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Social support needs: Discordance between home hospice nurses and former family caregivers

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Introduction

In recent years, use of home hospice care has increased in the US, (Teno et al., 2013) and as it continues to develop and evolve, agencies work to make improvements in both care delivery and satisfaction of family caregivers. In home hospice care, family caregivers provide the majority of care with support from hospice nurses who also coordinate hospice interdisciplinary team services (Berry & Griffie, 2010; Coyle, 2010; Egan City & Labyak, 2010). Though often a successful model, caregivers nonetheless report having unmet needs related to support for inhome care (Bee, Barnes, & Luker, 2009; Kutner et al., 2009; Newton, Bell, Lambert, & Fearing, 2002). If a caregiver has unmet needs and is in turn unable to effectively navigate the demands of care, both patient and caregiver health may suffer. Caregiving has been recognized as a major stressor for families and has adverse effects on caregiver quality of life, physical health, and emotional distress (Doorenbos et al., 2007; Given et al., 2004; Markowitz & McPhee, 2003; Nijboer et al., 2000; Weitzner, McMillan, & Jacobsen, 1999). Social support has been shown to reduce caregiver burden (Rodakowski, Skidmore, Rogers, & Schulz, 2012) and is related to better caregiver health (Baron, Cutrona, Hicklin, Russell, & Lubaroff, 1990). Often, home hospice nurses are in a position to provide different forms of social support to family caregivers. Researchers have sought to determine what family caregivers in home hospice need and how, from the caregiver perspective, to best meet them (Newton et al., 2002). Across studies, caregivers frequently reported needing help from hospice nurses with symptom management and self-care, coping, needing information, and Emotional support. These needs correspond to common functions of social support, (Cutrona & Russell, 1990) as shown in Table 1, with examples. Informational support consists of providing advice or useful information for

problem solving. For example, a nurse telling a caregiver what to expect or explaining a symptom or medication would be providing Informational support. Tangible support involves provision of goods, services, or other concrete ways of providing help. This would include providing medical equipment, like a hospital bed, or performing tasks, such as cleaning or changing a catheter. Esteem support includes bolstering a caregiver's confidence and self-efficacy through reassurance and encouragement. Emotional support involves offering empathy, acceptance, and often involves "being there" for someone or offering a compassionate presence. While Esteem and Emotional support are often linked and both help caregivers feel good about their role, the key difference is that the latter is a passive form of support (listening, taking in what the caregiver has to say), and the former is a more active form of support (working to build or reinforce the caregiver). Finally, Belonging support, or having networks of people to turn to for common interests and a sense of membership, is also important to caregivers. However, this may be less important to the relationship with one's health care provider; often this comes from family, friends, and other groups, such as church membership or support groups. Previous research has found needs for all of these five types of social support in coping with broadreaching life events, such as bereavement (Cutrona & Russell, 1990).

Though social support, or physical and emotional comfort and help, is obviously needed by caregivers and has been shown to be beneficial to psychological and physical health, (Holt-Lunstad, Smith, & Layton, 2010; House, Landis, & Umberson, 1988) support is not always effective. (Lehman, Ellard, & Wortman, 1986) In order for social support to be beneficial, the social support desired by an individual has to match the support provided to him or her, or be responsive to his/her needs (Maisel & Gable, 2009); this is known as the stress-support matching hypothesis (Cutrona & Russell, 1990). Psychological stress may increase if a different type of support is provided than what the recipient wishes to receive (e.g., Information is given when Emotional support is sought), whereas matched support may ameliorate stress response by adequately addressing the need (Horowitz et al., 2001; Linden & Vodermaier, 2012; Thoits, 1986). A broad range of factors, including understanding the needs and priorities of the support recipient, shape the type of support one may offer. By tailoring support to patient and family needs, health care providers are likely to not only meet needs, but reduce distress, and enhance coping for ongoing care provision.

