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Understanding Social Support Burden Among Family Caregivers

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Abstract

Despite the abundance of research on social support, both as a variable in larger studies and as a central focus of examination, there is little consensus about the relationship between social support and health outcomes. Current social support measures typically account only for frequency and size of network and a paucity of research exists that has explained social support burden, defined as the burden associated with accessing and receiving support from others. We analyzed audio-recorded discussions by hospice family caregivers about their caregiving problems and potential solutions to examine social relationships within networks and identify the processes that influence social support seeking and receiving. Using qualitative thematic analysis, we found that caregivers providing hospice care experience social support burden resulting from perceived relational barriers between friends and family, the inclination to remain in control, recognition of the loss of the patient as a source of social support and guidance in decision-making, family dynamics and decreased availability of emotional support. Social support researchers should consider how the quality of communication and relationships within social networks impacts the provision and subsequent outcomes of social support in varying contexts. Findings from this study suggest that hospice social support resources should be tailored to the caregiver's support needs and include assessment on the type of support to be offered.

Introduction

Research on family caregiving has detailed the considerable stressors faced by individuals providing care for an ill or aging relative; such stressors can exact a significant toll on caregivers' quality of life, physical health, and psychological well-being (Goode, Haley, Roth, & Ford, 1998; Schulz & Beach, 1999; Wilder, Parker Oliver, Demir, & Washington, 2008). An extensive body of research has linked physical and mental health with social support in the general population (Thoits, 1995; Uchino, Bowen, Carlisle, & Birmingham, 2012) and among family caregivers, specifically (Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Roth, Mittelman, Clay, Madan, & Haley, 2005; Thielemann & Conner, 2009). These findings have led to an overwhelmingly positive view of social support (Goldsmith, 2004) and resulted in a body of research focused almost exclusively on the positive aspects of social support for family caregivers. Positive outcomes of supportive conversations and networks suggest that feedback encourages healthy behaviors, communication assists in acquiring health information and seeking, and can also influence tangible health support and coping assistance (Goldsmith & Albrecht, 2011). However, Goldsmith (2004) has noted that the term social support is often used as "an umbrella term" representing a general belief that social relationships are linked to well-being.

Much less studied and, therefore, more poorly understood is social support burden which is characterized by the impediments or negative costs associated with seeking, maintaining, and receiving social support (Lincoln, 2000). The lack of investigation into the relational process associated with social support may, in part, be a by-product of the tools used to measure the construct of social support. Many social support measures and social network measures primarily operationalize support in terms of social network size and/or frequency of interaction, excluding substantive consideration of the quality of the communication and relationships within the social network (Goldsmith, 2004). This can be problematic, considering research that suggests that the quality of social support may be more strongly influenced by the functionality of the social network and relationships than network size and frequency of contact (Benkel, Wijk, & Molander, 2009; Wright & Miller, 2010). For example, complicated role obligations within social networks can result in *reciprocity failure*, defined by Wright and Miller (2010) as the real or perceived inability or unwillingness to reciprocate a service or favor. Presumably, inattention to the quality of social support in health contexts is predicated on the clinical practice premise that all social support is positive or that more social support is inherently better. Operating on this assumption ignores evidence to the contrary, compromises researchers' ability to fully understand the relationship between social support and caregiver well-being, and introduces serious limitations to individuals seeking to promote positive outcomes for family caregivers. The goal of this study was to gain a better understanding of the communication processes that shape social support seeking and receiving as burdensome.

Current approaches to social support and family caregiving

Research on family caregiving has commonly subscribed to the stress buffering hypothesis, presuming that more social support resources are best for managing the complex challenges of caregiving for a loved one (Cohen & Wills, 1985). Although research has concluded that

family caregivers need instrumental (e.g, respite care), emotional (e.g., counseling services), and informational support (e.g, educational resources) (Kutner et al., 2009; MacLeod, Skinner, & Low, 2012), a comprehensive review of the caregiving literature presents mixed results regarding social support benefits, with some studies demonstrating advantages for caregivers with more social resources, such as lower rates of depression and higher life satisfaction (Haley et al., 2003; Thielemann & Conner, 2009) and other studies failing to establish positive relationships between social support and desirable caregiver outcomes, such as caregiver adjustment (Smerglia, Miller, Sotnak, & Geiss, 2007). Also noteworthy are studies demonstrating that negative social interactions can have a powerful negative impact on individuals' emotional well-being (Haley et al., 2003; Lincoln, 2000), providing additional support for examining the quality of relationships and communication within social networks.

