (e.g., kind, friendly), and the similarity of numerous clients’ perceptions regarding the Center staff, imply that caring, friendliness, and kindness are characteristic, or normative, attributes of staff members’ behavior at the Center. That is, organizational members’ caring behaviors appear to characterize their everyday interactions with clients at the Center.

The second theme related to emotional support is: *Staff, volunteers, and other clients demonstrate empathy and understanding regarding clients’ cancer-related experiences.* Participants explicitly reported that Center staff, including volunteers, “understand[s]” (Whitney, Vanessa) their cancer experiences. Several participants believe that the Program Coordinator understands their experience because “she had cancer” (Taylor) and “knows” (Alyssa) what it is like to have cancer. Elaine said, “The vibe [at the Center] is very compassionate. You have people [staff and volunteers] that have been through it [cancer].” Likewise, Tara said, “It seems like [staff and volunteers] had cancer themselves or know somebody [who has or has had cancer].” Melanie said that when interacts with the Center’s staff and volunteers, they “voice understanding.”

In addition to staff, clients also perceive that other clients who have been diagnosed with cancer understand their feelings and experiences. For example, Tara said, “It's very helpful to have these women [in the breast cancer support group who] know exactly what you're feeling.” Similarly, Tabitha said, “I can say that these are people [other clients] who have walked the same path. Especially people with women's reproductive cancer, and that's the group I attend.” Stephanie said that clients expressed “empathy” toward each another. Vanessa reported “it’s just good to hear sometimes” when other clients say “you know, we know. I understand.”

Participants reported that staff, volunteers, and other clients regularly express empathy and
understanding regarding their cancer experiences. The regularity in the reports of these behaviors that meet emotional needs indicates that they are an organizational norm; that conclusion is reinforced by the fact that both organizational members (i.e., staff, volunteers) and organizational participants (i.e., other clients) are perceived to be empathic and understanding on an everyday basis.

The third theme related to emotional support is: Close relationships with the Center staff, volunteers, and other clients, foster a sense of belonging. Participants explicitly addressed the closeness and bonding that occurs at the Center. For example, participants reported having “close” (Tamra, Tabitha, Riley, Nora, Lily) relationships with other clients. Through group activities at the Center (e.g., support groups, exercise classes), participants developed close “bond[s]” (Nora, Whitney) with other clients. Sandra said that the other women in the yoga class are “close friends . . . [with whom] I can talk openly.” Whitney explained that clients at the Center have “an instant bond.” Carmen said that she perceives a “kindred spirit” to other women in the gynecological cancer support group. Riley, Tamra, and Taylor said they felt “camaraderie” with the other clients at the Center. Millie said the gentle strength class “has become a pretty tight group.” Nora reported that the yoga class has “just become a very, very close-knit group.”

Participants believe that because of having close relationships with other clients they are able to have open conversations. For example, Lena said, “When you share on matters of faith and soul . . . you just go to a whole new level. . . . There's a very deep friendship [emphasis added]. There is an openness [emphasis added] that has evolved.” Taylor said that it is “helpful” that she feels close enough to the other participants at the Center to talk about constipation as a side effect of chemotherapy treatment. She said, “You're not going to talk about your bowels to, you know, [just] anybody at all. But we [Center clients] all just talked about [it].”
Participants perceive that they also have a “bond” (Lindsay) with and feel “connected” (Paige) to staff members and volunteers. For example, Paige said:

[The Office Manager at the Cancer Support Center] has been like, she's been a savior [emphasis added] to me. . . . Me and her connected [emphasis added] the first time and I've come in where I had been totally stressed out and I'm just about ready to lose it and she comes in and I can let off on her or talk to her. . . . . She will stop whatever she's doing and talk to you.

Ginny said, “You feel like you're important, that you matter [when you’re at the Center]. . . . You just feel like you’re part of a family [emphasis added] here [at the Center].” Carmen reported that she always feels “welcome” at the Center. Several participants said that they felt at “home” (Tamra, Tara, Elaine, Audrey) at the Center. For example, Tara said, “I felt right at home [emphasis added] here when I came here.” The Center fosters feelings of belonging among participants both by connecting them to other clients and staff and due to the Center’s welcoming environment. Repeated and consistent reports of close relationships and a welcoming environment at the Center suggest that the Center’s organizational norms foster belonging.

Organizational norms are defined as what is considered common or usual within the organization (Schein, 2004). Organizational norms are enacted consistently through organizational members’ behaviors (i.e., norms emerge through everyday behaviors). A reflexive relationship exists between the everyday behaviors exhibited by organizational members and organizational norms. Everyday behaviors and organizational norms simultaneously influence one another.

The consistency and repeated nature of clients’ reported experiences of emotional support at the Cancer Support Center indicate that it is the Center’s organizational norms (e.g., staff
members’ caring, friendly behaviors) that establish a caring and empathic environment, which, in
turn, fosters a sense of belonging. These findings are notable. They indicate that an organization
itself, not just its individual members, can facilitate emotional support. In the context of previous
research on social support in healthcare contexts, observations of healthcare providers’ behaviors
that function to meet emotional needs were limited to and framed as interpersonal contexts (e.g.,
(versus its members operating as independent individuals) to create norms that facilitate
emotional support had not previously been established in the social support literature that
examined healthcare contexts (see also Chapter IV, Sources of support at the Cancer Support
Center). The Center’s organizational norms also may contribute to clients receiving
informational support.

**Informational support at the Cancer Support Center.** Clients reported that they received
substantial cancer-related information through the Cancer Support Center. Clients’ experiences
of receiving that information can be understood as *informational support.* Informational support
is conceptualized as the provision of informational resources (e.g., books, lectures), guidance,
and advice (e.g., Foa, 1971). Two themes emerged related to informational support experienced
at the Center.

The first theme related to informational support is: *The Center provides ready access to
cancer-specific information.* For example, Dale said, “I've got three or four books out [from the
resource library at the Center] . . . and I would not be able to find them at the [public] library.”
Clients reported that they were able to “find” (Melanie, Paige) “articles” (Melanie) about
gynecological cancer and “information” (Paige) on cancer reoccurrences through the Center.
Tamra said the Center “cover[ed]” clients’ informational “needs,” such as providing information
about new exercises during the gentle strength class. Riley said that through the counselor at the Center, her and her family found “a little more information [emphasis added] to help them better understand [cancer].” Thus, participants perceive the Center to be a source of cancer-specific information.

The Cancer Support Center provides cancer-related information through its resource library and informational counseling services (e.g., nutrition counseling, financial counseling). For example, the Center’s resource library loans cancer-related books and other materials (e.g., CDs, articles) to clients. Dale said that the Center’s library “has been a place of marvelous resources [books about cancer].” Similarly, Whitney said that it was “very helpful . . . having this library with all these CDs [on healing practices to use during chemotherapy].”

The Center also schedules financial, legal, nutritional, and medication counseling for clients. For example, Paige reported that the Program Coordinator at the Center “hooked [her] up” with a nutritionist to help her learn more about healthy eating and losing weight. Similarly, Elaine said that the Center “had [the nutrition counselor] come and talk to me while I was in treatment” about ways to incorporate more protein into her diet. Audrey reported that the financial advisors at the Center were helpful informational sources when she was navigating disability and social security benefits. After Riley was diagnosed with cancer she came to the Center for “financial advice.” Ginny met with an attorney at the Center who “helped” her handle her parents’ “estate” after they passed away. Carmen said, “I talked to the [Center’s] attorney about a living will.” Thus, through the Center’s resource library and informational counseling services, clients readily access cancer-related information.

Participants reported that Center staff and volunteers were particularly “helpful” (Ginny, Lena) in locating cancer-related information specific to individual needs. For example, Melanie
reported that the facilitator for her support group is “a researcher for any [emphasis added] of our questions.” Melanie indicated that when members of the gynecological cancer support group have specific cancer-related questions, the group facilitator finds resources for them. Similarly, Carmen said, “the [gynecological support group] facilitator’s a nurse so you can get a lot of medical information [through her].” Tara reported that the group facilitator for the breast cancer support group helped her to locate information on the dorsal flap reconstruction surgery (an invasive and somewhat uncommon surgery for breast reconstruction). She said, “[The breast group facilitator] called me and was trying to give me information about the dorsal flap.” Tara went on to say that she was able to go “back to the plastic surgeon” and ask questions using that information. Dale said, “The librarian [at the Center], she's really special. She takes the time with you and she said she would be always a resource if I needed her [to help me find specific cancer-related information]. She's been very kind.” Although clients generally reported that Center staff members were helpful, one exception was reported to this pattern of perceptions. A participant reported that a staff member interfered with an activity in which clients were getting information. However, generally Center staff and volunteers provide access to cancer-related information by repeatedly helping participants to locate resources. These repeated reports of recurring helping behaviors exhibited by staff and volunteers at the Center suggest that helping participants locate cancer-related information is a common practice within the organization. In addition to staff members, clients at the Center also serve as a source of informational support for other clients.

Participants reported locating cancer-related information by interacting with and asking questions of other clients. Through various group programs (e.g., support groups, workshops, exercise classes), clients share information related to their individual cancer experiences. For example, Howard said, “Maybe somebody already went through what I went through. So they
could kind of give you a little guidance [emphasis added] on what to do and maybe what not to do.” Similarly, Paige said, “just coming to [the Center provides the opportunity to] be able to talk to somebody else that's been through it.” Carmen explained that she likes the fact that the women in the gynecological support group all have been diagnosed with similar types of cancer and, thus, can offer “advice”:

The thing I like about [the gynecological support group] is, it's all women facing the same issue so everybody has advice [emphasis added] that they can offer, or you can say, “Oh, I have this side-effect. Has anybody ever had that,” . . . “What did you do for it?”

Ramona reported that it is “helpful” that “some [support group members] have been through their treatment for years and still come and [provide information] to people.” Thus, other clients, in addition to Center staff, also act as a source of cancer-related “advice” and “guidance” at the Center.

The second theme related to informational support at the Cancer Support Center is: The Center provides a safe environment in which participants can ask cancer-related questions and get sensitive information. Participants specifically used the terms “comfortable” (Dolores, Sandra) and “open” (Tabitha, Vanessa, Connor) to refer to the Center in the context of receiving information. For example, Carmen said, “[When you are at the Center] you never feel like a question is too dumb. You can say whatever.” Participants’ perceptions of the Center as comfortable and open indicates that the Center is a safe environment for obtaining cancer-related information. This is further reinforced by participants’ contrasts of the Center’s safe environment with other information-seeking environments (e.g., public libraries, public stores).

Participants contrasted their information-seeking experiences at the Center with information-seeking experiences in other contexts (e.g., public libraries, public stores). In the
latter, they often felt embarrassed and did not want to rely on those locations for information. Participants perceived the Center to be a safe environment for seeking sensitive cancer-related information. For example, Sandra said:

To go to a [public] library, to ask for help, to see something in a certain vein of [breast cancer], it's embarrassing. I hate to say that, but it is. [Interviewer: You don't want to go up to just some random library and?] No, and say, “I want information on breast cancer, the effects of this,” that type of stuff. I don't know. I guess the word “embarrassing” is the word for me to use.

Participants discussed the advantages of learning about make-up and wig techniques in the “Look Good, Feel Better” workshop, a program designed to teach female clients undergoing cancer treatment about ways to use cosmetic and skin-care products. For example, Riley said it was difficult to get help with make-up techniques at a store because “you feel like crap when you don't have any eyebrows and your hair's not growing back. Or your eyelashes have all fallen out.” However, she found the “Look Good, Feel Better” workshop helpful. Similarly, Taylor said:

[The Look Good, Feel Better workshop] was nice because I had never drawn on my eyebrows. . . . Now I'm drawing them on, because I lost [my] eyebrows, [my] eyelashes, everything. I'd never worn a wig, so they gave me a wig, because I was completely bald. [The workshop facilitator] showed me how to take care of it.

Multiple participants perceive that the Center is a safe, comfortable environment and expressed that they prefer to use the Center to seek sensitive cancer-related information instead of using other environments (e.g., public libraries, public stores). The consistency of these perceptions of the Center’s environment as safe and comfortable for information seeking signifies that these
environmental attributes (e.g., open, comfortable) are normative within the organization.

In summary, clients’ experiences suggest that the Cancer Support Center facilitates access to informational support through its informational resources, by creating opportunities for sharing information among clients, and by establishing a safe environment for seeking and receiving sensitive cancer-related information. The Center provides participants with ready access to cancer-related information that may be more difficult to locate elsewhere. In particular, numerous and consistent participant reports that Center’s staff and volunteers help participants find cancer-related information make evident that these helping behaviors are experienced as normative organizational practices. *Organizational practices* are common actions taken by organizational members that are informed by organizational knowledge, such as norms and belief systems (Schein, 2004). Numerous participants also reported that they were comfortable seeking sensitive information at the Center, in contrast to seeking this information elsewhere (e.g., public libraries, public stores). These findings reveal that participants attribute their ability to obtain sensitive information at the Center to the helpfulness of the staff and to the Center’s comfortable, safe environment. Further, these findings indicate that the Center likely has organizational practices (e.g., helping participants locate information) and norms (e.g., openness) that facilitate seeking sensitive cancer-related information.

Previous research indicates that people diagnosed with cancer may feel intimidated when asking for sensitive cancer-related information in healthcare contexts because, in contrast to the openness of the Center, in more traditional healthcare contexts information tends to be presented in a “direct” and “impersonal” manner (Mathieson & Stam, 1995, p. 295). The contrast between how information is provided in other healthcare contexts versus at the Center is sharp. Whereas participants perceive that the Center has an open, approachable environment for seeking
sensitive cancer-related information, the same information may seem inaccessible in other healthcare contexts. Having organizational members who consistently exhibit the willingness to help locate information suggests that this type of behavior may be an organizational practice. This practice, in conjunction with the apparent norm of providing a comfortable and open environment, constitute likely organization-wide facilitators of informational support.

**Instrumental support at the Cancer Support Center.** Instrumental support is characterized in the research literature (e.g., Foa, 1971) as voluntarily providing tangible goods (e.g., loaning money) or services (e.g., cleaning the house, driving someone to the doctor). A theme that emerged related to instrumental support is: *The tangible goods (e.g., wigs) and services (e.g., exercise classes, lymphatic massage) offered free of charge at the Cancer Support Center are especially helpful.* These goods and services can be understood as instrumental support.

Many participants emphasized that the Center provides “free” (Tabitha, Julia, Nora, Tara, Millie, Carmen, Paige, Alyssa, Whitney, Ginny, Lindsay, Audrey) goods (e.g., wigs) and services (e.g., massage, exercise classes). Millie said that the “best thing [about the Center] is it’s free.” Participants perceive that having services offered free of charge is especially helpful to those on a “limited income” (Tara, Tamra) or “limited funds” (Lucy). For example, Tamra explained that the “free” services and resources at the Center are “helpful” because she is “living on disability” and has “a limited income.” Paige said that her “first reaction [to cancer] was, ‘How am I going to pay for it [the costs associated with treating cancer]?’” She emphasized that it is helpful that the Center “don’t cost anything” because she already has financial concerns related to costs associated with cancer treatment. Similarly, Tara said, “I just think it's wonderful that they offer stuff at no charge to people, because there are a lot of people [with cancer] that are so tight on income that they can't afford anything.”
The Center’s provision of goods and services free of charge constitutes instrumental support. This support is especially valuable because some clients experience financial strains (e.g., due to costs of cancer treatment, limited incomes) and are otherwise unable to afford such services (e.g., massage, yoga classes) and goods (e.g., wigs) on their own. Thus, participants’ experiences at the Cancer Support Center demonstrate that a healthcare organization can be a source of instrumental support for people diagnosed with cancer by providing goods and services free of charge that can potentially benefit quality of life (see Chapter IV, Benefits of social support experienced at a Cancer Support Center).

*Spiritual support at the Cancer Support Center.* Spiritual support is defined herein as communication that functions to facilitate clarification or illumination of an individual’s life meaning or purpose or to facilitate closeness to the sacred or transcendent (however that is understood by the individual). One theme emerged related to spiritual support experiences at the Cancer Support Center: *The Cancer Support Center is a source of spiritual support.*

Participants explicitly reported that the Center provides “spiritual support” (Howard, Julia). The Cancer Support Center offers formal spiritual resources and programs to its clients (e.g., consultations with a chaplain, a spiritual support group). Participants indicated that they also had spiritual experiences as a result of participating in other programs and services, such as healing touch sessions and a mindfulness workshop.

Participants reported having conversations at the Center related to their understandings of the “meaning” of their experiences (e.g., their relationship with a higher power, coming to terms with being diagnosed with cancer). Many of these conversations took place within the context of the Center’s spirituality support group. For example, Connor said, “The support group itself is the source [emphasis added] of the ability to come to terms with the things that you need to come
to terms with emotionally, spiritually, mentally.” Lena said, “[The discussions in the spirituality support group] get to the heart of the matter, sometimes when you'd rather not get to the heart of the matter.” Carmen said these conversations helped her to think “that somehow you have to step above it and find strength.”

Clients reported experiencing a “connection” (Connor) to “faith” (Lena) and “spirit” (Connor) through discussions that occur at the Center. For example, Carmen said:

I really like that [the spirituality support group is] focused on how everybody ties [emphasis added] into, I call it God, but some people call it their higher power. . .

[Discussions in the spirituality support group are] all focused on kind of we're all [emphasis added] going through this journey.

Holly said, “[In the spirituality support group] we discuss with each other the ways of thinking things [such as issues of spirituality] through.” Connor’s experiences with the spirituality support group “help[ed]” him “with that mind, body connection, that spiritual connection.” Julia reported that she and a volunteer Reiki practitioner discussed her relationship with Jesus during a Reiki session. She said that the practitioner could “feel His presence” during their session. Julia said that she “prayed” before the session and that she believes that having that experience at the Center was “a God thing.” Participants perceive that, through the Center’s activities (e.g., spirituality support group, consulting chaplain), they have the opportunity to engage in communication explicitly focusing on spirituality. That is, participants attribute their spiritual support experienced at the Center to the fact that the Center offers spirituality-focused activities.

Participants reported experiencing centeredness, calmness, and self-reflection during the Center’s programs and services that do not explicitly focus on spirituality. The scholarly literature casts feelings related to peacefulness, such as centeredness, calmness, and self-
reflection, as spiritual experiences (Astin & Keen, 2006; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). Stephanie recounted an experience during a mindfulness\textsuperscript{18} workshop. She said:

I call it relax. I don't even know what I mean by that, other than I know. When you just flowing, flowing is a good word they use. You just kind of flow with it. You find so many, and it is like that, a river just flows with no destination, that expression comes to mind. . . . I found in those kind of situations, I am engaging my mind and my self-reflection [emphasis added], and others.

Howard said that after the spirituality support group he has “just a good feeling . . . you just feel even [emphasis added] and leveled off [emphasis added]. . . . I feel centered [emphasis added].”

Whitney explained:

I just thought healing touch, it sounds good, healing touch. I remember getting up [after the healing touch session] and feeling like a huge weight was lifted off of me. I thought, ‘How did you do that? How did that happen?’ I mean, it didn't make everything better, but it made a big difference.

Similarly, Lucy said that experiencing a healing touch session gave her a feeling of “calmness.”

Participants perceive that the activities and services they experience at the Center contribute to their feelings of centeredness, calmness, and self-reflection.

The Center provides participants with opportunities to consider issues of meaning, especially through activities that explicitly focus on spirituality. In addition, participants reported having spiritual experiences (e.g., centeredness, calmness) through other activities and services

\textsuperscript{18} The term mindfulness is used in multiple ways. It sometimes describes a state of being that involves being present in the moment. For example, Kabat-Zinn (1994) refers to mindfulness as “paying attention in a particular way; on purpose, in the present moment, and nonjudgementally” (p. 4). The term also is used to refer to practices that result in mindfulness as a state of being. Kabat-Zinn also refers to mindfulness as a “practice” (p. 3; e.g. mindfulness meditation) designed to enhance a mindful state of being. The Center’s workshop is designed to “practice mindfulness [through] meditation.”
offered at the Center. Participants’ experiences at the Cancer Support Center demonstrate that a healthcare organization can facilitate access to spiritual support by providing opportunities (e.g., activities, services) explicitly focused on spirituality.

In summary, participants perceive that the Cancer Support Center addresses their needs especially by providing emotional and informational support, but also by providing instrumental and spiritual support. Numerous participants’ experiences of social support were related to the Center’s organizational practices (e.g., helping clients locate information, asking clients how they are feeling) and norms (e.g., friendly, welcoming). For example, the Center staff’s and volunteers’ willingness to help clients locate cancer-related information is an example of one of the Center’s organizational practices that contribute to participants receiving informational support. Further, multiple reports of Center staff and volunteers’ collective caring and friendly behaviors indicate that behaviors that function to provide emotional support appear to be normative. Thus, the Center likely facilitates social support through its practices and norms. As such, clients’ experiences of social support functions are not limited to individual interpersonal encounters at the Center. Instead, organizational factors (i.e., norms, practices) appear to play a significant role in shaping clients’ experiences of social support at the Center. Clients’ experiences of social support at the Center also inform their perceptions of availability of support.

**Perceived availability of social support at the Cancer Support Center.** Perceived support is defined as the belief that support is available if or when needed (e.g., Cohen & Wills, 1985). Two themes emerged that relate to perceived support.

The first theme related to perceived support is: *The Center is viewed as a source of readily available social support (i.e., perceived support) because clients previously experienced*
receiving support there. The social support literature distinguishes between perceived support and received support (i.e., enacted support; Cohen & Wills, 1985). Some evidence has suggested that perceived support is relatively more important to positive health outcomes (e.g., Barrera, 1986). However, researchers have argued that the perceived availability of support is informed by actually having received support from a given source in the past (e.g., Hobfoll, 2009). That dynamic appears to be at work at the Cancer Support Center.

Because of prior experiences of receiving support at the Center, participants perceived that support is currently available to them. For example, Lucy had previously experienced support as a caregiver; later she recognized that support was available to her as a person with cancer. Lucy initially found out about the Cancer Support Center when her daughter was diagnosed with cancer. Lucy had brought her daughter to the Cancer Support Center throughout her daughter’s treatment. Several years later, when Lucy was diagnosed with cancer, she said she “knew” she could “come” to the Center and get “some things [support] for me.” Sandra said that she “felt comfortable coming back [after successfully completing treatment]” once she realized that the Center was open to people who were in remission, but who still needed support. Elaine said the Center had “been a tremendous support” during treatment and she continues to participate in activities and the breast cancer support group past treatment “because it [talking to other women with breast cancer] helps make it [cancer] not so scary.” Thus, participants perceive that the “Center,” as an organization, is available as a source of support when needed.

Participants also perceive support to be available at the Center because staff members reach out, without being asked, to inform them about specific services and programs that are available. The social support literature distinguishes between two types of support mobilization: unsolicited support (support provided without request) and help-seeking (requests for help).
(Eckenrode & Wethington, 1990). Obviously coming to the Center initially is an act of help-seeking; but thereafter, participants perceived that the Center’s staff often provides unsolicited support. Experiences of having received unsolicited support, in particular, seem to inform the participants’ perceptions of support availability at the Center. For example, Tamra said, “If you don't come in for a while, they will call and check on you, write you letters.” Dolores said that the Center is good at “just letting people know that they're available [to provide support].” Participants also reported that Center staff invited them to come in and participate in specific programs and services that might be relevant for them. For example, Holly said that she was too “timid” to schedule facials on her own at the Center. However, a Center staff member called Holly and initiated scheduling facials for her. Similarly, Julia participated in Reiki because the Office Manager called her and offered her the opportunity to use the service. Audrey reported that staff are “always . . . willing to help you and ask you what you need.” Thus, participants’ prior experiences of having received support, and particularly having receiving unsolicited support, inform their current perceptions of support available at the Center. Clients’ perceptions of available support also were informed by the substantial quantity of resources they saw being offered by the Center.

The second theme related to perceived support is: The Center offers a substantial quantity of services, resources, and programs. Clients reported that the Center provides many “opportunities” (Vanessa, Tamra) to receive support. Participants said that the Center offers “so much” (Tamra, Julia) and that the Center “do[es] a lot” (Whitney). Julia said, “I'm pretty much overwhelmed with what they [emphasis added] [the Center] do offer. No. I mean, they [emphasis added] [the Center] offer so much. It's more than I expected.” Audrey said, “Knowing that all these services exist under one roof [emphasis added] is wonderful. It's like a smorgasbord.” Lucy
said that the Center offered “so many choices” and said that it was like having “a menu” of possibilities. Similarly, Holly said, “It’s just a lot of support and there’s always a calendar of events.” The sheer number of services, resources, and programs offered cemented clients’ perceptions that support is available to them through the Center. That is, participants perceive that the “Center,” as an organization, is the source of the numerous support resources. Thus, the organization, rather than particular individuals, is viewed as the source of support at the Center (see Chapter IV, Sources of support at the Cancer Support Center).

In summary, clients perceive that support is available to them if they need it through the Cancer Support Center because (a) they have experienced receiving support, particularly unsolicited support, from the Center in the past, and (b) they see the Center offering a substantial quantity of support resources. These findings show that clients’ experiences of receiving social support, specifically through a healthcare organization, inform their perceptions of future support available from that organization. Clearly, participants perceived support to be available at the organizational level. That is, participants report available support offered by staff members on behalf of the “Center” and through the numerous services and resources offered by the “Center.” These findings are important because participants cast perceived support as an organizational phenomenon and not just an interpersonal phenomenon (see Chapter, IV, Sources of support at the Cancer Support Center). Previous research had established that perceived support is an interpersonal dynamic (Hobfoll, 2009); in contrast, the present findings support perceived support as potentially an organizational dynamic as well.

**Summary of nature of social support in a Cancer Support Center.** Participants’ experiences at the Center imply that the Center likely enacts organizational norms that effectively function to facilitate social support. These likely organizational practices and norms
at the Center appear to contribute to participants experiencing multiple support functions and to their perceptions of available support. In addition, participants access structural support through connections developed at the Cancer Support Center.

The Center appears to have *organizational norms*, enacted by staff, volunteers, and clients, that facilitate providing social support to participants. For example, participants report that the Center’s welcoming environment allows them to feel comfortable obtaining sensitive cancer-specific information. Numerous reports of the Center’s inviting environment suggest that ensuring an open, comfortable environment is an organizational norm. Participants indicate that the Center’s staff members and other participants consistently demonstrate empathic and understanding behaviors. These multiple reports of behaviors that function as emotional support can be understood as evidence of a perceived organizational norm. Participants consistently describe Center staff (e.g., front desk volunteers, administrators, housekeeper) as “friendly” and “kind,” which implies that exhibiting pleasantness is perceived as an organizational norm.

Participants report that they benefit from an organizational policy at the Center whereby all services and resources are “free of charge.” The Center’s mission (i.e., to provide support to people diagnosed with cancer) informs this organizational policy. This organizational policy likely functions to normalize providing help to clients. If so, the organizational norms enacted through this policy facilitate the communication of social support at the Center.

The Center’s *organizational practices* also appear to contribute to participants’ receiving social support. For example, participants reported that the Center staff routinely helps them locate specific cancer-related information. Staff members’ facilitation of clients’ information-seeking can be understood as a common organizational practice at the Center. In addition, participants report that Center staff reach out to them and inform them of available opportunities
at the Center. The recurring behaviors of reaching out and offering support indicates that unsolicited support likely is a common organizational practice at the Center. Finally, clients report that the Center provides a substantial amount of services and resources for their use. These numerous resources are evidence that the Center appears to engage in an organizational practice to create many opportunities for clients to receive support.

The Center provides participants with access to support by connecting them to resources (e.g., resource library, nutrition counselors) and other people who have been diagnosed with cancer. Participants’ reports of establishing supportive social ties at the Center indicate that the Cancer Support Center systematically creates opportunities for enhanced structural support for its clients. That is, through the staff, volunteers, and other clients at the Center, participants increase the number and relevant homogeneity of their social ties and essentially strengthen their support networks.

Finally, participants perceive that support is available to them through the Center when needed. That perception is informed by having previously experienced receiving support through the Center.

In summary, these results highlight that social support is experienced as normalized at the Cancer Support Center. In particular, these results suggest that organizational norms likely exist that shape and facilitate the communication of social support in the context of the Cancer Support Center.

**Nature of social support in healthcare.** Research Question 1b asked: “What are clients' perceptions regarding the structural nature, functions, and availability of social support they have experienced in the healthcare institution?” Themes emerged that can be understood in terms of the healthcare institution functioning to facilitate structural support and to enact specific support...
functions. However, participants’ accounts gave little evidence of perceived support in the context of the healthcare institution. Only a few participants identified perceived support in healthcare, and then it was only available if solicited.

**Structural nature of social support in healthcare.** A theme emerged related to structural support in healthcare: *The healthcare institution provides clients with ties to supportive healthcare organizations which, thereby, enhance clients’ structural support.* In turn, these new organizational ties become additional sources of support. Participants discovered the existence of support organizations, such as the Cancer Support Center, through their healthcare providers and by promotional materials provided at other healthcare organizations (e.g., hospitals, cancer treatment centers).

Participants reported that they were “referred” (Dolores, Carmen) to the Cancer Support Center and the *4th Angel Patient & Caregiver Mentoring Program* through other healthcare organizations (e.g., hospitals, cancer treatment centers). Several participants learned about the Cancer Support Center through their healthcare providers. For example, Vanessa said, “My doctor did mention [the Cancer Support Center]. . . . She says, ‘Make sure you check out [the Cancer Support Center].’” Dale said, “[Doctor] gave me a card to [the Cancer Support Center].” Tabitha said, “I was given the name of [the Cancer Support Center] in my oncology surgeon's office.” Tamra learned about the Cancer Support Center through a nurse. She said, “When I first started, there was a breast cancer nurse at the [Name of Cancer Treatment Center] . . . she told me about it.” Similarly, Ramona reported that her hospital’s breast cancer support nurse “told” her about the Cancer Support Center. Carmen said that “as part of their protocol” at her hospital the social worker refers people who have been diagnosed with cancer to the Cancer Support Center. Elaine said, “The Breast Care Coordinator gave me the pack of information. . . . She told
me about [the Cancer Support Center].”