Though home hospice nurses may identify particular caregiver needs, they still need to decide whether it is beneficial to offer support, what kind, and to what degree, based on the priorities of the patient and family as well as their own role as health care provider. Previous research with breast cancer patients has shown that there are different patterns of what type support is found to be most helpful from different ties (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Neuling & Winefield, 1988). While these patterns change over time, there is evidence that helpful support is provided by an entire network of family, friends, and providers and that the support most helpful from providers included not only information support, but often also Emotional and Esteem support. Thus, there is evidence that the role of the provider goes beyond supporting patients and caregivers tangibly through treatment and with information to make decisions, but also to bolster them emotionally and to ensure their confidence.

Although one of the key roles for hospice nurses' is to address family caregiver needs, caregivers continue to report multiple unmet needs. We suggest that perhaps rather than a lack of support, ongoing reports of caregiver unmet needs may, in reality be a mismatch between the types of support caregivers need and the types of support hospice nurses provide.

Objectives

The objectives of this study are to 1) identify which of 5 types of social support (Informational, Esteem, Emotional, Tangible, Belonging) are most cited by nurses and family caregivers; and 2) by comparing how frequently these types of support are mentioned by nurses and caregivers, determine the potential match in perception of support needs.

Methods

As part of a larger, multiphase project funded by the American Cancer Society (ACS PEP-11-165-01-PCSM; PI: Ellington), focus groups were conducted with former family caregivers and hospice nurses to discuss their experiences of home hospice care, and gather their opinions of the important issues involved in that care. All study activities were conducted with University IRB approval, including procedures for informed consent.

Inclusion Criteria and Recruitment

Inclusion criteria for former family caregivers included people who have previously served as an at-home caregiver for an adult who received hospice services within the previous 36 months and spoke English. Former family caregivers were recruited through a local hospice agency and a grief and bereavement support program. These organizations provided a list of those who agreed to be contacted about the study. The research team followed up by calling those individuals to explain the study and screen for inclusion criteria. Enrollment continued until an adequate number of participants agreed to attend one of two former family caregiver focus groups (n = 14).

Inclusion criteria for nurse case managers included nurses who had spent at least one year in the role of a hospice nurse case manager. Nurse participants were recruited from attendees for the 2012 Annual Assembly of AAHPM (the American Academy of Hospice and Palliative Medicine) and HPNA (Hospice and Palliative Nurses Association) in Denver, CO. A notice was distributed through the HPNA electronic newsletter, inviting interested individuals to contact a researcher who provided more study information, and screened for inclusion. Enrollment continued until there were an adequate number of participants for two nurse focus groups (n = 13).

Data Collection Procedures

Prior to the beginning of each focus group, all participants completed a demographic form which included information specific to their role as either family caregiver or as hospice nurse. These data are summarized in Table 2.

The family caregiver groups met in local University conference rooms. The nurse focus groups met in conference rooms at the 2012 Annual Assembly of AAHPM/HPNA assembly. All focus groups were moderated by a member of the research team experienced in conducting focus groups, while another member of the research team experienced in qualitative research observed, took notes, and assisted with asking follow up questions and probing responses. Both focus groups centered on the question of how to best support home hospice family caregivers. Facilitator questions included open-ended questions like, “Based on your experience, tell us what hospice family caregivers need the most.” Participants were also asked for examples of when caregivers were supported well and how things could have been done differently when things did not go well. The focus group discussions were audio-recorded, professionally transcribed and verified by the research team.