The “more is better” social support hypothesis embedded in clinical practice approaches (i.e., clinicians offering a multitude of resources to all patients/families) is further challenged by research suggesting that even well-intended acts of support may not be perceived as helpful by recipients and that an awareness of support receipt may, in fact, be harmful in some instances. Studies of the differences between perceived and so-called “invisible” social support (acts of support provided by the supportive partner that are not recognized or coded as support by the recipient), found that individuals receiving invisible support had decreased levels of depression while depression among individuals who received recognized support was higher (Bolger, Zuckerman, & Kessler, 2000). In addition, many studies have failed to consider whether received social support was provided without prompting by the individual experiencing the stressor or whether the individual solicited the support. This consideration segues into the literature on social support-seeking which paints an even less clear picture, with some research showing support-seeking to be an effective coping strategy and other studies suggesting it is actually associated with higher levels of psychological distress (see Thoits, 1995 for a review). It is clearly evident that gaps exist in the literature pertaining to the relationship between social support and well-being.

Assumptions about the general benefits of social support are particularly evident in standards of practice for hospice family caregivers. Hospice care recognizes the patient and family caregiver as the unit of care and includes the provision of supportive services for the benefit of both caregivers and terminally-ill patients. Hospice offers tangible, emotional, and informational support services through social work and chaplaincy care, respite care, and volunteer services. However, securing social support is problematic for hospice family caregivers often due to late enrollment in hospice wherein services cannot be implemented in time to be beneficial as well as the tendency for caregivers to seek help only after their own resources have been diminished (MacLeod et al., 2012).

For many hospice caregivers, family serves as the primary social network. Positive experiences within the family network can benefit caregivers. For example, caregiver feelings of gain, described as feeling useful, valuing sense of self, experiencing strengthened ties between caregiver and care recipient, and feeling satisfied, are influenced by interpersonal resources (socio-emotional support) often provided by family (Shirai, Silverberg Koerner, & Baete Kenyon, 2009). At the same time, not all experiences within

the family social network are positive or free of stress. For many caregivers, communication with other family members is a significant challenge (MacLeod et al., 2012). In addition, family issues may be a source of stress for caregivers who feel abandoned by family members who do not help with care (Kutner et al., 2009). Overall, more research is needed to investigate the relationship between social support and caregiver health (Uchino et al., 2012), including the possibility that communication within social networks may impede pathways for improvement in psychological or physical health outcomes.

Communication and Social Support

Communication researchers have demonstrated that seeking and receiving support is a complex communicative process that includes message production, message reception, and conversational interaction (Albrecht & Goldsmith, 2003; Burleson & MacGeorge, 2002). The perception of social support is created through an interpersonal communicative process between individuals within weak and strong-tie networks wherein one individual is experiencing uncertainty stemming from a difficult situation (Albrecht & Goldsmith, 2003; Burleson & MacGeorge, 2002). The provision of social support is influenced by the recipient, message, and communication situation and has an impact on personal relationships (Burleson & MacGeorge, 2002). Research on variance in supportive message types (MacGeorge, Gillihan, Samter, & Clark, 2003), sources of social support (Albrecht & Goldsmith, 2003), and weak-tie/strong-tie support networks (Wright & Miller, 2010) have demonstrated that social support is based on mutual reciprocation within interpersonal relationships (Egbert, Koch, Coeling, & Ayers, 2006) and is an aid in uncertainty management (Ford, Babrow, & Stohl, 1996).

