

Supporting home hospice family caregivers: Insights from different perspectives

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ABSTRACT

Objective: Our intention was to describe and compare the perspectives of national hospice thought leaders, hospice nurses, and former family caregivers on factors that promote or threaten family caregiver perceptions of support.

Method: Nationally recognized hospice thought leaders ($n = 11$), hospice nurses ($n = 13$), and former family caregivers ($n = 14$) participated. Interviews and focus groups were audiotaped and transcribed. Data were coded inductively, and codes were hierarchically grouped by topic. Emergent categories were summarized descriptively and compared across groups.

Results: Four categories linked responses from the three participant groups (95%, 366/384 codes): (1) essentials of skilled communication (30.6%), (2) importance of building authentic relationships (28%), (3) value of expert teaching (22.4%), and (4) critical role of teamwork (18.3%). The thought leaders emphasized communication (44.6%), caregivers stressed expert teaching (51%), and nurses highlighted teamwork (35.8%). Nurses discussed teamwork significantly more than caregivers ($z = 2.2786$), thought leaders discussed communication more than caregivers ($z = 2.8551$), and caregivers discussed expert teaching more than thought leaders ($z = 2.1693$) and nurses ($z = 2.4718$; all values of $p < 0.05$).

Significance of Results: Our findings suggest differences in priorities for caregiver support across family caregivers, hospice nurses, and thought leaders. Hospice teams may benefit from further education and training to help cross the schism of family-centered hospice care as a clinical ideal to one where hospice team members can fully support and empower family caregivers as a hospice team member.

KEYWORDS: Caregiver, Communication, Caregiver support, Hospice nursing, Comparative analysis

INTRODUCTION

Nearly two million families receive hospice services annually (National Hospice and Palliative Care Organization, 2015). Family caregivers (FCGs) often

provide the majority of direct patient care (Albright et al., 2016), including medication administration, provision of physical and emotional care, assistance with daily tasks, and overall management and coordination (Tjia et al., 2015). FCGs frequently report feeling unprepared to carry out these complex tasks and the physical and emotional energy required (Applebaum & Breitbart, 2013; Totman et al., 2015). Hospice FCGs' needs have been identified in multiple

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studies and are wide-ranging, including informational, emotional support, self-care, daily household tasks, and bereavement adjustment (McGuire et al., 2012; Donelan et al., 2002). Unaddressed FCG needs can impact physical and psychological health (Given et al., 2012; Northouse et al., 2012) as well as their ability to provide care (Park et al., 2010). The impact of the caregiving experience may extend long into bereavement (Kim et al., 2016).

The hospice philosophy centers around family-centered care, yet such care often remains a clinical ideal. Hospice care is provided by an interdisciplinary team of nurses, social workers, chaplains, physicians, and hospice aides. Medicare mandates that all hospices conduct regular interdisciplinary team meetings to promote collaborative and holistic care plans (Department of Health and Human Services & DHHS & Centers for Medicare & Medicaid Services, 2010). While academic medical centers have responded to the Institute of Medicine's call for increased interprofessional palliative care education and ongoing preparation throughout healthcare providers' careers (Institute of Medicine, 2003; 2010), hospice team preparation in community agencies is primarily limited to new employee orientation sessions (Baldwin et al., 2011). Most healthcare providers, including hospice team members, have been educated to provide direct patient care rather than family-oriented care (Baile et al., 2012). At the end of life, support for both FCGs and patients is of critical importance, yet members of healthcare teams may not know how best to involve FCGs (Levit et al., 2013; Institute of Medicine, 2015). Moreover, FCGs often fail to mention their most pressing concerns (Detmar et al., 2001; Williams & McCorkle, 2011). They may be overwhelmed and unprepared for home visits and lack confidence to voice their needs to busy providers (Carter, 2001; Pasacreta et al., 2000). Commonly, FCGs ignore their own needs to focus solely on patient needs (Caughlin et al., 2011; Harding & Higginson, 2001; McLaughlin et al., 2007; Zhang & Siminoff, 2003). Providing FCG support, and thus family-oriented care, continues to pose challenges within the everyday realities of hospice care.