Coding

To identify which of 5 types of social support (Informational, Esteem, Emotional, Tangible, Belonging) are most cited by nurse and caregiver groups and determine the match in perception of support needs, caregiver and nurse statements within focus group transcripts were coded for type of support. Talk categorized in previous analyses (Cloyes et al., under review) as within the broad theme of “Caregiver Needs” was extracted for analysis to narrow the scope to discussion surrounding support given to or needed by caregivers (i.e. eliminate extraneous talk or talk of institutional needs for nurses). Using the standard definitions of social support from the literature, (Cutrona & Russell, 1990) two coders independently categorized all unique statements, exclusively and exhaustively, into 6 categories. This included the 5 functions of social support: Informational, Esteem, Tangible, Emotional, or Belonging, and a “general need” category. The general need category was used when participants mentioned that caregivers were in need of support, without a specific mention as to what type of support that was; these were not included in further analyses. Coders used the description of the support the caregivers and nurses spoke of as “a caregiver need” as well as the context of the conversation to choose the best fitting category. After an initial round of coding, coders compared their output and worked to consensus. Though Belonging support was included in the initial coding system, it was not included as a final category as neither nurses nor caregivers mentioned this as a need. Additionally, provision of this type of support may be inappropriate from a health care provider and may signal a provider crossing his/her professional boundaries (National Ethics Committee of the Veterans Health Administration, 2003).

Results

Nurses had 40 unique statements of caregiver need; caregivers had 78. Examples of each of the 4 types of support were identified. As seen in Figure 1, nurses most frequently cited the need to provide Information (N=13, 32%), followed by Esteem (N=10, 25%), Tangible (N=9, 22.5%), and Emotional support (N=8, 20%). There were no statistically significant differences between the frequencies in these categories ($\chi^2 = 3.34$, $p = .34$, $df = 3$). Meanwhile caregivers most cited Tangible (N=25, 32%), then Information (N=22, 28%), Emotional (N=20, 26%), and Esteem support (N=11, 14%). There were marginally significant differences between the frequencies endorsed by caregivers ($\chi^2 = 7.2$, $p = .066$, $df = 3$).

Information support is a primary purpose of a nurse's role—to guide caregivers in knowing what to do, and therefore is logical that both groups would express that caregivers have a great need for this type of support from nurses. As one nurse noted,

“They need to know what's coming. Then, as impossible as it is to tell them, we tell them all different case possibilities...they just have a need to know what is going to happen.”

A caregiver had a similar sentiment,

“I think what they need to understand is as the caregiver the reality of that you're about to lose someone very, very close to you—we need you to educate us as much as possible about what you're going to encounter.”

This need for information encompasses not just information about the future, but also information about the current situation, and to all family caregivers. One caregiver described frustration with her lack of support in this area,

“It was very difficult for me to get any information at all. They're supposed to leave logs and they would rarely write in the log. They would communicate with my mother, who could never remember anything, and I gave them my phone number; I would tell them at every opportunity that I could, ‘Please let me know what's going on.’”

The complex nature of individual family structure (or culture) and ability to manage strain compounds an already challenging situation, where often caregivers are stressed and may not absorb information that is given. For instance, from a nurse,

“They're overwhelmed, or they can't hear you, or whatever it is. Maybe if you do go and they can wash the dishes and let it sink in a little bit it helps. The next day they go, ‘Were you talking about...whatever?’”

Despite these complexities and challenges, both caregivers and nurses seemed to agree that Informational support was important. While caregivers are often only involved with hospice once or twice in their lives, nurses have far greater experience that both groups see as a valuable resource.

The other type of support most obvious to be provided in the role of nurse is **Tangible support**, or providing goods and services. While nurses may see Tangible support as the most basic level of services they provide, even the simple act of the nurse visiting was seen as supportive by caregivers.

“When it got closer and these things were happening, we needed the nurse to come more. The nurse started out coming three times a week. And then she started coming by every day. We didn't even have to say—they just came.”

Tangible support may be particularly important to caregivers as this may not be available elsewhere within the support network. It may seem to be a simple thing to nurses, but caregivers rely on the materials they provide and, unlike some other forms of support, are unable to receive medications or supplies from other support sources, such as friends.

Additionally, nurses perform tasks that require a level of expertise or comfort not available to caregivers from other potential support providers. One caregiver said,

“With me, there were times I'd kind of make demands. Look, you're the nurse. I'm not. You can tell me this, this, and this. But there's some things I just need you to do. I don't know why.”