Compared to sociological and psychological perspectives of social support, which focus on casual mechanisms and the perception of availability and received support in order to ascertain positive or negative outcomes, a communication perspective accounts for supportive interactions that involve support seeking, provision, reception, reaction, and response (MacGeorge, Feng, & Burleson, 2011). Defining features of supportive communication include verbal and nonverbal behavior, intent to improve another's wellbeing, and intended responses to another individual's needs (MacGeorge, Feng, & Burleson, 2011). The interactive nature of supportive communication, with communication intent dependent upon an individual's ability and motivation to provide support to another, influences cognitive and affective message reception (MacGeorge, Feng, & Burleson, 2011). Individual responses to support are dependent upon a range of factors, including relational closeness, context of support message, and message (Feng & Lee, 2010). Given that individuals process supportive communication differently, supportive messages can have a negative evaluation if the recipient is not ready or able to receive support (Burleson & MacGeorge, 2002).

A normative approach to social support examines an individual's uncertainty management and considers the strategies adopted in response to support dilemmas (Brashers, Neidig, & Goldsmith, 2004; Goldsmith, 2001; Goldsmith & Fitch, 1997; Scott, Martin, Stone, & Brashers, 2011). A normative focus acknowledges that the quality of support may determine its effectiveness, rather than quantity (Burleson & MacGeorge, 2002). Social support is not

always perceived as supportive or helpful by those who receive the so-called social support (Goldsmith, 2004) and potential dilemmas of social support result from the difference between an individual's goals of support and support givers, resulting in an increase in stress and anxiety (Brashers, Goldsmith, & Hsieh, 2002). Taking a normative approach to hospice caregiver perception of social support examines how meanings of uncertainty may account for why social support may be judged as more appropriate and effective than others. We examined data collected from hospice family caregivers about problems related to caregiving and potential solutions to these problems. Our research was guided by the question: What factors influence perceived barriers to accessing and receiving social support for hospice family caregivers?

Method

Data were collected as part of an ongoing randomized controlled clinical trial to assess the impact of delivering a cognitive behavioral problem-solving intervention to family caregivers of hospice patients. Consenting family caregivers were randomized into a face-to-face intervention group or video-mediated intervention group. Data for the study presented here were collected between November 2011 and May 2012 from two hospice agencies located in the Pacific Northwest region of the United States. Institutional Board Review approval was granted from the supporting university where the study was conducted. For the purposes of this study, social support was defined as "functions performed for the individual by significant others (primary or secondary others)" (Thoits, 2011, p. 146).

Participants

Participants were hospice family caregivers. Given that the larger study involved the use of technology, caregivers enrolled in the study had to be 18 years or older, have access to a standard phone line or Internet, be without functional hearing loss, have no or only mild cognitive impairment, and have at least a sixth grade education. At the time of analysis, 28 caregivers had participated in the larger clinical trial. However, eight caregivers were omitted from the study sample because their loved one died before they could complete all three intervention visits, and one caregiver withdrew before the first visit. Thus, the total study sample consisted of 76 audio-recorded intervention visits (19 caregivers, each with three intervention visits and an exit interview). Table 1 provides a summary of participant demographics.

Procedure

Upon admission to hospice, caregivers were presented with the research opportunity by hospice staff. The research coordinator visited interested and eligible caregivers and obtained informed consent. Over the course of three intervention visits, caregivers were taught a social problem solving technique developed by Nezu and colleagues (2007) and adapted for use with hospice family caregivers (Demiris et al., 2010). In visit one, interventionists and caregivers discussed caregiving stressors and the benefits of having a positive problem-solving attitude. During visit two caregivers identified their most troublesome problem and brainstormed possible solutions. Finally, in visit three, caregivers evaluated alternatives and selected the most promising solution to implement.

The majority of intervention visits took place in the caregiver's home, with some caregivers preferring to meet in an alternate location. As a follow up to the study, participants were telephoned within a week after visit three for an exit interview. The exit interview included questions about the intervention, caregivers' communication with hospice staff, and their thoughts about whether or not hospice was able to meet all of their support needs. Discussions were digitally recorded and served as the corpus of data for this study. Intervention visits ranged in length from 16 minutes to 1 hour and 5 minutes, averaging 38 minutes each; exit interviews averaged 14 minutes.

