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Family Members' Experience with Hospice in Nursing Homes

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Abstract

Research has documented numerous benefits and challenges associated with receipt of hospice care in nursing homes; however, study of this partnership from the perspective of residents' family members has been limited. The purpose of this qualitative investigation was to explore family members' experience with hospice services received in the nursing home setting. Researchers conducted a secondary data analysis of 175 family member interviews using a thematic analytic approach. Findings highlighted the critical role of communication in supporting residents and their family members. Care coordination, support and oversight, and role confusion also impacted family members' experience of hospice care in the nursing home. Efforts directed at enhancing communication and more clearly articulating the roles of members of the health care team are indicated.

Keywords

hospice; end of life; nursing home; family; communication; collaboration

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Introduction

The number of nursing home residents receiving hospice services has grown in recent decades, doubling between 1999 and 2006.¹ Furthermore, as the so-called “silver tsunami” of the aging baby boom generation begins, the demand for long-term care is also projected to increase.² This growth will presumably increase demand for more end-of-life care as well, and emphasizes the urgency for establishing quality care practices in end-of-life points of care, such as nursing home facilities.

Utilizing hospice services in conjunction with nursing home care has several benefits. Hospice improves satisfaction with end-of-life care,^{3,4} decreases inpatient hospitalizations,⁵ and improves advanced care planning.⁶ End-of-life care is based on a caregiver coalition, where health care providers, family members, and patients coordinate care as a triad, versus the more traditional patient and provider dyad.⁷ Although research has focused on experiences and outcomes of the dyadic relationship, even utilizing family members as respondents in retrospective analysis, much less is known about the family members’ experience. In order to obtain an ideal caregiver coalition and inform quality, evidence-based practices, addressing the gap in knowledge surrounding family members’ experience receiving hospice in nursing homes is necessary. The current study aimed to address the following research question: What is the family experience of hospice in the nursing home?

Literature Review

A literature review was conducted using PubMed MEDLINE, CINAHL, Scopus, and PsycINFO with PsycARTICLES databases. Each database was searched using basic and advanced Boolean searches using key terms in a variety of combinations. To encompass hospice, alternate terms of “end of life” and “palliative care” were used additionally to maximize results, but inclusion was focused only on hospice and not “end of life” or “palliative care.” To capture the nursing home literature, the terms “long term care” and “long term care facilities” were added to the search. Finally, to account for family members, the terms “informal family members” and “caregiver(s)” were also searched. Reverse-search methods were employed and a final search using a general Internet search engine was conducted to locate any applicable grey literature, such as theses and dissertations. While neither “resident” nor “patient” was included in the search strategy, researchers noted that the terms were used interchangeably in the literature when referring to nursing home residents who were also hospice patients and, thus, adopted this convention when referring to residents/patients. To ensure applicability to the current study, literature was limited to those studies conducted with samples from the United States. After close scrutiny of hundreds of articles, it was determined that only 14 addressed the family member experience of receiving hospice care in the nursing home. Within this limited body of research, the family member experience is narrowly described, indicating a distinct gap in literature.

Previous studies have found that, while family members are typically able to identify ways in which the hospice-nursing home collaboration could be strengthened, they generally report a positive, supportive experience with hospice care in the nursing home.^{8,9} Family members have indicated that the nature of hospice support ranges from emotional or

spiritual support^{4,8} to providing additional oversight of the nursing home and the resident's care^{8,10,11} and providing patient advocacy.¹² The perception of hospice as an additional support for patients and families may provide insight into why receipt of hospice care in the nursing home is related to better overall quality of care ratings by family members, as research has shown that family members of residents who have earlier hospice enrollment prior to death are more likely to report better quality care ratings.³ Earlier and longer length of hospice care may translate into more opportunities for families and patients to receive the support of hospice services. This is congruent with family member reports that greater attendance to the patient and more social support are important to provide quality care at the end of life in the nursing home setting.¹³