Caregivers appreciate having the tools needed to do their jobs. A lack of supplies might be frustrating for caregivers and result in unmet needs, and often it is difficult for those without experience to plan to acquire the supplies necessary for what are often rapid changes in care needs. One caregiver marveled at the extent of the supplies available and needed, while another caregiver notes how unsure her family was of what support they needed to care for a dying family member.

“They brought in a bed. They brought in a porta-potty. They brought in a wheelchair, everything. Anything we wanted, they'd find and bring to us.”

“They would suggest things whatever they could see there was a need. ‘Oh, let's get you this, let's get you this.’ And they were really important and very needed, and so they came before I ever even knew I was missing it.”

Caregivers were tuned to the medication and services hospice nurses provided, but this was rarely mentioned as a need by nurses, except for organizational tools.

“Yeah, writing down. I try to give them a notepad and say, ‘as this goes along, write down whatever you want to ask me.’”

Another nurse mentioned the importance of tangible support, but noted the difficulty in providing care for caregivers rather than patients.

“You step in and say, ‘Please, please accept this [volunteer coming to help], because I think it would be good for you.’ And again, oftentimes they're able to say—maybe not at the time—maybe at the time they're mad at you—but later on they're able to say how much that helped them.”

Esteem support was frequently mentioned by nurses, but the least mentioned (by a large margin; see Figure 1) by caregivers. The high endorsement by nurses perhaps is a response to the previous research and training showing that caregivers feel overwhelmed, resulting in nurses attempting to compensate through reassurance.

“Encouragement that they are doing a good job. Many times they think they're not doing it right. Just us telling them that they're doing a wonderful job.”

“They need us to validate their feelings.”

Caregivers did agree that validation was valuable.

“I just needed reassurance. I needed somebody to tell me I hadn't done a bad job or caused something bad to happen.”

However, often the way caregivers framed the need for validation was of their own expertise.

“I appreciated that the hospice would ask me—they would get my opinion. They would respect that I had some knowledge of what would be best.”

Given this confidence in their abilities, one potential reason for the relatively low endorsement of a need for this type of support by caregivers may be selection bias—former family caregivers who needed less reassurance in their role may be more likely to participate in focus groups. While **Emotional support** is often desired by patients from health care providers (Arora et al., 2007), it is often thought to be provided more frequently from friends and family as these individuals are often closer and no specialized skill is required. For example, caregivers who talked about Emotional support from the hospice staff often discussed the opportunity to “bounce things off somebody that was understanding,” not necessarily providing any medical care. Often when caregivers talked about Emotional support from nurses, they spoke of the humanity and compassionate presence of that individual.

“One of the really special things that this nurse provided was a patient, a really caring quality. It was a human interaction, a warm human interaction.”

“It relaxes you to know that they really are there and that you are okay”

While for some, the nurse is a reassuring presence, for others this role may have been filled by family members, trusted friends, or church group members. One nurse who recognized the need for Emotional support in caregivers mentioned that she refers people “to therapy, or support groups” when they need Emotional support; it is possible that this is seen as an area for nurses to refer to other hospice resources. While it is important for nurses to listen to caregivers' issues, perhaps both groups see more active forms of support as more useful. For instance, a nurse suggested that Emotional support could lead to identifying issues to which nurses could lend other types of support.

“You have to listen to them, intensive, and not just one visit... part of our job is helping them figure out what they need... it's helping them get to the root of what's really bothering you about this?”

Discussion

This research identifies the types of support perceived as needed by recipients (family caregivers) and providers (home hospice nurses) to determine the match in support. Overall, family caregivers and nurses provided similar responses. However, the relative importance, as determined by frequency of each response, differed by group. Overall caregivers mentioned the support they needed twice as frequently as nurses (78 vs. 40 unique instances). Likely this is due to differences in perspective; while family caregivers are focused on the care of their individual patients, nurses also discussed care at a more systems level. Their talk regarding managing caseloads, nurse mentorship, and other institutional factors, while important to understand their role in supporting caregivers, was not directed towards individual support of family caregivers and thus not coded for purposes of this paper.

