Published in final edited form as:

J Hosp Palliat Nurs. 2014 July ; 16(5): 282–290. doi:10.1097/NJH.0000000000000066.

“A True Human Interaction”: Comparison of Family Caregiver and Hospice Nurse Perspectives On Needs of Family Hospice Caregivers

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Abstract

Context: Home hospice providers are concerned with family caregiver perceptions about the quality of care and support offered. More research is needed to understand experiences of family caregivers and what “support” means to these family members.

Objective: We compared perceptions of caregiver needs from the family caregiver and the nurse case manager.

Methods: Former family caregivers and hospice nurses participated in focus groups. Discussions were audio-recorded, transcribed, inductively coded and qualitatively analyzed to describe patterns and themes.

Results: Both groups described information, honesty, trust, respect, and control as important to caregivers feeling supported, and to the development of positive relationships between hospice and family. Caregivers and nurses, however, talked about the concepts of caregiver needs, relationship building, and effective support differently, which suggested two themes that captured these contrasts while highlighting the importance of relationship-building to both groups: “Breaking it down to build it up” and “Doing to, doing for, doing with”.

Conclusion: Caregivers and nurses cited similar elements necessary for successful relationships between caregivers and the hospice team, but how they described them differed and these differences shape perceptions of support. Greater understanding of similarities and differences could inform and improve training and education programs for hospice teams.

Introduction

The use of hospice care has risen precipitously in recent years with the growing movement to take care of family members at home, rather than in health-care institutions,¹ and as more families become aware of hospice services.^{2,3} Family caregiving responsibilities now include activities such as assessing and managing symptoms to keep patients comfortable, giving medication, coping with patients’ emotional and existential distress, and providing physical assistance.⁴ While there are many positive aspects to this shift in end-of-life duties,

if the family caregiver is overwhelmed and unable to effectively navigate the demands of care, the dying person may suffer unduly⁵ and the family caregiver is likely to be adversely affected.

Although many more patients are cared for and die at home than they did a decade ago,⁶ hospice nurse managers still play a very important role in the care of these patients. Hospice nurses manage patients directly, through assessment, teaching, and intervention, and through the family caregiver. The nurse's responsibility is to help support the family caregiver, in addition to supporting the patient.⁷ Effective communication between the nurse and the caregiver can improve symptom management for the patient, reduce caregiver burden and distress, and facilitate caregiver bereavement adjustment.⁸ Despite the critical nature of end-of-life communication, this topic is understudied,^{8–12} particularly in the context of in-home hospice care.

This qualitative study used descriptive and thematic analysis of focus group data to explore caregivers' feelings about whether they received adequate support from hospice services and staff, and about the nature of that support. We also used these methods to investigate similar questions from the perspective of hospice nurses. Data were gathered as part of a larger, multiphase study to increase our understanding of communication and interaction among family caregivers and the hospice interdisciplinary team, and to develop interventions to support effective communication between these two parties. By understanding the gap between ideal outcomes and actual practices, we can help develop practices that make this common, but extremely stressful, time in the lives of families more rewarding and less burdensome for both family caregivers and the hospice staff that assist them.

Methods

Study Aims

This study is part of a larger, multiphase project funded by the American Cancer Society (ACS PEP-11–165-01-PCSM). We sought to understand which aspects and issues each group thought contributed most to either positive or negative perceptions of services, and to compare family caregiver and nurse accounts about related to support of caregiver needs, as defined by the members of each group. All study activities were conducted with IRB approval, including procedures for informed consent.

Study Design

In this qualitative study we conducted a comparative analysis of focus group data from former family caregivers and home hospice nurse managers. We used inductive coding methods¹³ to develop a description of data content,¹⁴ to investigate emerging patterns and themes both within and across the caregiver and hospice nurse groups, and to develop patterns in cross-sample codes and categories into overarching themes that capture important similarities and differences.¹⁵

Inclusion Criteria

We invited nurses and former family caregivers to participate. Inclusion criteria for former family caregivers included being an English-speaking adult who had served as an at-home caregiver for another adult who received hospice services within the previous 18 months. Inclusion criteria for nurse case managers included being a nurse who had spent at least one year as a hospice nurse case manager.