A series of focus groups with bereaved individuals who had experienced the death of a family member in a nursing home or other setting revealed that, compared with those who received hospice services, family members whose loved ones did not receive hospice were more likely to report that they felt the need to advocate for their loved one's care.¹⁴ Family members in this and other studies noted that they perceived hospice to be a tool of "oversight" over their loved one's care when they were not available,^{8,10,11} which may have assisted or reduced the family's perceived need for advocacy. The addition of more caring professionals has been often cited as important to family members, who have reported that social support and the physical presence of someone supportive contributed to high-quality end-of-life care for residents in nursing homes.¹³ Research has also shown that families express concern about nursing home staff availability and question their expertise in end-of life-care.^{10,13} They have also reported trepidations over nursing home staff's level of respect for residents.¹⁵

Although hospice care is related to better quality outcomes in the nursing home, barriers to hospice services remain in this setting. A recent study found that, even when procedures were in place to systematically assess whether new nursing home residents would benefit from outside resources, residents eligible for hospice services were often not referred to hospice.¹⁶ Lack of knowledge of hospice benefits, on the part of both nursing home staff and residents' family members, was identified as a barrier to hospice referral. Other research has shown that family members find late hospice referrals (or no hospice referral) to be problematic.^{8–10,17} Other challenges noted by family members include poor interagency communication,¹⁸ lack of collaboration and care coordination, and overlapping professional roles.^{9,12}

Methods

Researchers conducted a secondary qualitative analysis of interviews obtained during a federally-funded randomized clinical trial of an intervention for family members of hospice patients (R01NRXXXXXX; PI: AUTHOR). Additional details of the trial, including the randomization process, have been published elsewhere.¹⁹ Interviews were conducted with participating family members approximately two weeks after the patients' death or hospice discharge. All study participants took part in an interview unless they declined to do so or were unable to be contacted after repeated attempts. While many participants in the original trial were receiving hospice services in other settings, only interviews of family members of

nursing home residents were included in the data set analyzed in the present study. Early in the original trial, interviewees were not specifically asked to comment on their experience receiving hospice services in a nursing home setting; however, it soon became evident that, for the family members of nursing home residents, understanding the nursing home-hospice collaboration was vital to fully understanding the hospice experience. Therefore, two broad, open-ended questions (followed by additional probes) were added to the interview guide to specifically elicit information about the hospice-nursing home experience: 1) What was it like to have your loved one receive hospice services in a nursing home? and 2) What benefits or challenges, if any, did you encounter while your loved one received hospice services in a nursing home? Interviews of all participating family members of nursing home residents, regardless of whether or not they were specifically asked about receipt of hospice in the nursing home setting, were analyzed in the present study. Interviews were digitally audio-recorded and transcribed verbatim by research staff prior to analysis. The parent project was approved by the Institutional Review Board of the sponsoring University. All data were stored on a secure password-protected server at the sponsoring University, and only authorized users with Institutional Review Board clearance and approval by the Principal Investigator were allowed access.

Data Analysis

Researchers conducted a thematic analysis of participant interviews. Among published qualitative methods, this process most resembled thematic analysis as explicated by Braun and Clarke²⁰, who outlined the following analytic steps: becoming familiar with the data, generating initial codes, and developing and refining themes. First, to become familiar with the data, researchers independently read all the transcribed content. Then, they met to develop an initial coding frame informed by both their preliminary review of the data and by a review of the existing literature (previously described). They coded 10% of the interviews as a team, discussing and refining coding definitions throughout the process. Next, they independently coded an additional 10% of the interviews, meeting afterward to calculate intercoder reliability, aiming for 80% agreement or better. They were unable to achieve 80% agreement after one round of independent coding and, thus, met again to discuss discrepancies and further refine and clarify code definitions. After a second round of independent coding, they achieved 83% agreement and divided the remaining interviews (70% of the sample) to be independently coded. Codes were ultimately grouped into conceptually similar themes that illustrated family members' experience of hospice in the nursing home, described below.

Findings

Patient and Family Member Characteristics

Researchers analyzed interviews conducted with family members of 166 nursing home residents (Table 1). Multiple family members of a small number of residents participated in interviews, resulting in a final analytic sample of 175 family members (Table 2). Residents whose family members participated in interviews were mostly Caucasian (94%), female (73.5%), and older (mean age of 86), which roughly corresponds with general population demographics of decedents who received hospice care in nursing homes (Miller et al.,

2010). Participating family members were also mostly Caucasian (92.6%), female (81.1%), and were most often the adult child of the resident (70.9%). The mean age of participating family members was 60.