The purpose of the present study was to identify the factors that enhance or threaten FCGs' perceptions of being fully supported and engaged by the hospice care team. We integrated and synthesized perspectives from key stakeholders. We describe and compare the perspectives of national hospice thought leaders, hospice nurse care managers, and former FCGs about what hospice FCGs need in order to feel supported and how nurses and other team members promote or threaten FCGs' sense of support.

METHODS

This descriptive study employed a mixed-methods analytic approach. All activities were undertaken with approval from the university's institutional review board.

Three distinct purposive samples were included: national hospice thought leaders, current hospice nurse care managers, and former FCGs who had provided care to a close family member receiving in-home hospice services.

A total of 11 national thought leaders participated in semistructured telephone interviews that lasted for 30 to 60 minutes. Some 13 nurses were recruited from a national professional conference to participate in one of two hour-long focus groups. FCGs of patients enrolled in home hospice services within the past three years were recruited through a local bereavement support group and a local hospice agency, and they participated in one of two hour-long focus groups ($n = 14$). Interviews and focus groups were audiotaped and transcribed verbatim. The details on recruitment can be found elsewhere (Ellington et al., 2013; Cloyes et al., 2014).

Open-ended questions were utilized to prompt both the thought leader interviews and focus groups. For example, thought leaders were asked, "What can you tell us about how nurses (and other team members) can best support FCGs in caring for their family member?" Nurse and FCG focus group participants were asked, "In your experience, what do home hospice FCGs need most to feel supported in providing care?" The topic of FCG perceptions of and experiences with support were probed with all participants.

Data from all three groups were aggregated and compared, triangulating material specifically related to responses regarding factors, situations, practices, or policies that promoted or threatened FCGs' perceptions of support during in-home hospice care. Two members of the research team (KGC, LB) performed line-by-line coding of these data using NVivo 10, generating structural, process, and in-vivo codes in three subsequent rounds of coding (Saldana, 2013). The first round of coding resulted in 384 unique codes. In the second round, comparative analysis of the coded data generated a hierarchical or "tree" coding schema that led to the identification of 16 higher-order categories that subsumed the first-round codes, and the third round led to the emergence of four core content categories that captured 95% (366) of all the primary codes and crosscut data from all three groups.

Category data were first compared using z tests to quantify differences in the frequency of core categories by group. This information was then folded back into the qualitative comparative analysis,

description of the content and characteristics of the core categories, and interpretation of study findings. In the Results section we compare the four core categories as identified within and described by each stakeholder group. In the Discussion section we summarize the triangulation of findings across stakeholder groups.

RESULTS

Four core categories regarding perceptions of FCG support emerged across stakeholder groups: “essentials of skilled communication” (30.6% of coded content), “building authentic relationships” (28%), “value of expert teaching” (22.4%), and “critical role of teamwork” (18.3%). Each category represented a substantial amount of the data in all three participant groups and linked key factors noted by thought leaders, nurses, and FCGs as promoting or threatening FCGs’ perceptions and experiences. [Tables 1 and 2](#) provide descriptions of the categories and exemplary quotes. Direct deidentified participant statements and phrases presented within the text are set off by quotation marks.

Essentials of Skilled Communication

FCG Perspectives

FCGs described skilled communication by their nurse and hospice team as essential to their own level of comfort, feelings of connection, and confidence in themselves, the team, and the process. FCGs valued hospice team members, particularly nurses, who took the time to engage family members as valued team members through careful explanations; these nurses coached FCGs to ask questions and voice concerns while also taking time to listen and explain. Almost every FCG raised the point that effective communication had to be accompanied by effective listening. Skilled communication also included recognizing the balance between too much and not enough, and a number of FCGs described scenarios where attempts to communicate were seen as too time-consuming, burdensome, and—at worst—invasive.

Hospice Nurse Perspectives

Nurses described sensitivity, perceptiveness, discernment, and technique as essential elements of communication to support hospice patients and FCGs. They described skilled communication as the ability to convey a caring attitude through specific actions based on knowledge of individual family characteristics like relationship dynamics, special rituals, or even family pets. Skilled communication

was also described as the ability to appear confident while balancing routine tasks with individualized assessment. Nurses repeatedly cited the need to be open-minded, receptive to the emotional state of the FCG, willing to negotiate the social and emotional dynamics of the situation, and to balance honest and direct information while attending to FCGs’ readiness to process information.