Recruitment Procedures

We recruited potential participants in the former family caregiver group through a local hospice agency and a grief and bereavement support program. We contacted potential participants, who had already agreed to be contacted, and followed up by telephone to screen them for inclusion criteria, and to explain the nature and procedures of the study. Enrollment continued until an adequate number of participants agreed to attend one of two former family caregiver focus groups (n = 14).

We recruited potential nurse participants from attendees of the 2012 Annual Assembly of AAHPM (the American Academy of Hospice and Palliative Medicine) and HPNA (Hospice and Palliative Nurses Association) in Denver, CO. We placed a notice in the HPNA electronic newsletter, and interested individuals were invited to contact a researcher who provided more study information, answered questions, 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 (Tables 1 and 2).

The two family caregiver groups met in conference rooms in the researchers' college. The two nurse focus groups met 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 (P.B.) while another member of the research team experienced in qualitative research observed, took notes, and assisted with asking follow up questions and probing responses (K.G.C.). The focus group discussions were audio-recorded and transcribed verbatim.

Focus group moderators began the discussion with an open question, "In your experience, what do you think home hospice caregivers need?" and asked for specific examples of when things went well or times when things could have been better. Discussion in the family caregiver focus groups centered on their experiences of feeling supported or not supported in their caregiving roles and responsibilities, their own perceptions of their needs and how these were addressed by hospice services, when they felt most uncertain about their caregiving, and in probing their opinions about what was most and least helpful during their experiences with their nurses and the hospice program.

Discussion in the nurse groups focused on positive aspects of and challenges for nurses working with family caregivers including communication, skills, knowledge and resources needed to provide care, and the nurses' perspectives on caregiver needs and challenges to meeting these needs.

Analysis

We checked transcripts for each focus group against audio recordings and read them multiple times before initial coding to sensitize our team to these data. Transcripts were imported into NVivo 9, which two members of the research team (K.C., J.C.) used to conduct coding and content analysis. We followed line-by-line inductive coding procedures in sequential phases of coding aimed at developing categorical schema and themes. Coding and analysis were supported throughout by additional memo writing, analytic notation, comparative analysis of coding and notations, and frequent discussion and debriefing among researchers.^{12, 14} Primary codes were grouped into larger categories according to frequency, similarity, and co-occurrence. Based on these analyses, we developed broader categories that explained relations among codes. This process resulted in a hierarchical structure, where one code identified an overarching category or concept and subordinate codes described how dimensions and characteristics of particular concepts related to each other. Finally, we developed two broad themes that unified the caregiver and nurse data in terms of overall focus on relationship building, while also describing important points of contrast between the groups.¹⁴

Results

Family caregivers and nurses identified many of the same concepts as being necessary to caregivers in order to feel supported and positive about their hospice experiences and about their interactions with the hospice team. Most of the responses about caregiver needs in both groups were related to the concept of relationship building, or forging positive and functional relations between family caregivers and hospice team members, with the ultimate goal of providing optimal patient care and a secondary goal of supporting family caregivers in this endeavor.

While both caregivers and nurses raised similar topics and concepts regarding caregiver needs, however, their perspectives differed considerably in how caregivers and nurses described the qualities of these concepts, how they related to each other, and how each group understood their role and significance in relation to meeting caregiver needs. In what follows, we describe these topics, concepts and themes as they emerged through analysis of the focus group data with each group, and across both groups.

What Family Caregivers Need: Major Concepts from Caregiver and Nurse Focus Groups

Concepts most frequently cited as important by family caregivers.—The following were the most frequently occurring categories found in the family caregiver focus-group data, with the most-related material coded as “what caregivers really need”, in order: Information, Explanation, Trust, and Respect and Knowledge (Table 3 compares the eight most frequently occurring discrete concepts and sub-concepts associated with caregiver

needs from both caregiver and nurse focus groups). These five needs were also interrelated. For example, caregivers closely linked information and explanation. Trust and respect were also closely related yet distinct, so that trust of the hospice nurse and other service team members was engendered through caregivers' sense that they were respected as "the primary caregivers"; lack of respect led to lack of trust. Caregivers highly valued knowledge extending beyond clinical information or skills acquisition to knowledge about the process of hospice services, the role of interdisciplinary team (IDT) members, and the right to ask questions, request help, seek clarification, or challenge unsupportive care.

