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Hospice family members' perceptions and experiences with end-of-life care in the nursing home

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Abstract

Objective—Despite the fact that more than 25% of Americans die in nursing homes, end-of-life care has consistently been found to be less than adequate in this setting. Even for those residents on hospice, end-of-life care has been found to be problematic. This study had two research questions; 1) How do family members of hospice nursing home residents differ in their anxiety, depression, quality of life, social networks, perceptions of pain medication, and health compared to family members of community dwelling hospice patients? 2) What are family members' perceptions of and experiences with end-of-life care in the nursing home setting?

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Methods—This study is a secondary mixed methods analysis of interviews with family members of hospice nursing home residents and a comparative statistical analysis of standard outcome measures between family members of hospice patients in the nursing home and family member of hospice patients residing in the community.

Results—Outcome measures for family members of nursing home residents were compared (n=176) with family members of community dwelling hospice patients (n=267). The family members of nursing home residents reported higher quality of life however, levels of anxiety, depression, perceptions of pain medicine, and health were similar for hospice family members in the nursing home and in the community. Lending an understanding to the stress for hospice family members of nursing home residents concerns were found with collaboration between the nursing home and the hospice, nursing home care that did not meet family expectations, communication problems, and resident care concerns including pain management. Some family members reported positive end-of-life care experiences in the nursing home setting.

Conclusion—These interviews identify a multitude of barriers to quality end-of-life care in the nursing home setting, and demonstrate that support for family members is an essential part of quality end-of-life care for residents. This study suggests that nursing homes should embrace the opportunity to demonstrate the value of family participation in the care planning process.

Keywords

hospice; nursing home; family; end-of-life; palliative care

In 2011 there were 15,671 nursing homes participating in Medicare and Medicaid programs. In that year more than 1.4 million nursing home residents represented 2.9% of all Americans over the age of 65 and 10.7% of those over 85 years of age.¹ More than one-quarter of older Americans die in a nursing home each year, yet research has repeatedly found the quality of end-of-life care they in those facilities is less than adequate.^{1,2} While some residents improve their care with their Medicare hospice benefit,³ considerable barriers remain for the majority of nursing home residents needing palliative care.^{2,4} Two systematic reviews of end-of-life care in nursing homes found challenges in identifying those facing end-of-life, pain management, collaboration with hospice providers, inappropriate hospitalization, lack of advance care planning, unmet family expectations, and communication problems between residents, family, and staff.^{5,6}

Nearly one in five hospice patients reside in nursing homes.⁷ To improve end-of-life care for those in the nursing home, rules for the Medicare hospice benefit were clarified in 1989, allowing residents in long-term care facilities access to their hospice benefits in this setting. Medicare regulation requires hospice programs to contract with individual nursing homes and provide all the services hospice would normally provide to its patients, including the coordination of care. However, while demonstrating benefit to residents,⁸⁻¹¹ hospice involvement in long-term care settings has not been without controversy and misunderstandings.^{4,5,12-14}

The purpose of this study was to explore end-of-life care in the nursing home setting from the perspective of family members of residents who received hospice care. This study

focused on two research questions; 1) How do family members of hospice nursing home residents differ in their anxiety, depression, quality of life, social networks, perceptions of pain medication, and health compared to family members of community dwelling hospice patients? 2) What are family members' perceptions of and experiences with end-of-life care in the nursing home setting?

Our study was informed by the work of Saltz and Schaefer,¹⁵ who developed a model for health care team collaboration that includes families. They identify four considerations for healthcare team collaboration inclusive of family: context, structure, process and outcomes. The organizational **context** influences team **structure**, which in turn impacts team **processes**, which ultimately determine how teams evaluate **outcomes**. The model is described as non-linear, with feedback loops between all components. For example, the culture and philosophy (context) of the nursing home may encourage or discourage family involvement in care. The (structure) composition, personality, education, background, and philosophy of the staff determine if there is a role on the team for family and whether family members are viewed as “lay” people (without detailed knowledge), or “specialists” (with a tremendous amount of knowledge regarding the patient). The involvement of family members in the problem-solving or decision making (process) is typically very important. If not involved, incorrect assumptions can be made about the patient and family (such as their goals of care or treatment) and care can be affected. Finally, families influence outcomes by providing feedback about the care.¹⁵ Family satisfaction can reinforce positive care, and dissatisfaction can lead to improvement or conflict. These four elements context or philosophy of care, structure, process for family input, and family satisfaction (outcomes) are components to patient/family centered care in any healthcare environment.