Participants also learned about the Cancer Support Center through informational materials, such as “pamphlets” (Paige) and “flyers” (Ginny, Connor), that were displayed at their doctors’ offices and cancer treatment centers. For example, Melanie said, “I found [the Cancer Support Center] at the cancer center of [Name of Hospital]. I happened to have been waiting in the waiting room and they had a flyer around.” Similarly, Connor said:

I saw a flyer in my doctor's office, a little brochure. . . . I had been looking for some kind of support group out there and there's just nothing. . . . I happened to look down on the counter one day, I was at my oncologist's [office], and saw it and picked it up and called [the Cancer Support Center].

Ginny said, “I just saw a flyer in her [oncologist’s] office about a speaker that night [at the Cancer Support Center].” Paige said, “The chemo [Name of Cancer Treatment Center] had a pamphlet [for the Cancer Support Center].” Holly said she learned about the Cancer Support Center during a class offered through her healthcare provider. She said, “Through some brochures and information, and when I took like, a chemo class. I started seeing brochures.”

Likewise, Stephanie said, “[Name of Hospital] has the brochures. . . . [The Cancer Support Center] was mentioned in all [hospital] materials.” Thus, most participants learned about the Cancer Support Center through referrals by their healthcare providers and/or by informational materials provided to them through healthcare organizations.

Participants also learned about the *4th Angel Patient & Caregiver Mentoring Program* through other healthcare organizations (e.g., hospitals). The *4th Angel Patient & Caregiver Mentoring Program* is a support organization in which people diagnosed with cancer are paired with another person who has been diagnosed with the same type of cancer (*Fourth Angel*)
Mentoring, 2016). 4th Angel participants are encouraged to talk to each other about their cancer experiences; this usually occurs via phone or email. Riley said, “[Healthcare provider] gave me other options of support outside of the realm of the hospital by allowing me to understand like the 4th Angel Program.” Lena said, “[4th Angel is offered] through the [Name of Hospital].” Millie said, “[Name of Hospital] told me about [4th Angel].” Participants who were referred to the 4th Angel Program learned about the organization and, thereby, gained access to people with similar cancer diagnoses. Participating in the 4th Angel Program functioned to create greater network homogeneity.

When healthcare organizations facilitate contact with the Cancer Support Center and the 4th Angel Program, those healthcare organizations indirectly connect clients to new supportive social ties. That is, clients access new supportive ties (e.g., other people diagnosed with cancer) through these new organizational ties. Thus, through healthcare organizations, clients gain access to enhanced structural support (see also Chapter IV, Nature of structural social support at the Cancer Support Center).

Participating in the Cancer Support Center and the 4th Angel Patient & Caregiver Mentoring Program effectively functioned to increase the size (number of ties) and relevant homogeneity (i.e., similarity of ties; for participants in the present study relevant homogeneity is having social ties with people diagnosed with cancer) of clients’ support networks. However, initial access to both of these organizations was gained through referrals from healthcare providers and other healthcare organizations (e.g., hospitals, cancer treatment centers). Although these findings are consistent with previous research, which has shown that healthcare providers commonly refer people diagnosed with cancer to support programs and resources (Matthews et al., 2002), these results demonstrate that healthcare providers and organizations facilitate clients’
access to additional supportive social ties by connecting their clients to new organizational ties. That is, healthcare organizations facilitate ties between clients and the support organizations.

Cassel (1976) argued that healthcare providers have the responsibility of ensuring that clients have adequate social support available. This responsibility also can be carried out at the organizational level. That is, organizations can facilitate ties between clients and other organizations that function, or have the role, to provide additional supportive ties. “Role” in this context is defined as the expected functions that an organization assumes based on what is deemed acceptable based on the social situation (Katz & Kahn, 1978). In the present context, healthcare organizations provide social support by connecting clients to healthcare organizations that explicitly assume the role of providing support (e.g., Cancer Support Center). Through these ties with support organizations, clients connect to new social ties (see Chapter IV, Nature of structural support in a Cancer Support Center). These new ties function to enhance participants’ support networks (both in size and homogeneity). Moreover, by referring people diagnosed with cancer to organizations like the Cancer Support Center, healthcare organizations fulfill their institutional responsibility to ensure that people have adequate access to support.

**Nature of social support functions in healthcare.** Participants’ reports suggest that they experience some of the help they receive through the healthcare institution as social support. Their experience of social support in this context appears to occur when their needs are met by actions that go beyond facilitating and/or providing medical care.

Participants explicitly report that their healthcare providers, staff members in healthcare organizations (e.g., administrative staff, social workers), and healthcare organizations (e.g., hospitals, cancer treatment centers) provide “support” or are “supportive” (Tamra, Elaine, Taylor, Connor, Ginny, Howard, Tabitha). Moreover, participants experience some actions
within healthcare as social support rather than simply as healthcare providers and staff doing their jobs well. This perception emerges when providers and staff members’ actions are characterized as both supportive and fulfilling responsibilities associated with organizational/institutional roles (e.g., physician conveying empathy while disclosing a potential side effect of treatment). Individuals’ previous experiences related to receiving support influence their expectations of support in the future (Hobfoll, 2009). For example, if participants previously received support from their healthcare providers, their expectations of support are likely influenced by those experiences (i.e., they expect to continue to receive support from providers because they previously received support).

When participants were interviewed, they were not explicitly asked to describe their expectations of social support in the healthcare institution. However, participants sometimes did indicate their expectations of support, either explicitly or implicitly, and both in terms of expectations being exceeded and expectations being violated. Specifically, participants sometimes characterize their healthcare providers’ behaviors as being more supportive than they “expect[ed]” (Julia, Melanie, Stephanie). For example, participants said that providers “went above and beyond” (Julia), “went out of [the] way” (Sandra), and “go well past [caring for physical issues]” (Tabitha) to provide “support.” In these and other cases, participants perceive social support as occurring when members of the healthcare institution go out of their way, or above and beyond, fulfilling the responsibilities associated with their jobs. Themes emerged related to informational, emotional, and instrumental social support functions enacted within the healthcare institution.

**Informational support in the healthcare institution.** Information, explanations, guidance, and advice can be understood as informational support (Foa, 1971). Obviously, as is consistent
with participants’ reports, they have received substantial information through the healthcare institution. However, providing information in itself clearly is a responsibility associated with the jobs or organizational roles played by healthcare providers. Nonetheless, many participants characterized the information-giving processes of healthcare providers as not only meeting their informational needs but doing so in a manner that also communicated concern and thereby went beyond what participants expected or associated with the providers’ roles. This recognition of going beyond what participants perceive as job- or role-related appears to drive their views of information-giving processes as supportive. Two themes emerged related to informational support in the healthcare institution.

The first theme related to informational support in the healthcare institution is:

*Healthcare providers’ spending extensive time in providing cancer-related information is understood as being supportive.* Beyond the informational content presented, participants viewed the extensive time committed to providing that information as supportive.

Participants explicitly characterize receiving complex cancer-related information from their healthcare providers as “support” (Ginny, Howard, Stephanie, Dolores). The clear commonality in participants’ accounts of labeling healthcare providers’ information-giving processes as supportive relates to the extensive amount of time those providers spent. Participants perceive that their healthcare providers spend ample “time” (Elaine, Dolores) explaining cancer-related information. For example, Elaine said, “All the doctors took time to listen to me, answer questions, spent as much time as I needed with them even if it was not during the appointment.” Holly reported that her oncologist could only “spend a half-hour” with her during the scheduled appointment. However, her oncologist compensated for this limited time by calling her later. Her oncologist said, “We didn’t get to discuss this in the office,” and
continued to discuss her treatment plan in order to ensure that Holly understood it. Dolores reported that she “really like[s] nurse practitioners [because] they . . . really have more time and give you a lot more information [than physicians].” Likewise, Melanie said that physician assistants and nurse practitioners “spend more time with you” than doctors “because . . . [doctors] usually have to see more [clients] and do more.”

As a clear pattern, many participants report that healthcare providers spend extensive time in providing information and as a result their informational needs are met.\(^1\)\(^9\) Moreover, the accounts imply that participants understand that providers have significant time constraints and thus found the time spent to be unexpected and tended to interpret such actions as “support” rather than simply as professionals doing their jobs well.

Despite participants attributing the amount of time providers spend with them to individual providers’ motives to meet the clients’ informational needs, the length of time providers spend with clients during oncology visits often is largely controlled at the organizational level (Gupta & Denton, 2008). Thus, the participants’ experiences of (seemingly unexpectedly) having healthcare providers spend sufficient and often substantial time in providing information implies that, in these cases, the healthcare organizations likely facilitated informational support by permitting lengthy appointments for people diagnosed with cancer.

The second theme related to informational support in the healthcare institution is: *Healthcare providers explain information carefully in order to ensure that clients understand complex cancer-related information (e.g., diagnosis, side effects, treatment plans).* Participants explicitly report that they believe their healthcare providers carefully “explain” (Tara, Tamra, Nora) information and attribute motives to their providers of wanting to ensure that clients

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\(^{19}\) One exception to this pattern was reported by Lily who said that “at first” her doctor was “pretty good” when “explaining” her cancer treatment plan. However, over time that the doctor seemed “rushed” and she “did not always get the information [she needed or wanted].”
“understand” (Tamra, Sandra) complex information related to their cancer. For example, Stephanie said, “When they were giving me chemo . . . [the physician provided a] very good justification, medically . . . to give me that drug.” Likewise, Nora said that her radiologist was “very good about explaining the radiation, the machines and all of that.” Sandra understood her doctor’s actions as being motivated by the desire for her to understand clinical research:

[Doctor Name] went out of her way [emphasis added] to make sure I understood what she was talking about. . . . She was explaining to me what the difference was and why, what the clinical studies were, and why they pushed this to be done.

Tamra attributed the same motive to her healthcare providers when she said they “make sure I'm understanding everything like my medicines, or if I need anything explained to me or if I need help with getting something medical-wise or anything, they help me with that.” Howard said that healthcare providers at the cancer treatment center were “very knowledgeable people” who “guided you through this journey.” Specifically, Howard said that his healthcare providers “told” him how to manage painful side effects, which he characterized as “support that they gave me.” Tara said, “My surgeon . . . brought me in the office and he had a booklet [on cancer] there. He went over everything [about the cancer] step by step. Explained everything about it. What my type was and all this stuff.”

Participants repeatedly report that their healthcare providers provide extensive information and explain that information in detail. Further, participants interpret providers’ information-giving behaviors as indicating that providers want to ensure that clients understand cancer-related information. Characterizations such as “out of the way” and “step by step” not only suggest that participants perceive that providers spend extensive time when necessary in order to explain technical medical information in detail, and in terms that clients can grasp, but
that participants interpret providers’ actions as indicating they also are concerned that their clients understand this complex information. Participants interpret these communicative efforts related to information giving as conveying that providers value clients’ understanding and spend time and effort to ensure it. From the participants’ perspectives, these types of actions are understood as providing “support,” that is, professionals doing more than simply doing their jobs. These multiple and consistent participant interpretations of members of the healthcare institution as communicating support while engaging in information giving suggest that taking extensive time to discuss cancer-related information, and discussing that information in clear detail, to arrive at clients’ understanding, may be standard practices within the healthcare institution in oncology contexts.

Despite the fact that the vast majority of participants report having had only positive experiences when their healthcare providers gave them important and sometimes critical information, three participants reported four cases of experiencing significantly problematic information giving. The problems were not rooted in the content of the information provided (although it was negative), but rather in the manner in which the information was communicated. When Holly was admitted to the hospital immediately after being diagnosed with cancer, one of the physicians at the hospital said, “Oh, big tumor you have there.” Holly said she was “terrified” by the blunt way the physician communicated with her. She said that after the physician made the “big tumor” remark “he didn't say anything” else. She attributed the doctor’s lack of openness to the fact that her adult children were present at the time. However, Holly said that she “was hoping for more information [from that physician].” Julia said she “didn’t initially feel like things were handled in the way [emphasis added] they should have been” when she was diagnosed. Julia’s surgeon called her, while she was on a break at work, and told her that she had
“cancerous” tissue and “it’s probably nothing.” Julia said it was “overwhelming” to be given the diagnosis over the phone rather than in person.

Carmen reported two separate experiences in which her providers engaged in problematic information giving. In the first instance, Carmen described her first oncologist as “not truthful” because she later discovered that he chose not to tell her that her tests results were clearly labeled as “consistent with metastatic cancer.” Instead he said that the issue “might just be related to the surgery or the scar tissue.” Carmen changed providers and, as a result, got a second opinion. When her second oncologist told her that her previous test results (which the first oncologist also had reviewed) had indicated metastatic cancer, she thought, “[The first oncologist] should have been straight up honest [instead of concealing the diagnosis]” and saw him as “not truthful.” Carmen changed oncologists. However she also had an issue with how with her new oncologist communicated information. Carmen said that during an appointment on New Year’s Eve her new oncologist read her scans to her and said “Oh shit. Happy New Year to you,” when she saw that Carmen’s cancer had metastasized. Although Carmen thought that how the information was communicated, with sarcastic and flippant language was “not really helpful,” she said “What [the oncologist] was trying to say is, ‘Gosh, this looks really bad. I feel sorry for you.’” Thus, although Carmen perceived the manner of information giving as problematic (in tone and language), because of her relationship with her provider, she still interpreted her provider as being concerned.

Although only three of 31 participants reported episodes of problematic information giving by providers, together these cases exhibit a clear pattern. They not only offer a contrast to the strong theme of generally positive information-giving experiences, they all involve cases of communicating “bad news.” In the literature, what constitutes bad news focuses on its negative
impact on the recipient. Cline and Meluch (in press) have defined “bad news” as “information that has a negative effect on recipients’ expectations or perspectives regarding the future (e.g., longevity, quality of life, choices) or creates negative cognitive, behavioral, and/or emotional effects that persist beyond the transaction.” Clearly, the four episodes described above center on bad news. So, although this study’s participants generally reported positive experiences with providers’ information-giving processes, these cases are in sharp contrast to that pattern. In particular, these cases indicate a tendency for providers to communicate bad news inappropriately and/or insensitively. This suggests that providers are less likely to behave in ways that function as social support when they are communicating bad news.

Participants attributed their negative responses to the communication of bad news (e.g., “overwhelmed,” “terrified”) not just to the content of the information (e.g., cancer diagnosis, cancer metastasizing), but more so to the manner in which that content was communicated (e.g., with bluntness, dishonestly, with sarcastic and flippant language, via a phone call). Participants’ characterizations of these negative episodes (e.g., “didn’t initially feel like things were handled in the way [emphasis added] they should have been;” healthcare provider was being “not truthful”) imply that their healthcare providers behaved in ways that violated participants’ expectations for the providers’ professional roles (e.g., delivering a cancer diagnosis in person, being truthful). Although these participants did not clearly indicate what expectations they had regarding supportiveness from their providers, they clearly had some expectations regarding how providers should communicate bad news. Their comments imply that they expected sensitivity and consideration (e.g., not sarcasm, not a phone call versus in person) and that those expectations were violated.

In summary, although providing informational content arguably is simply an expected
role-related responsibility for healthcare providers (i.e., providers routinely give health-related
information to clients), while providing social support is not, participants often characterize
providers’ information-giving processes as supportive in nature. Despite the fact that participants
did not explicitly specify their expectations with regard to support from their providers, when
providers’ information-giving processes were considerate of participants’ needs (i.e., for
supportiveness, sensitivity), participants appreciated those responses and interpreted them as
supportive. The inverse regarding participants’ expectations also is true. When participants stated
or implied that their expectations related to information-giving processes were violated (e.g.,
“didn’t initially feel like things were handled in the way [emphasis added] they should have
been,” healthcare provider was being “not truthful”), they interpreted their providers as
unsupportive.

Participants’ accounts suggest that much of the time they interpret healthcare providers’
implicit messages that are associated with providing informational content as constituting
support. For example, participants interpret providers spending extensive time discussing
complex cancer-related information with them (instead of feeling rushed) as conveying care and
consideration of participants and their informational needs. Participants also interpret healthcare
providers going out of their way to explain cancer-related information in a way that is clear and
understandable as meeting participants’ informational needs (e.g., explaining why a particular
medication is used, offering ways to manage painful side effects). In these specific ways, the
providers’ implicit messages, while conveying explicit informational content, are understood by
participants as communicating support. Participants’ accounts also suggest that they sometimes
interpret healthcare providers’ implicit messages (e.g., bluntness, sarcasm) as nonsupportive in
the context of communicating bad news. Specifically, in these cases participants perceived that
their healthcare providers were not supportive (e.g., “not really helpful,” not the way things should be “handled”); moreover they attributed their adverse reactions (e.g., “terrified,” “overwhelmed”) to those implicit messages. Again, these negative reactions emanated not just from the negative content (e.g., cancer diagnosis, cancer metastasizing), but also largely from the manner in which that negative content was communicated.

Participants’ general collective perceptions of members of the healthcare institution taking extensive time to discuss cancer-related information in detail, in order to arrive at clients’ understanding, suggests that these actions could be a standard practice within the healthcare institution (at least within oncology contexts). However, participants note instances in which providers did not take extensive time to explain complex cancer-related information in an understandable and sensitive manner, perhaps because these instances indicate that providers failed to adhere to an otherwise standard practice. These failures are particularly common when communicating bad news. (For a review of the issues and practices related to communicating bad news see Cline & Meluch, in press). Identifying what is standard practice within an institution based on these limited number of participants’ experiences, and without further observing the actions taken by members’ of the healthcare institution, is not possible in the context of the present study. However, numerous repeated and consistent participants’ experiences of these specific actions (i.e., spending extensive time, presenting complex information with the motive of ensuring that participants understand) do imply the existence of institutionalized organizational practices. Organizational practices that are consistent across multiple organizations suggest their institutionalization. Thus, these numerous reports of time-intensive and clear information-giving related to cancer enacted by multiple healthcare providers working at a variety of healthcare organizations, indicate that these actions may be standardized or
institutionalized practices.

Emotional support in the healthcare institution. Emotional support is the communication of caring and compassion (Foa, 1971). Behaviors that function as emotional support include listening, understanding, empathy, providing reassurance, conveying presence (i.e., being there for the person), showing concern, and expressing comfort through touch (e.g., providing hugs; Burleson, 1993; Dakof & Taylor, 1990; Lehman & Hemphill, 1990). The theme that emerged related to emotional support in the healthcare institution is: Healthcare providers are compassionate and caring toward clients.

Participants stated explicitly that healthcare providers are “compassionate” (Tabitha, Elaine, Lena). For example, Elaine said that when she was experiencing difficult side effects during her final rounds of intense chemotherapy her healthcare providers were “concerned” about her and even gave her the option of reducing the dose. She said “just the fact that they think of that kind of thing [reducing the dose]” so that she was not suffering as badly was helpful because “there was compassion [emphasis added] to it.” Elaine further said because of the providers’ concern and compassion she “never felt like a number.” Lena reported that when she was “scared” during her first radiation treatment the radiation technician took a moment to “listen” to her concerns and “was compassionate.” Dolores said that she appreciated when her providers “listen” and show “understanding.”

Lucy’s experience, when her doctor reassured her that her colostomy bag was not going to ruin her life, is an example of a healthcare provider exhibiting reassurance and empathy. Lucy said:

[The doctor] said, “Well, it looks like it's going to have to be a permanent colostomy.” I felt very sad. It was a loss. The tears are rolling down my face. He reassured [emphasis
added me in a beautiful way. I mean, what's more precious than a doctor who I found decisive, but had a wonderful empathic way of communicating to me. He reassured me, he asked his nurse who was standing there to open up the little drawer thing and bring out this two-piece apparatus that I would have to have. He said, “It's really not so bad.” Right away, it's like your life flashes before you. I'm thinking, “There goes my life.” [The doctor] said, “You can still have a full life.” He pulled down his scrubs . . . He put [the colostomy apparatus] against his body and he said, “It's really not [the end of your life].” He was easing, making it seem like it's not that bad. Some sarcastic person might say, “Easy for you to say, fella. You don't have to [have the colostomy bag].” That was not even the feeling. It was reassuring when he said that to me and demonstrated.

Many participants used the terms “caring” (Maggie, Alyssa) and “cares” (Whitney, Connor) to characterize the behaviors of healthcare providers and staff. For example, Whitney said, “When I go to see [my doctor], I feel like she cares personally about me.” Further, she perceived that her doctor sees her as “Whitney, the patient” instead of “patient number one thousand.” Whitney said, “It's just personal. It's being personal. Personally, really genuinely caring, not just a patient number.” Connor explained that he “feel[s] like” his neurosurgeon cares about him. Carmen described her healthcare providers as “just very nice” and reported that they often offer to “hug” her. Likewise, Elaine said the nurses at the cancer treatment center would “all come give me a hug . . . [and] were all tremendously supportive . . . [the nurses] just helped me through [the cancer treatment].” Stephanie said she is “very close to” her healthcare providers and they are “there for [her].” Taylor indicated that when she goes to the cancer treatment center the nurses always ask, “How are you?” Participants consistently report that
members of the healthcare institution exhibit caring behaviors, which can be understood as functioning as emotional support.

These reports indicate that participants’ interpret their providers’ actions (e.g., being understanding, showing concern) as indicating how providers view them (their relative roles) and their relationship (e.g., person to person versus provider to patient number). In these interactions, participants’ relationships with their providers are continually being negotiated (i.e., they are dynamic) through their communication (and specifically through providers’ actions and participants’ responses to these actions) (Wilmot, 1980). For example, participants interpret providers’ caring actions as meaning they are being seen as a “person” instead of a “patient.” These actions can be understood as the providers proposing a relationship in which the balance is shifted to a relatively more personal and relatively less formal relationship.

Although the majority of participants report that their healthcare providers are caring and compassionate, four participants reported encounters with members of the healthcare institution that offered a sharp contrast to that pattern. In these four instances, apparently the participants expected members of the healthcare institution to be compassionate, but they were not. Taylor thought the staff at the chemotherapy treatment center needed to be “more compassionate.” She said:

At the chemo, you know how you come up to the office, and they [the chemo staff] expected you to stand there. I can't stand that long. I was lucky to walk in. I was determined that I was going to do this. . . . I said, "Do you realize how," and I did sit down finally, I said, "Do you realize how sick everybody is that is in this office? They are the sick of the sickest, you are seeing the worst patients of all, and I know you think I'm being very critical, but this is where you need to be more compassionate than you've ever
been in your life [emphasis added], because these people are going through hell.” Even [Doctor] just didn't see where I was coming from.

Paige reported that she had “some kind of reaction” to mosquito bites on her legs when she was going through her chemotherapy. However, when she tried to call the doctor’s office to tell them what was going on, “The nurses wouldn't even listen. I was putting Clorox, peroxide, everything over the counter on my legs. That's how bad I was. . . . and nobody [healthcare providers] would listen.” Paige said “everybody [healthcare providers] dismissed me.” Paige said that even though healthcare providers “go through this [treating cancer] every single day” it is important that they “realize the person [not just a patient] that's in front of them.”

Although Whitney believed that many of her doctors did care about her, she remarked that one of her doctors “didn’t really seem like he cared personally about me.” This was in contrast to her experiences with other doctors. Whitney said, “I was like, ‘Does he know who I am?’ He just didn't have that personal. I don't know if it was just his, obviously, it was his personality, but he just didn't seem to care personally [emphasis added] which I think is important to feel like your doctor cares.”

Riley’s experience is unique in that she is the only participant in this study whose cancer was initially misdiagnosed. Riley reported that the first healthcare providers she interacted with about symptoms, that ultimately were diagnosed as breast cancer, were not “sensitive to her issues.” Riley had seen a doctor on several occasions about a lump on her breast that was growing. The doctors told her that she had “fibrocystic breast tissue” and said “don't worry about it.” After several months of going back and forth with these doctors and experiencing greater pain around the lump, Riley said she “was just mad” and that she “didn't believe them.” She called the hospital and said, “Can you please direct me to a doctor that has a heart? . . .
Somebody who's not a jerk.” Riley eventually changed providers and subsequently was diagnosed with breast cancer and began treatment.

In these four cases, participants had experiences within the healthcare institution that apparently violated their expectations that providers are or should be caring and compassionate. That is, the participants believed that the way (e.g., insensitive, dismissive, not listening) that these particular members of the healthcare institution interacted with them was in sharp contrast to the supportive behaviors they expected from healthcare providers (e.g., caring, listening). Although participants rarely explicitly articulated their specific expectations regarding support (e.g., compassion) from providers and staff members, when participants perceived that their healthcare providers acted inappropriately, their responses clearly indicate that their expectations were violated (e.g., healthcare staff needs to be more compassionate than [they have] ever been, “direct me to a doctor who has a heart”). Further, participants’ attributed their adverse reactions (e.g., “mad,” loss of confidence in providers’ competencies) to those violated expectations for support. Thus, although participants’ may not have expected caring and compassion to be exhibited consistently by members of the healthcare institution (e.g., providers “went above and beyond,” more compassionate than I “expected”), participants clearly had some expectations of support when they concluded that members of the healthcare institution had been insensitive and/or inappropriate (e.g., being dismissive, not listening).

In summary, with the exception of the four instances cited, participants repeatedly interpreted their providers as showing compassion while carrying out actions associated with their organizational roles (e.g., informing a client about a procedure, discussing dosage options). Healthcare providers commonly are classified as being in a “caring profession” (McGaghie et al., 2002). The concept of “caring profession” assumes that healthcare providers are internally
motivated to be compassionate. However, first and foremost, the healthcare institution expects healthcare providers to complete tasks associated with their formal organizational roles (i.e., provide medical care; Dugdale, Siegler, & Rubin, 2008). That is, healthcare providers are not necessarily required by healthcare organizations and the wider institution, as part of their formal organizational roles, to provide emotional support to their clients. Nonetheless, participants’ accounts of experiences within the healthcare institution indicate that healthcare providers often, but not always, do enact behaviors that function as emotional support. These behaviors are consistent with the underlying assumption of being “caregivers,” while simultaneously carrying out the tasks required with their organizational roles. Thus, participants perceive that healthcare providers exhibit caring and compassionate behaviors (e.g., listening, reassuring), which can be understood as emotional support, while also carrying out the actions required of their roles (i.e., in order to provide medical care), or “doing their jobs.”

When providers exhibit behaviors that can be understood as emotional support, those behaviors appear to alter participants’ understanding of the kind of relationship the provider is attempting to have with them. That is, participants perceive that when their providers exhibit compassion, caring, concern, and commitment, those providers are attempting to create a relatively more personalized relationship (i.e., person-to-person relationship, rather than a healthcare professional interacting with the client as a “number”) and relatively less formalized relationship.

Finally, the consistency in participants’ reports of the communication of caring and compassion by healthcare providers suggest that providers’ enactment of social support may be normalized (i.e., how many providers commonly act even if they do not always act in this manner) within oncology contexts in the healthcare institution. That is, the similarity among
participants’ reports of healthcare providers from numerous clinics and hospitals enacting behaviors that function as emotional support suggests a pattern across the healthcare institution at large rather than isolated instances that are limited to individual healthcare providers or individual healthcare organizations. However, providers’ communication of caring and compassion may function to normalize social support within the healthcare institution at large. That is, providers’ repeated and consistent expression of caring and compassion may influence the acceptance of these behaviors as normative within the healthcare institution.

_Instrumental support in the healthcare institution._ Instrumental support is conceptualized as help that involves providing tangible goods and/or services (Foa, 1971). Because social support has been conceptualized in the literature largely, if not exclusively, as everyday interpersonal communication (Cline, 2011), most observations and examples of instrumental support are from everyday interpersonal contexts. For example, bringing food to someone’s home, picking up a prescription, or driving someone to the doctor, often occur in everyday interpersonal contexts. However, instrumental support also can occur or be perceived to occur within organizational contexts. In the context of healthcare, clients may perceive members of the healthcare institution as completing their role-related tasks (e.g., schedule doctors’ appointments; intervene with third parties, such as pharmacies and insurance companies, to help clients obtain medical resources) in a _manner_ that conveys concern. That is, although many of these tasks are undoubtedly part of the responsibilities associated with the formal roles of members’ of the healthcare institution, clients may interpret the manner in which the tasks are completed as communicating social support.

The theme that emerged related to experiencing instrumental support in the healthcare institution is: _Healthcare providers and staff support clients by helping them to navigate the_
healthcare system in order to obtain needed resources. Participants perceive that healthcare providers and staff provide this kind of support in two ways.

The first way that participants perceive that healthcare providers and staff help them to “navigate” (Riley) the healthcare system is by “quickly” (Riley, Elaine) scheduling appointments that ensure participants receive needed medical care in a timely manner. Riley reported that her doctor “had everything [surgical procedures, chemotherapy] set up as quickly as she could.” Elaine reported that her providers and other staff members “quickly” handled all of her scheduling for her:

Everything was done for me. All the appointments, everything moved very quickly. If I needed a scan or something, they said . . . “Okay the doctor wants this, this, and this.” They called the departments, they set it up . . . for me was wonderful because I went, “Oh, do I have to go home and call up all these people?” Then I forget to do it and all this stuff. I mean, I went in, my permanent care doctor called the breast surgeon who in the meantime set up with the oncologist so I was able to meet with him the same day and get everything. So it was all pretty much done for me. . . . They set up all my appointments. Everything was done when I was in there for treatment. . . . I couldn't have asked for better.