Concepts most frequently cited as important by hospice nurses.—The most frequently occurring categories from the nurse focus-group data related to "what caregivers really need" were: Information, Education, Direct Communication, Reassurance and Validation (Table 3). As with the caregiver data, many aspects of these identified needs were interrelated. Information was perhaps the single most important caregiver need identified by the hospice nurses, and they closely linked this concept with clinical knowledge, including the ability to perform skills related to direct patient care. For nurses, information, knowledge, and skills were described in clinical, technical, and task-oriented terms. Honesty was defined as accuracy and truth of clinical information related to the patient. Nurses described reassurance and validation as similar concepts. While these tended to be more generalized and abstract than the other categories, they were linked with acknowledging the difficulty of family caregiving, and complimenting the caregiver on their efforts.

Thematic Analysis: Uncovering Contrasts and Tensions

Data analysis quickly showed that most of the concepts associated with caregiver needs by both groups were related to the idea that building effective relationships between family caregivers and the hospice IDT was a fundamental need, and foundational to perceptions of support and effective patient and family care. This overarching concept is exemplified in two central themes: *Breaking It down to build it up* and *Doing to, doing for, doing with*. Both themes relate to caregivers' and nurses' shared perspectives on the central value of relationship building to promoting effective caregiver-hospice team interactions and positive caregiver experiences of support, but they also capture important contrasts in how each group understands and experiences the process, the complexities and tensions that result from these differences.

Break it down to build it up: Connections between information, explanation, honesty and trust.—The name for this theme is drawn directly from a phrase repeated during focus group discussion by a particularly eloquent caregiver, and echoed by others:

I think if you have a big support base, then you know what to ask, because I had people say "When they come, you ask them this. And you ask this." But I think that the hospice nurse has to build that relationship. I mean she [the nurse] has to break it down... I think if she breaks down the process and tells what everyone's role is going to be, that will help the caregiver. Then she's able to ask the questions, but there has to be a starting point. (*Caregiver*)

For caregivers, the idiom “breaking it down” meant to deconstruct the elements of hospice care, from the various roles of team members and the structure of services to the rationale behind clinical decisions and patient care, into parts that are more easily grasped and understood by caregivers that may be overwhelmed or “broken down” themselves. Then the parts had to be explained in enough detail that caregivers could more easily comprehend how the pieces fit into the overall picture of hospice care. This idea was central to how caregivers understood and described their need for information, and how they connected information with explanation and trust as essential needs for relationship building.

For nurses, the idea of “breaking it down” related to clinical knowledge and skills, and honesty in the sense of giving clinically accurate information, ensuring that caregivers understood the patient’s condition and trajectory, and “breaking through” denial as a moral imperative served by communication of accurate information and knowledge:

And I think a lot of times the hospice nurse is the one that provides the patient with realistic or truthful, honest communication, information, that listening ear...
(*Hospice Nurse*)

The following sections elaborate contrasts between caregiver and nurses on information, honesty, and trust, as these concepts relate to the theme *Break it down to build it up*.

Information as a mode of connection or information as a source of clinical knowledge.

Caregivers described how they needed to receive information in an engaging manner, a manner that invited them into the process of hospice care and recognized their primacy in the role of the “real caregiver”. The manner in which information was communicated also had to attend to their need for inclusion, respect, and connection or it did not “count” as information, and in some cases could even be seen as “noise”.

So I never felt like I was ever lacking in information or in need. It was almost overbearing sometimes with the social worker and all those people who call you. I was—twenty-four-seven, I was busy with her, and with her daughters that would come and visit. And it was like, I don’t need this phone call. I don’t have time for this half-hour phone call. I’m fine, I’m fine. (*Caregiver*)

Caregivers saw even accurate, practical clinical or technical information as unhelpful if it was not communicated in a way that they perceived as both immediately useful and authentic. Information also had to be seen as connected to clear and accessible explanations and rationales that embraced the family caregiver as a team member and a peer.