Family Members' Perceptions of Hospice Care in the Nursing Home

Family members reported on several issues pertaining to hospice involvement in the nursing home. The data they provided described both challenges and advantages of the hospice-nursing home collaboration. Four themes, summarized in Table 3, emerged in the analysis: communication, care coordination, support and oversight, and role confusion. These themes are described below and supported with quotations drawn from family member interviews. For the protection of study participants, quotation sources are identified only by a three-digit study number assigned to individual participants. No other identifying information is included.

Communication—Both positive and negative issues related to communication accounted for over half of the coded data segments. Family members shared some communication methods that worked well for them, as well as instances where communication failed or was a challenge. The quantity and diversity in the communication-related segments of data emphasized the great importance family members place on this aspect of hospice care in the nursing home.

Family members explained how expanding the communication network to include hospice could sometimes complicate the communication process. They described how, especially when time was of the essence, contacting an additional party to provide care plan recommendations made the process cumbersome and inefficient. One family member highlighted this issue while discussing the management of her mother's pain:

Well, the floor nurse was trying to do everything that she could for my mom, and the thing was that we had to go through hospice to try to figure out how we could manage pain ... hospice did not manage her pain level very well. We had to keep switching and then we had to wait for the hospice nurse to get that to the doctor (Participant #127).

However, adding hospice to the communication network also facilitated communication by giving family members another outlet to access or by providing an additional advocate for the patient and family. One family exclusively contacted hospice since they found the process more efficient than contacting the nursing home: "We actually just started going just through hospice. And so that worked out better. I think that they got things done quicker" (Participant #300). Another family member explained that she thought hospice wielded a greater position of power than she did and could advocate better for the patient: "I think [hospice] made things a lot easier because, where the nursing home might not listen to me about some things, they would listen to [the hospice] team and things would get changed or taken care of" (Participant #174).

Family members commented on the communication between the nursing homes and hospices, as well. Some family members were impressed with the nursing home and hospice communication and collaboration: "...both of them worked together... I did appreciate the

way the hospice nurses worked with the [nursing home] nurses and they were a team” (Participant #186). Another family member explained the process of communication with the hospice nurse that worked well for her family:

Anytime we needed [the hospice nurse] or if there was anything we needed communicated to him, all we had to do was leave a note with the nursing station, and he immediately got back, either to us or to [the nursing home nurse] within minutes, we had a reply (Participant #169).

However, many more family members reported problems with communication between the hospice and nursing home. No consistent pattern emerged regarding the source of the communication problems; family members provided examples of ways communication originating from both organizations could be improved. For example, one family member lamented over the lack of communication:

There’s not enough communication we would think we would understand, and then they wouldn’t always know for sure, but the nurse told us it was good to call and clarify it there were times [that the nursing home and our family] weren’t on the same page [with hospice], and that’s the part I found the most frustrating (Participant #203).

Another family member explained how poor communication can be particularly frustrating to family members who are closely involved in their loved one’s care:

Well, before hospice was involved, he was already up to three [liters of oxygen]. So there was either some miscommunication or [mis]understanding. But I kept track of my dad’s medication pretty well, and I think if they’re going to make adjustments, they need to let the family member know that they’re adjusting medication, oxygen, whatever (Participant #198).

Although some family members indicated that communication issues were the responsibility of both the hospice staff and nursing homes, some attributed these instances to only one of the parties. A few family members reported that hospice staff’s lack of communication was problematic. One family member explained that hospice failed to appropriately communicate with the family and the nursing home: “They did not call us. We felt that they did not talk to the nursing staff where she was ... there was just no communication there” (Participant #127). Another explained that the hospice staff communicated with the nursing home, but did not communicate with the family member: “I think the hospice people maybe relied on the nursing home staff more than they [relied on or] communicated with me. So there could have been communication going on, but I wasn’t in that circle” (Participant #208).

Several family members mentioned the timing of hospice staff visits to the nursing home and how family members missed staff visits, thus missing an opportunity to communicate about the resident’s care. One family member clearly articulated this issue: “But, you know, with not being at the nursing home when any of the hospice [staff] came, I felt like I ... missed out on a lot” (Participant #040).