Data Analysis

Data from all three intervention visits as well as exit interviews with family caregivers were analyzed using thematic qualitative analysis. Members of the research team first reviewed the audio-recordings and identified segments of data during which caregivers discussed social support. Initially two members of the research team listened to audio-recorded discussions and identified and transcribed all instances in which caregivers spoke about their social network (primary and secondary group members), appraisal of support (positive or negative), and support type (informational, emotional, instrumental). To ensure that all discussions of social support were captured, each researcher independently transcribed social support content for five caregivers (three visits and exit interview each). The researchers then met and reviewed transcription, transcribed the data for five more caregivers independently, met and reviewed, and then split the remaining data set in half and transcribed independently.

Researchers adopted an inductive approach to thematic analysis, identifying themes that were linked to the data themselves, as opposed to applying an a priori coding template (Braun & Clarke, 2006). First, three members of the research team independently reviewed the data set and developed codes to classify items of information related to caregivers' comments about social support. Second, codes for each caregiver were sorted and organized through discussion to identify patterns and create memos, larger explanations and descriptions of meaning in the data. Finally, working with a baseline organization of memos, researchers independently reviewed the data set again to sort through the data and identify exemplars and assess saturation. Integration of memos and final development of themes was accomplished through joint review and discussion of the data. All memos and notes were compiled and contributed to the thematic analysis. Once thematized, the data were circulated among the research team to check for validity. Team members discussed and further shaped researcher-identified themes via open conversation and confirmed patterns of communication, shaping the final results.

Results

From the analysis, the following key themes emerged: perceived relational boundaries, inclination to be in control, loss of patient social support, and family dynamics. Each theme is detailed below to illustrate how caregivers perceived accessing and receiving social support as burdensome. Table 2 provides an overview of the themes.

Perceived Relational Boundaries

Caregivers described relational boundaries within their social network that impeded their ability and proclivity to seek social support. There was an overall perception among caregivers that asking for help during this very personal time was considered transitioning secondary support members (typically friends) to primary relationships. Similarly, primary (familial) relationships revealed relationship boundaries when caregivers recognized a lack of support from their family network. Although friends and family were considered within the social network, caregivers articulated that they were not comfortable seeking assistance as they were not sure if Relational boundaries varied for friends and family and are detailed below.

Friendships—Although friends were considered supportive, asking for support during hospice caregiving was seen as relational turning point that would move friends into the personal circle of family. Instrumental tasks, especially related to patient care, were viewed as “a lot of responsibility to ask of somebody” who was a “supportive friend”. Caregivers were reluctant to test the boundaries of existing friendships. Discrete boundaries within friendships positioned some supportive others as unavailable to caregivers who felt that seeking their assistance would only mean “pressuring them” into formidable help. There was overwhelming reluctance from caregivers to burden friends and overstep the boundaries of friendship. Caregivers who weren’t able to permeate relational boundaries and didn’t seek assistance reported a loss of supportive networks and further limited social support.

Likewise, caregivers reported a need to restrict friendships within their social network in order to protect the time needed to provide care to their loved one. Caregivers recognized the need to “preserve effort and energy for caregiving” by implementing boundaries within existing relationships. Ironically, working to “create boundaries in relationships outside” of caregiving impeded their own support network. Some friendships were seen as a hindrance for caregivers who did not have time to sustain friendship roles. One caregiver explained that her friends didn’t have “life loss” like she had, they had not lost a parent and had never dealt with illness and thus could not provide emotional support. Stress emerged as a result from the inability to serve as a friend as well as the loss of friendship networks. Support resources were not sought from friends within the social network as caregivers felt they could not reciprocate friendship tasks.

Family—Recognizing the need to ask family members for help revealed relational boundaries that were considered impermeable by most caregivers. Seeking support from family members was considered “the hardest part” of caregiving because caregivers “didn’t like asking” other family members for assistance. Hesitancy to ask for support from family members was stressful as it required caregivers to acknowledge a lack of support from within their family. Many caregivers felt that family members would interpret asking for help as a strategy to “facilitate guilt” and thus opted not to look to family for additional resources and assistance.