No caregiver in either group, however, talked about a nurse sitting down with the family caregiver for long periods devoted solely to imparting information or processing psychological or spiritual needs. They described nurses who were able to do this while attending to practical demands of care as being particularly helpful and adept:

“When my dad was dying, he had problems with breathing. He was really heavy, had a terrible time breathing. And so we called, and [the nurse] came right over. And he listened to my dad and he told us to raise the head of the bed, and he gave him some medication and he helped us....And so he told us all sorts of different

things we could do to make my dad more comfortable, and I was just really impressed with him. He was just a really great guy. I mean, because he just didn't come and do it, do it and leave. He came and explained how-- why it worked the way it did and what he was doing and why." (*Caregiver*)

The nurses' description of information focused more on step-wise information needed to complete patient care tasks safely, or on how to utilize hospice resources. Information was seen as serving a functional role in hospice care, and the nurses saw themselves and other IDT members as the primary sources of information and caregiver and patients as receivers of information. Effective delivery of information was generally described as occurring via typical approaches to patient and caregiver teaching, oriented toward teaching facts and checking for uptake regarding patient care tasks and trajectories.

"I think consistency of information is important as far as making sure that all the nurses encountering families have a certain amount of training...and [that they] refer with multi-learning methods to information, verbal, visual, demonstrative, as well as written material, not just a resource guide but sort of building on information in each [visit]. (*Nurse*)

Overall, the nurses tended to separate activities of imparting information from activities of relationship building and providing psychosocial support. They described the latter as "sitting down with the family and patient", "being present", and taking additional time apart from the provision of clinical care to "meet the caregivers where they are at". Thus, the provision of high-quality clinical care and meeting the relational, support needs of caregivers, were seen as two distinct needs for the nurses, met at different times other than through direct care, by "sitting down" with caregivers and having emotionally-focused discussions. Some nurse participants indicated that the goals of relationship building and provision of psychosocial support was someone else's job, better handled by a skilled social worker or chaplain because the demands of providing quality physical care in the time allotted was challenging.

Nurse 1: As a nurse, I am there to get their physical symptoms under control, so that the other team members can come in and do what they need to do, because to me, a hospice patient needs to be physically comfortable, that is most important thing more than psych, social and spiritual stuff.

Nurse 2: But the nurse may end up doing a lot of that. Physical first, [dealing with] the pain.

Nurse 1: Right, and I do some of that, but I also pass that onto my social worker and chaplain because they have more experience and expertise in that.

Trust, honesty and denial: Perspective matters.—Caregivers described trust and honesty as playing a major role in supporting caregivers and providing quality care. For caregivers, truthful and honest communication was as much about manner as content, and there was a close connection with explanation and trust--information may be honest and accurate, but without adequate explanation and the perception of respect it was seen as merely instrumental and therefore inauthentic. Nurses also saw honesty as respectful

interaction, but focused more on how accurate or truthful clinical knowledge served patient needs, patient autonomy and the hospice process. Nurses saw honesty as an antidote to caregiver denial, one that supported realistic problem solving and the family coming to terms with the patient's death.

Caregivers noted a necessary balance between honest, direct communication, and blunt or insensitive interactions. While they could reflect on how their own fatigue, strain, and emotional state might make them more apt to react to insensitivity, they agreed it was up to the IDT to modulate their interpersonal style if it was too gruff, or seemed not to attend to the situation of the caregiver as someone who may be coming to grips with death for the first time.

I like people to be honest and up front and tell me what's going on. But the way she did was always kind of-- Whoo! Right between the eyes... Oh, what'd she say?
"Dignity's out the window. Just get over it." (*Caregiver*)

Caregivers also discussed how they appreciated a combination of honesty, experience, professionalism, and kindness, interactions where frankness was accompanied by specific explanation and individualized care. Mixed messages undermined trust and threw caregivers off balance because they often didn't have the resources (including time) to process interactions until after they were over. For caregivers, this felt at best like disrespect, and at worst like a kind of betrayal:

She said, "I'll tell you when he's ready." Well, doggone it, she didn't. She didn't. I called her and I said, "I think he wants to see you. He trusts you. He wants to see you." But I had felt he was going, and I called her, I said, "You need to get over here now." (*Caregiver*)