Although several concerns with hospice staff communication emerged, more issues were attributed to the nursing home.

It was [the nursing home's] fault that they didn't communicate very well, because half the time they didn't know what he had been given [They] had to go back and look, and sometimes it was written down, sometimes it wasn't. And it was no fault of the hospice people, but it was the nursing home that didn't know half the time what they were even doing (Participant #272).

Another family member recalled feeling the need to monitor the nursing home and hospice for adequate communication when changes occurred:

I find it very important, not only with hospice, [but also] within the nursing home, to make sure that they're fully informed about the situation. So the transfer of information from one person to another is extremely important. If the person is filling in for the day or whatever, [they need to] be fully informed I always went over the situation when someone else came to make sure, "Now, do you realize that we changed this?" There were times when the hospice nurse would change usually the pain medication and the nursing home didn't get the change for some reason or didn't enter it into their books. So I had to monitor that That was something that I had to make sure. Well, one of the main things [was] the Lortab was a tablet. And then we went to a liquid 'cause she was having trouble swallowing pills. And there was a time or two, they'd come in with a Lortab. And I'd say, "No, no, no. Check your instructions. We're going with the liquid under the tongue" (Participant #208).

Care Coordination—Family members often mentioned issues related to the ability of the hospice and nursing home to organize and collaborate on the delivery of patient care. Care coordination issues ranged from a delay in introducing hospice service to issues related to the delivery of therapeutic interventions, including medication and durable medical equipment. For some family members, problems related to care coordination were frustrating.

Data describing the referral to hospice of a nursing home resident was grouped under the theme of care coordination. A number of family members expressed disappointment that hospice was not coordinated into the patient's care sooner, although the reason for delayed referrals varied. One family member reported that the resident's physician suggested hospice sooner, but the family refused and then later wished they had started hospice sooner. Another family member explained how a trusted nursing home nurse introduced the topic of hospice:

The day supervisor nurse said, "You know, this is the hardest part of my job, but we really feel that it's time that you talk to hospice." And I was shocked. And I just said, "Are you serious?" And he said, "Yes, I'm serious. And I'm sure" Well, that was in December, and she passed January 6. So I just wish I would have known how close she was and we could have called hospice in sooner (Participant #169).

When hospice service was initiated, family members were often satisfied with how quickly hospice was able to facilitate an addition or change. They reported that these changes generally improved patient safety and quality of life.

When [hospice] took over, they went right in there and got her a different kind of wheelchair that she couldn't get out of. And they got her a mattress for that bed so she couldn't get out of bed and fall like she'd been doing. And they just changed a lot of the equipment that the nursing home had been using, and it was so much better after that (Participant #207).

I just think that we needed hospice in order to be able to, I guess, regulate some of that additional medication and to change some things for her, and that was something good especially the medication when she was so agitated and so upset and I just didn't know what to do When hospice came on, those medications became available ... they had that at hand, where we had no other resource prior to that (Participant #203).

Support and Oversight—Although this was not universally true, family members tended to view hospice as an intermediary and ancillary service to the nursing home, but with an alliance to the patient and family. They perceived that the addition of hospice improved care for the resident, whether it was through additional staffing or additional oversight of the resident's care. One family member explained how she believed this helped:

[It was helpful] just having that extra set of eyes, like [the hospice nurse]. An extra nurse being there, ya know? Focusing on what's going on with her, you know, spending time chit chatting with her and doing this with her. Just different things, so that they could pick up on anything somebody else might not catch. Which, when you have somebody in a nursing home and they have 50 patients or however many are there and you've only got so many RNs, sometimes little things can get missed, and [hospice nurse name] just took the time to talk to her, be with her and do different things with her. And I know it was all trying to make sure there wasn't something going on that was getting missed or that needed to be addressed (Participant #32).

This theme did not necessarily indicate a concern for the quality of care from the nursing home, however. While the issue of poor nursing home care was mentioned by two family members, most family members did not provide overly negative feedback regarding the quality of nursing home care. One family member, who lived a great distance from the patient, explained:

Because I was far away, and I knew somebody was there to see him every day. Somebody could—even though he was getting good care in the nursing home, it was just--the knowledge that I knew somebody else was going to be there just made it so much easier for me (Participant #066).