Thought Leader Perspectives

Thought leaders also stressed the critical importance of individualized communication and the need to balance listening with other forms of communication behaviors. Skilled communication was viewed as a skill that nurses could teach and model for patients and FCGs, in order to empower FCGs in their interactions with the patient and other family members. Moreover, the need for clear and effective communication extended beyond nurse–FCG interactions: effective communication scaffolded and supported many elements in the continuum of care, including the delivery of high-quality hospice care.

Building Authentic Relationships

FCG Perspectives

FCGs felt that, while education and experience fostered a nurse’s ability to build and maintain supportive relationships, mindfulness and genuineness were also necessary. Nurses who actively practiced these skills were seen by them as willing to “open up” and “really care.” FCGs also reported confidence in relationships with hospice team members who genuinely helped FCGs feel connected and engaged while also maintaining professional boundaries. Once FCGs were confident that they shared an authentic relationship with members of the hospice team, they could handle a certain amount of tension when making joint decisions. Good relationships were not always about agreement but rather about the FCG’s sense of genuine connection with members of the hospice team.

Hospice Nurse Perspectives

Hospice nurses described openness, balance, self-reflection, and presence as qualities necessary for supportive relationships. Nurses saw these as qualities that led them to hospice nursing in the first place and grew with experience. Balancing tasks with interpersonal needs was often challenging, but necessary, for authentic relationships. Nurses described carefully negotiating multiple tensions between: (1) being useful versus being present, (2) being goal-oriented versus being mindful, (3) respecting the rhythms and norms of the family home versus being

Table 1. Summary of categories by stakeholder group

Category	Family caregivers	Hospice nurses	National thought leaders
Essentials of skilled communication	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Engages caregivers in the conversation as a valued member of the team Increases level of comfort, feelings of connection with the team, and self confidence <p>Characteristics of:</p> <ul style="list-style-type: none"> Nurses are personable, professional, and patient Taking the time to conduct individualized needs assessments coupled with careful questioning and listening 	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Builds confidence in caregivers <p>Characteristics of:</p> <ul style="list-style-type: none"> Ability to perceive relationship dynamics and special rituals Balancing direct information giving with readiness assessments Appear confident to promote confidence 	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Empowers patients and caregivers Supports continuity of care which reduces burden to caregivers <p>Characteristics of:</p> <ul style="list-style-type: none"> Balancing listening with other actions
Building authentic relationships	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Builds caregiver trust and confidence Helps caregivers feel connected to and engaged with the healthcare team <p>Characteristics of:</p> <ul style="list-style-type: none"> Willingness to open up and care Balancing professional boundaries while being genuine 	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Connects patients, families, and nurses Promotion of caregiver self-care <p>Characteristics of:</p> <ul style="list-style-type: none"> Willingness to be vulnerable and initiate contact Balancing multiple factors: goals, openness, respecting family norms, honesty in end of life outcomes 	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Caregivers feel acknowledged, encouraged, and supported <p>Characteristics of:</p> <ul style="list-style-type: none"> Ability to balance demands, assess and understand relationships within the family unit
Value of expert teaching	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Feeling of being respected, supported, and included in the caregiving process <p>Characteristics of:</p> <ul style="list-style-type: none"> Ability to explain information clearly and accurately Individualizing delivery of information 	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Supports connections among family members, the caregiver, and hospice team Good teaching leads to better outcomes <p>Characteristics of:</p> <ul style="list-style-type: none"> To be skilled at teaching, nurses valued the influence of skilled mentors in helping them shape their practice 	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Shapes the home hospice interaction <p>Characteristics of:</p> <ul style="list-style-type: none"> Hospice nurses must have ongoing meaningful learning and mentoring opportunities to integrate expert teaching into their practice
Critical role of teamwork	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Feeling supported, confident, and included as part of the caregiving team <p>Characteristics of:</p> <ul style="list-style-type: none"> Effective, consistent, and reliable teams Including the caregiver into the hospice team 	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Promotes better outcomes Supports family relationships <p>Characteristics of:</p> <ul style="list-style-type: none"> Nurses connect home hospice services with the larger healthcare system Consistency in interactions with patient and family 	<p>How it supports caregivers:</p> <ul style="list-style-type: none"> Promotes inter-agency communication and continuity of care Eases transition to hospice <p>Characteristics of:</p> <ul style="list-style-type: none"> Collaboration amongst team members