Millie explained that when she began having seizures “it was amazing” that she was able to see a neurosurgeon within a couple of days of calling the hospital. Similarly, Lena said she was able to get “in right away” to see her doctor whenever she needed to. Numerous participants’ reports indicate that staff members helped them schedule appointments quickly on short notice. This pattern suggests that it is not merely the fact that staff members complete scheduling tasks that is understood as support, but rather the attribution of support is rooted in the fact that staff
members do these tasks with a sense of urgency that mirrors’ participants’ experiences of an urgent need to access medical care quickly. Participants interpret these efforts by staff members and providers as reflecting understanding of participants’ needs as urgent (e.g., getting into see a doctor quickly). Thus, participants perceive that scheduling tasks, when completed quickly and/or without obstacle, conveys concern or support.

A second way that participants perceive that healthcare providers and staff help them navigate healthcare is by indirectly “help[ing]” (Tamra, Riley) them access medical resources. That is, healthcare providers and staff sometimes intervene with third parties (e.g., third-party payers, pharmacists) to help clients obtain needed medical resources (e.g., medical equipment, tests, and medication).

In these cases, the healthcare providers and staff do not provide the resources directly but rather facilitate clients’ gaining access to needed resources. For example, Tamra needed a machine to help her breathe and Medicare had denied the claim. She said:

The last time I was in the hospital the social workers in there helped me so much. Medicare was refusing. I needed a bi-pap machine because I don't breathe correctly. . . . Medicare kept refusing it for me. The last time that I was in the hospital with pneumonia, at the end of April and the first week of May, they [social workers at the hospital] fought and got me my bi-pap machine. They were wonderful.

A social worker at the hospital helped Alyssa to understand that she was eligible for Social Security benefits because she could not work. She said:

[The social worker] has been just a blessing. . . . She said, “You know, you can apply for Social Security benefits. You worked all your life.” Because I had told her “It's a struggle with me not working.” . . . So I said, “I think I'm unemployable.” She said, “Well, you
know you've worked all your life, you worked thirty-five plus years.” That was a real blessing. She's been a gem.

Although Riley lacked insurance coverage, her healthcare providers made sure that she was able to schedule appointments and procedures. They intervened to ensure that she got the medical care she needed. She said:

[Name of Oncologist] really was 100%. She had me set up to see a doctor [surgeon] for my mastectomy. . . . I told her I was losing my insurance and she [oncologist] looked at me, she goes, “You show up. I don't care. You show up. We will find a way to take care of this. I don't care. You show up to every appointment that is booked for you. You show up.” She goes, “We will figure it out. [Name of Hospital] will help you. They will pay for it if need be. You are not going to die because you can't pay.”

Tabitha said that the secretary at her oncologist’s office always “makes sure that you have your medication” by calling it into the pharmacy. Thus, participants consistently perceive that members of the healthcare institution go out of their way, often intervening with third parties (e.g., insurance companies, pharmacies), in order to ensure that they have access to needed medical resources.

Multiple participants characterize the processes by which members of the healthcare institution complete tasks as not only carrying out responsibilities associated with their organizational roles, but doing so in a manner that is also consistent with being an advocate (e.g., “fighting” Medicare) or protector (e.g., “makes sure” medication is obtained) and conveys genuine concern for participants’ wellbeing.

Participants repeatedly report that (a) members of the healthcare institution schedule appointments for them with urgency, and (b) intervene with third parties as an advocate or
protector to ensure that third parties provide needed medical resources (e.g., medication, medical equipment). In both cases, members of the healthcare institution do not provide direct medical help, but rather they engage in behaviors (e.g., moving quickly, intervening to ensure resources are obtained from third parties) that function indirectly as instrumental support by acting to ensure that participants receive needed medical resources from third parties. In the first case, the help is perceived as support because the scheduling is completed quickly in order to meet participants’ urgent needs for care. These actions, which clearly are part of members’ of the healthcare institution’s formal roles, often are experienced by participants as constituting support. Thus, it is not so much the actions themselves (e.g., scheduling an appointment, intervening with the insurance company), but the manner in which members of the healthcare institution complete those actions (actions commonly understood as organizational work), that is interpreted as supportive and effectively functions as instrumental support from the participants’ perspective.

In summary, participants experience the manner in which members of the healthcare institution provide information while simultaneously carrying out medical and administrative tasks as being supportive. Participants also perceive that their healthcare providers generally act in ways that convey caring, compassion, concern, and commitment. Participants’ recurring characterizations of the supportive manner in which members of the healthcare institution carry out their work invoke the concept of metacommunication.

As indicated in the literature review (see also Chapter II, Social support as communication), a message’s supportive value could come from metacommunication. Metacommunication commonly is explained as “communication about communication” (Wilmot, 1980, p. 61). More specifically, metacommunication is conceptualized as “anything
that ‘contextualizes’ or ‘frames’ messages to assist the participants in understanding the communication event” (Wilmot, 1980, p. 63). Metacommunication consists of cues that qualify the content of a message and can signify how it can or should be understood and/or its meaning and implications for the relationship of the participants in the communicative transaction in which it occurs (e.g., Bateson, 1951; Watzlawick, Bavelas, & Jackson, 1967; Wilmot, 1980).

Metacommunication can occur at episodic and/or relational levels and can be explicit or implicit (although it is most commonly implicit) in nature. Episodic metacommunication informs another person about how he or she should interpret the message (Wilmot, 1980). When explicit, the message contains verbal cues that direct how the message should be interpreted (e.g., saying “I was joking”). Implicit episodic metacommunication often relies on nonverbal cues (e.g., tone of voice) and/or contextual cues (e.g., formal versus informal settings) that imply how the message should be interpreted.

In contrast to episodic metacommunication, which focuses on interpreting meaning in the communicative transaction, relational metacommunication focuses on the meaning of messages for how the relationship is being defined (Cline, 1983). Interpersonal relationships are “dynamic and processual nature” (Cline, 1983, p. 356). Both parties involved are constantly and actively negotiating and renegotiating the definition of the relationship via cues embedded in their communication (i.e., their metacommunication). This level of metacommunication constantly frames, for both parties, “this is how I see you in relation to me” (Wilmot, 1980, p. 63). The cues that function as episodic and relational metacommunication are not mutually exclusive. Thus, the same cues may simultaneously inform the recipient about how to interpret the message and about the nature of the relationship being proposed by the other party (e.g., more or less personal, more or less formal, closer versus more distant).
In the present study, participants consistently point to the manner in which their healthcare providers carried out various job- and role-related tasks (e.g., spending extensive time, being compassionate and caring, acting quickly) when characterizing these actions as being supportive. That is, participants consistently report that members of the healthcare institution act in ways that they interpret to mean that the providers are willing to – or are offering to – have a relatively more personal, and thus relatively less formal, relationship with them. In this proposed relationship, participants perceive that the providers cast their roles as people rather than as “patients” or “numbers.” Thus, in fact, it is the metacommunication, or manner in which messages are presented, rather than the content of the messages, that leads participants to interpret healthcare providers as being supportive rather than simply fulfilling their job- and/or role-related responsibilities.

**Perceived availability of social support in healthcare.** Although participants consistently reported that they received social support through the healthcare institution, they provided very little evidence that they perceive support to be available to them in this context in the future, and then only if they actively solicit it. Three participants specifically expressed that their healthcare providers are available to provide support if they request it. That is, participants perceive that they need to actively engage in help-seeking behaviors and if they do so they will receive support. Participants report that their healthcare providers told them to “call” (Tamra, Ramona, Tara) if they have questions or concerns related to cancer. For example, Tamra said, “I can call the [doctor’s] office and talk to [name of RN], you know, if I'm not feeling well or whatever.” Ramona’s surgeon told her that she could “call” her “if there was any questions, any problems, anything.” After Tara was diagnosed, she was given an informational packet with “umpteen [business] cards” in case she “needed to call about anything.”
Note that the negligible reports of perceived availability of support in the healthcare institution is in sharp contrast to participants’ experiences of perceived availability of support at the Cancer Support Center (see Chapter IV, Perceived availability of social support at the Cancer Support). That is, participants perceive that the Cancer Support Center offers substantial unsolicited support and is available to provide substantial support if and when needed. Obviously the Center and other healthcare organizations (e.g., hospitals, cancer treatment centers) have different organizational goals (i.e., providing support to people diagnosed with cancer versus providing medical care). These differences most certainly influence perceived support. In a Cancer Support Center, where the mission is to provide support, being able to offer unsolicited support undoubtedly is more feasible than in healthcare organizations where the primary mission is treatment. Although healthcare providers often provide social support to people diagnosed with cancer (e.g., Dakof & Taylor, 1990; Helgeson & Cohen, 1996), the relatively glaring absence of participant perceptions related to perceived availability of support in the healthcare institution implies that people diagnosed with cancer may believe that such support is available on a limited basis and largely available only if they explicitly ask for it.

**Summary of nature of social support in the healthcare institution at large.** Participants’ experiences of social support in the healthcare institution at large imply that healthcare providers’ enactment of supportive behaviors may generally be normalized within the healthcare institution, at least in the oncology context. Specifically, participants’ experiences indicate that members of the healthcare institution often behave in ways that function as social support while simultaneously fulfilling their job- or role-responsibilities. Moreover, the manner in which healthcare providers interact with participants to convey support (e.g., spending extensive time, quickly scheduling appointments) effectively proposes to renegotiate the nature of the
relationship from a healthcare professional interacting with the client as a “number” to a person-to-person relationship. Participants gained access to supportive social ties when their healthcare providers and other healthcare organizations referred them to support organizations (e.g., Cancer Support Center, 4th Angel Patient & Caregiver Mentoring Program). Finally, only a few participants perceive support to be available to them through the healthcare institution at large, and then only if they solicit it.

Participants’ accounts indicate that, throughout the healthcare institution, healthcare providers and individual healthcare organizations exhibit patterns of socially supportive communication (e.g., compassionate, caring, understanding). For example, participants consistently reported that they were able to spend extensive time with their healthcare providers during appointments, which they interpreted to be supportive. Participants also repeatedly reported that their healthcare providers explained complex cancer-related information to them. Participants perceived that their healthcare providers were motivated by a desire for their clients to understand the complex cancer-related information they provide, in addition to fulfilling the information-giving responsibilities associated with their formal roles. Another example of behaviors perceived by participants as normative within the healthcare institution is healthcare providers consistently exhibiting compassion and caring. Participants’ consistent reports of compassionate behaviors enacted by healthcare providers possibly indicate that healthcare providers’ enacting social support in the form of compassion is normalized in the healthcare institution, at least in the oncology context. Finally, participants reported that healthcare providers and staff members help them navigate the healthcare system by acting quickly to help them schedule appointments and intervening with third parties to ensure that participants receive needed resources. Participants’ reports of the manner in which healthcare staff went about
completing these tasks suggests that participants interpreted these actions as both completing organizational tasks and being supportive. Although these socially supportive behaviors are not always exhibited (i.e., participants reported instances when members of the healthcare institution were nonsupportive), in general, participants’ experiences imply that providers enacting supportive behaviors in the healthcare institution may be normative (at least in oncology contexts).

Participants were able to access new supportive social ties because their healthcare providers and healthcare organizations referred them to support organizations (e.g., Cancer Support Center, 4th Angel Patient & Caregiver Mentoring Program). In turn, when participants engage with these support organizations, they are connected to new social ties and social ties who are similar to them (i.e., they gain both network size and homogeneity). Finally, only a few participants indicated that social support is available to them from healthcare providers in the future (i.e., perceived support), and then perhaps only if they solicit that support.

In summary, these results highlight that participants perceive that healthcare providers and other healthcare staff members (e.g., social workers) commonly provide social support to their clients. In addition, they report gaining access to additional supportive social ties through healthcare providers’ referrals to support organizations.

Sources of Social Support in Healthcare

Research question 2 (RQ2) asked: “What attributions do clients make regarding the sources (e.g., individual, organizational, institutional, other) of social support that they perceive, experienced, or expect to receive in healthcare?” Social support most often is conceptualized and studied as a form of everyday interpersonal communication (e.g., Cline, 2011; Goldsmith, 2004). Substantial research has examined the interpersonal sources of support found within personal
social networks of people who have been diagnosed with cancer (e.g., family members, friends; see Helgeson & Cohen, 1996; Nausheen et al., 2009; Zaza & Baine, 2002). Much less research has investigated individuals who represent healthcare organizations (e.g., healthcare providers, staff) as potential sources of social support (e.g., Neuling & Winefield, 1988; Rose et al., 1990). Further, researchers have not examined whether clients view healthcare organizations themselves (e.g., Cancer Support Center, individual hospitals) and/or the healthcare institution at large as possible sources of social support.

The present study considered three potential sources of support (i.e., individual, organizational, institutional). Sources of support are found in the attributions clients make regarding the parties or entities responsible for providing the support they receive (e.g., my doctor is caring, the oncology team is supportive).

Individual sources of support involve referring to a specific person who is identified either by name (e.g., Dr. Smith, Name of Program Coordinator at the Center) or by role (e.g., the social worker, my doctor). For example, a person might say, “the [Program Coordinator Name] helped me find a nutritionist” or “my doctor reassured me everything was going to be okay.” Organizational sources of support cast specific healthcare organizations as the entity responsible for providing support (e.g., Cancer Support Center, Hospital X). In the present study, specific healthcare organizations are understood as the source of support when participants indicate receiving support directly from the organization (e.g., the Center provides so much support, Hospital X was supportive) or when clients report receiving support from the collective staff of a specific healthcare organization (e.g., the staff at the Cancer Support Center is so supportive, everyone working at Hospital X is caring). Because a staff or team does not exist except by virtue of an organizational entity, references to “staff” or “team” as a source of support is
Institutional sources of support refer to the healthcare institution at large (e.g., healthcare system, healthcare industry). Institutional sources of support cast the healthcare institution at large, rather than individual organizations or individual staff members, as responsible for facilitating clients’ experiences of support. For example, clients may perceive that the healthcare institution’s values (e.g., “do no harm”) facilitate compassion shown by members of the healthcare institution and healthcare organizations. Themes emerged related to participants’ attributions of sources of support at the Cancer Support Center and within the healthcare institution at large.

**Sources of support at the Cancer Support Center.** Participants’ reports indicate they attribute support to both individual and organizational sources of support at the Cancer Support Center. Specifically, participants attribute support directly to individual staff members (e.g., Program Coordinator, Office Manager) and to the Center as an organization. Two themes emerged that relate to sources of support at the Cancer Support Center.

The first theme is: *Clients experience social support directly from individuals at the Cancer Support Center, but are more likely to credit the organization as the source of social support.* Although many participants attributed support directly to individual staff members, including volunteers, at the Center, participants more predominately attributed support to the Center as an organizational entity.

More than half of the participants (*n* = 18) attributed support they received at the Center to individual staff members. In these cases, participants referred to identifiable individual staff members or volunteers by name or specific role (e.g., “the cleaning lady,” “the yoga instructor”) as sources of support. For example, Lena said, “[Name of Program Coordinator] has just been as
nice and as cooperative as can be.” Paige referred to the Office Manager as a “savior” and said that “for some reason me and her connected.” Specifically, Paige said that when she is “totally stressed out” she can “talk to [Office Manager].” Paige also reported that the Program Manager directly “hooked” her up with a nutritionist. Lindsay said the Housekeeper “asks how you're doing, how you're feeling” and that she talks to her often when she is at the Center. Millie said when she sees “the cleaning lady” that the Housekeeper “knows” all of the clients by name and always “comes and says, ‘Hi.’” Participants attribute the support they receive from individual staff members to those individuals rather than to the organization as an entity.

Although clients’ experience of social support at the Center occurs via communication with individuals at the Center, they actually more strongly attribute the Center, as an organizational entity, as the source of that support. All 31 participants identified the organization as a source of support. In the present study (a) references to support coming from the organization by name – explicitly or implicitly – (e.g., “this place” is supportive, the Center provides support), and (b) references to support from the collective staff (“staff” and “team” existing only by virtue of the organization; e.g., “the staff” is supportive; “everyone” is supportive) are understood as indicating organizational sources of support.

Participants directly attribute much of the support they receive at the Cancer Support Center to the Center as an organizational entity. For example, Holly said, “[The Center provides] just a lot of support.” Lucy said, “[The Center] give[s] support and . . . offer[s] services that can help me.” Participants explained that the Center is “helpful” (Connor, Whitney) to them. Connor reported that the Center is “helping” him “internally, emotionally, spiritually.” Whitney described the Center as “a great organization” and said that it is “really helpful to [clients].” Howard explained that the Center is a “huge support system to the community.” Several
participants report that they are grateful to have the Center available to them as a source of support. For example, Sandra said, “I'm so grateful that [the Center] exists.” Similarly, Lucy said, “I’m so grateful that [the Center is] here.” Holly, Howard, and Alyssa referred to the Center as “a blessing.” Specifically, Alyssa said, “[The Center] is definitely a blessing.”

A large majority of participants (n = 24) attributed support to the collective staff at the Center. That is, most participants referred to the staff as a whole as supportive. For example, Alyssa, in discussing her experiences at the Center, said, “The staff [emphasis added] are just so nice and friendly.” Likewise, Tamra said, “They [emphasis added] staff care so much for you as a person. . . . I fell in love with the staff. They're [emphasis added] awesome.” Other participants discussed the staff’s specifically supportive actions. For example, Carmen said:

They're [emphasis added] staff always friendly, and they're [emphasis added] always nice, and they [emphasis added] always ask how you're doing, so they [emphasis added] carry a positive energy. . . . Everybody [emphasis added] that I've interacted with really seems to carry a positive attitude. . . . It goes all the way from the top, the administrator, all the way down to the lady that cleans the place.

In Julia’s experience at the Center, the staff “all [emphasis added] know me by name. They all [emphasis added] ask how I'm doing.” Tabitha reported that the staff is “delightfully warm and welcoming and helpful.”

In addition to referring to the staff collectively as “they,” participants used the term “everyone” (Dolores, Tara, Riley, Lindsay) to refer to the Center staff. Dolores explained that “everyone” on staff “is really friendly and nice.” Similarly, Riley said, “Everyone [emphasis added] has been very nice and happy to be here. They [emphasis added] seem excited when they're [emphasis added] here to sit and talk.” When Lindsay comes to the Center she said that
she finds “everyone [emphasis added] who works, who volunteers, here [at the Center] is very kind and very caring or they wouldn't be here.” Connor said, “Everybody [emphasis added] is really friendly and very kind and very helpful in anything that I've ever needed.” Thus, participants characterize the staff of the Center, collectively (e.g., “everybody,” “all,” “they”), as supportive. Participants’ repeated reports of receiving support from the Center’s collective staff suggest that their attributions of sources of support are not isolated to individual staff members and instead span the organization.

Participants directly attribute much of the support they receive at the Center to the Center and to its collective staff as an organizational entity. These multiple and similar attributions of receiving support to the organization indicate that participants’ experiences of support at the Center are not limited to individual staff members; instead they perceive that the organization itself effectively functions as the critical source of support. Logically, individuals are likely to be credited as responsible for support because they are the most immediate sources of support. However, all of the participants who attribute support to individual staff members at the Cancer Support Center also attribute support to the Center as an organizational entity. Remarkably all participants indicated that the Center was a source of support. Conceivably, the Center staff collectively adheres to deeply embedded norms that facilitate support which, in turn, lead participants to be more likely to attribute support more widely to the Center as an organizational entity, rather than to individual staff members.

The second theme related to sources of support at the Cancer Support Center is: Clients refer to the mission of the Center as a basis for attributing support to the Center as an organization. The Center, as an organization, has the expressed mission (see also Chapter IV, Description of the Organizational Context at the Cancer Support Center) to provide support to
people experiencing cancer. The Center’s explicit mission is “to provide a caring, relaxed environment offering supportive services and programs for individuals and families on their cancer journey.” Many participants, who indicated that the Center is a source of support, also explicitly discussed the mission or purpose of the Center as being to provide support through various programs and services to people diagnosed with cancer. Although the Center’s formal mission statement does not explicitly say so, participants clearly perceive that the Center’s mission is to facilitate providing diverse and holistic forms of support (e.g., emotional, spiritual).

The family who founded the Center often says, “There is more to cancer than chemotherapy and surgery.” The Center’s promotional materials often include this quotation. This quote implies that people experiencing cancer are in need of various types of support (e.g., emotional, spiritual) beyond medical care. Participants explicitly reported that the Center’s mission is to provide various forms of support to meet the needs of clients. For example, Millie said, “[The Cancer Support Center’s mission is to] offer support not just for mental, but physical, emotional health, mental, everything. They offer it all and they do it well.” Audrey explained that the Center “offers so many levels of support, from therapeutic to just the psychological.”

Likewise, Taylor said:

[The Center is] addressing all the issues, financial, emotional, social issues, family issues, stress issues. You know, they were even talking about one day having adult coloring books that they would give out, that people would color. They are addressing all those issues. . . . I think they are, in my thoughts, they're addressing everything they should here. You see all the different things you can do. Physical, mental, emotional, yeah, social. And it's much more than you know.

Lindsay’s description of the Center also addresses that its purpose is to provide diverse forms of
support. She said:

[The Center] give[s] free things to help people who have cancer. They will help you with your will [last will and testament]. They'll help you with Social Security. They'll help you do some financial planning. You can get a free wig from there, and they have support groups there. . . . They have exercise programs. You will meet so many wonderful people that will become your friends, that will help you deal with what you're going through, that will teach you things.

Ramona also perceives that the Center purpose is to provide diverse forms of support. Specifically, she said the Center is “providing what support can be provided . . . really everything, physically, emotionally, some spirituality, and the power of talk, and know that you're not alone in it.”

Participants also discussed how the Center’s non-profit status is associated with its mission to make support accessible. Three participants explicitly discussed the Center’s non-profit status (see Chapter IV, Description of the Organizational Context at the Cancer Support Center) when explaining the mission of the Center. Participants perceive that the Center’s mission is to provide support to participants rather than to make money. Tamra observed that the Center is “here strictly for us [clients]” instead of to make money. Similarly, Alyssa said, “I strictly feel there is no big moneymaking [goal] or anything like that [with the Center]. I believe they truly just want to help people diagnosed with cancer.” Elaine described the Center as “a non-profit organization” and said that the Center is “not making money off this [providing support].” These participants’ comments on the fact that the Center is a non-profit organization suggest that they perceive the purpose of the Center to be the wellbeing of its clients rather than increasing profits.
Participants described the mission of the Center accurately; that is, it exists in order to provide support to people experiencing cancer. In addition, participants believe that the Center focuses on helping people diagnosed with cancer instead of making money. Participants’ reports demonstrate that they have a sophisticated understanding of the Center’s mission (i.e., to provide additional support to people experiencing cancer). Thus, participants’ attributions to the Center as a source of support may be a reflection of their accurate understanding of the Center’s stated mission.

In summary, although many participants attribute support to individual staff members at the Center, participants consensually express that the Center itself, as an organizational entity, is a source of support. The case of the Cancer Support Center is significant in the context of the present study because it demonstrates that clients can recognize and attribute social support not only to this particular cancer support organization, but also to organizational entities in general. Prior scholarship typically has conceptualized social support as something provided by individuals in everyday interpersonal communication (e.g., Cline, 2011; Albrecht & Goldsmith, 2003) rather than by organizational entities. The results of the present study expand conceptualizations of social support from being largely, if not exclusively, an interpersonal communication phenomenon to potentially being an organizational communication phenomenon.

**Sources of support in the healthcare institution.** Participants’ reports indicate that they receive support from individual (e.g., healthcare providers, social workers) and organizational sources (e.g., hospitals, cancer treatment centers) in the healthcare institution at large. For example, participants referred to individual healthcare providers (e.g., my doctor is caring) and healthcare organizations (e.g., the hospital was so caring) as being supportive. In addition, participants expressed beliefs regarding how the healthcare institution facilitates their
experiences of support. Two themes emerged related to participants’ experiences of support in the healthcare institution at large.

The first theme related to sources of social support within the healthcare institution at large is: Clients generally attribute the support they receive from individual staff members (e.g., providers, social workers) directly to the individual sources rather than to the wider healthcare organization. Although a few participants referenced the collective staff (e.g., healthcare team, the staff) of healthcare organizations (e.g., hospital) as being supportive, participants’ reports predominantly attribute the support they experienced in those organizations to individual staff members (e.g., nurse, social worker).

More than half of participants indicated that they received support from individual healthcare providers. For example, Tamra said:

[My breast cancer nurse] will come and talk to you . . . when you have chemo. She will come look you up and ask you about your feelings, and how you are doing, and how's your family and everything. . . . She is fabulous!

Carmen was assigned a chemotherapy nurse throughout her treatment and she described the nurse as “very nice, very helpful.” Ginny reported a unique instance of her healthcare provider, as a particularly supportive individual, providing support to both her and her fiancé. She said:

Sexually, the medication really affects you. It really does, but it didn't for me for a long time, but eventually, it did and so [the doctor] tried to help my partner, who was my fiancé, deal with that. He wasn't good with it. He didn't rise to the occasion and deal with it well at all, but the fact that [the doctor was] there supporting [us]. [The doctor] would have him [fiancé] come in. . . . My doctor . . . because she wanted him [fiancé] to understand what was going to be happening to me and to know that what he was
experiencing was normal. In fact, she talked about it long before it ever was an issue for me.

Connor referred to his neurosurgeon as the “greatest neurosurgeon in the world.” He further described his neurosurgeon as “caring” and “a good guy.” Participants’ reports of receiving support in the healthcare institution consistently focus on individual healthcare providers who have directly provided support to them.

Participants report that they are grateful to staff members for the support they provided as individuals. For example, Sandra said that she was “grateful” that her oncologist “went out of her way” to explain complex information related to her cancer. Alyssa expressed that the social worker at the hospital has been “a blessing” and that she helped her obtain her Social Security benefits. When Lena was first diagnosed, her nurse reassured her that she would “come out the other side.” Lena explained that she “appreciated” her nurse’s comments because they gave her “hope.” Julia was concerned about her radiation and reported that her radiologist went “above and beyond” to make sure that her concerns were heard. Participants’ reports imply that participants attribute the support they experienced in healthcare to individual healthcare providers and staff members who provided that support of their own volition. However, a few participants did reference the collective staff as a source of support in healthcare organizations.

Participants’ accounts included only five instances in which the source of support was attributed to the collective staff (e.g., the staff, healthcare team) of healthcare organizations rather than to individuals. Riley said:

[The hospital] had so many helpful people [on staff] pointing me in directions that I needed to go. I’ve really felt that the [Name of Hospital] was great with just helping explain, teach me, help me financially to navigate things.”
Likewise, Lena said, “All the care I received at [Name of Hospital] from the secretaries through doctors, everybody, they [emphasis added] were so kind. I kept telling them, ‘I appreciate your kindness. You don't know what this means.’” Other participants reported that their healthcare “teams” (Tamra, Alyssa, Tabitha) were supportive. Alyssa referred to her doctor and his staff (e.g., nurses, secretaries) as a “team” and explained “the whole team [is] very caring.” Similarly, Tamra said, “It's just such a nice, supportive team that they [oncologist’s office] have built up there.” Tabitha characterized her oncology “team” as being “a group of folks that show a ‘commitment.’” These few instances show that, in fact, some participants did attribute support to organizational entities. However, the dominant theme was that participants attributed support to individual staff members (e.g., physicians, nurses) rather than to the organization.

Most participants’ reports of receiving support from individual healthcare providers did not extend to include organizational entities. Instead, participants’ reports predominantly indicated that individual staff members (e.g., healthcare providers, social workers) were supportive. Participants’ repeated attributions regarding sources of support indicate that they may be more likely to see individual healthcare providers as supportive versus the healthcare organization itself. These results resonate with previous research that indicates that clients perceive their providers’ communication to be more important than other organizational variables (e.g., design of the healthcare buildings, the administration of the organization; Duggan & Thompson, 2011). Thus, although healthcare organizations may have a collectively supportive staff that functions as an organizational entity, individual healthcare providers may be more likely to be perceived as the source of support among clients of healthcare organizations.

The second theme related sources of social support within the healthcare institution at large is: Clients characterize the organizations that comprise the healthcare institution at large
as businesses whose focus is on the financial bottom line, which inhibits rather than facilitates support. Participants generally perceive that healthcare organizations are businesses that focus on making money and that that focus inhibits client care and limits available support.

This study’s participants collectively perceive healthcare organizations as businesses. The majority of participants explicitly contributed to the theme that healthcare organizations (e.g., hospitals, insurance companies) are focused on profit; that is, on the financial “bottom line” (Ginny, Carmen, Lily, Elaine, Ramona). For example, Lily said, “I think [healthcare is] all about the bottom line.” Carmen expressed that health insurance companies similarly are focused on the financial bottom line:

I find the insurance companies are not really focused on you, it's a bottom line kind of business with them. . . . I haven't had any experiences that would lead me to believe that it wasn't their bottom line.

Alyssa perceived the healthcare industry to be composed of “a lot of people” who “make a lot of money off of [cancer treatment].” Julia described healthcare organizations as a “business.” She said that healthcare organizations are “there to make money.”

Beyond expressing that healthcare organizations are driven by profit-based motives, a few participants accused the healthcare industry of actively avoiding finding a “cure” (Alyssa, Vanessa, Lily, Audrey) for cancer because treating cancer is so lucrative. Alyssa explained:

That [is] interesting because to see my bill, it's astronomical! Each week. This newest drug [is] ten times more expensive. . . . I feel that, honestly, I feel that they could cure cancer if they really wanted to. [Interviewer: Meaning it's, they don't do it because [cancer’s] a moneymaker?] You're wiping out a whole industry [if you cure cancer]!