Being in control

The most salient self-description of caregivers involved their ability to “be in control” of the situation, make decisions, and manage patient care. Many caregivers perceived themselves as “control freaks” or “perfectionists”, revealing how their inability to delegate and relinquish control impeded their ability to receive social support from others. Their stories about interactions with hospice staff depicted dominant personalities who limited social support resources by trying to provide all care duties while simultaneously concealing their own stress (“when I’m not doing well, people don’t necessarily know”). An adult daughter caring for her mother explained that she had “a tendency to want to take on everything” and reported that delegating was difficult. Another caregiver recognized her own internal struggle to maintain control: “I crave stability and the open-ended nature of the events that are about to unfold is a stressor for me.”

Attempts to maintain control revealed caregivers’ tendency to micro-manage patient care and block the use of supportive resources. Caregivers talked about the need to gate-keep available resources, explaining that supportive services created more responsibility for them. Caregiver preparations for leaving a patient were considered more work than actually leaving. Once employed as a full-time teacher, one caregiver summarized:

...having all this extra help is kind of like making lesson plans for a substitute. I've got to plan out what I'm going to do, what's going to be accomplished, and I don't really see it as lightening anything for me but rather increasing...

For caregivers, overseeing “the revolving door of people” who came to help, including home health aides, volunteers, and hospice staff, required them to “spend all the time marshaling forces.” Comparing no help to patient assistance was not necessarily seen as supportive, as one caregiver reflected:

After not having anybody for a while and then having somebody here all the time kind of makes me—adds to my stress...because it's good that she's here and does the things to help, but sometimes it's just too much.

The “swinging door” of staff and high frequency of staff turnover left caregivers feeling uneasy.

The inclination to remain in control kept supportive staff in limited roles as the majority of caregivers conveyed that they did not trust “others” to provide adequate care to their loved one. Several caregivers explained that their way of doing things was “the only way to do it.” For example, one caregiver commented: “Somebody else is not going to do it the way I would do it. And that’s my problem.” Another caregiver illuminated this way of thinking by stating: “I’ve always been one to take on everything because I always think I can do it, the way that I want it done and nobody else can do that.”

Care provision, according to caregivers, required medical knowledge and expertise that could not be handled or trusted by anyone else. Patient symptoms, medication side effects, and needed medical equipment were cited as barriers to obtaining adequate support. A woman caring for her partner dying from ALS summarized:

Even if someone else could come in, it's not within their job description, especially as a volunteer, to know how to turn on her suction unit or get her in the right position if she needs to use her cough assist machine or the commode.....more help really just doesn't make a difference the hospice aide really only comes in to give baths.

Other caregivers echoed these feelings and felt that high care demands prohibited their ability to seek trusted help.

Trust was considered essential to quality care delivery for their loved one and necessary for caregivers to be able to receive, accept, and feel supported. Caregivers talked about wanting support from individuals who were "a known entity... not just a stranger." Feeling the effects of instrumental support was only possible with staff trust. Likewise, consistency of staff was viewed as optimal in establishing trust and caregivers explained that variance in staff from week to week "won't make any difference." Given that caregivers had no control over staff assignment or frequency in staff changes, they balked at having additional "strangers" coming in and out of their home.

Very few caregivers described themselves as unaccustomed to the position of decision-maker. For these caregivers, however, being in charge was scary, unfamiliar, and created intense anxiety ("It's like I've got this mental block"). Frustration emerged from the inability to make decisions ("everything seems so mentally hard") and the inability to direct and delegate ("I'm just so confused in my head right now because nothing is going as I want it to go"). Their inexperience with decision-making and delegating left them feeling out of control and unable to seek social support resources. A woman who was providing her mother's care concluded: "The things that you think got settled and there will be no difficulty, end up being phenomenally hard". Caregivers who weren't accustomed to being in charge ("I've never really handled decisions well") desired delegation skills as they reported "not being sure how to delegate." Social support burden was also created from their inability to say no to others and the need to please everyone.