Table 2. *Notable quotes by category and stakeholder group*

Category	Caregivers	Hospice nurses	National thought leaders
Essentials of skilled communication	<p>Maybe that's part of the initial conversation that they should have ... "You need to let us know are we taking too much of your time? Our goal is to be helpful, but are we taking too much of your time? Are we being intrusive in any way?" In other words, talking about the process of how they approach the whole thing that they're doing.</p> <p>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.</p>	<p>I mean, it may be some silly little thing—you talk about animals ... That animal is important to them. And by you showing it's important to you too, you're communicating to them that you care.</p> <p>There's a difference between being a nurse and ... learning the new communication of hospice. I think you need some basics, and then go in, and work your way with your family yourself.</p>	<p>Then suddenly at this time also when they're [patient and family] most vulnerable, they're transferred into a different system of care. So I think communication is critically important, and that's really where I think we [healthcare providers] fall down on communication because unless we communicate very, very well ... they lose all the history and they lose the continuity ... When the family asks a question about the disease ... sometimes they don't get a comprehensive answer at all because the hospice nurses doesn't even know the information.</p>
Building authentic relationships	<p>She [nurse] would size up, "Do I need to be this way or that way to get through to them?" And she really had that. But she had learned that. She'd gotten it through practice. But there are things that one can do from an educational perspective that are helpful in that regard. Because I think what we are all saying is, we felt—those of us who had a good experience—we're saying that we felt kind of a sense of confidence in the relationship.</p> <p>"It was more of a working around. Sometimes you don't always agree with them [hospice team] and maybe you don't always get along with them, but for my husband I tried.."</p>	<p>It's also maybe giving yourself permission to fail. Not necessarily to fail with a medication dosage or something, but to try and make an effort to reach out and touch someone that first time and break the contact barrier, whatever it is. Give yourself permission to maybe not always know the right thing. And it's through that trial-and-error time and time again that you just—skill just happens.</p> <p>I think especially for really difficult cases that you're involved with, reflecting "Could I have done something differently? How else could this have gone?"</p>	<p>You've got to look at the [family] relationship too and take that into consideration, so it's a tremendous number of things that really need to be considered that I think is just too easy to lose if you're going in and only focusing on that patient, and looking at the family caregiver simply as a means to an end for patient care.</p> <p>I think they [caregivers] simply need recognition and confirmation in general. Again, it's more than just information.</p>
Value of expert teaching	<p>But a lot of times there were things going on with her [the patient] that I needed to get medical explanations [for]. And the first unit [first hospice agency] that we had, I didn't get a lot of that. Second unit [second and current hospice agency], everything I needed to know they provided—and they're still now providing.</p>	<p>They had never sat down as a family and seen those pictures and understood the constellation of things that were happening with their father and what he was going through. And they were just in awe. There were like, "If only we had had this. It would have helped us." It was like their imaginations were worse than the facts. And then yet understanding the facts helped them be able to handle what was going on.</p>	<p>[describing what is needed to develop expert teaching]. . . ongoing education, leadership training and mentorship, because that's a huge issue in public hospitals, the lack of mentors and lack of leadership development</p>