From drug pharmaceuticals, to the medical profession, to the hospitals. . . . But I think
there's a cure out there. . . . You hear everyone's trying the whole raising money to cure cancer. I think they could [cure cancer] if they wanted to.

Audrey described cancer research as “just a money machine.” Specifically, Audrey explained that she notices that there is a lot of “money that’s getting poured into” cancer research and yet she questions, “Why aren't we making more progress?” Lily said, “I'm one of those people who's starting to think there is a cure for cancer but it's such a money making endeavor . . . hospitals make money, doctors make money, nurses make money.” Ginny explained that she feels like the healthcare industry is not motivated to find a cure because finding a cure “doesn't fit with the economics of big pharmaceutical companies” (i.e., pharmaceutical companies make a lot of money because of the current treatments being used). Vanessa said:

        When they were cloning the sheep how many years ago. That's something new they did and I'm like, “They can do that, but we can't find a cure for cancer?” Everything's about bigger and better from Monsanto and our food supply to just, if there's no financial objective, it's kind of not [a priority].

Thus, participants perceive that healthcare organizations, particularly those that treat cancer, are driven primarily by making money. In addition, participants perceive that healthcare organizations (particularly the pharmaceutical industry) are afraid they will lose profits if they discover a cure for cancer and, thus, are not motivated to do so.

        Participants perceive that the business-oriented approach of healthcare organizations interferes with providing care and support. For example, Tamra said, “I think all in all [hospitals] just got too much about the business and the money and not about the patient.” When Holly discussed the issues with “the healthcare system and the shortage of staffing” she said that she finds cuts to staffing to be “horribly discouraging” because they prevent many healthcare
providers from being “able to spend some time with . . . [the] patient.” Julia explained that although the “purpose” of healthcare “is to treat illness,” in actuality healthcare administrators are more focused on increasing profits. She said:

It's just messed up. . . . The upper echelon [healthcare administrators] . . . perspective is [healthcare is] a business. They're there to make money. Even the nonprofit [hospitals]. I don't care, they're still there to [make money]. There's a budget. . . . The mission should be doctors and nurses shouldn't be restricted from taking care of people. There shouldn't be all this insurance companies. I'm very simple. I don't want to get it too complex, but it's too complex from what it really needs to be. The insurance runs the whole thing. It shouldn't be that way.

Ramona said, “I would love to see those days come back [when] it was physicians taking care of medicine and now it's corporations doing it.” Similarly, Terri believes that the pharmaceutical and insurance companies have “too much” influence over how healthcare providers interact with clients. She said, “The pharmaceutical companies and the insurances companies have too much to say about what doctors can do and can’t do. That is so bad.” Thus, participants perceive that making money, instead of client wellbeing, is what drives healthcare organizations. Further, participants’ perceptions of the business approach in healthcare suggest that healthcare organizations (e.g., pharmaceutical companies, health insurance companies) can interfere with providers’ ability to care for and potentially provide social support to clients.

Participants’ perceptions of the financial motivations of healthcare organizations resonate with Etzioni’s (1961) typology of organizational work. Etzioni’s typology classifies organizations as being motivated by financial incentives (i.e., making money) and/or by normative incentives (i.e., morality). Etzioni’s typology classifies healthcare organizations as
primarily motivated by normative incentives (i.e., doing what is right for clients’ wellbeing), but also having financial incentives in order to maintain the organization. However, in the present study, participants’ beliefs about the motives of healthcare organizations are in conflict with Etzioni’s classification. That is, although participants clearly believe that healthcare organizations should be motivated primarily to take care of their clients (i.e., have a normative incentive), in reality, participants perceive that healthcare organizations actually are largely focused on financial incentives. Further, participants perceive that the financial motivations of healthcare organizations interfere with the quality of care provided to clients. In addition, participants’ perceptions of the financial motivations of healthcare organizations suggest that healthcare providers are inhibited by organizational decisions (e.g., cutting staff, limiting available time to spend with clients) in terms of providing greater quantities – and quality – of social support.

**Summary of sources of social support in healthcare.** Participants’ reports commonly attribute the support they receive at the Center to the Center as an organizational entity in addition to attributing support to individual staff members. In contrast, participants attribute the support they receive in the healthcare institution at large more commonly to individual staff members (e.g., healthcare providers, social workers) rather than to the healthcare organizations (e.g., hospitals, cancer treatment centers). Further, they believe healthcare organizations within the larger institution are, in fact, businesses that are motivated primarily by financial profit. Participants perceive that the financial motivations of healthcare organizations interfere with the quality of care clients receive and potentially interfere with providers’ ability to provide social support. In contrast, participants perceive that the Center is driven by the motive to facilitate client wellness rather than by financial incentives.
Benefits of Social Support in Healthcare

Research question 3 (RQ3) asks, “What are clients’ experiences and perceptions of the benefits or potential benefits, if any, that they associate with social support in their healthcare experiences?” The benefits of social support often are conceptualized in the literature as the positive health outcomes associated with the perception of available and/or received social support (e.g., Cassel, 1976; Cobb, 1976; Cohen & Wills, 1985; House et al., 1988). Health outcomes can be physical, mental, social, or emotional in nature (see the often cited definition of health from the World Health Organization, 1948). The following section identifies and discusses themes related to the benefits of social support experienced in healthcare contexts. Research question 3 addresses the health benefits, broadly speaking, of social support at the Cancer Support Center and in the healthcare institution at large.

Benefits of social support experienced at the Cancer Support Center. RQ3a asks, “What are clients’ experiences and perceptions of the benefits or potential benefits, if any, that they associate with social support in the Cancer Support Center?” Four themes emerged related to clients’ perceptions of the benefits of social support experienced at the Cancer Support Center.

Center reduces clients’ feelings of isolation. The first theme is: Clients feel isolated and alone due to their cancer diagnosis and treatment; however, their interactions at the Cancer Support Center reduce that isolation. Participants reported feeling isolated following their cancer diagnosis. However, they also reported that the Center became an important resource for interactions with others, which helped to reduce those feelings.

Participants explicitly report that they felt “isolated” following their cancer diagnosis (Howard, Tamra) because they were unable to interact with others as often as they did prior to diagnosis. For example, Howard said, “You're in bed. You're in your bedroom most of the time.
Maybe you'll walk out to the kitchen or living room for a little bit. And then you're back in bed again. You're back into that isolation.” Lucy needed to be admitted to an extended care facility after her surgery. She said that it “was hard” to “not have the support of my friends” because she was unable to “go out” and spend time with them. Melanie explained that she “went into my own cocoon for that whole summer [while in treatment].” Further, Lena said, “I think there is an aloneness to the whole thing [cancer treatment].”

The Center offers clients an environment where they can participate in social activities and interact with other people. Julia said that she “was kind of stir crazy” when she was in treatment because she “wasn’t allowed to work.” She said, “This place [the Cancer Support Center] was like a God-send [emphasis added]. I wanted to do something, but I couldn’t work. I had a really hard time when I was off work.” Holly reported that prior to coming to the Cancer Support Center she “felt alone sometimes.” Alyssa said, “[Coming to the Center is] better than just sitting home and not doing anything. You get out and you see people. You just feel better.” These reports suggest that the Center functions to facilitate social interactions through its many activities and that social interaction reduced clients’ feelings of being isolated. Further, the similarity of these reports implies that the social interactions, which clients have at the Center, are viewed as an important part of participants’ daily lives.

Participants reported that they are disappointed when they have to “miss” (Ramona, Nora, Carmen, Alyssa, Tara) activities at the Center. Further, participants indicate that when they are unable to come to the Center they feel the loss of the social interaction (e.g., support group meetings, talking to other clients after exercise classes) they would have there. For example, Connor was unable to come to the Center for several months after a surgery. He said, “It killed [emphasis added] me not to come here [and interact with the other spirituality support group
members] for six months. It really did. It really did.” Tara explained that after her surgery she missed a breast cancer support group meeting. She said, “It was frustrating to me because I really wanted to be here.” Similarly, Carmen said she “hate[s]” missing her support group meetings at the Center. When participants cannot attend activities at the Center they are unable to have social interactions with other clients. Thus, participants imply that they feel the loss of the interaction they would have, and are disappointed, when they are unable to attend Center activities (e.g., support groups). These multiple and similar reports of being frustrated when participants are unable to interact with others at the Center suggest that sustaining the relationships they built at the Center is valuable to them.

Through social interaction at the Center, participants meet other people with similar cancer experiences, which helps them to feel not as “alone” (Dale, Ramona, Lena). For example, Ramona said that by coming to the Center and talking to other participants she realized “that you’re not alone in [having cancer].” Similarly, Dale said that coming to the Center “gives us an opportunity to say, ‘Wow, there's another person down the street or two miles away or ten people here [at the Center] just with the same [emphasis added] condition [cancer].’” Elaine said coming to the Center “helps make [cancer] not so scary.” Riley voiced that the Center’s children’s activities were beneficial because her son could “see other [kids] in a similar situation” (i.e., having a parent diagnosed with cancer). Participants perceive that people who are similar to them are available for interaction at the Center (see also Chapter IV, Nature of structural support at the Cancer Support Center; and Chapter IV, Emotional support at the Cancer Support Center). These reports suggest that participants feel less isolated as a result of having social interaction with others who they perceive to be similar.

In summary, multiple participants’ reports suggest that the interactions they have at the
Center reduce their feelings of isolation and aloneness. People diagnosed with cancer often report experiencing social isolation. *Social isolation* refers to the experience of being separated from and/or losing of relationships in one’s social network (Charmaz, 1983). The present findings resonate with Charmaz’s (1983) observation that people diagnosed with cancer may find that they are unable to interact with others as a result of their diagnoses. For example, people diagnosed with cancer may be unable to see their friends at work if they are on sick leave. People diagnosed with cancer also may find it difficult to interact with people who do not understand their experience(s) with cancer. The Cancer Support Center provides participants with an environment to interact with similar others. Participants’ numerous and consistent reports suggest that clients attribute reduced feelings of isolation to those social interactions at the Center.

*Clients are not stigmatized at the Center.* The second theme related to benefits of social support experienced at the Cancer Support Center is: *Clients, who report being treated as not “normal” and/or “different” elsewhere, feel comfortable and treated as normal at the Cancer Support Center.* Some participants reported being treated as not *normal* or as *other* following their cancer diagnosis. However, participants reported that they were treated as *normal* at the Center. In addition, participants found other clients who they perceived to be similar to themselves at the Center, which reduced their feelings of otherness and enhanced their sense of normalcy.

Although some participants report that their cancer diagnosis changed their relationships with their family and friends for the better (e.g., “cancer brought us closer” (Carmen, Tamra), husband is a “rock” (Elaine, Maggie)), many participants perceived that people “act[ed]” (Howard, Sandra) like they were no longer “normal” (Maggie, Howard) after they were
diagnosed with cancer. For example, Howard said:

This one lady that is a friend, she came [over to my house to visit]. . . . [When she saw me] I was really skinny. I didn’t look good. She looked at me like I was like some monster [emphasis added] walking in.

Howard also said that his cousin looked at him like he was a “freak” and commented on his significant weight loss when she saw him at a family party. Lena said that it was “traumatic” when she shaved her head. She said that she was nervous that others would treat her as “different” because she was “a bald lady.” Maggie said that she did not want “pity eyes” and “people looking and me” because of her terminal breast cancer diagnosis. She said, “I wanted to be treated normally [emphasis added].” Participants perceive that because of their cancer other people act like they are no longer normal. Specifically, participants’ reports suggest a pattern of participants feeling devalued in the relationships where they no longer are considered “normal.”

Participants perceive that other people are afraid of cancer and this fear affects their interpersonal relationships with people who do not have cancer. Participants explicitly reported that people are “afraid” (Connor, Elaine) of the “cancer” label. Connor said, “People are afraid of the "C" word [cancer]. They're frightened by it. They're frightened it will happen to them. I was too.” Similarly, Tabitha said, “[Cancer is] difficult to talk about because people are terrified.” Elaine said, “[People are] afraid. I don't think they're afraid they're going to catch [cancer] or something, but they don't know what to say so they don't say anything.” Lindsay reported that at work “I wasn't even allowed to talk about my cancer, because it would upset my coworkers too much.”

Some participants chose to conceal their diagnoses because of how other people might respond to them. For example, Howard said:
There's some people [that] I don't even tell them I have [prostate] cancer, or have had
[throat cancer]. . . . I don't even tell them. . . . [If] you go ahead and tell somebody, and
then they think of you as . . . different [emphasis added].

Similarly, Holly said, “I was a little frightened to let everybody know [about the cancer
diagnosis], or anybody know, and who to let know, and to what degree to let them know.”
Alyssa said she made her sister “swear to secrecy” when she told her sister about her cancer
diagnosis. However, Alyssa’s sister “kept saying, ‘When are you coming out [and telling
everyone about your cancer diagnosis]?’” Ramona said that she chose not to tell people at first
because she “didn’t want to deal with other people.” Thus, participants perceive that people do
and will treat them differently if or when they are labeled as having “cancer.”

The experience of being treated as not “normal” or “different” invokes the concept of
stigma (Goffman, 1963). People diagnosed with cancer often report feelings of otherness or
being stigmatized (Mathieson & Stam, 1995). Goffman (1963) defines stigma as “an attribute
that is deeply discrediting” (p. 3). He conceptualizes stigma not as an attribute of an individual
but rather as an attribute of relationships. That is, stigma is differentiates “us” and “them”
relationships, where some individuals are considered normal and others are devalued due to
difference. When stigmatized, individuals may be treated as “not quite human” (Goffman, 1963,
p. 3). Further, stigmatized individuals often are explicitly labeled as members of a distinct group
(Smith, 2011). For example, people diagnosed with cancer are commonly labeled “cancer
patient” and “cancer victim” (Park, Zlateva, & Blank, 2009; Smith & Hipper, 2010), and later as
“cancer survivor.” One way that people at risk of being stigmatized manage their identity is by
attempting to “conceal” the attribute that may “mark” them as stigmatized (Goffman, 1963, p. 3).
That is, they often attempt to “pass” as normal (Goffman, 1963).
Multiple and consistent reports of participants being treated as not “normal” or as “different” imply that they experienced stigma because of their cancer diagnosis. Moreover, attempts to conceal diagnosis make clear that participants are aware that their very identities are threatened by being known as a person diagnosed with cancer. Although participants may feel forced to conceal their diagnosis elsewhere in order to avoid being stigmatized, participants report that the Cancer Support Center is a place where they can be open and comfortable being known as a person who has been diagnosed with cancer.

Many participants arrive at the Center having experienced being stigmatized. However, in contrast to their experiences outside of the Center, participants report that the Center is “open” (Taylor), “accepting” (Stephanie), and “comfortable” (Melanie, Dolores) for them as a person who has cancer. For example, Melanie said, “I believe every cancer patient needs a place [such as the Cancer Support Center] to feel comfortable about [having cancer].” Taylor said that at the Center clients can “just be open” about their cancer experiences. She also said that the staff, volunteers, and other clients let “you talk about anything you want to talk about” in contrast to people outside of the Center, who may not be receptive to discussions about cancer. Participants perceive that because the Center’s explicitly stated purpose is to help people who have been diagnosed with cancer (see also Chapter IV, Sources of support at the Cancer Support Center), that support is more readily available there than elsewhere. Specifically, Carmen said, “[At the Center conversations are] focused . . . [on] issues related to cancer. Whereas you don't go look in the phone book and say, ‘Okay, [I need to find a] counselor for issues related to cancer.’” Sandra reported that the staff and volunteers at the Center “treat you more like an individual instead of a project.” Thus, participants believe they do not need to conceal their cancer diagnosis at the Center, in contrast to needing to do so in some other contexts. As a whole, these reports suggest
that clients are comfortable being open about their cancer experiences at the Center, where they are treated as “normal” rather than stigmatized as “different” or as “other.”

In addition to feeling comfortable and being open at the Center, participants also report perceiving themselves to be similar to other clients. Participants’ perceptions of being similar to other clients at the Center suggest that they do not feel “otherness.” Rather than being a part of “them,” they experience being a part of “us” at the Center. Participants explicitly reported having a “sense of community” (Tabitha, Ginny) with the other clients at the Center. For example, Holly said that when she interacts with other clients she “know[s] the people [other clients] are with you, and know[s] that they've been through the same thing [cancer].” Tara said, “It's very helpful to have these women know exactly what you're feeling.” Tabitha reported that the other women in the gynecological cancers support group “are people who have walked the same path.” Thus, participants perceive that they are part of a group of similar people at the Center and are treated as “normal” rather than stigmatized as “other” or “different.”

In summary, participants’ repetitive reports of other people treating them as “different” rather than “normal” due to cancer imply that many clients arrive at the Center having been stigmatized elsewhere. However, the consistency of participants’ reports of feeling comfortable, accepted, able to be open, and similar to other clients at the Center, are in sharp contrast to their stigmatizing experiences in other contexts. That is, they are not stigmatized in their interpersonal relationships and interactions within the organizational context of the Center. These findings imply that the Center has norms (e.g., of being comfortable, open, and accepting) that function to define clients as “normal” in contrast to stigmatizing them, and thereby influence interpersonal dynamics at the Center. Although previous research often has cast stigma as occurring in the context of interpersonal relationships that are influenced by sociocultural contexts, present
findings suggest that organizational factors may influence stigma (including in interpersonal relationships that are developed within organizations).

**Center validates clients’ identities.** The third theme that emerged related to benefits of social support experienced at the Cancer Support Center is: *Clients report significant changes to life perspectives due to their experiences with cancer and perceive that they can be open about those changes at the Center.* Participants report that having cancer is a life-changing experience. Participants also report that they are able to discuss these significant experiences openly with other clients and staff at the Center.

Most participants perceive that having cancer has changed the way they think and go about living their lives in significant ways, including changing the nature of their relationships with others (e.g., family, friends). Participants explicitly report that having cancer has changed their life “perspective” (Audrey, Lena, Holly, Julia, Ramona). For example, Melanie said, “What I did discover though is your whole attitude of life changes [after being diagnosed with cancer].” Tabitha said, “I consider cancer as part of the fabric of my life.” Ramona said that when you have “had cancer” your life “perspective” changes. Similarly, Holly said, “[Having cancer] changed my life.” Taylor expressed that “you reevaluate your life” when you are diagnosed with cancer. Audrey said that being diagnosed with cancer is a “wake-up call” and “reality check.” She said, “You examine your life” and you develop a “different perspective.” These accounts imply life-altering experiences.

Participants’ reports of life-altering experiences invoke the concept of *transformation.* Thombre and Rogers (2009) define *transformation* as “an event that initiates a process of self-communication within individuals and changes their lives, so as to refocus priorities and self-identity” (p. 252). Transformative experiences change individuals’ values and behaviors (e.g.,
interpersonal values that affect relationships and associations, health and wellness behaviors) and have lasting effects on their lives (Thombre & Rogers, 2009). Many people who have been diagnosed with cancer report experiencing transformation (Mathieson & Stam, 1995; Thombre & Rogers, 2009). Prior research indicates that diagnosis is the initiating point of transformation for many people who have cancer (Thombre & Rogers, 2009). However, the transformation process is ongoing long after the initial diagnosis, and often evolves through treatment, following declaration of remission, and beyond.

Participants perceive that their changes in life perspective, as a result of having been diagnosed with cancer, are ongoing and characterize this evolution as a journey. Participants use the term “journey” (Julia, Melanie, Tara, Tabitha, Lena, Carmen, Lily, Sandra, Howard) to refer to their ongoing experiences with cancer and resulting changes. Further, they indicate that the Cancer Support Center helps them to express their feelings and experiences related to these changes and new perspectives. For example, Elaine believes that even after people are in remission their cancer experience is ongoing:

Now what? I think that's a part of the cancer experience that people don't expect or understand that might potentially come and I think that's where [the Cancer Support Center] helps out because there is that life beyond [cancer treatment]. You just don't turn it off and say, “Okay, I'm done with this [cancer] now.” . . . You have a different outlook. Your life is different. You may be physically different. It's different. This is not just a flip a switch off, “Okay, I'm done. Thank you, good night.” That's not the way it works.

Likewise, Nora explained that the Center was helpful after she completed treatment:

Once you get through your treatments and you get to a certain phase it's like, "Okay. Now what? Where do I go, what do I do?" That's where yoga has fulfilled that, that little void
as to what's the next step. When people say they're cancer-free I have a hard time with that because I'm not quite sure we're ever totally cancer-free. [Interviewer: You're saying mentally [cancer is] always there?] Right. It's always hanging in the background. It's always there. Especially like when they have all the cancer walks and stuff. You just relive it and relive it and the yoga brings you back to a place where, "Hey, I am okay. It's going to be fine."

Lindsay said, “You do need [the Cancer Support Center] because people forget [that you are different] once you're done [with treatment].” Tabitha described the Center’s commitment to the “metamorphosis” that clients experience:

I think from the core of the development of this place, [the Center is] looking towards helping the person [with cancer]. . . . [The Center has] a butterfly as their emblem. You are in a stage of metamorphosis [when you have cancer; emphasis added].

Lena reported there is “openness” at the Center among clients when discussing the “hard experiences” that they have gone through and how these experiences have changed them. She said the Center “seem[s] to address, in a more holistic way, the person who is traveling this very hard journey, and their family.” Riley noted that “[the Center is] not just for people with cancer, but people who have already beat cancer and are survivors. I feel [continuing coming to the Center] is a great benefit.”

Participants’ reports indicate an ability to be open about their ongoing journey and life-altering perspectives at the Center. This is in contrast to their experiences in some other contexts. Specifically, participants report that other people “forget” that they are still affected by having been diagnosed with cancer, expect them to be “done” with cancer, and use the term “cancer-free.” Participants’ reports suggest that other people outside of the Center do not always
acknowledge, accept, or understand their ongoing changes or new life perspectives. As a result, participants perceive that they often are not welcome or able to be open about these changes in their life outside of the Center. Thus, participants’ patterned reports of being able to be open and express their feelings related to ongoing changes and perspectives at the Center, suggest that participants’ transformative processes are accepted and validated there.

In summary, multiple participants report that coming to the Center allows them to be open about their ongoing cancer journey and life-altering experiences. These accounts suggest that the Center validates participants’ transformational processes. That is, the Center as an organization facilitates participants’ open conversations about their ongoing journey and changing perspectives by providing a safe space and encouraging interactions whereby participants’ transformative processes are welcomed, addressed, and valued. These experiences at the Center offer sharp contrast to being ignored, forgotten, and/or devalued elsewhere. These results are important because they suggest that a healthcare organization can create an environment that normalizes the existence of transformative experiences and open interaction about them. Such an environment may be critical for someone whose transformation is invalidated in other contexts (e.g., others expecting a person in remission to act the same as prior to diagnosis because she or he is “cancer-free;” people “forgetting” that a person who is in remission had cancer).

*Relaxation and stress relief at the Center.* The fourth theme that emerged related to benefits of social support experienced at the Cancer Support Center is: *Clients relax and experience stress relief as a result of participating in activities and using services at the Center.* Participants reported that they felt relaxed, which helped to relieve stress, when they participated in activities and used services at the Center.
Numerous participants report experiencing relaxation and stress relief specifically as a result of using integrative services at the Center. Participants explicitly reported that they were able to “relax” (Maggie, Dolores, Alyssa, Taylor, Stephanie, Julia) and “release [stress]” (Sandra, Paige) because of using integrative services (i.e., Reiki, healing touch, facials, foot reflexology, massage) and participating in particular activities (i.e., yoga, mindfulness workshop) at the Center. For example, Maggie said, “The Reiki helps me relax. I really needed the relaxation. [It] took away the anxiety.” Similarly, Holly found the Reiki to be “wonderful and so relaxing.” When Dolores comes to the Center for foot reflexology she finds that it “is really relaxing.” Taylor explained that the aromatherapy facials at the Center are “very relaxing.” Further, Taylor also reported that healing touch was “relaxing” because “you got to lay down, and . . . [the healing touch practitioner] put[s] on some nice incense, and . . . nice music, and it [is] quiet and serene.” The Office manager invited Julia to a Reiki session, which she found “relaxing” and it reduced her pain. After Alyssa participates in yoga at the Center she “just feel[s] very relaxed and very stretched.”

Some participants report that being able to relax helps to relieve their stress. For example, Paige said:

[The facials are] nice because it's something to take the stress off. I've done the massages. That also too because with chemo, it really tightens you. . . . You need something to take the stress off, because all you're doing is sitting at home building, building, building, building, unless you have something to get it out,

Vanessa explained that she “really enjoy[s]” yoga at the Center because “it's calming at the same it gives you a little bit of physical activity.” Similarly, Lucy reported that she feels “a calmness” after her healing touch sessions. Through yoga at the Center Sandra feels like she is “releasing”
People commonly report increased stress in response to being diagnosed with cancer (Zabora et al., 1997). Social support scholars explain that an enhanced ability to manage stress is a key benefit of social support (Albrecht & Goldsmith, 2003). Cohen and Wills (1985) define stress as, “feelings of helplessness and the possible loss of self-esteem” (p. 312). Although stress is rooted in how individuals feel about problems, stress also can have physical manifestations (e.g., high blood pressure, muscle tension) when cortisol levels (i.e., the stress hormone) rise (E. Scott, 2014), and ultimately affect specific physical health conditions. However, when individuals are able to relax, their stress is reduced, and, some of the physical manifestations of that stress are ameliorated. Thus, experiences at the Center that contribute to reducing participants’ stress can have potentially important physical and mental health consequences.

Many participants reported that they were able to use services (e.g., gentle strength classes, yoga, massage) that provided relaxation and stress relief because the Center made them available free of charge (see Chapter IV, Instrumental support at the Cancer Support Center). For example, Tara explained that it is helpful that the Center does not “charge you anything for any services [Reiki, massage] whatsoever.” Likewise, Paige described the Center as a “place to go” to get foot reflexology and massages “free of charge.” Audrey said that because “all these services are free” (e.g., massages, oil therapies) she can “take advantage” of them. The Center was “helpful” to Sandra because she could come the yoga class and get a massage for “free.” Specifically, she reported, “I would never pay to go take a yoga class because I can't spend money on me when I'm in desperate need of taking care of my family.” Thus, participants were able to experience relaxation and stress relief because of being able to participate in these
services free of charge at the Center.

In addition to a pattern of participants reporting physical and mental relaxation and stress relief as benefits of using the services and activities at the Center, a few participants reported additional physical health benefits. Physical health outcomes that participants associated with using services at the Center include pain relief, reduced numbness, and reduced nausea. For example, Taylor reported that the facials were helpful in moisturizing her face because “the chemo really dries out your skin.” She said, “The [foot] reflexology was good, because believe it or not, [the foot reflexology practitioner] said that different places on your feet, the nerve systems affect your body, and I could feel it, I could actually feel it.” Lindsay said:

The Reiki was absolutely wonderful. I feel that that gave me so much energy and health. There was times when I was so nauseous. . . I would come [to the Center] so sick and I would go back to work feeling so much better. It's amazing how much I found that Reiki and the foot reflexology helped the nausea, and as time went on, the weakness, and gave me strength, physical strength, but the nausea was overwhelming . . . so it helped tremendously.

Paige reported that the foot reflexology was “great” because it helped to reduce the numbness in her legs and hips, which were “side effects from [the] chemo.” Julia reported that she experienced reduced pain as a result of using integrative services. She said:

I had a lot of problems with my legs during my chemo. You know how when you do a really hard leg workout and you can't move the next day? That's how I felt. I had a really hard time doing steps and walking and stuff. It started after my third chemo and I was still having leg problems and then I had my fourth chemo that day and I was thinking, “Oh my gosh, how am I ever going to get through this fourth chemo. My legs are already
aching from the third.” [Office Manager] called and she's like, “Hey I've got a 6:00 [p.m.] Reiki cancellation, do you want to come up?” And I thought, “Well it's not going to hurt.” . . . I came up and I had never done [Reiki] before, and I did that session. . . . I stepped up off the table and the pain in my legs was probably an eight out of ten when I came up, and it was like half of that. It was like a four out of ten.

Thus, in addition to stress relief, a few participants reported experiencing additional physical health benefits (e.g., reduced pain, lessened nausea) as a result of using the Center services.

Participants perceive that the services and activities at the Center provide them with relaxation and stress relief and, in a few cases, additional physical health benefits. Repeated reports of experiencing relaxation and stress relief at the Center indicate that physical and mental health benefits result from the supportive services and activities at the Center.

**Summary of benefits of social support at the Cancer Support Center.** Participants perceive that they gain health benefits as a result of participating in and using the Center’s activities and services. These perceptions imply that the Center, as an organization, facilitates health benefits. These health benefits emanating from the organization are social (e.g., reduced social isolation, being treated as normal rather than stigmatized), mental and emotional (e.g., feeling understood, reduced anxiety), and physical (e.g., reduced stress, reduced pain, lessened nausea) in nature.

Participants’ reports explicitly attribute these health benefits to the Center’s supportive environment and services. Specifically, participants attribute reduced feelings of isolation and aloneness to interactions they have with other clients at the Center during Center activities. Participants attribute personal growth to openness about their cancer journey and life-altering experiences at the Center. They report that the Center’s welcoming, accepting, and comfortable
environment facilitates their ability to be open. Further, the Center’s organizational environment is in contrast to the stigmatizing interpersonal experiences many participants have had in their personal networks. Specifically, participants attribute being treated as “normal” and as part of the “us” rather than “them” to interactions that occur at the Center. Finally, participants attribute mental and physical health benefits to relaxation and stress relief achieved through the Center’s services and programs. In addition, these health benefits often are only accessible because the Center offers its services free of charge (see Chapter IV, Instrumental support at the Cancer Support Center). Thus, not only participants’ use of the services, but the availability of the services free of charge, leads to physical and mental health benefits.