Loss of Patient Social Support

Disease progression and decline prevented patients from communicating with caregivers about relational topics and decision-making, leaving some caregivers with a loss of social support that had steadily been fulfilled through their relationship. One woman shared her struggle:

...I mean [patient]'s been my best friend and confidante for 19 years. Her [sic] and I have talked about some of the most intimate and challenging things ... I think I still deserve some relationship even though she's sick.

No longer having the patient as a source of social support often left caregivers unable to make decisions with confidence, particularly when they were required to make decisions on the patient's behalf. Further, unavailability of social support from their dying loved one required some caregivers to acquire an entirely new skill set in order to seek out social support from new sources. The loss of the patient's ability to engage in conversations was

particularly evident among caregivers caring for patients with dementia, as they described a loss of emotional support once sustained through a relationship with the patient.

Major role shifts in relationships, primarily with adult children providing care for their parents, illuminated the emergence of a new family role and further obfuscated support needs. An adult daughter shared how her family was changing:

I mean as a family, my mother has been the matriarch, the one who keeps all of us together. So that role now belongs to my sisters and [me] to do. And this is part of stepping into her role. This is part of doing what she would have been doing and she can't do anymore.

Stepping into this new role, this daughter further described how much responsibility it was and how unprepared she was to take on this new identity within the family. The loss of patient social support was characterized by a high need for informational resources and caregivers reported a lack of available time to do research and gather information.

For caregivers who were able to maintain communication with their loved one, there was commonly an apparent need for caregivers to receive patient permission to seek support. Caregivers looked to patients for support with decision-making, especially as it related to obtaining supportive resources for tasks previously performed by the patient. In obtaining tangible assistance, caregivers were sensitive to how this would impact their loved one's feelings. A caregiver who wanted more information on the dying process explained why she didn't actively seek information:

I've never wanted to ask that in front of him (patient). I don't know how he feels about that and what he would think of me asking that ... I'm not one to keep things from him.... that's why it's been difficult because I don't want to ask a doctor with him there, but yet I want the answers.

The approval of patients was described as instrumental in influencing whether or not caregivers sought additional sources of support from hospice, friends, or family.

Family Dynamics

For some caregivers, family relationships were already strained prior to the patient's illness and family communication patterns negated discussions about hospice care. Consequently, family relationships were, by default, a source of stress and burden rather than a network that naturally provided instrumental, informational, or emotional support. First, social support barriers were present between family members who did not previously engage in routine family relationships. One woman explained the relationship she has with her sister:

We don't normally communicate much except through our parents and I really didn't think that we would get to this age and still have it be that way, but it's a pattern that was established a long time ago.

Overcoming long-standing communication barriers to facilitate mutual support was anticipated to be too burdensome. As a result, several caregivers detailed strategies to handle care on their own and limit family involvement.

Second, many caregivers commented on the emotional burden associated with providing support to family members. The difficult nature of caring for someone who was dying strained family relationships and left caregivers reflecting on the lack of emotional availability of other family members. Family members become so stressed that they were not able to support each other. When asked if she had emotional support, a woman caring for her mother replied:

Peripherally, because my dad is distressed. We do talk stuff through but it's within a parameter. In terms of my own personal emotional support, I don't see any way that there is anything... it's just me... I feel like I am alone.

Caregivers recognized that family members processed their hospice experiences differently which made it difficult for family to support one another. A common strategy shared by caregivers was to “avoid arguments” with other family members despite their frustration about care.

Third, caregivers shared that support could not be found within their primary network because avoidance was a longstanding family practice. One caregiver described how her family's reaction to illness was due to her Japanese background:

In my own subculture family ... it's like if you don't talk about [illness], it will go away...we in the family haven't resolved how to deal with these things ... I haven't had anywhere to go with it, and I become less and less productive. I can see it, but it just makes it worse.

Another caregiver explained that she and her mother were “holder-backers” and were “really embarrassed to cry” in front of others. She described “learning the skill” to hold back her tears as a way of coping with stress and anxiety. Lack of communication about prognosis and hospice care between family members left many caregivers without an emotional support system within the family.