Continued

Table 2. *Continued*

Category	Caregivers	Hospice nurses	National thought leaders
	I just loved that he would tell us why he was doing what he was doing and how it was helping my dad so that we could do it ourselves when different things happened.	I think you can teach someone to do opioid conversions, you can teach someone how to manage—a bowel routine—you can teach all those things. But the manner, the approach, the special healing nature of that, isn't something that's so quickly learned.	
Critical role of teamwork	<p>I really felt like part of the team. What I didn't realize, and they had to tell me—I was kind of like “I just have one more question. I don't want to take any of your time.” They said, “We're here for you, too. We're definitely here for you, too.” ... I was just floored by how much they did on my behalf, and they really saw me as a member of the team.</p> <p>The team [hospice team members] should be on the same page. I got the same story from the social worker.</p>	<p>We got to the point in IDT where we would actually talk about who has the best relationship with the patient, who had the best relationship with the [caregiver]. We would say, “Okay, you work on this. You work on that.” It was different for everybody, so we all had to make out notes and keep track. But we knew from some patients, the chaplain was the key, and they were actually the primary support from the team. I could do whatever I possibly could, but I just didn't click with that person. When you know that they're being cared for by another member of the team, it's okay, as long as you can meet your needs and you don't have any direct conflict and they're satisfied with your care.</p> <p>We were talking about confidence, and building team confidence. As a nurse, I am building up that social worker, building up that chaplain, building up the other team members. That's really important to do, so that they [caregivers] don't think, “There's only one person who knows me. There's a whole group of us.”</p>	<p>Teamwork is important ... in terms of appropriate screening, assessment and referral, especially spiritual screening and psychosocial screening ... because it goes without saying that the focus can't just be on the patient and physical symptomatology, although that's an incredibly important piece.</p> <p>Certainly, all the fuss that today is about interdisciplinary care, and so it's not at all about the nurse going in to do this alone. It's about nurses collaborating with social workers and volunteers and physicians and the whole team in order to orchestrate a plan of skill for family caregivers.</p> <p>We also don't [focus] a lot of attention on how nurses work as far as leading interdisciplinary teams to deliver care to family caregivers.</p>

forthright and invested in best-care practices, and (4) attending patient needs versus supporting FCGs.

Thought Leader Perspectives

Thought leaders described the process of establishing authentic relationships between hospice team members and FCGs as including assessing and understanding existing family relationships, identifying and meeting unique patient and FCG needs, and balancing other professional obligations and duties. Thought leaders described relationship building as occurring at both the emotional and practical levels, and particularly noted the importance of nurses acknowledging and encouraging FCG patient care efforts.

Value of Expert Teaching

FCG Perspectives

FCGs highly valued expert teaching and linked this concept most closely with nurses and other team members who had the ability to convey information in an accurate, clear, and individualized manner. Nearly every FCG described their own experience of needing or wanting to understand *why* certain things were happening. Even if understanding was not fully achieved at the time, nurses who attended to this need by providing explanations and sharing their own thought processes were seen as being respectful and inclusive of the FCG.

Hospice Nurse Perspectives

Nurses discussed expert teaching in terms of both teaching families and how they themselves had been taught as a hospice nurse. They discussed how expert teaching from experienced nurses/teachers had (1) helped them make connections between information, rationale, and process, and (2) informed and shaped their practice, ethics, and sense of identity as a hospice nurse. The nurses learning from experienced mentors acquired the skills and knowledge to support connections between family members and the hospice team. Nurses felt that poor patient and family teaching led to poor outcomes and regarded home hospice as an important opportunity to provide the kind of patient and family education that is not typically delivered in other settings.

Thought Leader Perspectives

Thought leaders noted the value of expert teaching in hospice nurse education and how this in turn shaped the nurse–FCG interaction. Similar to hospice nurses, they discussed how meaningful learning opportunities were important to support the development of nurses and the many challenges of

providing these experiences to new hospice nurses. One noted the critical gap in available mentors and future leadership training. Others cited how hospice education for nurses tends to focus on clinical skills and symptom management and that nurses tended to teach similar clinical skills to FCGs—a type of teaching that one thought leader described as “very skills-directive.” Thought leaders expressed skepticism as to the effectiveness of the skills-directive approach.

Critical Importance of Teamwork

FCG Perspectives

FCGs appeared to be most aware of the presence of a team approach when things worked well. When the team did not work well, FCG descriptions indicated either a lack of information about the purpose of the hospice team and the roles of team members or a sense that the term “team” itself was more a marketing strategy than a reality. When efficiency, consistency, and reliability were demonstrated by the hospice team, FCGs reported feeling supported and confident even if they were unsure of the various roles played by specific team members. FCGs also described how important it was for them to feel included as part of the caregiving team. However, even an efficient and dependable team could engender a negative experience if the FCG felt that “they came in and took over.”