**Benefits of social support experienced in the healthcare institution.** Research Question 3b asks, “What are clients’ experiences and perceptions of the benefits or potential benefits, if any, that they associate with social support in the healthcare institution?” Participants benefit from the social support that they receive from members of the healthcare institution. Two themes emerged related to the benefits of social support experienced in the healthcare institution.

The first theme is: *When clients feel supported by members of the healthcare institution, they feel comfortable with and more likely to follow their providers’ suggested treatment regimens.* Participants indicate that because of their providers offering social support they felt at ease with and, thus, were more willing to follow suggested treatment regimens (e.g., chemotherapy, surgery).

Participants explicitly reported that healthcare providers put their mind at “ease” (Julia, Lucy) and they were “comfortable” (Tamra, Alyssa, Elaine) with their cancer treatment (e.g., surgery, chemotherapy, radiation) because of the support their healthcare providers provided. For example, Julia was concerned about having radiation near her heart because she has a family
history of heart failure. Julia said that she told her doctor that she “was very leery of my radiation because [the breast cancer is] on my left side. Nobody in my family dies of breast cancer, they all die of heart failure.” She said, “My radiation doctor . . . went above and beyond. . . . He did everything he could to ease my mind about the radiation. I felt he did a really good job [easing my mind].” Lucy said that the way her doctor explained how her colostomy bag would work “was easing, making it seem like it’s not that bad.” Nora reported that she was anxious about her second surgery. However, Nora’s breast cancer surgeon explained her situation (i.e., reason for second surgery) in detail and assured her that she would not “show up in [the surgeon’s] office down the road . . . because . . . the margins [were not] clean.” Nora said that her breast cancer surgeon was “very understanding,” which put the need for the surgery into “perspective” and “brought me back to earth.” Tamra said that she is “comfortable” with the “supportive team” at her doctor’s office. Specifically, Tamra reported that her providers “always” explain complex cancer-related information to her so she is “comfortable” with her “medicines” (i.e., medication). Alyssa explained that when her chemotherapy was not working, her physician was very concerned and showed her that he was doing everything he could to help. She said, “[Doctor Name] is working like a dog trying to get something [chemotherapy] to last a little longer. I feel very comfortable and very cared for.” Elaine reported that her doctor considered lowering the dose of her last chemotherapy treatment because he was “concerned” about her “getting dehydrated” and feeling “bad.” However, because of the “compassion” her doctor showed, Elaine said she felt “comfortable [taking the full dose].”

Dale reported that he refused treatment because he did not feel supported by his healthcare providers. Dale’s experience is the inverse of feeling comfortable with and following suggested treatment regimens because of support provided by healthcare providers. He said that
he has “refused all treatments” because “the oncologist, the urologist, sees me as a cancer person and just throws their standard medical [treatments].” He went on to say:

Nobody has looked at me in the eye and said, "You're a person. You're a human. Let's look and see what's going on with you." [Interviewer: No one’s understood Dale and all of the things that make you a person and all your beliefs?] Yeah. I don't even know if it'd be successful, but if somebody [doctor] just would do that [“see what’s going on with you”], then I would consider them part of my team. I lose confidence in a second if they just start, "Well, this is what we're going to do for you."

Dale’s experience supports the theme by providing an instance of a participant deciding not to follow treatment recommendations because of a lack of support.

Participants’ reports indicate that providers’ support influenced how comfortable participants were with suggested treatment regimens and thereby influenced their willingness to follow them. This finding resonates with prior research on the relationship between client adherence and provider communication (e.g., DiMatteo, 2004; Squier, 1990; Zolnierek & DiMatteo, 2009). Squier’s review indicated that when providers are “understanding” (p. 325) clients are more likely to adhere to recommended treatment regimens. More recently, Zolnierek and DiMatteo’s (2009) meta-analysis found a significant positive correlation between physicians who communicate well (e.g., collaborate with clients, provide support to clients) and adherence to recommended treatment regimens. In the present study, participants’ willingness to follow their providers’ treatment recommendations appears to be directly related to feeling supported (e.g., agreeing to surgery because of the provider’s understanding, agreeing to a higher chemotherapy dosage because of the physician’s concern).

The second theme related to the benefits of social support experienced in the healthcare
institution is: *Clients gain access to cancer-related resources because of support they receive in healthcare.* Participants’ reports indicate they were able to obtain cancer-related resources because of support they received from healthcare providers and healthcare organizations (see Chapter IV, Instrumental support in the healthcare institution).

Healthcare organizations directly provided some resources to participants (e.g., wigs, informational resources, medical equipment). For example, Millie said:

The best thing that [Name of Hospital] ever did was soon as I was diagnosed, they have this huge notebook with an elastic tab and this little thing that it wraps around and in the notebook, there's a place for a legal pad, a pen, and then this accordion file thing with different slots. They would give you different information about your chemo, so you could put your chemo in a slot. Then there was a tumor, brain tumor recovery type, what to expect, and that could be another slot. Another one was about seizures and what to expect. It was so nice to have this notebook I could open up, I could put my appointments in it, and different things that they gave me, different things I collected from here. It was a great way to stay organized.

Lucy explained that her nurse helped her obtain her colostomy supplies. She said that the nurse “gave me one of these big magnet things with [the supply warehouse phone] number. . . . I [use it to] call [the warehouse] once a month and they send [the supplies] UPS.” Tara reported that she was able to obtain a mastectomy bra directly from her hospital. She said:

[The hospital has] a boutique that you can go into and get stuff [wigs and other cancer-related items]. I had a wedding to go to and I got permission to wear a regular bra . . . so it didn't look awkward or anything. . . . [The hospital] lends [the mastectomy bra] out and then they clean it and sterilize it for the next person who needs it. It's kind of like this gel
breast. . . . That was really nice because some of this stuff [mastectomy bras] can get pretty expensive.

Alyssa reported that she was able to get a “free wig” from her hospital. Further, Alyssa’s hospital had a skincare program in place for people experiencing cancer. She said:

[The hospital] work[s] in conjunction with this company called [Name of Skincare Company]. . . . [The skincare] doesn't have any toxins in it and it doesn't absorb into your blood stream. . . . I heard Gwyneth Paltrow uses it. People like that can afford it. Then [the hospital] decided to start offering it to cancer patients. . . . They gave us this whole line of product free. Worth $1500.00! So each little bottle is worth a couple hundred dollars. If I want to order it I can get it at a very reduced price at the pharmacy at the [Name of Hospital].

Healthcare providers also intervened with third parties (e.g., Medicare, pharmacies) to ensure that participants were able to obtain needed resources. (See also Chapter IV, Instrumental support in the healthcare institution.) For example, the hospital social worker helped Alyssa file for Social Security benefits. Tamra reported that the social workers at her hospital intervened with Medicare and made sure that she was able to get her “bi-pap machine” to help with her sleep apnea.

Participants’ reports indicate that they benefitted from support provided by healthcare organizations and their healthcare providers in the form of receiving various cancer-related resources (e.g., wigs, medical supplies, informational resources). Participants perceive that they gained access to these resources as a result of the support provided via healthcare organizations and/or their members. In addition to the material benefits, participants indicated financial benefits because some of these items are costly and participants cannot otherwise afford these
resources (e.g., participants cannot afford to purchase expensive mastectomy bras and specialized skin care).

In summary, participants clearly perceive that they benefit from support they received from individual members of the healthcare institution (e.g., healthcare providers, staff members) and individual healthcare organizations (e.g., hospitals, clinics). Participants’ accounts pointed to two primary benefits. First, participants’ reports indicate that supportive actions by individual healthcare providers influenced their comfort with following or adhering to suggested treatment regimens. Participants’ adherence to recommended treatment regimens is important because it affects health outcomes (e.g., Zolnierek & DiMatteo, 2009). Second, support provided by healthcare providers increased participants’ access to medical resources (e.g., medical equipment) that some otherwise could not afford on their own. Having the support of healthcare providers and healthcare organizations may be the key to facilitating clients’ access to cancer-related resources. Thus, participants perceive benefits due to the social support they experienced within the healthcare institution at large.

**Summary of benefits of social support experienced in healthcare.** Participants indicated that they experienced benefits as a result of the support they received at the Cancer Support Center and within the healthcare institution at large. However, the types of benefits experienced at the Center versus in the healthcare institution differed.

Participants’ reports indicate that they experience four main benefits (i.e., themes) as a result of participating in activities at the Cancer Support Center. First, they experienced reduced isolation as a result of interacting with other clients and staff at the Center. Charmaz (1983) found that individuals diagnosed with cancer commonly feel isolated as a result of their illness.

Second, by interacting with others who also have been diagnosed with cancer,
participants experienced reduced feelings of isolation. Participants also report being treated as “normal” and are accepted by other clients and the staff at the Center in contrast to being stigmatized elsewhere. Being stigmatized changes the communication between individuals and often damages the identity of people diagnosed with cancer (Mathieson & Stam, 1995). Participants reported that their communication with people in their social networks changed (e.g., others were “afraid” to talk about cancer, distanced themselves, and in some cases avoided the participant; some participants felt the need to conceal their diagnosis), whereas at the Center participants were able to be open about their diagnosis and talk openly about their cancer-related experiences.

Third, participants report being open at the Center about transformative changes to their lives that have resulted from having cancer. Participants’ reports of being comfortable expressing their transformative experiences at the Center suggest that the Center’s environment is accepting and validating of those experiences. This finding is particularly important because people diagnosed with cancer sometimes find that others are unwilling to accept or do not understand their transformation (Thombre & Rogers, 2009).

Finally, participants report experiencing relaxation, stress relief, and some physical health benefits (e.g., reduced pain, lessened nausea) after using services and programs at the Center. The fact that stress is linked to worsened health outcomes makes its management critical to individuals experiencing cancer (E. Scott, 2014).

Participants reported experiencing two primary benefits as a result of the support they received from healthcare providers and other healthcare organizations. First, they indicated that they felt comfortable adhering to recommended treatment regimens when their providers were supportive. Street et al. (2009) indicate that providers’ supportive behaviors can have important
implications for clients’ health. The present results indicate a likely relationship between social support received in healthcare contexts and adherence to suggested treatment regimens, and thus a likely relationship between support and health outcomes.

Second, the support provided by healthcare providers and organizations helps participants to access medical resources (e.g., medical equipment, informational resources). That is, when healthcare providers and healthcare organizations provide social support to clients, clients may find greater access to varied medical resources.

In summary, support experienced both at the Cancer Support Center and in the healthcare institution had important health benefits for participants. However, they experienced different health benefits in the two contexts.
Chapter V

Discussion

This study explored how, from the perspective of clients, the communication of social support comes to be perceived as institutionalized in healthcare settings. Specifically, this study sought to understand the ways in which social support is experienced and perceived as institutionalized, from the perspective of people diagnosed with cancer. The study considered clients’ experiences in two contexts: the Cancer Support Center and the healthcare institution at large. The overarching research question guiding this study was: *What is the nature of social support that clients experience and perceive as institutionalized in healthcare organizations?*

This chapter first provides an overview of the study. Next, the study’s results, in terms of specific themes regarding participants’ perceptions of social support are identified, integrated, and discussed in order to provide answers to three specific research questions. Based on the composite findings of the study and prior research, a model emerged to explain how clients’ experience of social support and related processes within healthcare organizations lead to perceptions of institutionalized social support and experiences of support-related health benefits. That model is presented and discussed. Next, key findings are discussed in terms of their contributions to scholarly literature and their practical implications in healthcare contexts. The chapter concludes by acknowledging the limitations of this study and identifying future directions for research.

Overview of the Study

Very little research has examined organizational and institutional influences on the communication of social support in healthcare contexts (e.g., Ansmann et al., 2014; Lammers & Lambert, 2016; Stone, 2013). Further, scholars have not considered clients’ experiences and
perceptions regarding the institutionalization of social support in healthcare settings. Although prior research has examined social support in the context of provider-client relationships (e.g., Neuling & Winefield, 1988; Goldsmith & Albrecht, 2011; Street et al., 2009), few studies have discussed the roles of healthcare organizations and the healthcare institution at large in facilitating and/or impeding the communication of social support (Ansmann et al., 2014; Stone, 2013). This area of research constituted a gap in the extant literature.

The examination of social support is significant in the context of healthcare and, especially in oncology contexts. Social support is associated with positive health outcomes (e.g., Goldsmith & Albrecht, 2011; Uchino, 2004). Healthcare organizations’ and the healthcare institution’s facilitation or obstruction of the provision of social support likely are associated with health outcomes, and particularly those of people diagnosed with cancer.

Cancer is one of the most pressing health concerns in the U.S. Researchers have emphasized the necessity for healthcare providers and healthcare organizations to provide social support and supportive resources to people diagnosed with cancer (e.g., Quillin et al., 2009; Sloan & Knowles, 2013). Further, the American College of Surgeons’ (ACS) (ACS Commission on Cancer, 2012) most recent care standards have called for healthcare organizations to provide greater support resources to people diagnosed with cancer. When healthcare organizations are unable to meet the ACS standards in-house, they can partner with cancer support organizations to help meet the support needs of clients who have been diagnosed with cancer. Although cancer support organizations are relatively common in the U.S. (National Cancer Institute, 2015b), few studies have examined the context of cancer support organizations (Matthews et al., 2002; Rosenbaum & Smallwood, 2013). In particular, researchers have not examined social support in the context of cancer support organizations. This study examined social support in the context of
a cancer support organization, specifically the Cancer Support Center.

Three specific bodies of literature informed this study: (a) organizational culture, (b) institutional theory, and (c) social support. Both organizational culture and institutional theory studies attempt to explain how macro-level (e.g., organizational, institutional) beliefs, norms, and rules influence micro-level interactions (e.g., interpersonal communication) in organizational contexts. The present study employed these perspectives to understand supportive communication processes.

The first body of literature informing this study was organizational culture scholarship. Although the examination of “culture” can occur in a variety of contexts (e.g., organizations, families), organizational scholars have used conceptualizations of culture to examine artifacts, values, and assumptions of organizations (e.g., Chiles & Zorn, 1995; Keyton, 2011, 2014). Organizational culture both emerges and is enacted through the interactions and shared understandings among organizational members (Keyton, 2011, Schein, 2004). That is, a reflexive relationship exists between organizational culture and interactions among organizational members, whereby the organization’s culture influences and is influenced by interactions among organizational members. Organizational culture analyses are generally narrowly drawn. That is, organizational culture analyses typically examine the culture of an individual organization or group of organizations. The present study considered how the organizational culture of the Cancer Support Center shaped clients’ experiences of social support.

Although examining organizational culture allows researchers to understand how shared knowledge emerges among organizational members within the same organization (e.g., a cancer support center), organizational culture scholarship does not capture how broader institutional influences shape organizational structures and interactions. This study also considered
institutional influences on interactions that occur in healthcare organizations. Institutions are the overarching belief systems to which similar organizational bodies adhere in order to remain legitimate (Lammers & Barbour, 2006). This study used the dual perspectives of organizational culture and institutional theory in examining clients’ experiences regarding social support within healthcare organizations (e.g., a cancer support center, hospitals, cancer treatment centers).

Scholars’ interest in examining institutions has focused on the ways in which institutional beliefs, norms, and rules shape interpersonal interactions within organizational bodies (Lammers & Barbour, 2006). Although organizations individually (and sometimes collectively as well) have varied organizational artifacts, values, and assumptions, institutionalists recognize that organizations must generally be structured similarly in order to be considered legitimate (e.g., Greenwood et al., 2008; Lammers & Barbour, 2006). Institutional theory argues that, through the communication of institutional beliefs, norms, and rules, institutions are sustained across organizations. Thus, institutional theory is used to examine institutionalizing processes that occur both within and across organizations.

*Institutionalizing* is comprised of the processes through which institutional beliefs and norms are established and routinely practiced through patterns of behavior within and across organizations (Zucker, 1977). Institutional theory and institutionalizing processes were relevant to the present study because it focused on the ways that people diagnosed with cancer experience and perceive institutional influences (e.g., norms, beliefs, rules) in the communication of social support within healthcare contexts.

Social support has been examined for more than four decades because of its relationship to better health outcomes (e.g., Goldsmith & Albrecht, 2011; Roy, 2011; Uchino, 2004). From a communication perspective, social support can be understood as verbal and nonverbal
communication that provides individuals with actual assistance or the perception that assistance is available within their social relationships, and thereby helps the individual to manage uncertainty (see also, Albrecht & Adelman, 1987; Albrecht & Goldsmith, 2003). Social support scholarship has investigated the relationship between social support and health outcomes for a variety of chronic conditions (e.g., cancer, diabetes, heart disease). Specifically, social support research has examined the ways in which social support helps individuals buffer stress associated with health crises and, as a result, have better health outcomes (e.g., Cohen & Wills, 1985; Uchino, 2004). Social support is particularly important for people diagnosed with cancer. They are in need of support to help buffer numerous physical, mental, and social stressors (e.g., Helgeson & Cohen, 1996; Sloan & Knowles, 2013).

The present study focused on socially constructed phenomena: (a) the organizational culture of the Cancer Support Center, (b) the healthcare institution at large, and (c) the communication of social support. Social constructionism is a meta-theoretical framework that is based on the premise that, through interaction, individuals come to share meanings about their reality (Tracy, 2013). That is, individuals come to share and agree upon the meanings of social phenomena (e.g., institutions, social support).

This study used a constructivist grounded theory approach that is based on the premises of social constructionism (Charmaz, 2014). This approach allowed the researcher to acknowledge the socially constructed nature of the social phenomena of interest in this study (i.e., clients’ perceptions of the institutionalization of social support in oncology contexts of healthcare) and to answer specific research questions related to clients’ perceptions of institutionalized social support processes at a cancer support center and in the healthcare institution at large.
The participants in the study were clients at the Cancer Support Center. The Center’s mission is to be a source of support to people experiencing cancer. The Center provides resources to people diagnosed with cancer and their families. Thirty-one individuals who had been diagnosed with cancer, and regularly used the Cancer Support Center, were interviewed. During semi-structured in-depth interviews, participants were asked about their experiences of social support both at the Cancer Support Center and more broadly in oncology contexts within the healthcare institution. Transcripts of participants’ interviews were analyzed using constructivist grounded theory (Charmaz, 2014). Coding was conducted systematically using comparative methods (i.e., datum is compared with datum; Charmaz, 2014). The researcher coded the transcripts, using methods described by Charmaz, in order to derive themes related to the research questions. The resulting themes address each of the three specific research questions and are summarized in table form.

Summary and Discussion of Findings

Results were reported in the form of themes that addressed each of the three specific research questions. The following section reviews and discusses those themes in order to answer the specific research questions.

Nature of social support in healthcare. The first research question asked: “What are clients’ perceptions regarding the structural nature, functions, and availability of social support they have experienced in healthcare?” Results were reported separately for two contexts: the Cancer Support Center and the healthcare institution at large. (See Table 1.)

Nature of support at the Cancer Support Center. Participants’ collective responses indicated that they repeatedly experienced social support at the Cancer Support Center. Participants specifically experienced structural support (i.e., in the form of new and
homogeneous social ties) and support that functioned to meet their various needs (i.e., emotional, informational, instrumental, and spiritual support) at the Center. In addition, participants perceived support to be available at the Center in the future as needed.

**Structural support at the Center.** Two themes emerged related to participants’ experiences of *structural support* at the Cancer Support Center (themes 1-2). First, many participants arrived at the Center having experienced diminished structural support following their cancer diagnosis. Second, the Center facilitated social ties through which participants’ experienced structural support. The major finding related to structural support at the Center suggests that participants’ *access to supportive social ties was facilitated through the Center.* Thus, when the support networks of people diagnosed with cancer are diminished (as was the case for many participants in the present study prior to arriving at the Center), cancer support organizations (e.g., the Cancer Support Center, the *4th Angel Mentoring Program*) can facilitate access to new supportive social ties and particularly ties with similar others (i.e., people who also have been diagnosed with cancer).

**Functions of social support at the Center.** Several themes emerged indicating that, through social support experienced at the Center, participants experienced having an array of their needs met. The themes indicate that they received emotional, informational, instrumental, and spiritual support at the Center.

Three themes emerged indicating that participants repeatedly experienced what can be understood as *emotional support* at the Center (themes 3-5). Participants’ noted that, collectively, the Center’s staff members – including its volunteers – as well as other clients have been genuinely caring and friendly and demonstrated empathy and understanding.
Table 1

*Themes Related to Research Question 1: Structural Support, Functions of Support, and Perceived Support*

<table>
<thead>
<tr>
<th>CONTEXT</th>
<th>Form of Support</th>
<th>Theme Number and Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>CANCER SUPPORT CENTER</td>
<td>Structural Support</td>
<td>1 Many clients experienced diminished structural support following cancer diagnosis.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 Structural support is facilitated through social ties developed at the Center.</td>
</tr>
<tr>
<td></td>
<td>Functions of Support</td>
<td>3 Center staff and volunteers are genuinely caring and friendly.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 Staff, volunteers, and other clients demonstrate empathy and understanding regarding clients’ cancer-related experiences.</td>
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<tr>
<td></td>
<td></td>
<td>5 Close relationships with the Center staff, volunteers, and other clients, foster a sense of belonging.</td>
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<tr>
<td></td>
<td></td>
<td>6 The Center provides ready access to cancer-specific information.</td>
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<tr>
<td></td>
<td></td>
<td>7 The Center provides a safe environment in which participants can ask cancer-related questions and get sensitive information.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8 The tangible goods (e.g., wigs) and services (e.g., exercise classes, lymphatic massage) offered free of charge at the Cancer Support Center are especially helpful.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9 The Cancer Support Center is a source of spiritual support.</td>
</tr>
</tbody>
</table>
Table 1 (continued)

*Themes Related to Research Question 1: Structural Support, Functions of Support, and Perceived Support*

**CONTEXT**

<table>
<thead>
<tr>
<th>Form of Support</th>
<th>Theme Number and Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Support</td>
<td>10 The Center is a source of readily available social support because clients previously experienced receiving support there.</td>
</tr>
<tr>
<td></td>
<td>11 The Center offers a substantial quantity of services, resources, and programs.</td>
</tr>
</tbody>
</table>

**HEALTHCARE INSTITUTION**

| Structural Support | 12 The healthcare institution provides clients with ties to supportive healthcare organizations, which thereby enhance clients’ structural support. |
| Functions of Support | 13 Healthcare providers’ spending extensive time in providing cancer-related information is understood as being supportive. |
|                  | 14 Healthcare providers explain information carefully in order to ensure that clients understand complex cancer-related information (e.g., diagnosis, side effects, treatment plans). |
|                  | 15 Healthcare providers are compassionate and caring toward clients. |
|                  | 16 Healthcare providers and staff support clients by helping them to navigate the healthcare system in order to obtain needed resources. |

In addition, participants reported that they developed close relationships with staff and other clients at the Center, which fostered their sense of belonging at the Center. These repeated
reports of staff and other clients enacting behaviors that function as emotional support imply that these behaviors are normative at the Center.

Participants’ accounts indicated that they received substantial informational support at the Center (themes 6-7). They reported that the Center provided ready access to substantial cancer-related information tailored to their needs. Participants collectively reported that Center staff members often helped them find cancer-related information specific to their personal situations. These repeated reports suggest that helping clients locate information is an organizational practice at the Center. That is, multiple participants experienced the same information-giving behaviors enacted by organizational members, thus indicating that helping clients find cancer-related information specific to their needs may be a practice within the organization. Moreover, participants experienced the Center as a safe, comfortable environment in which to seek and discuss highly sensitive cancer-related information.

Participants’ reports further revealed that they received important forms of instrumental support (tangible goods and services) at the Center (theme 8). They indicated that they received tangible goods (e.g., wigs, informational resources) and services (e.g., massage, Reiki) through the Center. Further, receiving these goods and services free of charge was particularly helpful.

Finally, one theme indicated that the Center’s services and activities were a source of spiritual support (theme 9). Specifically, some participants indicated that through conversations at the Center they felt a “connection” to “faith.” Others often reported feeling “centered” and “calmness” as a result of participating in particular Center programs and services (e.g., healing touch, a mindfulness workshop).

**Perceived support at the Center.** Two themes emerged that support the conclusion that participants strongly perceived that support is available to them at the Center in the future as
they need it (themes 10-11). These perceptions appear to be strong for two reasons. First, because they received substantial support at the Center previously, participants perceive that support is available to them in the future. Moreover, participants repeatedly experienced Center staff offering support to them without needing to ask for it (i.e., unsolicited support). Receiving unsolicited support is important in terms of sustaining self-esteem (Eckenrode & Wethington, 1990). Engaging in help-seeking may make a person feel vulnerable, and thereby threaten self-esteem (Nadler, 1983), whereas unsolicited support does not have the same negative impact on self-esteem. The consistency among participant reports related to receiving unsolicited support at the Center implies that offering support resources to clients is a normative organizational practice. Second, the substantial quantities of support resources offered at the Center, as evident in participants’ accounts, logically reinforce participants’ beliefs in the availability of future support. Creating many opportunities for participants to receive support resources potentially appears to be an organizational practice at the Center.

**Nature of support in the healthcare institution.** Participants experienced social support in the healthcare institution at large. First, members of the healthcare institution referred them to support organizations which, in turn, enhanced their structural support. Second, members of the healthcare institution acted in ways that participants interpreted as meeting support needs (i.e., they engaged in emotional, informational, and instrumental support functions). Only a few participants indicated that they perceived support to be available in healthcare organizations, and then only if they request it (i.e., if they engage in help-seeking).

**Structural support in healthcare.** A theme emerged related to the indirect impact of healthcare institutions on participants’ structural support (theme 12). Specifically, participants experienced enhanced structural support (both in network size and relevant homogeneity).
because healthcare providers and healthcare organizations (e.g., hospitals, clinics) informed them of – or referred them to – cancer support organizations (e.g., the Cancer Support Center, the *4th Angel Mentoring Program*). In turn, those support organizations actually facilitated structural support by connecting participants to support staff and to other people who had been diagnosed with cancer.

Cassel (1976) argued that healthcare providers and healthcare organizations have the responsibility to ensure that people diagnosed with cancer have a sufficient support network. Essentially, Cassel believed that healthcare providers and healthcare organizations are uniquely positioned to assess clients’ support resources and make referrals in order to ensure that clients’ support needs are met. Recently, scholars have called for healthcare providers to identify clients who are in need of greater support and to facilitate their access to support (e.g., Mookadam & Arthur, 2004; Street et al., 2009). People diagnosed with cancer may have difficulty accessing support organizations on their own – often because they would not know about those organizations if healthcare personnel do not inform them upon diagnosis (Guidry, Aday, Zhand, & Winn, 1997; Rosenbaum & Smallwood, 2013). People diagnosed with cancer often find it helpful when healthcare providers and organizations intervene by providing referrals to cancer support organizations (Guidry et al., 1997). Most participants in the present study were referred to the Cancer Support Center and/or the *4th Angel Mentoring Program* through healthcare providers and organizations. This highlights the significant impact that such referrals can have on clients’ ability to meet their support needs; indeed such referrals indirectly enhance clients’ structural support by connecting them to support organizations.

*Functions of social support in healthcare.* Participants’ reports indicate that they experienced informational, emotional and instrumental support in the healthcare institution. In
some cases the behaviors that participants perceived to function as social support were narrow in scope (e.g., staff members acting quickly to schedule appointments functioned as instrumental support) or implicit rather than explicit in nature (e.g., providers treating participants like a “person” instead of a “number”).

Two themes emerged in participants’ accounts that support the conclusion that healthcare providers offered substantial informational support (themes 13-14). Specifically, participants reported that their providers spent extensive time explaining complex cancer-related information. They also reported that their providers explained cancer-related information in detail and in a manner to ensure that they understood it. They interpreted these efforts as evidence of support. Participants’ consistent and repeated reports of providers spending extensive time explaining complex-cancer related information so that clients understand it suggest that these information-giving behaviors may possibly be standardized practices within oncology contexts in the healthcare institution.

Participants’ accounts provide evidence of receiving emotional support in healthcare, specifically from their individual providers (theme 15). Their accounts repeatedly characterize their healthcare providers as caring and compassionate. These multiple and consistent reports may indicate that caring and compassionate behaviors are normalized in oncology contexts in the healthcare institution. Further, participants indicate that when providers interact with them in caring ways, they interpret the providers as indicating they are willing to have a relatively more personal and less formal relationship (e.g., being treated like a “person” instead of a “patient”).

Despite the numerous reports of providers being supportive, some participants reported experiences with negative cases in which members of the healthcare institution acted in a highly unsupportive manner. Most of these negative cases involving notably unsupportive behavior that
occurred when their providers were discussing “bad news” (e.g., cancer diagnosis, cancer metastasis; see also Chapter IV, Informational support in the healthcare institution). “Bad news” is information that has a negative impact on the individual receiving the information (Cline & Meluch, in press). Participants indicated that these instances, which they seemed to experience as egregious violations of care, affected them in highly negative ways (e.g., participants reported feeling “overwhelmed” and “terrified” as a result of this highly unsupportive communication). Clearly they expected their providers to be more caring and compassionate.

Finally, participants experienced instrumental support from healthcare staff and providers in the form of helping them to navigate the healthcare system (themes 16-17). That support came in two specific ways. First, participants interpreted providers and staff members quickly scheduling appointments to meet participants’ needs as being sensitive to their own sense of urgency. That is, participants indicated that it was the manner in which the task was carried out (i.e., quickly), rather than completing the task itself (scheduling), that signified support. Second, representatives of healthcare organizations supported them indirectly by intervening with third parties to ensure that participants received needed medical resources (e.g., ensuring pharmacies filled prescriptions on time, working with Medicare to approve claims).