In terms of most frequent types of support endorsed by each group, nurses most often mentioned Information, Esteem, Tangible, and finally Emotional support, but there were no significant differences between frequencies, suggesting nurses saw these types of support to be needed in equal measure across their caseloads. This suggests that previous research on caregiver needs (Bee et al., 2009; Kutner et al., 2009; Newton et al., 2002) has not been lost on hospice nurses; they make an effort to attend to supporting caregivers across appropriate domains.

Caregivers, however, had marginally significant differences in the frequencies of their responses. They most mentioned Tangible, followed by Information and Emotional support, and least mentioned Esteem support. The relative frequency of needs discussed in the group may indicate a differential need for prioritizing physical items and information over validation in their role as caregivers. In previous research on breast cancer patients (Reynolds & Perrin, 2004), the match of support (receiving wanted support and not receiving unwanted support) predicted well-being above and beyond the amount of support received and the simple satisfaction with that support. The authors also note there was variability in terms of the types of support desired across the population; what was desired by one patient was not desired by others.

These individual differences in types of support desired are likely based on the situation and the existing skills and resources of the individual. Families dealing with more challenging issues, such as ongoing unresolved pain or complex family dynamics, may require more support across types from health care providers than other families. Additionally, family caregivers with greater external resources, such as broader social networks, may require less support from health care providers, particularly in terms of Emotional and Esteem support. Each family's needs are likely to be different and vary over time in a unique fashion (DuBenske et al., 2008). Even within our sample of family caregivers, there were disagreements as to what was seen as helpful, emphasizing the need for skilled individual patient and family assessment by the hospice team.

A limitation of this study is found in its retrospective focus group design. From the perspective of family caregivers, some of the conversation revolved around what would have been helpful, rather than what actually occurred, and particularly with this group, selection bias may have affected our findings. Additionally, as this is a descriptive study, there were no outcome measures. From the analysis of focus group transcripts, we were unable to determine whether particular types of support or a better match of desired and received support would lead to improved perception of care or well-being. Finally, it is important to note work on invisible support (Bolger & Amarel, 2007; Bolger, Zuckerman, & Kessler, 2000), which indicates that support that is not noticed by the recipient may be most beneficial as it reduces many of the negative side effects of support, such as feelings of indebtedness or lowered self-efficacy.

Our findings suggest that home hospice nurses take a global perspective of support provision across their caseloads and are addressing a broad spectrum of support needs, including Informational, Tangible, Esteem, and Emotional, across their caseloads. Family caregivers may value certain types of support more or less. Given that matching support types has been

linked to improved outcomes (Cutrona & Russell, 1990; Linden & Vodermaier, 2012), it is important to focus on this match in health care populations particularly vulnerable to psychological stress, including family caregivers of home hospice patients. This research has implications for interventions to match support provision to caregiver needs, as has been done in other realms (Crane & Constantino, 2003) or for education for home hospice providers to ensure that they are not only sensitive to the possibility of a broad range of needs, but the necessity to tailor care to those needs.