Another family member echoed her satisfaction with her mother's nursing home and how the addition of hospice was supportive:

I always felt like the [nursing home name] gave a 100 percent in the way they took care of my mother. So when you added hospice to it, it became 110 or 120 percent then. It just it was just, you know, it just became everything I could need (Participant #203).

One family member even extended the theme of “oversight” from the residents to the nursing home staff, speculating that nursing home staff performance may have improved due to hospice staff presence: “I think that with hospice coming in too, you know, I think that she might have actually got even a little bit more care just because they knew someone else was watching” (Participant #300).

Role Confusion—Study participants indicated that the delineation of roles between hospice and the nursing home was confusing at times. Family members shared numerous stories describing confusion among the nursing home staff and hospice staff regarding division of tasks. One family member suggested that some nursing home staff members may even have capitalized on the addition of hospice to forgo some responsibilities:

Neither of them seemed to be aware of what the responsibilities of the other one was. What happened was that as soon as the nursing home care nurses found out she was going to be moving to hospice they dropped everything. “Well, that’s hospice.” “No, we’re still paying for you to do certain things here and you need to do that” There just didn’t seem to be a smooth transition (Participant #108).

Another participant reported, “Sometimes, I didn’t know whether something was to be taken care of by the nursing home or by hospice. And there were a few things that I had to search and find out just not knowing the system” (Participant #198).

Discussion

The purpose of this study was to explore family members’ experience with hospice services in the nursing home facility. Similar to much of the existing research, this study found that family members generally view hospice care in the nursing home as supportive; however, they are also typically able to identify opportunities for improving these important services. The congruence between these findings and extant research is important, as many studies in this area are qualitative and, consequently, highly context-dependent rather than generalizable. Continued exploration of this issue is vital if research is to shape practice and policy as it pertains to end-of-life care in the nursing home.

The need for effective communication is clear from the volume of data segments surrounding this topic. Previous research of family members of nursing home residents utilizing hospice care has identified concerns over the exchange of information between hospice and nursing homes,¹² thus emphasizing the concern about communication that was reported in the current study. Family members have also frequently reported having insufficient information to make decisions regarding loved ones’ end-of-life care²¹ and have indicated that they especially value good communication during this time.^{22,23}

Collaborations between nursing homes and hospice organizations may present communication challenges and confuse the process of care delivery from the perspective of

family members. Family members' reports of problems with communication between the two parties have been documented in previous studies,^{8,12,18} and the current findings emphasize this problem. Family members value trust and support from health care providers when they have a loved one in the end of life stage²² and problems with effective communication can negatively impact this relationship.

Although, intuitively, it seems that adding an additional party to the treatment team would be a challenge to communication, family members in this study reported that was not always the case. By increasing access to information (in this case from hospice staff), family members were provided with additional contacts to address concerns or to advocate on the resident's behalf. Shield and colleagues⁸ reported similar findings; family members in their study reported there was more communication when hospice was involved in nursing home care than before. The great emphasis on effective communication may, in part, contribute to other findings that suggest families view quality of care more positively when hospice is involved in the nursing home setting.³

Hospice is a valuable resource to residents, families, and nursing homes, but this value can decrease when effective communication is not instituted and maintained. Miller²⁴ reported that even nursing home and hospice administrators have identified communication as a primary factor for effective collaboration between the two entities. In the current study, family members who reported great satisfaction with hospice care in the nursing home were emphatic in their support and appreciation, thus emphasizing that with proper communication, the hospice and nursing home collaboration can be an invaluable service to all parties.