The same caregiver goes on to describe how, suspecting her husband was nearing death and worried about his pain, she called the nurse again:

She said, "Oh, gosh, I didn't know he was so bad." And I'm thinking, "What do you mean you didn't know he was so bad? You were just here yesterday." So I don't know if she was trying to make up for something, forgetting. If she forgot, tell me you forgot, but don't try and blow it off. I want to know. Be up front with me.
(*Caregiver*)

Trust is directly linked with caregiver confidence in the IDT and perceptions of support. Thus, caregivers appeared to be very sensitive to discrepancies between agency messaging and IDT behavior:

I think that they need to reinforce that over and over and over-- "We're here for you. What do you want? What do you need?" You hear that over and over and over, and that relaxes you to know that they really are there, and you are okay.
(*Caregiver*)

Honesty was also frequently cited by nurses as a critical caregiver need, and an imperative to be straightforward with patients and caregivers about the dying process and about the patient's trajectory. This need was often expressed as a counterpoint to denial, which came up often in the nurse data. Denial was problematic for nurses because, from their

perspective, it prevented caregivers from adequately preparing or responding to the needs of the patient, and from appropriate adjustment to the changing circumstances. Denial hindered relationship building. As one nurse stated, “You want to tell them, and you want to be straight with them, but then they don’t want that. So it’s very hard.” Nurses reported that denial was also a source of difficulty in working with caregivers and patients who are questioning or challenging the hospice team’s activities. Because of these experiences, nurses also saw honesty as an important foundation for relationship building with family caregivers, although from a different perspective:

You need to meet the family where they’re at, whether they’re in denial, whether they’re accepting hospice, you really need to meet them where they’re at, whether their cultural practice is different than yours, and you need to reassure them that they’ve made the right decision. (*Nurse*)

Doing to, doing for or doing with: Tensions between respect and control.—

Both caregivers and nurses described specific actions that fell along a continuum captured by the phrase *Doing To, doing for, or doing with*, and how differences in these categories were associated with positive or negative perceptions of respect, validation, and control. Caregivers described *Doing to* as taking control and performing tasks without providing explanation, treating patients or caregivers as objects of care. Both caregivers and nurses described *Doing for* as a more relational orientation, performing care on behalf of caregivers or patients, yet still one step away from fully involving caregivers.

Both groups also described *Doing with* as the most skilled and expert form of practice, where clinical care is carried out and goals are met in a way that invited family caregivers into the process, building relationships in the process of carrying out concrete and goal-directed actions. A nurse *Doing with* was seen as mentoring or modeling for caregivers. It demonstrated the ability of the nurse to make the rationale for hospice services and clinical care visible and accessible, by clinical interventions and information, as they modeled care provision, a skill directly linked to how caregivers connected information, explanation, and relationship building. This theme is also supported by the caregiver-identified needs of respect and recognition, the nurse-identified caregiver need for validation, and tensions that emerged across both groups concerning the give and take of control that happens when hospice care takes place in the family home.

“We are the real caregivers:” Respect and validation.—Caregivers talked about needing to have their own expertise and knowledge recognized and being made to feel like part of the caregiving team. They often expressed variations of the idea that while professional hospice workers may be the experts on death and dying in general, family caregivers are the experts on the family member for whom they care.

I was really tuned in on what she wanted, what she needed, what would work for her and what didn’t. And so what I appreciated was that the hospice would ask me-- they would get my opinion. They would respect that I had some knowledge of what would be best. And so they were just-- they just worked with me really, really well. (*Caregiver*)

I think anybody that comes to help should be a companion to you, to your family. So they should be listening to you. I mean, they have the knowledge, the skill, but they should be listening. Because, like with me and my husband, we'd been married 36 years. And so you don't want somebody taking that away. (*Caregiver*)

Caregivers are keenly aware of their established primacy in providing care to a dying family member and do not want to be excluded from the experience. This experience is described by caregivers as “peaceful”, “beautiful” and “rewarding”:

I just think we had a really, really great experience with our hospice group, and [the nurse] was just-- I just loved that he would tell us why he was doing what he was doing and how was it helping my dad so that we could do it ourselves when different things happened. (*Caregiver*)

Nurses described permission-giving and the use of empowering words as strategies to provide much-needed validation for family caregivers. As one nurse said, “You know, we try to empower them, because truly, they'll be able to do more if you do that”. Nurses consistently identified giving permission and allowing caregivers to determine what they can and cannot do as a way to support and validate the efforts of caregivers:

Some family members are totally, “I can't do this. You're going to have to do it for me. I just can't.” But others say, “I think I know what to do and I think I can do this. Am I doing okay?” and they need that reassurance. (*Nurse*)

Reassurance is seen as a key principle to empower a successful caregiver, no matter the outcome of specific caregiving task.