Methods

This study used secondary data that were collected during a clinical trial of a hospice family intervention funded by the National Institute of Nursing Research (R01NR011472). The trial facilitated hospice family involvement in care planning through web-conferencing. Family caregivers of hospice patients were randomized into either a usual care or an intervention group. The intervention group used web-conferencing technology to participate in their plan of care meetings every two weeks while the others continued to receive their usual hospice care and not participate in those meetings. Additional details of the trial, including the randomization process, have been published elsewhere.¹⁶ The trial involved four clinically separate hospice programs from one Midwestern state from 2010–2014. The trial is registered with clinicaltrials.gov (NCT01211340) and approved by the University of Missouri Institutional Review Board and the administrative review bodies of the hospice programs.

Using a mixed method approach, research question one, which compares the outcome measures of nursing home and community dwelling family members, was answered using outcome measurement data from all family members enrolled in the trial in either of the two settings. Research question two, which explores only the perceptions of family members regarding end-of-life care in the nursing home setting, was answered with an analysis of interviews with family members of residents in that setting to lend insight into the potential

meaning of the outcome measures. We used a retrospective secondary data analysis of the measures and interviews regardless of their intervention or control assignment. We compared measures to those of family members of community-dwelling hospice patients. We included the measures taken at enrollment and the last measure closest to death or discharge from hospice.

We collected family member demographics, as well as the patient Palliative Performance Score (PPS)¹⁷ as documented by the hospice admission nurse. Clinical measures for family members of residents/patients in both groups included the Generalized Anxiety Disorder-7 (GAD-7) assessed respondents' level of anxiety,¹⁸ and the Patient Health Questionnaire-9 (PHQ-9) assessed their level of depression.¹⁹ The Caregiver Quality of Life Index-Revised (CQLI-R) assessed a family member's perception of the quality of their life and has specific subscales related to emotional, financial, physical, and social quality of life.²⁰ We used the Lubben Social Network Scale-6 (LSNS-6) to measure the amount of social support available for an individual.²¹ We also used the Caregiver Pain Medicine Questionnaire (CPMQ), a measure that assesses family members' perceptions of pain medication.²² Finally, the Short Form-12 (SF-12) was used to assess general health, mental health, and physical health.²³ These measures were collected upon study enrollment and every two weeks thereafter by telephone or email.¹⁶

Data were entered into identical databases at each site and backed up to a central site weekly. Regular reports of potentially erroneous or missing data were generated to ensure high data quality. We compared characteristics of patients and their participating family members according to whether the patient lived in a nursing home or within the community. Categorical variables were compared using the chi-square statistic, and the means of continuous variables were compared using *t*-tests.

Interviews were conducted with the family members of nursing home residents who enrolled in hospice by phone two weeks following the death or hospice discharge of the resident. No interviews were included with the community dwelling family members. We used a semi-structured interview instrument whose primary purpose was to understand the family members experience with the clinical trial. As the interviews were transcribed, the rich descriptions of family experience in the nursing home led to this secondary analysis. Comments in the interviews reflect comments regarding the nursing home care while enrolled in hospice. Comments made regarding experience with hospice care (unrelated to the nursing home experience) were specifically excluded. Family members of patients who transitioned in or out of a nursing home while enrolled in the larger study were excluded.

All interviews were transcribed verbatim. Transcripts were coded and analyzed by three members of the research team (KW, AL, DPO). Initial codes were developed and discussed using the challenges of end-of-life care in the nursing home identified in the literature as well as the observations of the interventionists in the study. An excel spreadsheet was created to assist tracking codes. Coders reviewed 30 transcripts together, discussing utterances and refining the coding categories. Twelve interviews were then independently coded and results compared; reliability was satisfactory (Kappa .83). The coding of the final 48 transcripts were coded independently by two of the coders.

Results

There were 166 nursing home residents and 246 community-dwelling hospice patients, with 176 and 267 participating family members respectively. In both settings there were a few patients with two family members who participated in the study. The average length of time the patients were enrolled in hospice was not significantly different between groups. Nursing home residents were enrolled in hospice between of 4 and 1018 days with a mean of 145 days and a median of 100 days. The community dwelling patients were enrolled in hospice between 6 and 1133 days with a mean of 134 days and a median of 75 days. This stay is longer than average because the larger study did not accept those who had a life expectancy of less than 2 weeks. The characteristics of family members of patients in the two settings are presented in Table 1, and patient/resident characteristics are presented in Table 2. Family members of nursing home residents were more likely to be adult children of the patient (70.9%) than family members of community-dwelling hospice patients (42.3%), who were more likely to be the patient's spouse ($p < .0001$). In general, family members of nursing home residents reported higher household income than family members of community-dwelling hospice patients ($p = .0004$). Compared with patients living in the community, nursing home residents were more likely to be women ($p = .0002$), older ($p < .0001$), less likely to have cancer ($p < .0001$), or have significantly lower PPS (Palliative Performance Scale) scores ($p < .0001$), indicating they had a lower life expectancy than community-dwelling patients.