Family members reported that they and their loved ones derived numerous benefits from the nursing home-hospice partnership when communication and coordination of care were performed in an effective manner. Specific benefits included improved medical equipment and medication management. This is consistent with existing research, which suggests that family members perceive hospice providers as end-of-life experts and are generally satisfied with the comfort measures hospice aims to provide.^{8,10}

Challenges with collaboration between hospice and the nursing home are also well documented. Family members in several other studies mention the issue of receiving a late referral to hospice.^{3,8-10} Although the responsibility of hospice referral may not be solely that of the nursing home staff, they are the primary caretakers of the patient and, as such, have greater opportunity to identify decline indicative of the need for a hospice assessment. Shield and colleagues⁸ reported that many family members perceived nursing home staff to be inattentive to the deterioration of patients, despite their everyday involvement in the patient's care. Teno et al.¹⁷ also identified family concerns over nursing home staff's ability to recognize when a resident is nearing end of life. Finally, a survey of successful partnerships between nursing homes and hospices revealed that formal and informal procedures to identify potential hospice patients within nursing homes was helpful to maintaining successful collaboration.²³

The lack of collaboration and referral to hospice may be attributed to another theme that emerged, that of role confusion. Family members reported confusion over the delineation of duties extended to hospice providers, families, and nursing home staff. This lack of understanding may be related to insufficient education of nursing home staff and family members. Role confusion is documented in existing literature, as well.^{9,12} Wetle et al.⁹ explained that family members are commonly unsure of the extent of hospice services and may misunderstand the degree of hospice's involvement and availability. Other studies identified family concerns that nursing home staff may delay or cease certain care tasks when they assume that hospice staff will perform them.¹² Families have stated that more education, for both families and nursing home staff, is needed to ensure quality end-of-life care for nursing home residents.¹³

Family members' doubts over nursing home staff's proficiency at providing end-of-life care may relate to the final theme that emerged: support and oversight. Some family members described the relationship between the three parties, not as a triad, but as a dyad where hospice was on the "side" of the patient and family. Although some family members identified hospice as a support to the nursing home, there were numerous insinuations that this support was due to lacking resources in the nursing home, such as the nursing home being understaffed. Families have identified more support from hospice than with nursing home staff alone in past research⁴ and, despite nursing home staff reports that they feel responsible for family's emotional and spiritual support at the end of life, many family members report not feeling supported by nursing home staff during this phase of their loved one's life.¹⁰ In fact, several studies have identified hospice as a support for families. The view that hospice provides oversight of the nursing home staff is documented in previous research^{8,10} and may further account for family members' perceived alliance with hospice. This alliance may exacerbate a somewhat tenuous relationship between hospices and nursing homes, which may be interrelated to challenges with communication and collaboration.

The current findings are well supported with the previous research that also examines nursing home and hospice collaboration. However, the importance of communication is well emphasized in the current study and emerges as a systemic factor in all issues of collaboration. A model of persistent and thorough communication among all parties may indeed improve the experience for family caregivers and nursing home and hospice providers, alike.

Implications for Practice and Research

Findings from this study provide additional routes for future research opportunities. This study contributes to a larger body of knowledge regarding family members' experiences with hospice service in nursing home facilities. Further insights into more specific communication issues and analysis of these issues may also be gained by additional research. Of greatest importance seems to be the need for interventions that foster communication among families, hospice, and the nursing home.

The findings in the current study provide for some substantial suggestions for improved communication. For example, using the nursing home facility's administrative staff or offices as a point of written communication worked well for one family, as hospice staff and

family were able to exchange written messages through this system that was centered in the nursing home. Timely response of all parties was cited by study participants as an effective communication strategy. Family members reported feeling frustrated with inefficient communication channels that impeded quality pain and symptom management, particularly when urgently needed medication adjustments were indicated. Finally, some family members reported that they were not always certain when hospice staff would be present at the nursing home or that hospice staff tended to arrive at the nursing home during times when family members were unable to be there due to work or other responsibilities. By creating a structure of regular communication or appointment windows for resident care at the facility, hospice and the nursing home may be able to better collaborate with families.

Limitations

These findings must be interpreted in the context of some study limitations. Oftentimes, the family caregivers became well acquainted with the research staff that conducted these interviews. As a result of these lengthy relationships, the study participants often viewed researchers as affiliated with the hospice and, therefore, may have been reluctant to make statements that might have been perceived as critical of hospice. This study is further limited by the use of secondary data, since the interviews were initially conducted as an evaluation of a larger study. Because the semi-structured interview guide evolved over time to include questions specifically addressing the hospice-nursing home partnership, it is possible that the experiences of some early study participants are not reflected in these findings. Finally, as with most qualitative research, the goal of the study was not to generate findings that are generalizable to a broader population. Although the congruence of the present study's results and previous research bolsters support for these findings, they are by their nature highly dependent upon the context and setting from which they were drawn.