The give and take of control.—*Doing to and doing for* were generally associated with caregiver perceptions of having the hospice team assume control without caregiver permission. Yet, caregivers also described times when *Doing for* was seen as a source of relief. In these examples, however, they did not see themselves as relinquishing control, but as accepting help. Caregivers reported they want to retain control unless they needed specific help with tasks. Control is negotiated based on the context of each situation, a matter of finessing the give and take of when to do *for*, *to* and *with*. The nurses reported difficulty in accepting the norms of a family culture that ran counter to the evidence-based practice on which they build interventions and teaching, and the caregivers reported feeling challenged when a nurse comes into the home only to take over a role they have been in for months or years.

Caregivers described nurses and other team members who did not make efforts to *do with* as “just going through the motions”, doing their jobs but not necessarily supporting the caregivers. They interpreted this as a message that it would take too much time, money or resources to involve them, and made them feel excluded. At these times they felt the most out of control and reported the most negative experiences.

Importantly, neither their desire to be treated as a team member nor their sense of confidence was contingent on their willingness or ability to provide direct patient care, but on their connection with and knowledge of the patient.

I mean, you don't want them to take over. You've done that for years. Like with my husband and I. We got him that far. He only was expected to live two years and he made it five. So then when they come in and take over, you're floundering. And sometimes when there are problems, you don't know how to fix it because they just keep it away. And so you want to. And you're going, "Oh gosh, what do we do? What do we do?" And I hated that. And so I thought, "I have to take control back," because then I was comfortable. (*Caregiver*)

The nurse focus groups did not identify a need for caregivers to feel a part of the team, or discuss the concepts of respect and professional vs. family caregiving, in the way that the caregiver groups did. However, they did discuss challenges of the give and take of control, and how this is complicated in the home setting:

I think control was often a huge issue for families and not wanting to let go of that. I call it taming my tigers. The biggest problems I've had is when someone hasn't really listened to what they need. And they're rushing in with their agenda instead of letting it happen. We know what's best. Or we like to think we know what's best, but they're not always ready for it. So, it's just making sure the timing is a fit for the family. (*Nurse*)

Nurses recognized the need for family caregivers to feel in control, but understood this in the context of a professional need to accurately and effectively assess and address the real needs of the family. Hospice nurses are in a difficult position of negotiating a challenging trade off--assuming control to meet the needs of caregivers and families, who may be struggling, with the ultimate goal of providing effective patient care.

Control was also described as a tool to diminish caregiver role strain. For example, nurses talked about caregivers jumping ahead of the current situation and in essence overwhelming themselves. For example: "I will tell you when there's something in there [book on hospice services provided by the agency] that you have to know today. I will tell you when I see the change. Don't worry about memorizing what's going to happen at the end." By maintaining control of the information, nurses "bridge" the caregiver through difficult times and provide an extra layer of support.

Discussion

Discussion of the implications of our study results focuses on two points: 1) the importance of understanding relationship-building from multiple perspectives; 2) the need for mentorship models that enable hospice workers and caregivers to translate well-meaning professional abstractions related to caregiver support and family-centered care into specific actions that support effective and positive relationship building within the real-world context of home hospice care.

Importance of Relationship Building in Hospice: Need for Multiple Perspectives

Although caregivers and nurses shared an understanding that strong relationships are foundational to effective care and support, their descriptions of what constituted effective relationship building, and how this is best accomplished, differed. For example, nurses

tended to describe relationship building in terms of emotional or psychological support and as separate and distinct from providing clinical information to meet physical patient needs. Caregivers, however, saw information and explanation as critical building blocks of a functional and effective relationship—not as separate components of the relationship—between the caregiver and the nurse, and with the hospice team. For caregivers, there was not a hard distinction between practically supportive and emotionally supportive interactions. In fact, they described the most positive and satisfying interactions as providing both at the same time, through the seemingly simple yet expert strategy of nurses sharing their thought processes, explaining as they go, and “breaking it down”.