Hospice Nurse Perspectives

The hospice nurses discussed teamwork in terms of the necessity of coordinated interdisciplinary team efforts for promoting better outcomes and the role of the hospice nurse in facilitating team interactions. The nurses identified themselves as having multiple roles on the team (leaders, managers, and patient/FCG advocates) and saw themselves as the “interface” that connected home hospice services with the larger system. The interdisciplinary nature of the team care model was seen as particularly useful. A number of nurses stressed how one can feel alone or “out there” when providing care and that having a team one can “count on” complements and extends the efforts of the nurse. However, nurses indicated that they themselves first had to understand each team member’s role, and only then could they clarify the role of other team members for families.

Thought Leader Perspectives

This group reinforced the idea of nurses serving as interdisciplinary team leaders and case managers, but at least one thought leader identified the need for more knowledge regarding how nurses

Table 3. Comparison of category-related talk proportions by stakeholder group

Stakeholder group	Essentials of skilled communication	Building authentic relationships	Value of expert teaching	Critical role of teamwork
Total	112/366 (30.6%)	103/366 (28%)	82/366 (22.4%)	67/366 (18.3%)
Thought leaders	44.6% (50) ^a	28% (29)	29% (24) ^c	37.3% (25)
Hospice nurses	26.7% (30) ^a	32% (33)	19.5% (16) ^c	35.8% (24) ^b
Family caregivers	28.5% (32) ^a	39.8% (41)	51% (42) ^c	26.8% (18) ^b

^aDifferences significant at $p < 0.05$ level. ^bDifferences significant at $p = 0.05$ level. ^cDifferences significant at $p < 0.01$ level.

collaborate with team members. They also identified the importance of teamwork in appropriate holistic screening, assessment, and referral. The interdisciplinary team could play a key role in promoting inter-agency communication and in supporting continuity of care across the continuum from hospitals to palliative care programs to hospice services. The transition to hospice can represent a significant disruption for patients and FCGs. Effective teamwork could mitigate the negative effects of this transition.

Descriptive Comparison of Categories across Groups

While four categories represented issues raised by all three stakeholder groups, there were notable differences as to which category each group focused on. Thought leaders mentioned skilled communication most often, while nurses talked most about teamwork, and FCGs talked most about expert teaching. Refer to [Table 3](#) for a summary comparing the proportion of category-related talk from each group and the corresponding z tests. Thought leaders mentioned skilled communication as an important factor underlying FCG support significantly more often than FCGs and nurses ($p < 0.01$). Nurses cited teamwork significantly more than FCGs ($p < 0.05$). FCGs discussed expert patient and family teaching significantly more than thought leaders and nurses ($p < 0.01$).

DISCUSSION

In this study, we asked former FCGs, hospice nurses, and national hospice thought leaders about how to best support and engage hospice FCGs. Similar to other qualitative studies on hospice stakeholders (Kutner et al., 2009; Lau et al., 2009), we found evidence of broad alignment across stakeholder groups in what supported hospice FCGs; however, there were also distinct differences. All three groups emphasized that skilled nurse communication is based on individualized assessment, openness to the family

experience, and careful listening. Despite this agreement, a notable difference was found in stakeholders' perceptions of communication directionality. FCGs viewed skilled communication as a two-way interaction, inviting and valuing their participation. In contrast, nurses and thought leaders tended to discuss communication as an interaction directed from the provider to the patient and family. Nurses described good communication as a skill that nurses possessed and enacted, while thought leaders saw it as a skill to be shared with families. Recognizing the importance of communication, organizations have increased provider education efforts (Walczak et al., 2015), which has been shown to improve patient and family outcomes (Uitterhoeve et al., 2010; Fukui et al., 2011; Visser & Wismans, 2010). Despite these increased efforts, skill development for talking with families is often overlooked (Krimshstein et al., 2011; Fineberg, 2005).