Perceived support in healthcare. Although participants consistently reported that they received social support in the healthcare institution through individual healthcare providers, at the same time only a few perceived support to be available to them in the future, and then only if they would actively request or solicit it. These perceptions related to availability of social support through the healthcare institution are in sharp contrast to perceptions of available social support at the Cancer Support Center, where participants believe that support is readily available to them in the future.
Sources of social support in healthcare. The second research question asked: “What attributions do clients make regarding the sources (e.g., individual, organizational, institutional, other) of social support that they perceive, experienced, or expect to receive in healthcare?” Results were reported separately for two contexts: the Cancer Support Center and the healthcare institution at large. (See Table 2.)

Sources of support at the Cancer Support Center. Two themes emerged related to participants’ attributions of sources of social support at the Cancer Support Center (themes 17-18). They indicate that although participants experienced social support directly from individuals at the Cancer Support Center, they were more likely to credit the organization as the source of social support. Further, participants invoked the mission of the Center as a basis for attributing support to the Center as an organization. In fact, participants unanimously attributed support to the Cancer Support Center as an organizational entity. They did so by crediting the organization itself and the collective staff as sources of support.

Sources of support in healthcare. Two themes emerged related to participants’ attributions of sources of social support within the healthcare institution (themes 19-20). First, participants generally attributed the support they received from individual staff members (e.g., healthcare providers, social workers) directly to those individual sources rather than to the wider healthcare organization. Second, participants characterized the organizations that comprise the healthcare institution at large as businesses whose focus is on the financial bottom line, rather than on providing care. In fact, participants saw the financial/business motivations of healthcare organizations (e.g., “bottom line,” “making money”) as actually interfering with healthcare providers’ ability to care for clients and be supportive.
Table 2

*Themes Related to Research Question 2: Sources of Social Support*

<table>
<thead>
<tr>
<th>CONTEXT</th>
<th>Theme Number and Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CANCER SUPPORT CENTER</strong></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Clients experience social support directly from individuals at the Cancer Support Center, but are more likely to credit the organization as the source of social support.</td>
</tr>
<tr>
<td>18</td>
<td>Clients refer to the mission of the Center as a basis for attributing support to the Center as an organization.</td>
</tr>
<tr>
<td><strong>HEALTHCARE INSTITUTION</strong></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Clients generally attribute the support they receive from individual staff members (e.g., providers, social workers) directly to the individual sources rather than to the wider healthcare organization.</td>
</tr>
<tr>
<td>20</td>
<td>Clients characterize the organizations that comprise the healthcare institution at large as businesses whose focus is on the financial bottom line, which inhibits rather than facilitates support.</td>
</tr>
</tbody>
</table>

Thus, participants perceived that organizational influences actually inhibit rather than facilitate providers’ ability to engage in social support with their clients.

*Benefits of social support in healthcare.* The third research question asked: “What are clients’ experiences and perceptions of the *benefits or potential benefits*, if any, that they associate with social support in their healthcare experiences?” A large literature exists indicating that social support has significant health benefits (e.g., Goldsmith & Albrecht, 2011; Roy, 2011; Uchino, 2004). Whereas the health benefits of the support participants experienced at the Center
were holistic and included positive physical, mental, social, and spiritual health consequences, the health benefits of support in the healthcare institution at large primarily related to physical health. Results were reported separately for two contexts: the Cancer Support Center and the healthcare institution at large. (See Table 3.)

**Benefits of support at the Cancer Support Center.** Participants experienced holistic health benefits as a result of their participation in Center activities and use of Center services. Four themes emerged that characterize the health benefits of support experienced at the Cancer Support Center (themes 21-24). These benefits related to social, emotional, mental, and physical health.

Participants reported feeling isolated due to their cancer diagnosis and treatment prior to coming to the Center. Through their interactions at the Cancer Support Center participants came to feel less isolated. Outside of the Center they were stigmatized; that is, they were sometimes treated as not “normal” and/or “different.” However, in the Center’s open and welcoming environment they were treated as “normal” and as part of the “us” (one of many people experiencing cancer) rather than as one of “them.”

Participants also reported experiencing significant changes to their life perspectives following their cancer diagnosis. Participants’ experiences of life-altering changes can be understood as transformation. “Transformation” occurs when individuals experience an event (e.g., a cancer diagnosis) that changes their outlook on life and often results in changes to core values and behaviors (e.g., interpersonal values affect relationships with others; health and wellness behaviors; Thombre & Rogers, 2009). Other people who had not been diagnosed with cancer often did not understand or sometimes even acknowledge participants’ transformative experiences and related changes in life perspectives.
Table 3

Themes Related to Research Question 3: Benefits of Social Support

<table>
<thead>
<tr>
<th>CONTEXT</th>
<th>Theme Number and Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>CANCER SUPPORT CENTER</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Clients feel isolated and alone due to their cancer diagnosis and treatment; however, their interactions at the Cancer Support Center reduce that isolation.</td>
</tr>
<tr>
<td>22</td>
<td>Clients, who report being treated as not “normal” and/or “different” elsewhere, feel comfortable and treated normally at the Cancer Support Center.</td>
</tr>
<tr>
<td>23</td>
<td>Clients report significant changes to life perspectives following diagnosis and perceive that they can be open about those changes at the Center.</td>
</tr>
<tr>
<td>24</td>
<td>Clients relax and experience stress relief as a result of participating in activities and using services at the Center.</td>
</tr>
<tr>
<td>HEALTHCARE INSTITUTION</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>When clients feel supported by members of the healthcare institution, they feel comfortable with and more likely to follow their providers’ suggested treatment regimens.</td>
</tr>
<tr>
<td>26</td>
<td>Clients gain access to cancer-related resources because of support they receive in healthcare.</td>
</tr>
</tbody>
</table>

However, participants could be open about their transformative life changes at the Center and felt that the staff and other clients accepted and understood their new life perspectives.

Finally, participants reported that the use of integrative services and participation in Center activities were relaxing and relieved stress, factors that affect both physical and mental
well-being. In addition, some participants reported experiencing additional physical health benefits, such as pain relief and reduced nausea, as a result of participating in the Center’s activities and services.

Participants’ reports indicated that, outside of the Center, they often had negative interpersonal experiences (e.g., isolation, stigmatization, invalidation). However, through the Center, participants were able to interact with others like themselves, which helped to reduce their sense of isolation, made them feel part of a community of people with similar experiences, validated their transformation, and provided them with an array of holistic health benefits.

Benefits of support in healthcare. Participants experienced health benefits as a result of the support they received in the healthcare institution at large, but these benefits were limited largely to physical health. Two themes emerged that relate to benefits of support experienced in the healthcare institution at large (themes 25-26).

First, because of receiving social support from their providers, participants felt comfortable with and were more willing to follow – or adhere to – those providers’ suggested treatment regimens (e.g., chemotherapy, surgery). Prior scholarship has supported the existence of a positive relationship between social support and adherence to suggested treatment regimens (e.g., DiMatteo, 2004; Squier, 1990; Zolnierek & DiMatteo, 2009). Receiving social support from providers may be especially critical for people experiencing cancer because adherence in oncological contexts often is both highly challenging (e.g., due to side effects of treatment) and critical for survival.

Second, participants gained access to resources (e.g., medical equipment, expensive skincare) because of support they received in the healthcare institution. Prior research has indicated that people diagnosed with cancer need help navigating the healthcare system in order
to obtain resources (Quillen et al., 2009; Sloan & Knowles, 2013). The present findings indicate that, because providers and healthcare staff members offered support to clients, clients were able to obtain needed health-related resources (e.g., insurance coverage, disability benefits, medications, medical equipment, expensive skincare products).

Although participants experienced health benefits as a result of support from both the Cancer Support Center and the healthcare institution at large, the benefits due to support at the Center were more diverse (e.g., emotional, spiritual, physical) than in the healthcare institution, where benefits related mainly to physical health. This contrast is perhaps not surprising. In general, healthcare organizations (e.g., hospitals, cancer treatment center) not only have the mission to provide medical care and to promote physical health, they tend to follow a biomedical model of healthcare (a model that gives primacy, and sometimes exclusivity, to physical health; Engel, 1980). Cancer support organizations often also promote physical health and wellness, but may be more likely to do so by following a holistic model of healthcare that addresses health from a multidimensional approach.

**Summary of Discussion of Findings.** In summary, participants experienced social support through both the Cancer Support Center and the healthcare institution at large. Participants’ experiences at the Center and in the healthcare institution indicate that they were connected to structural support (i.e., new supportive ties) through support organizations; they often had been referred to these support organizations through clinical healthcare organizations. Participants’ reports of receiving social support at the Center that addresses various support functions (e.g., informational, emotional, instrumental, spiritual) suggest that the Center is an important support resource for meeting participants’ needs. Participants’ reports of receiving social support through the healthcare institution also indicate the relative prevalence of particular
members of the healthcare institution (i.e., most often doctors) acting in a manner they perceived to be supportive. Although participants attributed support to the Center as an organizational entity, participants generally viewed individuals, rather than the healthcare organizations themselves, as the sources of support within the broader healthcare institution. On the contrary, participants believed that healthcare organizations often interfere with clients receiving care and support. Finally, participants experienced health benefits because of social support provided at the Center and in the healthcare institution. However, they experienced more holistic health benefits (e.g., mental, emotional, social, physical) through the Center, whereas they experienced primarily physical health benefits through the healthcare institution. Together the study findings suggest critical processes associated with social support, and possible relationships among them, that lead to important perceived outcomes (i.e., institutionalized social support, health benefits). These posited processes and relationships are presented and discussed in the form of an emergent model.

**Emergent Model**

The findings of the present study and prior research form the basis for an emergent model of clients’ perceptions of institutionalized social support and experience of health benefits in healthcare organizations (see Figure 2). The model depicts how clients experience social support and related processes within healthcare organizations and proposes how these processes influence perceptions of institutionalized social support and experiences of related health benefits.

**Perceptions of social support at the Cancer Support Center.** People diagnosed with cancer experience substantial social support at the Cancer Support Center.
Figure 2. A model of perceptions of processes related to social support in healthcare organizations.
The emergent model proposes that the social support and related processes that clients experience at the Center lead to perceptions of institutionalized social support and holistic health benefits. In the proposed model, the perception of institutionalized social support emerges from dynamics that create the experiences of normalized received support, perceived support, and a culture of caring. The model also proposes that holistic health benefits emerge from dynamics that create clients’ experience of normalized received support, socioemotional processes, and perceived support.

**Clients’ decisions to come to the Center.** According to the proposed model, two factors influence clients’ decisions to come to the Center: (a) *inadequate social support* in their personal networks, and (b) *referrals to the Center* from healthcare providers.

*Inadequate social support* is the experience of not receiving a sufficient quantity and/or needed quality of social support in one’s personal network (e.g., family members, friends). According to the emergent model, clients experience inadequate social support following their cancer diagnosis. Numerous participants in the present study experienced inadequate social support in their personal support networks, including diminished social support, distancing, avoidance, and abandonment. Prior research indicates that people diagnosed with cancer commonly experience inadequate support (e.g., Dunkel-Schetter, 1984; Hegleson & Cohen, 1995; Wortman & Dunkel-Schetter, 1979). Other people commonly avoid them and/or avoid discussing the cancer diagnosis, stigmatize them, and/or minimize their problems and feelings. The emergent model proposes that clients’ experience of inadequate social support influences decisions to come to the Cancer Support Center.

A second influence on clients’ decisions to come to the Center is *referrals to the Center* by healthcare providers. Many participants in the present study decided to go to the Center after
healthcare providers recommended that they visit the Center and/or gave them information about the Center (e.g., brochures, information cards). Guidry et al. (1997) argued that healthcare providers’ referrals to cancer support resources (e.g., cancer support organizations, support groups) influence whether people diagnosed with cancer will choose to use these resources. As a result of such referrals, clients may view going to the Center as unsolicited support. That is, clients may perceive that referrals are offers of support that they can choose to accept, rather than needing to engage in help-seeking. Help-seeking requires individuals to disclose personal vulnerabilities and weaknesses which can have negative psychological effects, such as reduced self-esteem and threats to identity (Nadler, 1983). In contrast, unsolicited support is particularly helpful because accepting freely offered support is less likely to threaten one’s self-esteem or identity (Eckenrode & Wellington, 1990). Thus, clients who are referred by their providers to the Center may perceive that support at the Center is unsolicited and, thus, less threatening, and therefore may be more likely to come to the Center.

**Enhanced network support.** Enhanced network support refers to improvements to the size and/or quality of clients’ social networks. According to the model, clients experience enhanced network support at the Center, specifically in terms of both network size and relevant homogeneity. In the present study, participants’ support networks increased in size as a result of developing new social ties at the Center. Many of these new ties also enhanced relevant homogeneity (i.e., similarities among social ties); that is, clients developed relationships with other people who also had been diagnosed with cancer. People diagnosed with cancer often believe that individuals with cancer are better able to understand their experiences than other people (e.g., Ussher et al., 2006), resulting in greater social support. According to the model, enhanced network support results in clients actually receiving substantial social support at the
Center, which they experience as normalized.

_Normalized received support_. Received support is support that is enacted or actually provided. In the emergent model, clients experience received support as normalized when it is consistently and repeatedly provided at the Center. The model proposes that clients experience social support as normalized at the Center under four conditions: (a) all individuals provide support, (b) support is consistent over time, (c) support is unsolicited, and (d) support fulfills numerous and varied functions.

In the present study, participants experienced support received at the Center as normalized. First, all individuals at the Center (e.g., staff, volunteers, other clients) provided support to participants, regardless of whether providing support is a responsibility associated with their organizational roles (e.g., Office Manager, Housekeeper). Second, participants experienced receiving support at the Center over time rather than as isolated episodes. In fact, some participants observed other individuals (e.g., family members) repeatedly receiving support at the Center prior to going to the Center themselves. Third, clients experienced much of the social support they received at the Center as unsolicited in nature (see Clients’ decisions to come to the Center). Fourth, the support that participants received at the Center served multiple functions and, thus, met multiple needs. Participants received emotional, informational, instrumental, and spiritual support at the Center.

The emergent model proposes that clients perceive that _normalized received support_ influences their experiences related to:

- Perceived support;
- Socioemotional processes;
- Culture of caring;
• Holistic health benefits; and
• Institutionalized social support.

First, the model proposes that when clients experience normalized received support at the Center they develop the belief that, because they have received support in the past, it will be available in the future (i.e., perceived support). Second, when clients experience normalized received support at the Center, the positive supportive interactions with all of the individuals at the Center leads them to feel accepted and understood, feel treated as normal, and believe that their realities are validated (i.e., positive socioemotional processes). Third, clients attribute support to the organization (i.e., culture of caring) because it is normalized; that is, it is consistent and repeatedly provided by all individuals (e.g., staff, other clients) at the Center. Thus, clients perceive that instead of support emanating from one or more individuals, in fact, support emanates through the combined and consistent supportive actions of collective individuals acting on behalf of the Center. These consistent and supportive actions enacted by the collective individuals at the Center function to enact organizational norms, policies, and practices. A reflexive relationship exists between normalized received support and the culture of caring. Specifically, the consistent and substantial support provided by all individuals at the Center indicates to clients that social support is normalized at the Center (i.e., normalized received support). The normalization of social support creates the impression of a culture of caring at the Center. However, the organizational culture (i.e., culture of caring) also serves to maintain and reinforce supportive behaviors as normative at the Center. That is, the culture of caring creates expectations for supportive behaviors that are consistently enacted by all individuals at the Center. Fourth, received social support (e.g., information, relationships, services) helps clients to manage stress, uncertainty, and pain, which results in clients experiencing holistic health benefits.
(i.e., mental, social, physical). Prior research also supports a strong association between receiving social support and experiencing health benefits (e.g., Roy, 2011; Uchino, 2004, 2009).

Fifth, the emergent model proposes that clients’ experience and perceptions of normalized support at the Center is one of three factors that contributes directly to perceiving that the support is institutionalized (i.e., *institutionalized social support*). The consistent and repeated experiences of social support at the Center create the perception among clients that social support is standardized, habitual, and understood as legitimate (i.e., they are institutionalized).

**Perceived support.** Perceived support is the belief that support will be available in the future if needed (e.g., Cohen & Wills, 1985). The emergent model proposes that clients experience perceived support at the Center. In the present study, participants who experienced normalized received support at the Center perceived that support would be available at the Center in the future if needed. This finding is consistent with previous research which established that perceived support is informed by having received support in the past from a particular source (Hobfoll, 2009).

The model further proposes that *perceived support* influences clients’ perceptions related to:

- Culture of caring;
- Holistic health benefits; and
- Institutionalized social support.

First, the model proposes that clients attribute perceived support to the Center’s *culture of caring*. That is, the Center’s culture of caring is a source of *perceived support* (i.e., future available support) because that culture of caring has been a source of received support in the past. A reflexive relationship exists between perceived support and the culture of caring. Clients’
perceived support and the culture of caring influence one another, whereby perceptions of available support reinforce the culture of caring and the culture of caring serves to maintain perceptions that support will continue to be available in the future. Second, according to the model, clients experience holistic health benefits as a result of perceived support. When clients perceive support to be available in the future, they experience relatively less stress and uncertainty regarding whether they will have sufficient support. Experiencing less stress and uncertainty is important because stress can negatively affect both physical and mental health (E. Scott, 2014). Previous research also has established that perceived support commonly results in positive physical and mental health outcomes (e.g., Barrera, 1986; Cohen & Wills, 1985). Third, clients’ perceived support is one of three factors that contribute directly to perceptions of institutionalized social support. That is, when individuals develop the perception that support will be available in the future they perceive that within the organization the behaviors that function as support are standardized, habitual, and legitimate (i.e., support is institutionalized).

Socioemotional processes. In the proposed model, socioemotional processes are the social interactions that create positive or therapeutic psychosocial processes. The emergent model proposes that clients experience four positive socioemotional processes as a result of receiving social support: (a) feeling accepted, (b) feeling understood, (c) feeling that others are treating them as normal, and (b) believing that their realities are validated.

Participants in the present study reported that they felt accepted, rather than rejected and judged (which commonly occurred in personal networks), at the Center. They also reported that they felt understood because of the empathy provided by others at the Center. Participants experienced stigmatization outside of the Center, but experienced being treated as normal at the Center. Participants’ transformative experiences often were dismissed and/or misunderstood by
According to the emergent model, clients’ experience of positive socioemotional processes result in holistic health benefits (i.e., social, mental, physical). Clients experience positive social processes at the Center (e.g., feeling accepted and understood) that have therapeutic effects which, in turn, result in better social, mental, and physical health (e.g., reduced social isolation, reduced anxiety, reduced pain,).

**Culture of caring.** The term *culture of caring* refers to clients’ perception that the Center, as an organization, is itself a source of support. A culture of caring develops out of the enactment of collective and normalized supportive behaviors at the Center. The fact that received support is normalized leads clients to attribute support to the organization as a whole rather than just to individuals.

In the present study, all participants attributed support directly to the Center as an organizational entity. The unanimous attribution to the Center as the source of support implies that the Center, as an organizational entity, shapes and likely facilitates the social support that clients experience. The emergent model proposes that the *culture of caring* at the Center is one of three factors that contribute to the perception of institutionalized social support. Clients’ consistent experience of supportive behaviors as part of the culture of the organization contributes to their perception that they these behaviors are standard, habitual, and legitimate within the organization (i.e., the behaviors are institutionalized).

**Holistic health benefits.** *Holistic health benefits* are positive health outcomes that occur across multiple dimensions of health (i.e., social, mental, and/or physical health, often-cited definition of health from the WHO, 1948). The emergent model proposes that clients experience holistic health benefits as a result of social support and related processes.
In the present study, participants experienced health benefits at the Center that affected their social, mental, and physical wellbeing. In particular, they felt less socially isolated, they experienced reduced stress, and they gained relief from pain as a result of the social support and related processes that they experienced.

**Institutionalized social support.** Institutionalized social support refers to supportive behaviors that are standardized (i.e., rule-like), habitualized (i.e., customary), and legitimate (i.e., acceptable) to the extent that they are taken-for-granted aspects of life within an organization. According to the emergent model, clients’ experiences of social support and related processes at the Center result in the perception that social support is institutionalized at the Center. As indicated by the model, normalized received support, a culture of caring, perceived support, and positive socioemotional processes contribute directly to the perception of institutionalized social support.

**Perceptions of social support within the healthcare institution at large.** The emergent model proposes that social support provided by individual healthcare providers within the healthcare institution at large creates dynamics that ultimately contribute to physical health benefits.

**Profit motive.** Profit motive refers to clients’ perception that a primary incentive of healthcare organizations is financial gain. The model proposes that clients perceive that the financial incentives of healthcare organizations negatively affect the social support they receive from individual providers and staff within healthcare organizations, as well as from the organizations themselves.

Participants in the present study identified the profit motive of healthcare organizations as a factor that negatively affects the support that they receive from individual providers and staff.
Specifically, they contended that healthcare organizations limit staff size and the amount of time that providers can spend with clients, which results in less access to social support from providers.

**Provider social support.** Provider social support refers to the social support that clients actually receive from their healthcare providers and other staff members. According to the proposed model, clients primarily receive social support in the healthcare institution at large from individual healthcare providers. Participants in the present study reported experiencing social support from healthcare providers and, to a lesser extent, from other staff members. First, participants experienced compassion and caring from providers, which functioned as emotional support. This compassion and caring was communicated implicitly rather than explicitly. That is, providers communicated caring by carrying out their job in a supportive manner (e.g., responding with urgency to clients’ scheduling needs, spending extensive time explaining complex cancer-related information). Second, participants received substantial information from their providers, which functioned as informational support. Third, participants experienced instrumental support when providers intervened with third parties (e.g., pharmacies, Medicare, insurance companies) to ensure that they received needed medical resources. Extant literature also indicates that providers offer social support that serves informational, emotional, and instrumental functions for people diagnosed with cancer (e.g., Hegleson & Cohen, 1995; Neuling & Winefield, 1988; Sloan & Knowles, 2013).

Although the emergent model clarifies specific functions of support offered by providers, provider referrals to the Center is a specific example of informational support relevant to the model (i.e., referrals connect clients in clinical healthcare organizations that treat cancer to the Center). Providers’ referrals to the Center effectively function to facilitate clients’ structural
support. Participants in the present study indicated that providers’ referrals to the Center influenced their decision to come to the Center (see Factors that influence clients’ decisions to come to the Center).

The emergent model proposes that provider social support is associated with having a personalized relationship with providers and with access to medical resources. First, according to the emergent model, clients who receive support from providers believe that they have a relatively personalized relationship with them. Participants in the present study indicated that because their providers acted in a manner that indicated that they care about them (e.g., implicit compassion and caring, providing extensive information), participants perceived that they had a relatively personalized relationship with them. Second, according to the model, when providers intervene with third parties, as a form of support, clients have access to medical resources. Participants in the present study indicated that their providers were caring and responded to their urgent needs by intervening with third parties (e.g., Medicare, pharmacies) so that they were able to obtain important medical resources (e.g., bi-pap machine, medications, third party payment coverage) that they could not otherwise access.

**Personalized relationship.** Personalized relationship refers to clients’ perception that they have a relatively more personalized relationship, in contrast to a formal one, with their providers. Providers’ implicit relational metacommunication specifically creates the impression that providers care about their clients as people and, thus, clients perceive that they have a relatively personalized relationship with those providers. Participants in the present study perceived that their providers carried out their work in ways that indicated that they cared about the participants (e.g., responded to participants’ urgent needs, were caring and compassionate). These implicitly caring behaviors led participants to conclude that they have a relatively
personalized relationship with these providers.

According to the model, having a relatively more personalized relationship with healthcare providers leads clients to feel more at ease with decision-making processes related to treatment. When providers act in ways that create the impression of a caring and personal relationship with clients, clients perceive that their providers are treating them like a “person” instead of a “patient.” Being seen as a “person” instead of a “patient” means, in part, that providers care about the physical, mental, and/or emotional effects of the treatment (e.g., high dose of chemotherapy, permanent colostomy surgery) in negotiating treatment decisions with their clients. Clients who perceive that their providers include their concerns in decision making, are more likely to trust their providers and to trust the treatment regimens that they suggest. In the present study, participants experienced comfort with making treatment-related decisions. For example, participants implied that when their providers demonstrated that they cared about their concerns (e.g., telling a participant that because they do not want her to experience more intense side effects they will lower chemotherapy dosage, reassuring a participant that surgical procedure would not ruin her life), the participants trusted both the providers and the treatment regimens they recommended. Because participants believed their providers were concerned about the physical and mental effects they could experience as a result of the proposed treatment, the participants felt relatively more comfortable with the decision-making process regarding treatment.

Comfort with treatment decision-making. Comfort with treatment decision-making refers to clients feeling comfortable with and trusting their providers during treatment decision-making because they perceive that their providers are considering their perspectives and concerns and are willing to adjust their recommendations to accommodate client wellbeing (e.g.,
considering a different dosage of chemotherapy dosage, considering a different surgery). The model proposes that clients who are comfortable with treatment-related decisions are relatively more likely to follow the treatment regimens recommended by and/or negotiated with their providers.

In the present study, participants who felt comfortable when making treatment-related decisions potentially were relatively more likely to follow the treatment regimens. When participants felt that their providers were willing to negotiate and adjust their recommendations to meet clients’ concerns, they felt comfortable with the treatment decision-making process. According to the emerging model, when clients perceive that their providers have responded to their concerns they will adhere to the negotiated treatment regimen. Specifically, when clients perceive that their treatment regimens have been adjusted to meet their needs, they are relatively more likely to follow the treatment regimen.

Adherence to negotiated treatment regimens. Adherence to negotiated treatment regimens refers to clients actually following the treatment regimen recommended by and/or negotiated with their providers. The model proposes that when clients adhere to negotiated treatment regimens (e.g., chemotherapy, surgery) they experience physical health benefits. Clients choose to follow, or not follow, the treatment that has been recommended by their providers. According the model, when clients actually receive the treatment because they adhere to the recommended or negotiated treatment regimens, they experience relatively better health outcomes. Prior research indicates that adherence to treatment regimens (e.g., chemotherapy, surgery) is associated with proved physical health outcomes (e.g., remission of cancer; DiMatteo, 2004; Zolnierek & DiMatteo, 2009).
Medical resources. Medical resources refers to medical equipment, medications, and other medical-related resources (e.g., medical tests) that clients need in order to complete planned medical care. The model proposes that when clients obtain the medical resources they need, their physical health improves. Specifically, obtaining medical resources (e.g., medication, medical equipment) is important because these resources allow clients to continue and/or complete their planned medical care, which in turn, results in physical health benefits. In the present study participants were able to obtain the medical resources that they needed (e.g., medical equipment, medication), which allowed them to potentially complete their medical care (e.g., take the medication, use the medical equipment) and potentially resulted in better physical health (e.g., less pain, better sleep).

Physical health benefits. Physical health benefits are positive physical health outcomes (e.g., less pain, quicker recovery time from surgery) that ultimately result from social support and related processes. According to the model, physical health benefits result directly from adherence to negotiated treatment regimens and access to medical resources needed to complete medical care. Specifically, when clients actually receive the treatment and medical resources needed to complete their planned medical care, they are able to continue and/or complete the medical care, which results in better physical health outcomes.

Discussion of emergent model. According to the emergent model, clients’ perceptions and experiences of social support and its outcomes differ in the context of the Cancer Support Center versus in the healthcare institution at large. They differ in terms of clients’ perceptions of institutionalized social support, clients’ attributions of sources of support, and the nature of the health benefits clients experience as a result of social support and related processes.

The model proposes that clients experience institutionalized social support at the Cancer
Support Center. According to the model, the first key difference between clients’ experiences of support is that clients perceive social support to be institutionalized at the Cancer Support Center, but not in the healthcare institution at large. This difference is significant in the context of the present research because it speaks directly to the overarching research question that guided the study. That question was: *What is the nature of social support that clients experience and perceive as institutionalized in healthcare organizations?*

The model proposes that clients experience and perceive institutionalized social support at the Center as a result of three specific social dynamics. They are: *normalized received support, perceived support,* and *a culture of caring.* Culture of caring arguably is the most critical process necessary for clients to experience and perceive social support as institutionalized.

The first social dynamic that leads directly to the perception of institutionalized social support is normalized received support. The model posits that clients who experience normalized received support at the Center perceive that social support is institutionalized. Clients’ consistent and repeated experiences of social support at the Center create the perception that social support is standardized, habitual, and understood as legitimate (i.e., it is institutionalized).

The second social dynamic that leads directly to the perception of institutionalized social support is perceived support. Clients’ past experience of receiving normalized support informs their perceptions about the availability of future support, which logically matches their past perceptions (i.e., that the support they have received is institutionalized). That is, when clients perceive that support available in the future they are more likely to perceive that the behaviors that function as support within the organization are standardized, habitual, and legitimate (i.e., support is institutionalized in that organization).

The third, and most critical, social dynamic that contributes directly to perceived
institutionalized support is a culture of caring. Clients who experience and perceive social support throughout their collective interactions within healthcare organizations attribute social support to the culture of caring. This culture of caring reinforces and maintains the standardization, habitualization, and legitimization of institutionalized social support. Thus, the culture of caring is critical to the sustainability of institutionalized social support in healthcare organizations.