The nurse focus groups did not discuss the transmission of information as an opportunity to establish or maintain emotional connection with the caregiver—for them, this was accomplished through separate processes, often as “taking the time”, “sitting down with them”, “really listening” and “being present”, all important strategies in interpersonal communication. The nurses thus tended to separate activities of imparting information from activities of relationship building and providing psychosocial support. They described the latter as taking additional time apart from the provision of clinical care to “meet the caregivers where they are at”.

Our results show that family caregivers are able to express complex and difficult experiences concretely. Other research^{7,8,10} has also found that caregivers are able to give clear concise reports through interviews and focus groups about caregiving experiences. Caregiver accounts remain an important but underutilized source of data in the field.^{11,12} Therefore interventions to improve education of the hospice team should draw more on the experience of caregivers through systematic in-depth study rather than solely on brief quality-improvement surveys. Moreover, caregivers should be involved in designing studies and interventions. Community based participatory research has been associated with improved support interventions among hospice caregivers and volunteers in Canada.⁹

Modeling Mentorship and Support

Many caregivers shared powerful stories of working with expert professionals and of having interactions in which they felt fully supported and connected into the process of hospice care as the primary caregiver and as a valued member of the team. Invariably, these participants told stories of nurses who “broke it down” for the caregivers, as described above. Their descriptions evoked what might, in another context, be called expert teaching. This form of interpersonal interaction did not merely consist of transferring clinical information, demonstrating patient care skills, or setting aside “special” time to “sit down with” family caregivers, but entailed an ability to communicate the deeper and more complex aspects of relationship building through active engagement, explanation, and teaching as mentorship.

Both caregivers and nurses provided compelling stories of their positive experiences with this kind of mentorship, whether between caregivers and nurses, between less experienced and more experienced hospice nurses, or between members of the IDT. Caregivers described this expert teaching as willingness and ability to “break it down”; nurses described experiences with their own master teachers and mentors who helped them learn hospice care by allowing them to “ride along”, explaining and sharing insights throughout the course of

providing care. In such a “doing with”, or teaching and learning relationship, it is less important to caregivers that nurse care managers present as “experts” or always “in control”, than that they are open to allowing caregivers to assume a role as a team member while building the caregivers’ capacity in caregiving at the end of life.

In a previous study in which we interviewed thought leaders in the field of home hospice,¹⁶ participants identified skilled mentorship as a critical need in hospice, one which is particularly challenging to meet because of the egress of more experienced nurses, an influx of newer nurses, and the number of hospice nurses who don’t have access to such support because they practice in rural or under-resourced areas.^{17,18} Indeed, much of the nurses’ focus group discussion was on mentorship needs and the dire need to be taught how to be a hospice nurse. In order to mentor caregivers, nurses need their own mentors and the opportunity to have this skill modeled for them, and to practice it.

Limitations

Although this study provides important insights into ideal and realized support of family caregiver needs, findings should be interpreted with caution. Both the qualitative approach and the participant sample limit the generalizability of our findings. The nurse perspective may reflect a broader perspective than the views of former family caregivers. The nurse sample represented diverse geographic locations and variability in hospice and nursing experience; whereas, the former family caregivers came from one region of the country and about half had enrolled in the same hospice agency. In addition, we only collected the opinions of nurse case managers and former family caregivers. Capturing the perceptions of all members of the hospice care team would provide a more comprehensive picture of contrasts and similarities among the various stakeholders.

Conclusion

Our research provides insight into what family caregivers and hospice nurses identify as supporting caregiver needs, and especially on how their perspectives and understandings of these needs converge and contrast. This work is an important step in understanding the caregiving experience from the perspectives of all stakeholders. We found a substantial amount of overlap in what both groups identified as “what family caregivers really need”; both groups described relationship building as essential to feeling recognized and valued, and as foundational to providing the best hospice care possible. However, there were also important contrasts in how caregivers and nurses understood caregiver needs and the concepts and practices associated with them. These differences shape the experiences of both family caregivers and hospice nurses. When their understandings of caregivers needs and relationship building became too widely divergent, both parties tended to have negative experiences.