Overall, caregivers easily rationalized why they didn't have more family support. They reported not asking other family members for instrumental or informational support because they recognized that the family had other stressors (“we have a number of things going on in our family besides just this”). It was generally accepted that other family members could not take on the caregiving role (“it's going to be harder on my sister”) and that geographical distance impeded family members' ability to provide any source of support. Caregivers felt that they were better positioned to absorb this family responsibility (e.g., “I don't work”). Other family members who had children or worked full time were viewed as having a legitimate reason for not participating in care (“I can't always depend on my kids, both of my kids work”). Interestingly, single or divorced caregivers appeared to assume the caregiving role within the family by default, with the only exception being self-described dominant personality types or those with particular expertise (“I'm the leader because I have a medical background”). For these reasons, caregivers did not approach or pressure family members to become more actively involved in care in order to alleviate their own caregiving burden.

Discussion and Future Directions

Several factors influenced caregivers' perceived barriers to accessing and receiving social support, revealing caregiver uncertainty about their social network and subsequent coping strategies that actually created social support burden. Congruent with prior research, this study found that the act of seeking support is influenced by weak and strong-tie relationships within the social network and may not be desirable (Wright & Miller, 2010). Uncertainty about relational boundaries among weak and strong-tie relationships (friends and family) and recognized limitations within their family network impeded caregivers' proclivity to seek support. Caregivers in this study reported psychological distress and anxiety about seeking support from others that compounded their caregiving responsibilities.

The degree to which individuals seek and receive support within their social support network are influenced by coping needs (Wright & Miller, 2010). Caregivers' appraisal and interpretation of social support as burdensome was a result of coping strategies used to manage the highly stressful context of hospice caregiving. Consistent with their approach to most problems, some caregivers "took control" as a way of managing uncertainty and impeded the ability of weak-tie social network members to provide social support. It has been surmised that the communication processes and characteristics that foster communication as supportive or negative could be in response to antecedents of poor health (Segrin & Domschke, 2011), and in the context of caregiving, fatigue, loneliness, and other aspects of caregiver burden could also influence social support burden. Further research is needed to explore caregiver preferences for strong or weak-tie support as well as ways to help facilitate and mediate social support seeking and receiving.

During hospice care in the United States, greater communication between hospice staff and caregivers are presumed to reduce caregiver burden (Raleigh, Robinson, Marold, & Jamison, 2006) and increased educational materials are considered necessary to aid in education and acceptance, thereby lowering bereavement risk and improving outcomes for caregivers (Roberts & McGilloway, 2008; Zimmermann, 2012). However, hospice clinicians do not have instruments available that can help to determine a caregiver's risk of developing psychosocial problems that may indicate a need for social support services (Hudson et al., 2010). Assessment scales for family caregivers focus primarily on satisfaction with care delivery with little attention given to the perceived supportive care needs of family caregivers (Hudson et al., 2010). In the absence of standardized caregiver assessments, the majority of hospices utilize some type of their own form of design to assess bereavement risk, which may or may not be evidence-based or valid (Demmer, 2003), and continue to assume that the more social support resources (i.e., large social network, secondary insurance, use of respite care) provide optimal caregiver support. Our findings reveal that receiving social support is burdensome for some caregivers while other caregivers continue to struggle for support because of their inability or reluctance to ask for help. All of the caregivers in this study reported increased stress and burden from the receipt of hospice social services or when having to ask to help, demonstrating that more social support services are not always best as it is dependent on a caregiver's need for specific types of support (i.e., instrumental, emotional, or informational) with not all caregivers requiring equal amounts of all three types of support.

As this study demonstrates, the process of accessing social support is not only a matter of obtaining social resources. It also requires being able to communicate support needs and being psychologically and practically prepared to accept offers of support from others. This has two important theoretical implications. First, rather than emphasizing the support recipient, this study extends our understanding of the support seeker (i.e., the hospice caregiver). For hospice caregivers, support seeking was inhibited by message production and perceived message reception. Caregivers experienced social support burden by worrying about whether or not social support seeking (a) could be elicited clearly and (b) that the need for support would be recognized by a potential support provider. Second, the caregiver's ability and motivation to seek support also influenced the supportive communication process. Study findings demonstrate that caregivers were motivated to seek support but lacked the skill to develop successful messages. Thus, social support burden emerged from the lack of ability to adequately seek support verbally.