According to the proposed model, together these three social dynamics contribute directly to clients’ experiences and perceptions of institutionalized social support. The culture of caring, however, is the most critical social dynamic contributing to clients’ perceptions of institutionalized social support. Within the healthcare institution at large, clients’ perceptions of receiving social support emanate from *individuals* rather than from *a culture of caring*. This is the case because, within the healthcare institution at large, clients experience social support as coming primarily from their individual healthcare providers. Receiving support solely or largely from individual providers in the healthcare institution at large signifies to clients that the support they receive is the result of caring individuals, rather than the enactment of standardized, habitual, and legitimate supportive behaviors within the organization or across organizations (i.e., they do not experience social support as institutionalized in the healthcare institution at large). Thus, clients’ perceptions of *institutionalized social support appear to occur when they have experienced a culture of caring instead of caring individuals*.

According to the model, a second key difference between clients’ experiences of social support at the Center and within the healthcare institution at large is that clients attribute social support to different sources in the two contexts. At the Center clients attribute support to *the Center*, as an organization; this suggests that they perceive a culture of caring at the Center. In
contrast, in the healthcare institution at large they attribute social support to *individual healthcare providers*. The model suggests that *for clients to attribute social support to the organization, the organization must have a caring culture in which social support is clearly perceived as normalized*.

The organizational culture (i.e., a culture of caring) of the Center is founded on the collective enactment of the Center’s norms, policies, and practices. For example, participants expressed that collectively the Center’s staff are friendly, caring, and welcoming, which suggests that staff members were enacting organizational norms. Participants’ reports also indicated that staff members offer support to them without participants requesting help; they also help clients to locate personalized cancer-specific information. These accounts imply the enactment of organizational practices. Finally, participants discussed receiving support through the Center’s policy of providing services free of charge. All participants in the present study attributed support directly to the organization; this indicates that the organization creates a culture of caring that facilitates clients’ social support. However, within the healthcare institution at large, participants attributed support almost solely to individuals, rather than to healthcare organizations. Participants perceived that providers who were supportive were caring individuals, acting on personal values, rather than staff members who were supportive because they were enacting organizational norms, practices, and/or policies (i.e., they did not perceive a culture of caring in the healthcare institution at large). Thus, from participants’ perspective, in the healthcare institution at large, healthcare organizations do not have norms, practices, and/or policies in place that facilitate the communication of social support. Moreover, participants often perceived that healthcare organizations within the healthcare institution at large often have profit motives that actually interfere with the social support they received.
According to the model, a third key difference between clients’ experiences of social
support at the Center and within the healthcare institution is found in the nature of the health
benefits experienced in the two contexts. The emergent model proposes that clients experience
*holistic* health benefits, or benefits on multiple dimensions of health (i.e., mental, social,
physical), as a result of social support and related processes at the Cancer Support Center. In
contrast, the model proposes that clients largely, if not solely, experience *physical* health benefits
within the healthcare institution at large.

Normalized received is the most critical and central social process that leads to holistic
health benefits at the Center. Normalized received support contributes to reducing clients’ stress,
which, in turn, contributes to multiple dimensions of clients’ health. Stress is associated with
negative physical and mental health outcomes; therefore reducing stress has mental and physical
health benefits. Further, clients’ perceptions that support is available to them when needed, helps
to reduce stress. The model suggests that five differences exist between normalized received
support experienced at the Center and social support from individual healthcare providers
experienced in the healthcare institution at large, that, in turn, result in differences in health
benefits experienced in the two contexts.

First, all individuals at the Center provide support, which results in clients receiving
substantial support. In contrast, within the healthcare institution at large, clients receive support
primarily from individual healthcare providers. Second, support often is offered to clients (i.e.,
is unsolicited) at the Center. Because support is offered, instead of requested, clients may be
more likely to perceive that it is available in the future as needed (i.e., perceived support). In
contrast, support more often needs to be requested (i.e., clients must engage in help-seeking to
gain support) within the healthcare institution at large. Third, social support is experienced over
time and with greater continuity at the Center compared to the healthcare institution at large where social support generally is provided in isolated episodes.

Fourth, at the Center, clients receive both explicit and implicit support, but much of the support is communicated explicitly (e.g., helping clients locate cancer-specific information, staff members listen to clients to understand). In contrast, within the healthcare institution, clients receive support that is more often implicit than explicit (e.g., spending extensive time providing cancer-related information, providers act in a caring and compassionate manner when carrying out their work). Fifth, support provided at the Center addresses multiple functions (i.e., emotional, informational, instrumental, spiritual). However, support that clients receive within the healthcare institution at large tends to be limited to needs related to medical care.

The differences in the types of benefits that clients experience in the two contexts is rooted in the expansiveness of support that clients experience at the Center in contrast to healthcare institution at large. At the Center, clients receive a substantial quantity of support at the Center that is communicated consistently by numerous individuals, across time, and addresses a range of health dimensions (e.g., identity, anxiety, pain, stress). In contrast, clients’ experiences of provider social support within the healthcare institution at large are limited. That is, clients receive a limited amount of support through their healthcare providers that primarily address physical health dimensions (e.g., pain, preventing cancer metastasis).

Contributions to the Literature

The findings of the present study and the proposed model that emerges from those findings, which examined the nature of social support that clients experience and perceive as institutionalized in healthcare organizations, make three primary contributions to the scholarly literature. Those contributions relate to organizational and institutional influences on social
support in healthcare, expanding the concept of social support to include organizational as well as individual sources of support, and understanding the potential importance of the role and impact of implicit metacommunication in providers’ communicating social support and negotiating and defining the nature of provider-client relationships.

**Establishing institutionalized social support within healthcare organizations may require normalized received support, perceived support, and a culture of caring.** The present study and the emergent model suggest that, *in order for clients to perceive institutionalized social support in healthcare organizations, those organizations may need to provide normalized received support, develop perceptions of future available support, and create an organizational culture of caring.* When behaviors are normalized, or commonly exhibited, within an organizational and/or institutional context they also may come to be understood as institutionalized (Zucker, 1977). Institutionalization is defined as the process through which beliefs and norms are established, standardized (i.e., rule-like), habitualized (i.e., customary), and legitimatized (i.e., acceptable) through patterns of behavior to the extent that they are considered taken-for-granted aspects of life within and across organizations (Zucker, 1977). Identifying clear institutionalizing processes through which social support is normalized *across* healthcare organizations – and thus across the healthcare institution – would require investigating multiple organizations and, thus, is beyond the capacity of the present research. However, the present findings support an emergent model that posits that normalized received support, perceived support, and a culture of caring contribute directly to perceptions of institutionalized social support within a healthcare organization.

First, the emergent model proposes that clients’ experience of social support as normalized at the Center results in their perceptions of institutionalized social support.
Participants reported that the Center’s staff collectively act in ways (e.g., friendly, understanding, caring, welcoming) that are indicative of social support being normalized (i.e., normalized received support). Clients’ perceptions of normalized received support at the Center are reinforced by their experience of all staff members enacting caring, whether or not their organizational/job-related roles involve providing support (e.g., the Housekeeper and Office Manager also are supportive). In addition, Center staff members repeatedly engage in supportive actions (e.g., offering unsolicited support resources, helping clients locate cancer-related information) that appear to constitute organizational practices of caring. Finally, the normalized received support that clients experience at the Center serves multiple functions (i.e., emotional, informational, instrumental, spiritual) and, thus, meets clients’ multiple needs. The normalized received support that clients consistently and repeatedly experience at the Center contributes to their perceptions of institutionalized social support. Specifically, when clients experience social support in consistent and repeated ways, they may perceive that it is a standardized, habitualized, and legitimate aspect of organizational life.

Previous research has not established whether social support can come to be normalized within an organization through supportive norms, practices, and policies. Further, prior research had not investigated the role of normalized received support in developing clients’ perceptions of institutionalized social support. The emergent model posits that normalized received support contributes to the perception of social support being institutionalized.

Second, the emergent model proposes that clients’ perception of availability of support in the future contributes to perceived institutionalized social support. Clients’ past experiences with receiving normalized support at the Center contribute to their perceptions of perceived support (i.e., support is available in the future). Participants who perceive that normalized social support
will also be available in the future are likely to perceive that social support is habitual within the organization (i.e., institutionalized). Prior research has not considered whether perceived support can be influenced by the norms, practices, and policies of an organization, and in turn, can influence clients’ perceptions of institutionalized social support.

Third, the emergent model proposes that clients’ perceptions of a culture of caring contribute to perceived institutionalized social support. Participants’ reports indicate that they perceive the Center, as an organization, to be the source of the support they experienced there. Moe specifically, participants attribute the support they have received at the Center directly to the Center’s organizational culture of caring. An organizational culture is created, enacted, and maintained through the communication of organizational norms and practices.

Although normalized received support and perceived support also are experienced through repeated and consistent enactment of supportive norms, practices, and policies, experiencing a culture of caring arguably is the most critical social process that leads to clients’ perceptions of institutionalized social support within a healthcare organization. Specifically, the norms, practices, and policies that influence clients’ perceptions of social support being institutionalized are developed, reinforced, and maintained through the culture of caring. Specifically, the culture of caring establishes what behaviors are accepted as standard, commonly enacted (i.e., habitual), and legitimate, which, in turn, leads to their institutionalization. Thus, the culture of caring is critical to determining how certain behaviors come to be perceived as taken-for-granted aspects of life within the organization.

Clients’ experiences of social support at the Center suggest that, indeed, organizational norms and practices at the Center undergird an organizational culture that contributes to the communication of social support among organizational members and the organization’s clients.
Organizational culture’s contribution to clients’ perceptions of the communication of social support in healthcare contexts has not previously been established. Although prior research found that the organizational culture in healthcare contributes to healthcare providers’ perceptions of their ability to provide social support to clients (Ansmann et al., 2014), research had not examined clients’ perspective in this context. Further, previous research had not considered if – or how – organizational culture contributes to perceptions of institutionalized social support. The supportive and caring organizational norms and practices consistently implied in participants’ multiple accounts in the present study undoubtedly explain why clients may perceive an organization’s culture of caring – more than an organization’s individual members – as contributing to institutionalized social support.

Although, participants experienced social support as relatively prevalent within both the Cancer Support Center and the healthcare institution, their perceptions of institutionalized social support differed in the two contexts. Clients perceived social support to be institutionalized at the Center but not within the healthcare institution at large. The very nature of social support that participants experienced at the Cancer Support Center differed from support experienced in the healthcare institution at large. For example, social support often was communicated explicitly as well as implicitly at the Center; but the supportive communication that participants described in the healthcare institution at large often was communicated implicitly. Participants also were more likely to report some experiences of non-supportiveness and inappropriate behavior in the healthcare institution. Finally, although participants consensually attributed social support to the Center as an organizational entity, they generally attributed social support to individual providers in the healthcare institution rather than more widely to the healthcare organizations.

Participants’ reports of receiving social support through members of the healthcare
institution, and in particular from physicians, suggest that such behaviors may be normalized to some degree across healthcare organizations. However, it is not at all clear what the source of the normalization of such behaviors is or the extent to which these behaviors are institutionalized across healthcare organizations. Three types of evidence question whether or the extent to which these behaviors are actually institutionalized across organizations. First, participants perceived that members of the healthcare institution (especially physicians) commonly, but not always (e.g., in healthcare organizations other than the Center), act in supportive ways (e.g., caring, compassionate). That is, the negative experiences that participants had in the healthcare institution at large suggest that social support may not be institutionalized to the extent of being habitualized across healthcare contexts. Second, many participants expressed believing that healthcare organizations are driven by motives that actually interfere with the communication of social support (e.g., their “bottom line” approach inhibits care; reductions to staffing prevent providers from sufficient spending time with clients); by extension, those factors would also interfere with institutionalizing social support in the healthcare institution at large. Third, participants generally attributed individuals (e.g., physicians, nurses) rather than the healthcare organizations as the sources of support within the broader healthcare institution. Thus, participants’ attributions of individuals as the sources of social support suggests that they may perceive that support is provided by (possibly isolated) caring individuals (who may be caring and compassionate because of choosing a “caring profession”), rather than by the healthcare organizations and/or the healthcare institution at large.

In summary, the present study’s findings and the emergent model contribute to the scholarly literature by identifying specific social processes that likely contribute to perceptions of institutionalized social support. The culture of caring is a potentially a critical social process
necessary for to establishing, standardizing, habitualizing, and legitimizing social support within the healthcare organization (i.e., to create perceptions of institutionalized social support).

Specifically, for clients to experience institutionalized social support within healthcare organizations, the organizational members must collectively and consistently enact norms, practices, and policies that manifest a culture of caring. When clients repeatedly and consistently experience the culture of caring, they perceive that social support is standardized, habitual, and legitimate (i.e., it is institutionalized).

Clients may credit organizational entities, as well as individuals, as sources of social support in healthcare. This study’s results and the emergent model that is built on those results explicitly expanded current conceptualizations of sources of social support from largely, if not solely, individual sources to include organizations as potential sources of support. The present study examined participants’ attributions regarding the sources of support (i.e., individual, organizational, and/or institutional) they experienced in healthcare contexts. Results indicate that participants consensually attributed social support at the Cancer Support Center to the Center as an organizational entity. However, in contrast, results indicated that, in the healthcare institution at large, participants generally attributed support to individuals (and mostly to healthcare providers) rather than to organizational entities (e.g., hospitals, cancer treatment centers, clinics). These results contribute to the scholarly literature by suggesting that healthcare organizations, not just individual organizational members, may be credited as the sources of clients’ support.

The present findings suggest the need to expand conceptual understandings of social support from being almost exclusively an interpersonal dynamic, to including the possibility of social support as an organizational dynamic. That is, participants’ attributions of support as emanating from the Center indicate that organizational entities can provide support to their
clients. Recognizing that social support can be viewed as emanating from or on behalf of healthcare organizations is important because it indicates that healthcare organizations can play a crucial role not only in helping to satisfy clients’ needs for support, but in facilitating positive health outcomes.

Prior research has examined social support primarily in everyday interpersonal contexts (e.g., Cline, 2011; Goldsmith, 2004). That is, social support generally has been studied in terms of the support that is provided by one (or sometimes more) individual(s) to another individual in the context of close personal relationships in social networks (e.g., family, friends). However, the present study suggests that clients may recognize and identify healthcare organizations as a source of support, as well as the entity responsible for the health benefits resulting from that support. In this study, participants’ attributions of support to the Center imply that clients may perceive that healthcare organizations themselves provide support and, thus, are directly responsible for the resulting health benefits.

Participants’ attributions of support at the Center are in sharp contrast to their attributions of support in the healthcare institution at large. Participants consensually attributed the support they experienced at the Center to the Center as an organizational entity, whereas they largely attributed the support they experienced in the healthcare institution to individuals (i.e., healthcare providers, staff members) rather than to the organization(s). Although participants often reported that their individual providers and other individual staff members in the healthcare institution were supportive, they rarely attributed the source of support to the healthcare organizations, that is, to organizational entities. Thus, although clients may attribute social support so some healthcare organizations (e.g., the Cancer Support Center), based on the present findings clients are relatively unlikely to do so in traditional or clinical healthcare organizations.
Implicit metacommunication plays an important role in defining supportiveness and the nature of provider-client relationships. The present study clarified that metacommunication plays a particularly important role both in creating the image or perception of supportiveness and, thereby, in negotiating and defining the nature of provider-client relationships in healthcare. Specifically, findings indicated that clients often understand providers as communicating social support via their implicit metacommunication.

Participants interpreted the “manner” in which providers’ completed their work to constitute being supportive rather than simply doing their jobs well. This “manner” can be understood as metacommunication. Metacommunication is defined as “anything that ‘contextualizes’ or ‘frames’ messages to assist the participants in understanding the communication event” (Wilmot, 1980, p. 63).

One could easily argue that providing information, scheduling appointments, and providing “care” and “compassion” in medicine is simply “doing one’s job” and nothing more. However, the present study shows that participants draw nuanced distinctions regarding what is simply expected as part of fulfilling a job or professional role versus what they understand to function as social support. In their minds, providers communicate support for them when they spend extensive time explaining cancer-related information and do so in an understandable way, and when they conduct their work in a manner that communicates empathy and caring. That is, participants’ accounts often indicate that it is providers’ metacommunication, rather than their explicit communication, that signifies when providers are giving support as opposed to simply “doing their jobs.”

Prior scholarship has indicated that healthcare providers often provide social support to their clients (e.g., Neuling & Winefield, 1988; Sloan & Knowles, 2013). However, previous
studies have done very little to explain what differentiates the image or perception of providers’
doing their jobs well from providers engaging in social support. In addition to providers’
metacommunication playing an apparently important role in clients’ determination of whether
those providers are supportive, that implicit metacommunication of support also appears to
influence clients’ perceptions of the nature of their relationships with providers. That is, it also
functions as relational metacommunication. Participants consistently reported that members of
the healthcare institution acted in ways that participants interpreted as indicating that providers
were willing to – or offering to – have a relatively more personal and, thus, relatively less formal
relationship with them. That is, clients seemed to perceive that certain actions (e.g., spending
extensive time and ensuring understanding when delivering complex cancer-related information,
acting compassionately and caring, treating the client like a “person” instead of a “patient”)
indicate that providers are willing to have a relatively more personal versus formal relationship
with them. Having that kind of relationship may be critical to clients trusting providers and
appeared to play an important role in some participants’ treatment decisions (e.g., regarding
surgery, chemotherapy).

Researchers have examined the models of relationships between clients and providers
(e.g., paternalistic, participatory) for more than four decades (see Ballard-Reisch, 1990;
Beisecker & Beisecker, 1993; Charles, Gafni, & Whelan, 1999a; 1999b; Emanuel & Emanuel,
1992; and Szasz, Knoff, & Hollender, 1958, for reviews regarding models of provider-client
relationships). Examining models of provider-client relationships is important because research
has indicated that differences in the nature of the communication implied by these models of
provider-client relationships may influence health and organizational outcomes differently (e.g.,
clients may transfer to different healthcare providers if they disagree with physicians who do not
include them in decision making; the extent to which clients perceive that they have a role in
treatment decisions influences likelihood of following suggested treatment regimens; Ballard-
Reisch, 1990; Brown, Stewart, & Ryan, 2003). Previous conceptualizations of provider-client
relationship models have not explicitly accounted for the role of implicit metacommunication
(and, thus, likely overlooked important indicators related to social support) in defining the nature
of the relationship between provider and client. Understanding the role of implicit
metacommunication in communicating social support in provider-client relationships may help
to clarify how provider-client relationships are negotiated and defined, which, in turn likely is
associated with health outcomes.

In summary, the present study makes potentially important contributions to the scholarly
literature. First, it suggests that, in order for clients to perceive social support as normalized
within healthcare organizations, the healthcare organization may need to create a caring culture.
Scholars need to consider that the social support provided within healthcare contexts is
influenced to some degree, and possibly substantially, by organizational and institutional norms.
Second, in healthcare, clients may credit organizational entities, in addition to individuals, as the
source(s) of social support. Clients’ attributions of support to organizations is important because
it suggests that organizations may be able to directly provide the support that clients need and,
thereby, also facilitate positive health outcomes. Finally, this study recognizes that implicit
metacommunication may have important influences on clients’ perceptions of supportiveness in
healthcare and, as a result, on how provider-client relationships are negotiated and defined.

**Practical Implications**

The present study findings have potential implications for the ongoing operations of
existing cancer support organizations and for traditional healthcare organizations (e.g., hospitals,
cancer treatment centers, clinics) that provide cancer treatment. Specifically, this study’s findings suggest: (a) the benefits of partnerships between traditional healthcare organizations and cancer support organizations, and (b) the benefits of developing a culture of caring in traditional healthcare organizations.

First, findings suggest that traditional healthcare organizations may reap benefits from partnering with cancer support organizations. Specifically, cancer support organizations may be better equipped than traditional healthcare organizations to meet the needs of clients, which would make partnerships beneficial to traditional healthcare organizations. Existing cancer support organizations, in contrast to traditional healthcare organizations, likely have requisite expertise in providing support, have established programs and staffing, and have an already established culture of caring. Traditional healthcare organizations would need to develop cancer support programs, staff those programs, and (re)train all individuals in the organization to enact supportive practices, norms, and policies in order to establish a culture of caring. Traditional healthcare organizations may find that partnering with cancer support organizations allows them to provide support resources to clients without having to establish potentially costly cancer support units internally.

Second, results suggest that creating an organizational culture, whereby clients perceive traditional healthcare organizations as “caring organizations,” may enhance clients’ satisfaction with their healthcare. Clients who experience a culture of caring within their healthcare organizations may be more satisfied with the healthcare that they receive because they are also receiving greater social support. Further, when clients receive greater social support through a culture of caring they may have better health outcomes. Healthcare organizations also may be able to use evidence of clients’ satisfaction with healthcare to promote the organization and to
attract new clients, which, in turn, may benefit the organization financially.

Potential benefits of partnerships between traditional healthcare organizations and cancer support organizations. The present study’s findings suggest that traditional healthcare organizations, such as hospitals, clinics, and cancer treatment centers (i.e., those that provide medical care) may benefit from creating partnerships with cancer support organizations. Specifically, cancer support organizations, like the Cancer Support Center, may already have important organizational structures and normative processes in place to facilitate social support. However, traditional healthcare organizations may find that it difficult to replicate these organizational structures and processes that function to facilitate social support. In addition, cancer support organizations, in contrast to traditional healthcare organizations, have the requisite expertise, past experience, and extant programs and structures that can facilitate client access to social support. Healthcare organizations that provide cancer treatment, and are accredited through the American College of Surgeons (ACS), are now required (as of 2015) by the ACS to provide support services either internally or through partnerships with cancer support organizations. Creating partnerships with extant cancer support organizations may benefit cancer treatment organizations in terms of organizational efficiency and possibly a higher quality of healthcare.

The most recent version of the American College of Surgeon’s Commission on Cancer (2012) (see also Chapter I, Cancer support initiatives in healthcare) requires healthcare organizations that provide cancer treatment to offer support resources (e.g., informational support, emotional support) in-house and/or partner with cancer support organizations. Specifically, the ACS standards require healthcare organizations to provide supportive services (e.g., psychological counseling, financial consultations) and support resources (e.g., cancer-
related information) to clients. Healthcare organizations can choose to offer support services internally (e.g., through in-house cancer support services or units) or by partnering with cancer support organizations like the Cancer Support Center.

Partnerships with cancer support organizations may benefit cancer treatment organizations (i.e., traditional healthcare organizations). That is, cancer support organizations likely can provide the support services that healthcare organizations would otherwise need to develop internally to meet the ACS standards. The present study’s findings related to the Cancer Support Center indicate that it provides many, if not all, of the support services (e.g., cancer-related information, counseling) required to meet the ACS standards and, in fact, provides support that likely exceeds those standards. Further, the present study findings suggest that cancer support organizations, like the Center, may already have established a culture of caring to provide substantial support resources, whereas traditional healthcare organizations may not have the extant ability to do the same. That is, traditional healthcare organizations would need to create new cancer support units, hire and train new staff members for these new units, and develop other organizational structures to support these new units, which would require traditional healthcare organizations to incur additional costs. Thus, partnering with cancer support organizations may be more cost effective for traditional healthcare organizations than developing these same services internally.

Partnerships with cancer support organizations are potentially useful to traditional healthcare organizations in a second way. Although traditional healthcare organizations that provide cancer treatment provide social support that leads to physical health benefits, the support that clients receive through cancer support organizations is more likely to take a holistic rather than a biomedical approach. Holistic approaches, also sometimes referred to as integrative care,
focus on providing care to the mind, body, and spirit, in addition to offering medical treatment (Block, 2009; Lappé, 1979). In holistic care, individuals are likely to experience numerous health benefits (e.g., mental, emotional, social) in addition to physical health benefits.

Although traditional healthcare organizations (e.g., hospitals, clinics, cancer treatment centers) are important resources for people diagnosed with cancer in terms of obtaining medical care, cancer support organizations may provide services (e.g., integrative therapies, support groups) that one often would not find at traditional healthcare organizations, including those with in-house support units designed to meet the ACS standards. Receiving support that benefits one’s health holistically is particularly valuable for people diagnosed with cancer. People diagnosed with cancer often experience mental (e.g., depression, anxiety, stress) and social health challenges (e.g., social isolation, stigma) in addition to physical health issues (American Cancer Society, 2013; Charmaz, 1983; Mathieson & Stam, 1995). Thus, health benefits that facilitate holistic health are particularly beneficial because when clients’ have better holistic health, they are likely to have better physical health outcomes as well (e.g., reduced stress affects physical as well as mental health). Benefits of healthcare from a holistic perspective may include increased interactions with other people diagnosed with cancer, which may help to reduce social isolation and stigma. People who have access to social interaction generally have better mental health and, thus, may have better physical health outcomes (e.g., clients who have better mental health may be less likely to experience some negative physical side effects as a result of cancer treatment; Spiegel, 1990). Other benefits of a holistic approach to healthcare may include stress relief and relaxation that promotes both physical and mental wellbeing.

In summary, healthcare organizations that provide cancer treatment may benefit from partnering with and/or referring clients to cancer support organizations because these
partnerships can help them fulfill the requirements of the ACS without developing support services internally. In addition, partnerships with cancer support organizations may help healthcare organizations that provide cancer treatment because clients may receive additional support services that benefit their health holistically, which may, in turn, promote better physical health and wellbeing.

**Benefits of creating an organizational culture of caring in traditional healthcare organizations.** The present study’s findings suggest that traditional healthcare organizations may benefit from creating an organizational culture of caring. This study’s results imply that traditional healthcare organizations that have an organizational culture of caring are likely to have relatively more satisfied clients, and as a result, better health outcomes. In addition, having clients who are highly satisfied with a “caring organization” may help to improve the organization’s reputation.

**Social support and better health outcomes.** Healthcare organizations should be motivated to facilitate social support because of its relationship to better health outcomes (e.g., Goldsmith & Albrecht, 2011; Roy, 2011; Uchino, 2004). The present study’s findings suggest that healthcare organizations can play an important role in facilitating social support for clients. Based on present results, healthcare organizations may be likely to find that having an organizational culture of caring increases client adherence and client access to medical resources, both of which may lead to positive health outcomes.

Research has established that particular aspects of interpersonal communication between providers and their clients, and social support specifically, is associated with better client adherence to suggested treatment regimens; in turn, better adherence is associated with positive health outcomes (e.g., Squier, 1990; Zolnierek & DiMatteo, 2009). The present study’s findings
indicated that participants who experienced being supported by their providers felt more comfortable with them and, thus, were more willing to follow suggested treatment regimens. If, as the present study’s findings suggest, social support specifically is positively related to client adherence to recommended treatment regimens, healthcare organizations may find that having a culture of caring will help to increase client adherence and, thereby, promote positive health outcomes. Healthcare organizations can also promote positive health outcomes by engaging in supportive actions that facilitate clients’ access to important medical resources.

Clients may experience relatively more positive health outcomes when they have ready access to important medical resources (e.g., access to urgent appointments, specialized medical equipment, medications, insurance coverage, disability benefits). Prior research indicated that people diagnosed with cancer may have difficulty navigating the healthcare system, including difficulty in being able to obtain needed medical resources (Quillin et al., 2009). This study suggests that organizational members may play an important role in facilitating clients’ access to medical resources by providing social support to help them navigate the healthcare system. For example, participants noted that they were able to schedule appointments more quickly when staff members (e.g., secretaries, providers) acted with understanding in response to their need for urgency. In addition, participants were sometimes able to receive important medical resources (e.g., insurance coverage, disability benefits, medical equipment, medications) when staff members intervened with third parties (e.g., pharmacies, Medicare). Thus, when healthcare organizations have a caring culture (e.g., as evidenced by acting with urgency; intervening with third parties to ensure clients receive needed medical resources), clients are likely to have better health outcomes that result from having more ready access to relevant medical resources.

Healthcare organizations benefit from improving clients’ health outcomes. Obviously
healthcare organizations have the fundamental responsibility to promote clients’ health. However, better client health outcomes also are associated with reduced healthcare costs incurred by the organization (e.g., adherence and better health outcomes help to avoid unnecessary hospitalization, prevent illness; and reduce diagnostic testing; Iuga & McGuire, 2014). Thus, having an organizational culture of caring that facilitates social support may promote better client health outcomes, which are beneficial to healthcare organizations in terms of its mission and in terms of reducing healthcare costs.

**Benefits of clients’ satisfaction with a caring organization.** This study’s findings suggest that clients who receive social support through what they perceive to be a “caring organization” are likely to be highly satisfied with their healthcare. High client satisfaction is useful to healthcare organizations because it may improve their reputation. In addition, having a reputation as a “caring organization” may be useful to healthcare organizations in terms of receiving recognition (e.g., awards) from professional associations.

Having an organizational culture of caring (e.g., such as the organizational culture at the Cancer Support Center) may be an important factor in clients’ satisfaction with the organization. The present study indicates that participants who received social support through a caring organizational culture were highly satisfied and attributed their satisfaction with the organization to the organization itself (e.g., “this is a wonderful facility [the Center]”). Thus, healthcare organizations may be able to increase client satisfaction by fostering a caring organizational culture. Having a caring culture is beneficial in numerous ways. A caring organizational culture may not only increase client satisfaction, but also may indirectly help a healthcare organization promote its reputation. Previous research has found associations between client satisfaction and the reputation of healthcare organizations (e.g., being recognized nationally by professional
associations; Luxford, Safran, DelBanco, 2011). Further, when clients are satisfied with their healthcare organizations, they are more likely to continue using those organizations for future healthcare and more likely to refer family and friends to the organization as well (Issac, Zaslavsky, Cleary, & Landon, 2010). Thus, healthcare organizations may find that investing in fostering an organizational culture of caring can help increase their client satisfaction ratings and promote their organizational reputation as a “caring organization,” as well as improve clients health outcomes.