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References

- Arora NK, Finney Rutten LJ, Gustafson DH, Moser R, Hawkins RP. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psychooncology*. 2007; 16(5):474–486.10.1002/pon.1084 [PubMed: 16986172]
- Baron RS, Cutrona CE, Hicklin D, Russell DW, Lubaroff DM. Social support and immune function among spouses of cancer patients. *J Pers Soc Psychol*. 1990; 59(2):344–352. [PubMed: 2213497]
- Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs*. 2009; 18(10):1379–1393.10.1111/j.1365-2702.2008.02405.x [PubMed: 18624779]
- Berry, PH.; Griffie, J. Planning for the actual death. In: Ferrell, BR.; Coyle, N., editors. *Oxford Textbook of Palliative Nursing*. 3rd. New York: Oxford University Press; 2010. p. 629-644.
- Bolger N, Amarel D. Effects of social support visibility on adjustment to stress: experimental evidence. *J Pers Soc Psychol*. 2007; 92(3):458–475.10.1037/0022-3514.92.3.458 [PubMed: 17352603]
- Bolger N, Zuckerman A, Kessler RC. Invisible support and adjustment to stress. *J Pers Soc Psychol*. 2000; 79(6):953–961. [PubMed: 11138764]
- Cloyes KG, Carpenter JG, Berry PH, Reblin M, Clayton MF, Ellington L. “A True Human Interaction”: Comparison of Family Caregiver and Hospice Nurse Perspectives on Needs of Family Hospice Caregivers. under review.
- Coyle, N. Introduction to palliative care nursing care. In: Ferrell, BR.; Coyle, N., editors. *Oxford Textbook of Palliative Nursing*. 3rd. New York, New York: Oxford University Press, Inc; 2010. p. 3-11.
- Crane PA, Constantino RE. Use of the Interpersonal Support Evaluation List (ISEL) to guide intervention development with women experiencing abuse. *Issues Ment Health Nurs*. 2003; 24(5):523–541. [PubMed: 12775549]
- Cutrona, C.; Russell, D. Type of social support and specific stress: Toward a theory of optimal matching. In: Sarason, IG.; Sarason, BR.; Pierce, GR., editors. *Social Support: an interactional view*. New York: Wiley; 1990. p. 319-366.
- Doorenbos, Ardith Z.; Given, Barbara; Given, Charles W.; Wyatt, Gwen; Gift, Audrey; Rahbar, Mohammad; Jeon, Sangchoon. The influence of end-of-life cancer care on caregivers. *Res Nurs Health*. 2007; 30(3):270–281. [PubMed: 17514724]
- DuBenske LL, Wen KY, Gustafson DH, Guarnaccia CA, Cleary JF, Dinauer SK, McTavish FM. Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliat Support Care*. 2008; 6(3):265–272.10.1017/S1478951508000400 [PubMed: 18662420]
- Egan City, KA.; Labyak, MJ. Hospice palliative care for the 21st Century: A model for quality end-of-life care. In: Ferrell, BR.; Coyle, N., editors. *Oxford Textbook of Palliative Nursing*. 3rd. New York, New York: Oxford University Press, Inc; 2010. p. 13-52.