Inherently, reactions and responses to supportive communication impact relationships. Still, we know little about how these interactions have impacted support providers or the skills necessary for these interactions to become supportive. The ability and motivation of those who attempt to provide support communication were not taken into account in this study, and warrant an area of future research in exploring social support burden. Failed supportive communication may be due to a lack of interest or motivation of providers rather than the caregiver's recognized need to engage in coping mechanisms (MacGeorge, Feng, & Burleson, 2011). Future attention should explore the characteristics of effective and ineffective support messages during hospice caregiving and aim to determine the specific conditions or timing of these messages (e.g., initial hospice admission or one month post admission) that may reduce variability in message reception.

These findings have important implications for health care researchers, professionals, and others who seek to promote the well-being of family caregivers. Research examining the impact of social support on caregiver outcomes should include consideration of the quality and type of support provided, not just the quantity or frequency. The importance of this is apparent when considering the data presented here and is further supported by other research indicating that the quality not quantity of social support is related to outcomes such as depression and hopelessness (Beedie & Kennedy, 2002). Hospice clinicians would benefit from recognizing family caregivers' unique needs and challenges.

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Table 1

Summary Demographic Variables for Caregivers

Variable	Caregiver
Mean Age	61 years (range 45–88)
Sex	
Female	79% (15)
Male	21% (4)
Race	
White/Caucasian	79% (15)
Black/African-American	10.5% (2)
Asian-American	10.5% (2)
Education	
Less than high school	5% (1)
High school	11% (2)
Some college	21% (4)
2 year college degree	16% (3)
4 year college degree	26% (5)
Master's degree	16% (3)
Professional degree (MD, JD)	5% (1)
Relationship to patient	
Spouse/partner	32% (6)
Adult child	58% (11)
Niece	5% (1)
Grandchild	5% (1)
Resides with patient	
Yes	58% (11)
No	42% (8)

Table 2

Overview of thematic findings and examples from the data.

Theme	Description	Example
Perceived Relational Boundaries	Although friends and family were considered within the social network, caregivers articulated that they were not comfortable seeking assistance as they were not sure if relational boundaries were permeable and what the impact would be on the relationship.	<i>"I don't want this to be an overstepping of bounds in terms of the long-term friendship that we've had. I don't want them to be uncomfortable saying, "Oh gosh no. I don't have the time just now" or feeling pressured to cancel something that was important to them just so they can come and hang out with [patient] for a little while. I wouldn't want to push those boundaries in the friendship... I don't want to guilt trip them, although a part of me wants to."</i>
Being in Control	Caregivers self-reported that they were most comfortable being in control of the situation, resulting in micro-management of staff, difficulty trusting others, and viewing help as an uncontrollable additional stressor.	<i>"...having all this extra help is kind of like making lesson plans for a substitute. I've got to plan out what I'm going to do, what's going to be accomplished, and I don't really see it as lightening anything for me but rather increasing..."</i>
Loss of Patient Social Support	The loss of shared decision-making and support provided by the patient was felt by caregivers who reported a lack of confidence and a need to seek patient permission for supportive services.	<i>"...I mean [patient]'s been my best friend and confidante for 19 years. Her [sic] and I have talked about some of the most intimate and challenging things ... I think I still deserve some relationship even though she's sick."</i>
Family Dynamics	Family relationships were a reported source of stress and burden; co-caring forced family relationships not previously established, decreased emotional support between family members, and sustained avoidance as a long-time family practice.	<i>"In my own subculture family ... it's like if you don't talk about [illness], it will go away...we in the family haven't resolved how to deal with these things ... I haven't had anywhere to go with it, and I become less and less productive. I can see it, but it just makes it worse."</i>