**Summary of benefits of being a caring organization.** In summary, healthcare organizations are likely to benefit significantly from being “caring organizations.” Healthcare organizations may find that, by having an organizational culture of caring, their clients will be more likely to adhere to suggested treatment regimens, and have more ready access to necessary medical resources, and thereby experience better health outcomes among clients. Those improved health outcomes may help to reduce healthcare costs within organizations. Finally, clients are likely to be highly satisfied with their care at a “caring organizations” which may benefit the organization’s reputation.

**Limitations**

The present study has several limitations. Those limitations are associated with the study’s methodology, sample, and exclusive focus on client perspectives.

**Limitations related to qualitative methodology.** All research methodologies have inherent limitations. The present study used qualitative research methods to explore a social phenomenon (i.e., clients’ perceptions of institutionalized social support) that had not previously been examined. Although the study’s findings identified potentially critical constructs, and relationships among them, that may explain social support processes that lead to client
perceptions of institutionalized social support, the methodology did not permit the researcher to assess the strength of the constructs or to verify the relationships among them. Using qualitative research methods did allow the researcher to richly describe participants’ experiences and perceptions of the nature of institutionalized support in healthcare organizations. Through the data analysis, the researcher was able to identify possible trends in the data in the form of themes and possible associations among constructs that emerged as important in the study (e.g., solicited support versus help-seeking; access to homogenous social ties and health benefits). Those results informed an emergent conceptual model. Quantitative research is needed to more precisely explore the strength of constructs and posited relationships among them identified in the model (see following section, Quantitative examinations of social support in healthcare organizations).

**Limitations related to demographic characteristics of sample.** The study’s sample was a potential limitation because of its gender composition. It was comprised predominantly of female participants. As a result, the present study’s findings may not adequately capture male clients’ experiences and perceptions of social support in the healthcare institution.

The gender composition of this study’s sample was disproportional relative to the Center’s population (based on the Center’s client list as of June 2015). The Cancer Support Center has a predominantly female clientele. As of June 2015, 75.9% of the Center’s client population self-identified as female and 24.1% of the Center’s population self-identified as male. The study’s sample over-represented females; 90.3% of the study’s participants self-identified as female and 9.7% self-identified as male. However, no distinctive differences emerged between the themes to which male and female interviewees contributed at the point that analysis achieved theoretical saturation. That is, no evidence indicated that the codes and themes that emerged from male participants’ interviews were different than those of the female participants.
Recognizing the over-representation of women in the study may be important when interpreting and applying the present study findings in terms of generalizability of findings. First, women diagnosed with cancer are more likely than men diagnosed with cancer to join support groups (e.g., Krizek, Roberts, Ragan, Ferrara, & Lord, 1999). Thus, finding that the Center’s clientele is disproportionately female is not surprising. Although women clearly are more likely than men to seek support through the Center (as well as through support groups in general), having a predominantly female sample likely limits the generalizability of results to men. Second, some evidence indicates that the communication dynamics of women’s face-to-face support groups likely differs from those of men (see e.g., Cline, 1999). Third, evidence indicates that gender can be an important influence on communication dynamics in healthcare settings. Previous research found that gender influences the nature of provider-client interactions in healthcare settings, particularly with regard to interactional control (e.g., Street, 2002). Because the present study’s results are based on a sample composed primarily of women, results related both to social support and to healthcare interaction are not able to capture potential patterns of gender differences in the experiences and perceptions of social support within healthcare contexts. Thus, the present study findings need to be interpreted with caution because, even though gender did not appear to influence those experiences and perceptions, prior research has established that client experiences in healthcare can differ based on gender.

**Limitations related to focusing on regular users of the Center.** The present study’s sample was limited by the fact that it focused on individuals who were regular users of the Cancer Support Center (i.e., regular clients at the Center). This poses the possibility of systematic bias in reported experiences and perceptions of social support at the Center. The sample was composed of people who actively sought social support through a
support organization and became regular users of that organization’s activities and services. This regularity of use suggests that participants were satisfied with the Center and the support it offered. The study was unable to capture the perspectives of individuals who were referred to the Center, but chose not to use it, or of individuals who came to the Center, perhaps once or twice, and then stopped using the Center (or use it infrequently). In particular, individuals who stopped using the Center may have reported very different experiences and perceptions of social support in that context. They might have been less satisfied and/or may have had different support needs than people who use the Center regularly (e.g., the study’s participants may have been more likely to use the Center because many of them experienced diminished structural support following their cancer diagnosis).

**Limitations related to focusing solely on client perspectives.** The present study’s findings are based solely on examining clients’ perspectives and do not consider the perspectives of other organizational members (e.g., Center staff members; healthcare providers and staff members’ perspectives). Clients, not surprisingly, are not likely to have a very complete understanding of organizational and institutional factors that may influence the provision of social support in this context (e.g., clients may not be aware of the organizational policies, or organizational and institutional norms, or broader laws or rules that govern or influence their care).

By focusing exclusively on clients’ experiences and perceptions of institutionalized social support in healthcare settings, the study was unable to identify whether other organizational members (i.e., the Center’s staff; healthcare providers and staff at clinical organizations) experience having organizational and/or institutional norms influence their motivation to – or their ability to – provide social support to clients. Specific organizational processes and practices
may facilitate and/or impede the ability of these organizational members to provide social support to clients. Thus, examining the perceptions of clients alone limits the ability of the researcher to fully grasp the extent to which social support is institutionalized in healthcare organizations.

In summary, this study has several limitations related to its methodology, sample, and exclusive focus on client perspectives. However, this study’s limitations, as well as its findings, provide insight into opportunities for future research.

**Directions for Future Research**

Based on the present study’s findings, several directions for new research are apparent. The following section identifies three general directions for future research.

**Quantitative examinations of social support in healthcare organizations.** Future research should use quantitative methods (e.g., quantitative data collected through surveys) to examine the trends suggested by the results of the present study (i.e., which were in the form of themes) and to explore the relationships posited in the emergent model (see also above, Limitations related to qualitative methodology). For example, the present study indicated that clients’ feelings of isolation were reduced as a result of the interactions and support they experienced at the Center. A future study could verify if this apparent association between reduced feelings of isolation and support received at the Center exists and, if so, the strength of the relationship. To quantitatively explore the relationships posited by the emergent model and examine other trends suggested by the present study’s result, future survey research could be conducted with a larger and representative sample within the Cancer Support Center or across multiple cancer support organizations. In addition to quantitatively examining clients’ experiences and perceptions of social support in healthcare organizations, future research also
should examine organizational representatives’ experiences and perceptions.

**Organizational representatives’ perceptions of institutionalized social support in healthcare organizations.** Future research should examine the nature of social support that healthcare providers and other staff members experience and perceive as institutionalized in healthcare organizations. Examining providers’ and other staff members’ (e.g., Center staff members; secretaries, receptionists, and social workers, etc., in clinical healthcare organizations), perceptions and experiences of organizational and institutional norms influencing social support provided to clients will help to fill gaps in the present research.

Understanding providers’ perceptions will help to explain whether providers perceive healthcare organizations and the healthcare institution as facilitating or obstructing their ability to provide social support to clients. In addition, examining providers’ perceptions related to social support in their work will help researchers to identify whether providers perceive social support to be part of their jobs and, if so, to what extent. Understanding providers’ motivations for providing social support to clients also may help clarify the extent to which providers are internally motivated to be supportive or whether they are motivated by external factors, including norms within the organization and within the healthcare institution at large. Finally, understanding providers’ perceptions of the institutionalization of social support is particularly important because it may help researchers and practitioners to identify structures and processes that may facilitate and/or impede social support for the clients of healthcare organizations.

**Personal caregivers’ perceptions of institutionalized social support in healthcare organizations.** Future research also should explore how personal caregivers (most often family members) experience and perceive institutionalized social support in healthcare organizations. Social support clearly is important for people diagnosed with cancer; however, personal
caregivers also have significant support needs that often go unaddressed in healthcare contexts (Nicholls, Hulbert-Williams, & Bramwell, 2014). If personal caregivers do not receive adequate social support in order to meet their own needs, they may experience caregiver burnout and, thus, be unable to provide quality social support and care for the person diagnosed with cancer (Northouse, Williams, Given, & McCorkle, 2012). Researchers have not considered how healthcare organizations facilitate social support to personal caregivers. Researchers also have not examined the extent to which personal caregivers use support services offered through healthcare organizations (e.g., the caregiver support group at the Cancer Support Center).

Examining the adequacy of personal caregivers’ support networks and, in particular, their experiences and perceptions of social support available to them as caregivers through healthcare organizations, is an important step forward in understanding the ways that healthcare organizations can help to provide the best care to people diagnosed with cancer.

In summary, the present study’s findings and limitations suggest several directions for future research. Future research should use quantitative methods to examine the trends and patterns suggested by the results of the present study. In particular, future research should examine apparent associations among key variables that emerged in the present study. Future research also should examine providers’ and other organizational staff members’ experiences and perceptions regarding social support in healthcare organizations in order to better understand how, and the extent to which, providing social support to clients is institutionalized in healthcare contexts. Finally future research should examine the support experiences of personal caregivers for people diagnosed with cancer in healthcare contexts because, if caregivers’ support needs are not met, they may not be able to adequately care for people diagnosed with cancer.
Appendix A
Letter of Support

April 20, 2015

Andrea L. Meluch
PhD Candidate
Communication and Information Doctoral Program
Kent State University

Dear Andrea:

I am pleased to inform you that [the Cancer Support Center] has given approval for you to conduct research related to the study, *Understanding the Organizational and Institutional Origins of Social Support in a Cancer Support Center*. The Care Coordinator will work with you to identify appropriate participants for your interviews, and provide the needed space onsite to conduct the interviews.

[the Cancer Support Center] has agreed to partner in this study on the condition that all participant information will be kept strictly confidential. We understand that confidentiality will also be a requirement for approval by the Institutional Review Board (IRB) at Kent State University, and that no recruitment will occur until you have received IRB approval.

We are pleased that, upon completion of the study, you have offered to present findings to [the Cancer Support Center]. We look forward to seeing what can be learned from your study. Hopefully the results will be valuable to [the Cancer Support Center] in particular, as well as to other organizations whose mission is to support people with cancer and their caregivers.

Sincerely,

[Executive Director Signature]

[Executive Director Name]
Executive Director

cc: Rebecca J. Cline, PhD, Professor, School of Communication Studies

Note: All organization identifying-information was removed (i.e., names, letterhead, logo, address, phone, email, website) throughout appendices in order to protect the identity of the Center and the Center’s clients.
Appendix B

Recruitment Letter

[Publish Date]

Dear [Subject]:

I hope this letter finds you well. Recently, Andrea Meluch, a Kent State University graduate student and researcher, approached [the Cancer Support Center] about conducting a research study to explore the cancer experience and support in organizations like [the Cancer Support Center]. We are very excited about this study and would like to take this opportunity to invite you to consider participating in the study. The title of the study is "Understanding Social Support in a Cancer Support Center." Andrea’s research is interested in learning about the support that you have received during your cancer experience. This study will be important because the results will assist health care organizations, like [the Cancer Support Center], in better understanding the support needs of people with cancer and their personal (e.g., partner, family member, close friend) caregivers.

To be eligible to participate in the study you must be at least 18 years old, have been diagnosed with cancer or are a caregiver to someone diagnosed with cancer, and participated in activities at [the Cancer Support Center] at least (4) times in the past four (4) months. Participation will consist of a one-hour interview conducted at [the Cancer Support Center] at a convenient time. As compensation for your participation, you will receive a $20 gift card to Giant Eagle for your time.

Remember, you don't have to take part in this study, and deciding not to participate will not affect your present or future relationship with or benefits to which you may be entitled from [the Cancer Support Center]. We do hope you will consider participating so we can learn from the study and continue to improve our services.

Andrea will be at [the Cancer Support Center] to discuss her research with you and have a sign-up sheet available if you are interested. You can also contact directly Andrea about and possibly participating in this study using the contact information below.

Andrea Meluch  
Kent State University  
Phone: (XXX)-XXX-XXXX  
Email: XXXXXXXXXX

Thank you,  
[Program Coordinator]  
[Contact Information]
Appendix C

Recruitment Script

**Introduction (read by staff member at [the Cancer Support Center]):** Andrea Meluch is a researcher at Kent State University who is here to talk to you today about a research project that she is currently conducting for her dissertation and to see if you might be interested in participating.

**Recruitment script (read by researcher):** Good morning/afternoon/evening, Thank you for letting me come to [NAME OF ACTIVITY] today to quickly discuss my research. For my dissertation research, I am exploring the support needs that people have during the cancer experience and how support is communicated in an organization like [the Cancer Support Center].

As part of this research I am interviewing clients from [the Cancer Support Center] who have participated in at least four activities in the past four months. I am looking for people with cancer and I am also looking for caregivers of people who have been diagnosed with cancer who might be interested in participating in this research.

Interviews will take place here at [the Cancer Support Center] and last for about an hour. All participants will receive a $20 Giant Eagle gift card for their time. Participants must be 18 or older to participate.

Participation in this study is completely voluntary, and deciding not to participate will not affect your present or future relationship with or benefits to which you may be entitled from [the Cancer Support Center].

If you are interested in participating, I have a sign up sheet here, where you can write down your name and contact information and I will follow-up with you soon. Signing up here is not a commitment to participate, just an indication that you are interested in possibly participating in the project. Please let me know if you have any questions.

Thank you for considering participating in my study.
Appendix D

Flyer

Please consider participating in a research study on Social Support and the Cancer Experience.

This research study is exploring social support for people with cancer and their family caregivers. The results from this study may be used to help cancer wellness centers and other healthcare organizations understand how to offer better support to people with cancer and their family caregivers.

Participation will consist of a one-hour interview conducted at [redacted] at a convenient time.

All participants will receive a $20 gift card to Giant Eagle for their time.

Eligibility to Participate:
• At least 18 years old.
• Have been diagnosed with cancer or are a caregiver to someone diagnosed with cancer.
• Participated in activities at [redacted] at least (4) times in the past four (4) months.

If you are interested in participating please contact Andrea Meluch (Kent State University Researcher) at:

Phone: [redacted]
Email: [redacted]

This study has been approved by the Kent State University Institutional Review Board and has the support of [redacted]. Participation in this study is completely voluntary, and deciding not to participate will not affect your present or future relationship with or benefits to which you may be entitled from [redacted].
Informed Consent to Participate in a Research Study

Study Title: Understanding Social Support in a Cancer Support Center

Principal Investigator: Dr. Janet Meyer

Co-Investigators: Ms. Andrea Meluch, Dr. Rebecca Cline

You are being invited to participate in a research study. This consent form will provide you with information on the research project, what you will need to do, and the associated risks and benefits of the research. Your participation is voluntary. Please read this form carefully. It is important that you ask questions and fully understand the research in order to make an informed decision. You will receive a copy of this document to take with you.

Purpose:
This study is exploring how healthcare organizations offer support to people experiencing cancer. Specifically, the study is designed to understand the support needs of people experiencing cancer and how healthcare organizations provide or inhibit support.

Procedures
To participate in this study you will be asked to fill out a short demographic questionnaire and to participate in a one-on-one interview with the researcher. The interview will last between 45 minutes and 75 minutes. At the end of the interview you will receive a $20 gift card to Giant Eagle.

Audio Recordings
Your interview will be audio-recorded for research purposes. All audio-recordings will be transcribed and any personally identifying information discussed in the interview (e.g., names, hometown) will be removed from the transcripts and not used in analyses or publication. Upon completion of transcription and de-identification of transcripts, all audio-recordings will be destroyed. If you would like to listen to the interview after it has been completed please let the researcher know and a digital audio-file (e.g., .mp3, .mp4) can be given to you.

Benefits
This research will not benefit you directly. However, your participation in this study will help to better understand how healthcare organizations offer support to people with cancer and how these organizations can improve the support experiences for people with cancer and their personal caregivers.

Risks and Discomforts
There are no anticipated risks beyond those encountered in everyday life when discussing your cancer experience. However, some of the questions we discuss may be upsetting, or you may feel
uncomfortable answering them. If you do not wish to answer a question, you may skip it and go on to the next question.

**Privacy and Confidentiality**
Study information will be kept confidential within the limits of the law. Any identifying information will be kept in a secure location and only the researchers will have access to the data. Research participants will not be identified in any publication or presentation of research results; only quotes from de-identified transcripts will be used.

**Compensation**
You will receive a $20 Giant Eagle gift card for your time.

**Voluntary Participation**
Taking part in this research study is entirely up to you. You may choose not to participate or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Your decision to participate will not change any present or future relationships with [the Cancer Support Center]. [the Cancer Support Center] will not have access to any data that contains any personally identifiable information.

**Contact Information**
If you have any questions or concerns about this research, you may contact Andrea Meluch at (XXX)-XXX-XXXX or XXXXXXXXXX, or Dr. Janet Meyer at (XXX)-XXX-XXXX. This project has been approved by the Kent State University Institutional Review Board. If you have any questions about your rights as a research participant or complaints about the research, you may call the Kent State University IRB at (330)-672-2704.

**Consent Statement and Signature**
I have read this consent form and have had the opportunity to have my questions answered to my satisfaction. I voluntarily agree to participate in this study. I understand that a copy of this consent will be provided to me for future reference.

Participant Signature ____________________________________ Date __________________________
Appendix F

Audio-recording Consent Form

AUDIORECORDING CONSENT FORM

Understanding Social Support in a Cancer Support Center
Ms. Andrea L. Meluch, Dr. Janet Meyer, and Dr. Rebecca Cline

I agree to participate in an audio-recorded interview about support and the cancer experience as part of this project and for the purposes of data analysis. I agree that Andrea Meluch may audio-record this interview. The date, time and place of the interview will be mutually agreed upon.

________________________________________  __________________________________
Signature                                    Date

I have been told that I have the right to listen to the recording of the interview before it is used. I have decided that I:

_____want to listen to the recording  _____do not want to listen to the recording

Sign now below if you do not want to listen to the recording. If you want to listen to the recording, you will be asked to sign after listening to them.

Andrea Meluch may / may not (circle one) use the audio-recordings made of me for transcription and analyses purposes. The transcribed and de-identified data may be used for:

_____this research project _____publication _____presentation at professional meetings

________________________________________  __________________________________
Signature                                    Date
Appendix G

Demographic Questionnaire

Thank you for your participation in this research study. Please fill out the following questionnaire:

I am: Male Female

I am ____________ years old.

I am:
  Single/ Never Married
  Married
  Domestic Partner
  Widowed
  Divorced
  Separated

I have:
  No children
  One child
  Two children
  Three children
  Four children
  Other (please specify): _________________

I consider myself: (check all that apply)
  American Indian/ Alaskan
  Asian/ Pacific Islander
  Black (not of Hispanic origin)
  White/ Caucasian (not of Hispanic origin)
  Other (please specify): ______________________

Are you of Hispanic or Latino origin?

  Yes
  No

The highest level of education I have completed is:
  Some high school
  High school/ GED
  Some college
Associate/2-year technical degree
Bachelor’s degree
Graduate degree

I have been diagnosed with stage ______________, ______________ (type) cancer.

I have been diagnosed with cancer in ___________ months/year
Appendix H

Interview Protocol

[Offer respondent something to drink. Make sure respondent is comfortable.]

[Conduct Consent Process]

I. Introduction [2 minutes]

Introduction: My name is Andrea Meluch and I am conducting this interview for research that I am conducting as a doctoral student at Kent State University. Before we get started, I want to tell you a little bit about this study.

Purpose: [The reason for the interview] In general, my research focuses on health communication. I am trying to learn about something that I call social support. What that really means is learning about how people get the care and help they need. So I am interested in how people get the help and care they need when they have cancer. So I am here to learn about your personal experiences of support specifically related to your experiences with cancer. Everyone has different experiences and I want to hear about yours.

Ground Rules: During our time together today, I will ask you some questions to guide our conversation. This study is designed to learn more about people’s cancer experiences in healthcare, so that we can understand what works well and what needs to be improved. I am here to listen to and learn from you. This study could not take place without your participation, so I would like to thank you for your willingness to participate. Your participation is valuable. Hopefully what we learn from this study will provide healthcare organizations with insight into what they do well and where they need to improve to help people like you and your family members.

There are no right or wrong answers to any of these questions. If I happen to ask any questions that are confusing or that you do not understand, please feel free to tell me. Also if I happen to ask any questions that make you at all uncomfortable, you do not need to answer them or we can come back to them later if you wish. If at any point you wish to take a break for any reason (e.g., to get a drink, use the restroom, make a call), please let me know. I want you to be as comfortable as possible while we talk.

II. Getting to Know You [5 minutes]

I would like to begin by learning a little about you…

1. Tell me a little about yourself?

   Reminder: Use reflective listening (i.e., paraphrase what respondent said to check and communicate understanding). Noted by [RL]
2. Tell me a bit about your cancer experience in general (e.g., when were you diagnosed, what treatment have you received).

[RL]

3. What initially brought you to [the Cancer Support Center]?  

[RL]

Summary

III. Family and Friends Support Experiences [10-15 minutes]

Sometimes when people experience an illness or some kind of personal challenge, other people in their lives (e.g., family members, friends) step up and “are there” for them to help in the situation. Also sometimes we expect that others will be there to help us through a challenging time, but they really are “not there” for us or they are even unhelpful. I would like to hear you talk about this aspect of your experiences with cancer – the help that you received from others, if that has happened, or the help that didn’t happen but you had thought others would provide.

A. People Who Helped

Let’s start first with having you talk about the help you may have received from others. Perhaps people in your personal life have been there for you in your experience with cancer. These people may include family members, friends, colleagues, or anyone else in your personal life who really has helped you and let you know that they care.

1. Tell me about your experiences with the people in your life who you believe have supported - or are supporting you - during your cancer experience.

2. What are the types of things that others have said or done that you have found to be particularly helpful?

Could you want to give me a specific example.

Follow-up:
Why do you think these types of things were or are especially helpful to you?

Summary of Helpful Experiences

Would you like to add anything else about these helpful experiences?
B. People Who Didn’t Help

Sometimes when we are experiencing life’s challenges, we expect or anticipate that certain other people will “be there” to help us. But sometimes people do not provide support at all. Or other times, we can tell that individuals, like our family and friends, are really trying to helpful, but it turns out that what they said or did really didn’t help us or maybe even felt hurtful. We all have had these sorts of experiences at various times in our lives.

So now I would like to hear you talk about any experiences you may have had with people who you thought would provide help but they didn’t – or – with people who were trying to provide help, but you found what they said or did to be unhelpful or maybe even hurtful.

1. Tell me about your experiences with people who did not provide help – or whose attempts to be helpful didn’t work very well for you.

Perhaps you could give me a specific example.

*Potential follow-up question:*
What about these experiences [these things] was particularly unhelpful to you?

2. What did the person say or do that was unhelpful (hurtful)?

3. What do you wish the person had done/said instead? Why?

*Summary of Unhelpful (Hurtful) Responses.*

*Would you like to add anything more about these unhelpful (hurtful) experiences?*

IV. Support Experiences with the Cancer Support Center [15 minutes]

Now that you have told me about your experiences with support from people in your personal life, I would like to have you talk specifically about your experiences at [the Cancer Support Center].

1. I want to begin by having you talk about the specific services or programs that you and/or your family have used or attended at the center.

2. Tell me about your reactions to these experiences. How have they worked out for you?

*Potential follow-up questions:*
What do you feel like you get out of these programs?
I would like to hear you talk about what have you liked or found helpful about participating in these events/activities or programs?

[RL]
3. How do [the Cancer Support Center] staff interact with you while you are attending these programs? What sorts of things do they do?

*Potential follow-up question:*
I wonder if you could give me a specific example of something a staff member at [the Cancer Support Center] said or did for you that you thought was particularly helpful. How was that helpful to you?

[RL]

Some of the programs at [the Cancer Support Center] are group programs that create the chance for people to interact with others who have similar experiences with cancer. These can include support groups and workshops. I wonder if you have participated in any of these – or had interactions with other people who have cancer in your times at [the Cancer Support Center.] would like to have you talk a little about these experiences.

(If no skip to question 7)

4. Tell me about your experiences in interacting with others who also have cancer.

*Potential follow-up questions:*
What have those conversations been like?
e.g., Who did you talk with?
What sorts of things did you talk about?

5. I wonder how helpful you found these experiences to be.

6. In what ways were they help (or unhelpful)?

*Potential follow-up questions:*
I wonder if you would give me an example of a conversation that happened with another person who has cancer – that occurred at [the Cancer Support Center – or with someone you met at the Cancer Support Center] that seems particularly memorable to you.

*If appropriate:*
What do you think is particularly valuable to you about having these kinds of interactions with others who have cancer?

[RL]

I have looked at [the Cancer Support Center]’s newsletters and their website. It looks to me like they offer a lot of resources that someone like you might be able to use – if you choose to do so. You may have found some of these resources to be particularly relevant or really useful for you. And perhaps some of them didn’t seem very relevant or useful for you in particular.
7. Were there any resources that did not seem particularly relevant or useful or helpful to you?

[RL]

8. I wonder if you have thought about any resources or programs that [the Cancer Support Center] does not offer to people with cancer that you think might be useful. If so, tell me about those?

9. I would also like to know if you have experienced any barriers that get in the way of using a particular resource at [the Cancer Support Center]. (For example, sometimes a person’s schedule may not work for when an activity or event occurs) If so, could you tell me about that?

*Summary of Support Experiences at [the Cancer Support Center].*

I want to give you the opportunity to add anything else you would like to say about your experiences at [the Cancer Support Center]

V. Support Experiences in the Healthcare Institution [10 minutes]

Now that you have told me about your experiences at [the Cancer Support Center], I would like to have you talk a little bit more broadly about your cancer experiences in healthcare in general. When I say “healthcare in general,” I’m referring to visits with doctors, hospital stays, interactions with nurses, and other experiences that you have experienced in these healthcare contexts, outside of [i.e., not at the Cancer Support Center], during your cancer experience

1. To start with, tell me what your general healthcare experiences related to cancer have been like.

2. How helpful did you find the people at…. [places named]

*Potential follow-up questions:*
What made them helpful?
What made them unhelpful

[RL]

3. To what extent did you or do you feel supported by your doctors/ healthcare providers/nurses?

4. What sorts of things do your healthcare providers do or say that make you feel like they care or are trying to be helpful?
Potential follow-up questions:
Perhaps you can give me a specific example of something that a healthcare provider said or did that you felt showed he or she cared about you or was trying to be helpful to you. What do you think that healthcare providers do or need to do for you to decide that that person cares about you or is trying to help you?

[RL]

5. Most of us who have spent any amount of time in health care have had both good and bad experiences with healthcare providers. So I would guess that you may have had both kinds of experiences in the context of cancer.

What sorts of things have healthcare providers done or said that made you feel like they didn’t care about you?

Potential follow-up question:
Tell me why you felt like your healthcare providers didn’t care about you or were not being helpful during this [these] experience(s)? What did they do or say that led you to the conclusion that they didn’t care or weren’t really being helpful.

Summary of Support Experiences in Healthcare.

I would like to see if you would like to add anything more about your experiences of support in healthcare in the context of cancer before we move on? These could be either positive or negative experiences.

Additional RL or Summary as Needed.

VI. Responsibilities of Healthcare Organizations [10 minutes]

Now I want you to talk about what you see as the roles and responsibilities of healthcare providers and healthcare organizations. When I say roles, what I am wondering is what you think healthcare providers and the organizations that they work for should be doing.

Specifically, as a community and as individuals we may have specific opinions about the various responsibilities that should be carried out by different organizations. For example, if we look at educational organizations, we may believe that teachers and schools have the responsibility to educate future generations and prepare them for the future.

So let’s talk about healthcare in general. Many people have expectations about what their healthcare organizations should be like or what they should do.

1. What role(s) do you think that healthcare organizations, like Summa Healthcare or the Cleveland Clinic or University Hospitals, have or should have in society?
2. What are some of the positive things that you believe healthcare organizations do for society?

Sometimes what we find is that people do not feel like healthcare organizations give them everything that they need, or that people feel like they are “just a number” when they are dealing with these organizations.

3. Please tell me about a time where you felt like your healthcare provider (meaning your doctor or nurse) or the healthcare organization itself made you think that they didn’t care about you as a person.

Possible follow-up questions:
Why did you feel that way?
What would you hope – or maybe expect – the organization or the healthcare providers would have done instead?

4. Most of us have had an experience in healthcare and of course in other contexts as well, where we felt like the organization or the people working for the organization did not care about us as individuals. What do you think healthcare providers (doctors and nurses, staff members) and the organizations that they work for can do to help patients feel like they care?

Follow-up questions:
What specifically do you feel like a healthcare organizations can do to make sure patients have the care that they need?
What do you think healthcare providers can do to make sure patients know that they care?

[The Cancer Support Center] is a unique wellness organization and it is different than some of the bigger healthcare organizations that we have been talking about. Obviously [the Cancer Support Center] does not provide medical treatment for cancer.

5. What role do you think [the Cancer Support Center] has in the community?

Follow-up questions:
What are the positive things that you think [the Cancer Support Center] does?
Do you think that [the Cancer Support Center] gives patients and families experiencing cancer the support that they need?

Summary of Roles/Responsibilities of Healthcare.

Would you like to add anything about your opinion on the role of healthcare organizations?
VII. Closing [2 minutes]

I just have a couple of closing questions I would like to have you think about before we finish up. We have talked a lot today about your experiences at [the Cancer Support Center] and in healthcare.

1. I would like to know what your final thoughts are about our conversation today?

I would really like to thank you for your participation [give them gift card]. This study could not take place without your participation, so your work here today is very important.

2. Before we end I would like to know if you have any questions for me.

End.
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