- Given B, Wyatt G, Given C, Sherwood P, Gift A, De Voss D, Rahbar M. Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*. 2004; 31(6):1105–1117. [PubMed: 15547633]
- Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. *PLoS Med*. 2010; 7(7):e1000316.10.1371/journal.pmed.1000316 [PubMed: 20668659]
- Horowitz LM, Krasnoperova EN, Tatar DG, Hansen MB, Person EA, Galvin KL, Nelson KL. The way to console may depend on the goal: Experimental studies of social support. *Journal of Experimental Social Psychology*. 2001; 37:49–61.
- House JS, Landis KR, Umberson D. Social relationships and health. *Science*. 1988; 241(4865):540–545. [PubMed: 3399889]
- Kutner J, Kilbourn KM, Costenaro A, Lee CA, Nowels C, Vancura JL, et al. Keech TE. Support needs of informal hospice caregivers: a qualitative study. *J Palliat Med*. 2009; 12(12):1101–1104.10.1089/jpm.2009.0178 [PubMed: 19764830]
- Lehman DR, Ellard JH, Wortman CB. Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *Journal Of Consulting And Clinical Psychology*. 1986; 54:438–446.
- Linden W, Vodermaier A. Mismatch of desired versus perceived social support and associated levels of anxiety and depression in newly diagnosed cancer patients. *Support Care Cancer*. 2012; 20(7):1449–1456.10.1007/s00520-011-1228-3 [PubMed: 21744030]
- Maisel NC, Gable SL. The paradox of received social support: the importance of responsiveness. *Psychol Sci*. 2009; 20(8):928–932.10.1111/j.1467-9280.2009.02388.x [PubMed: 19549083]
- Markowitz AJ, McPhee SJ. Complexities in prognostication in advanced cancer: “to help them live their lives the way they want to”. *JAMA*. 2003; 290(15):2056. doi:10.1001/jama.290.15.2056290/15/2056 [pii]. [PubMed: 14559960]
- National Ethics Committee of the Veterans Health Administration. Ethical Boundaries in the Patient-Clinician Relationship: National Center for Ethics in Health Care, Veterans Health Administration, Department of Veterans Affairs. 2003
- Neuling SJ, Winefield HR. Social support and recovery after surgery for breast cancer: frequency and correlates of supportive behaviours by family, friends and surgeon. *Soc Sci Med*. 1988; 27(4):385–392. [PubMed: 3175721]
- Newton M, Bell D, Lambert S, Fearing A. Concerns of hospice patient caregivers. *ABNF J*. 2002; 13(6):140–144. [PubMed: 12592831]
- Nijboer C, Triemstra M, Tempelaar R, Mulder M, Sanderman R, Gam. Patterns of caregiver experiences among partners of cancer patients. *Gerontologist*. 2000; 40(6):738–746. [PubMed: 11131090]
- Reynolds JS, Perrin NA. Mismatches in social support and psychosocial adjustment to breast cancer. *Health Psychol*. 2004; 23(4):425–430.10.1037/0278-6133.23.4.425 [PubMed: 15264980]
- Rodakowski J, Skidmore ER, Rogers JC, Schulz R. Role of social support in predicting caregiver burden. *Arch Phys Med Rehabil*. 2012; 93(12):2229–2236.10.1016/j.apmr.2012.07.004 [PubMed: 22824248]
- Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, et al. Mor V. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*. 2013; 309(5):470–477.10.1001/jama.2012.207624 [PubMed: 23385273]
- Thoits PA. Social support as coping assistance. *J Consult Clin Psychol*. 1986; 54(4):416–423. [PubMed: 3745593]
- Weitzner MA, McMillan SC, Jacobsen PB. Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *Journal of Pain & Symptom Management*. 1999; 17(6):418–428. [PubMed: 10388247]

Figure 1. Mentions of Type of Support by Nurse and Family Caregiver

Table 1
Types of Social Support Provided by Home Hospice Nurses

Support Type	Nurse Example	Caregiver Example
Information	"They need information as to how to deal with this."	"They just said, 'Okay, you want an answer to your question. I'm going to give you that answer.' And it was so great."
Esteem	Sometimes reassurance that they are doing a good job... Some people are doing a great job and don't realize it."	"I just needed reassurance. I needed somebody to tell me I hadn't done a bad job or caused something bad to happen"
Tangible	Getting a caregiver to agree for a volunteer to come. Giving them the time that you know is important for their self-care."	They would suggest things whenever they could see a need...they came before I ever even knew I was missing it."
Emotional	"A listening ear about what's going on in the family, personally, as well as the patient... Ask about how the caregiver is doing."	"She didn't make me feel like she was in a rush to get out... You could tell that she cared."

Table 2
Focus Group Demographics

Variable	Nurse (n=13)	Caregiver (n=14)
Age (M; SD)	51; 10	61; 11
Gender (N; %)		
Male	1; 8	2; 14
Female	12; 92	12; 86
Race/Ethnicity (N; %)		
White	13; 100	12; 86
Black/African American	0; 0	2; 14
Hispanic	0; 0	1; 7
Education (N; %)		
High School	1; 8	1; 7
Some College	1; 8	3; 21
4-year Degree	8; 61	6; 43
Masters, Professional Degree	3; 23	4; 29
Years Experience (M; SD)		
As a Nurse	23; 12	
Employed at Current Hospice	7; 6	
Relationship to Patient (N; %)		
Spouse		8;57
Mother		4;29
Mother-in-law		1;7
Time (M; SD)		
Years Patient Ill		3;5
Months in Hospice		4;5
Months Since Death		11;9