Conclusion

The findings of the current study suggest that family members of nursing home residents who receive hospice services value communication among family, hospice, and nursing facility above all other issues. Furthermore, other topics that are important to families may also be related to communication. This requires that an infrastructure conducive to effective and efficient communication be put into place in order to create quality care. Mechanisms for communicating the hospice role to both facility staff and families may be the first step. Consistent and thorough communication throughout the process may be supported by interventions that initiate and maintain communication among all three parties.

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Table 1

Summary of Resident Characteristics

Demographic Characteristic	(N = 166)
Sex	
Female	122 (73.5)
Male	44 (26.5)
Age (years)	
Mean (standard deviation)	86.0 (9.8)
21–50 years	0 (0.0)
51–60 years	5 (3.0)
61–70 years	6 (3.6)
71 or more years	154 (92.8)
Unknown	1 (0.6)
Race	
Caucasian	156 (94.0)
African American	6 (3.6)
Other	4 (2.4)
Education	
Less than high school	42 (25.3)
High school/GED	60 (36.1)
Some college/trade school	32 (19.3)
College/graduate/professional degree	19 (11.5)
Other/unknown	13 (7.8)
Marital status	
Married	30 (18.1)
Divorced	23 (13.9)
Widowed	108 (65.0)
Other	5 (3.0)

^a N (%) unless otherwise indicated

Table 2

Summary of Family Member Characteristics

Demographic Characteristic	(N = 175)
Sex	
Female	142 (81.1)
Male	33 (18.9)
Age (years)	
Mean (standard deviation)	60.0 (11.6)
21–50 years	30 (17.1)
51–60 years	57 (32.6)
61–70 years	57 (32.6)
71 or more years	29 (16.6)
Unknown	2 (1.1)
Race	
Caucasian	162 (92.6)
African American	7 (4.0)
Other	6 (3.4)
Education	
Less than high school	13 (7.4)
High school/GED	32 (18.3)
Some college/trade school	55 (31.4)
College/graduate/professional degree	69 (39.4)
Other/unknown	6 (3.4)
Marital status	
Married	124 (70.9)
Divorced	23 (13.1)
Widowed	16 (9.1)
Other	12 (6.9)
Relationship to patient	
Spouse	16 (9.1)
Adult child	124 (70.9)
Other relative	26 (14.9)
Other/unknown	9 (5.1)
Family member employment	
Full time	60 (34.3)
Part time	17 (9.7)
Retired	65 (37.1)
Not employed	12 (6.9)
Other	21 (12.0)
Family member income	
<\$20,000	24 (13.7)
\$20,001–40,000	42 (24.0)

Demographic Characteristic	(N = 175)
\$40,001–70,000	54 (30.9)
Over \$70,000	40 (22.9)
Unknown/not reported	15 (8.6)

^aN (%) unless otherwise indicated

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Table 3

Themes Describing Family Members' Experience with Hospice in the Nursing Home

Theme	Summary	Sample Quotation
Communication	Family members emphasized the importance of communication among hospice, the nursing home, and the family in shaping their experience with hospice in the nursing home.	"There's not enough communication we would think we would understand, and then they wouldn't always know for sure there were times [that the nursing home and our family] weren't on the same page [with hospice], and that's the part I found the most frustrating" (Participant #203).
Care Coordination	Family members often mentioned issues related to the ability of the hospice and nursing home to work together to care for the resident and family.	"When [hospice] took over, they went right in there and got her a different kind of wheelchair that she couldn't get out of. And they got her a mattress for that bed so she couldn't get out of bed and fall like she'd been doing. And they just changed a lot of the equipment that the nursing home had been using, and it was so much better after that" (Participant #207).
Support and Oversight	Many family members considered hospice providers to serve as an additional monitor of care and as a support to the nursing home staff.	"Even though he was getting good care in the nursing home ... the knowledge that ... somebody else was going to be there just made it so much easier for me (Participant #066).
Role Confusion	Issues regarding role confusion between hospice nursing home staff	Neither of them seemed to be aware of what the responsibilities of the other one was (Participant #108).