Greater understanding of these points of connection and disconnection could inform training and education for hospice team members, and could help design interventions aimed at improving consistency of positive, supportive interactions among caregivers and team members. Our results, if combined with other similar studies, could also be used to design measures of quality and satisfaction that would be invaluable to hospice providers, and

ultimately, to families. More research, qualitative and quantitative, should endeavor to include and systematically investigate the experiences and insights of those who directly engage in home hospice interactions, in order to apply resulting knowledge to better outcomes for families, caregivers and patients and the co-creation of “a true human interaction.”

Disclosures and Acknowledgements

This study was funded by an American Cancer Society 2011–2013 Pilot and Exploratory Grant (ACS PEP-11–165-01-PCSM, L. Ellington, PI). We wish to thank the family caregivers and nurses who generously shared their time and experiences with our research team.

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Table 1

Characteristics of former family caregiver focus group participants

Variable	Nurse (n=13)
Age (M; SD)	51; 10
Gender (N; %)	
Male	1; 8
Female	12; 92
Race/Ethnicity (N; %)	
White	13; 100
Black/African American	0; 0
Hispanic	0; 0
Education (N; %)	
High School	1; 8
Some College	1; 8
4-year Degree	8; 61
Masters, Professional Degree	3; 23
Years Experience (M; SD)	
As a Nurse	23; 12
Employed at Current Hospice	7; 6

Table 2

Characteristics of RN hospice care manager participants

	Nurse (n=14)
Age (M; SD)	61; 11
Gender (N; %)	
Male	2; 14
Female	12; 86
Race/Ethnicity (N; %)	
White	12; 86
Black/African American	2; 14
Hispanic	1; 7
Education (N; %)	
High School	1; 7
Some College	3; 21
4-year Degree	6; 43
Masters, Professional Degree	4; 29
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

Table 3

Eight most frequently coded caregiver needs: Caregivers vs. Nurses

Freq.	Caregivers	Nurses
1	Information <ul style="list-style-type: none"> • What to expect • Roles of hospice team members • Medication and patient care tasks 	Information <ul style="list-style-type: none"> • Patient trajectory and clinical status • Hospice resources
2	Explanation <ul style="list-style-type: none"> • Explaining rationale for treatment and services 	Education <ul style="list-style-type: none"> • Teaching caregivers patient care skills (e.g. Medication administration)
3	Trust <ul style="list-style-type: none"> • Actions of team match agency's stated services • Confidence that team will be there when needed and follow through 	Direct communication <ul style="list-style-type: none"> • Honesty as truth-telling (e.g. patient status) • Countering denial • Tailoring delivery to
4	Respect <ul style="list-style-type: none"> • Respect for patient • Respect for caregivers' knowledge about patient • This is our home; this is my family 	Reassurance <ul style="list-style-type: none"> • Telling caregivers they're doing a good job • Normalizing the experience
5	Knowledge <ul style="list-style-type: none"> • About resources • About rights (egg. To ask questions; to voice concerns; to interview potential hospices) 	Validation <ul style="list-style-type: none"> • Acknowledging how hard caregiving is • Complimenting caregiver efforts
6	Individualized care <ul style="list-style-type: none"> • Treat patient as a unique person • Treat caregiver as unique person • Get to know our situation, our family 	Control <ul style="list-style-type: none"> • Allowing caregivers to maintain control where possible • Nurses taking control of patient care for caregivers as needed
7	Anticipation of patient and caregiver needs <ul style="list-style-type: none"> • Hospice team balances experience with particular needs of individual caregivers • "We don't always know what to ask" 	Family centered care <ul style="list-style-type: none"> • "Dealing with" difficult family dynamics • Balancing patient autonomy with caregiver and family needs
8	Inclusion <ul style="list-style-type: none"> • As valued member of the team • In decision making • Keeping them informed 	Confidence <ul style="list-style-type: none"> • Caregivers feeling up to the tasks of patient care • Self-efficacy