While the essentials of skilled communication were largely about behaviors that promoted or hindered effective interactions between hospice team members and FCGs, the idea of building authentic relationships centered on the character and quality of these interactions and the affective outcomes of this process. Conceptually, this can be thought of as fostering a patient-centered or family-centered approach that addresses FCG and patient concerns and thus the potential for impacting physical and emotional health outcomes (Clayton et al., 2011). Authentic relationships are supported by skilled communication (Salmon et al., 2011) but also generate a sense of confidence in being cared for and treated in a manner responsive to physical and emotional needs. Better understanding of how to elicit FCG needs is central to effective communication and the FCG's perception of authenticity, being listened to, and being cared for. Both the *building* and *authentic* aspects of skilled communication are important for each group. All stakeholders recognize that relationships between FCGs and the hospice team start with an awareness and sensitivity that is not necessarily automatic, and must happen quickly and be

consciously maintained. Authenticity was also seen as a critical component of building supportive relationships, especially for FCGs, and based on dependability, honesty, and inclusion. Moreover, thought leaders and FCGs pointed out how missteps can be overcome if there is a solid foundation based on relationships.

The most important aspect of support for FCGs was the value of expert teaching. FCGs in high-burden situations often report an increased need for caregiving information and support (Cagle & Kovacs, 2011; Parker Oliver et al., 2013). They described feeling confident and supported when nurses provided both detailed instruction and explanations underlying specific tasks, policies, and procedures. While nurses and thought leaders recognized the importance of expert teaching when working with patients and their families, this was not discussed as a priority for FCG support. Instead, they focused on the importance of nurse mentorship. Thought leaders emphasized the need for and challenges of sustaining mentoring opportunities for new hospice nurses. There has been a growth in hospice and palliative nursing certifications (Hospice and Palliative Credentialing Center, 2016); however, it is difficult to ensure ongoing mentoring within the profession.

While teamwork was highlighted by nurses and thought leaders as centrally important, it was mentioned far less often by FCGs. FCG discussions often reflected confusion about the role of various hospice team members and how they worked together. This may be due to the comparative lack of team implementation and communication training for providers (Baldwin et al., 2011). FCGs also discussed their role, or lack thereof, as a valued member of the team. In contrast, thought leaders and nurses focused on how to lead and coordinate hospice team care and introduce the hospice team to the family. This reflects the current state of clinical practice in which high-functioning healthcare teams and interprofessional education are highly valued, rarely modeled, and less frequently taught (Brandt et al., 2014; Taplin et al., 2015).

The findings from our study highlight the shared general perceptions of important factors in supporting hospice FCGs. Yet, when it comes to enactment of true family-oriented hospice care, there are clear areas where professional views and values were discordant with the expressed needs of hospice FCGs. Despite the mission of hospice to provide family-oriented interdisciplinary team care, the daily provision of hospice care may not always fully embrace or support collaboration between the FCG and the hospice team. In particular, nurse care managers tended to describe effective FCG support as an outcome of nursing practice as opposed to a collaboration be-

tween nurse and FCG. Our findings suggest that, similar to other healthcare systems (Kent et al., 2016), hospice struggles to fully integrate FCGs into the care process. New models to encourage the inclusion of FCGs are needed to improve the integration of FCGs into hospice care. For example, interventions using videoconferencing to include FCGs in hospice interdisciplinary team meetings have demonstrated promise in terms of improving communication, providing emotional support to FCGs, and increasing the opportunity to create family-oriented plans of care (Parker Oliver et al., 2010). Future studies are needed to examine whether such interventions can be expanded into standard care, so that hospice teams can more effectively include FCGs (Parker Oliver et al., 2010).

LIMITATIONS OF THE STUDY

The comparison of differing methods (thought leaders completed individual interviews while nurses and FCGs participated in focus groups) may have resulted in data with a differing emphasis for category findings. Because thought leaders and nurse participants were recruited nationally and FCGs were recruited locally, their perceptions could have varied based on location. Furthermore, while qualitative methods produce generative data with sociological depth, they may also limit the transferability of findings.

CONCLUSIONS

FCGs require support from the hospice team, yet this is often given from the provider-as-expert perspective. The FCGs in our study emphasized that FCG support was developed through a shared partnership and by being valued as an essential member of the hospice team. Hospice nurses and leaders shared differing perspectives. Overall, our findings illustrate the need for a more critical examination of the intersection between key stakeholders' perspectives of ways to provide high-quality and family-oriented hospice care that addresses FCG support. The development and integration of interdisciplinary education opportunities in hospice to teach strategies and techniques for effective communication, expert teaching, authentic relationship building, and team building would ultimately improve FCG and patient outcomes.

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