The measures administered to family members are summarized and compared in Table 3. Family members of nursing home residents and community-dwelling hospice patients did not differ significantly upon admission or at last measure in their health, anxiety, depression or perceptions of pain management. The family members of community dwelling patients had significantly lower social support upon hospice admission than the nursing home family members ($p = .05$); however, there was no longer a statistically significant difference at the time of the last measure. The primary difference between family members of patients in these two settings is in the quality of life they reported. Upon enrollment and at last measure the nursing home family members had a significantly better financial, physical, and social quality of life ($p = .05$). While there was no difference upon enrollment, at last measure family members of nursing home residents also had a significantly better emotional quality of life ($p = .014$).

Family perceptions of end-of-life care in the nursing home

There were 86 (49%) family members of hospice nursing home residents interviewed. Of these 86 interviews, 56 (65%) discussed some aspect of end-of-life care in the nursing home setting, even though they were not asked questions that specifically addressed those issues. A total of 166 utterances were coded from these interviews. Analysis found six general themes, representing the Saltz and Schafer framework (context, structure, processes, and outcomes) for family collaboration with healthcare teams. The themes included hospice collaboration, family expectations, communication, resident care issues (non-pain), pain management, and positive end-of-life care experiences. A summary of the themes, their operational definition, and narrative examples are presented in Table 4.

Hospice collaboration in the nursing home

More than half of those sharing information related to end-of-life care in the nursing home had comments related to the collaboration between the nursing home and the hospice. These comments were both positive and negative, and reflected good and poor examples of communication and role delineation between the hospice and the nursing home staff. The majority of comments from family members were positive. Several individuals reported that they appreciated the “extra oversight” provided by hospice in this setting. One family member (02-0090-0040) noted, “When the hospice came on board, it just soothed my worries.”

Family Expectations

Half of all family members discussing end-of-life care in the nursing home mentioned situations in which their expectations for care were not met. Utterances were coded in this category if it was clear that family members held an expectation of something and pointed blame or gave praise specifically identifying what should have been done or what was done. One family member (01-0285-0091) shared their frustration that they had to figure out themselves how to help hydrate their loved one.

And so as far as hydration went, I think it wasn't made clear to us should we try to give her some liquids? Should we try to give her anything by a syringe or anything like that, or whatever? So we just did it on our own. We took a straw and put our finger on the end and got some fluids in and put a little bit in her mouth.

Likewise, a family member (01-0261-0085) expressed frustration with obtaining medications, “As a family member, I found myself needing to ask for additional meds. Or they just weren't in there as quickly and as on time as I felt like they should have been.”

Communication

Nearly half of the family members discussing end-of-life care shared difficulties communicating with nursing home staff or with the nursing home staff communicating with one another between shifts. One family member (2-0015-0004) said, “They didn't communicate with us at all. ... We told them if anything was, you know, if our dad was really going downhill or, you know, please call us.” Similarly, family members were frustrated with poor communication between nursing home staff members as noted by a daughter (02-0468-0203):

...she's been in the nursing home a little over about a year and a half now, each shift of the nursing home doesn't seem to know what the other shift knew. There's not enough communication we would think we would understand and then they wouldn't always know for sure...”

Resident care issues

Nearly one-third of families discussing end-of-life care in the nursing home gave examples of specific concerns related to the physical care of their loved one. Pain management concerns were not included in this category and were examined separately due to the

attention it receives in the literature. The resident care issues involved four sub-themes: hydration/nutrition, bed sores, falls, and problems with medical equipment.

Several family members had concerns regarding the nutrition or hydration of their loved one. One common example was mentioned by a daughter (2-0104-0048) noted:

The nursing home can't deny food. And even after we were told and after we believed that she was not able to swallow, there were still people on the staff that didn't want her to be hungry so they were trying to feed her.

Another theme was concern related to personal care and the bed sores that were believed to result from inadequate attention. One example shared was from a daughter (02-0090-0040) describing her mother's care:

She had pressure sores on her bottom. And I asked them. I put a note up in the bathroom. "Please wash mom with the adult wet wipes." And there [were] always two bags [of adult briefs] in her closet. So there was no reason for them not to, you know, get one out of the closet and take it to her and help her. Sometimes they wouldn't even help her get her old one off or a new one on.

Falls from the bed or chairs were another concern mentioned by several family members. One family member (02-0684-0272) expressed this concern with their father's falls.

There were a few incidences where he fell out of the chair I did take a recliner up there, and one time he fell backwards out of the chair. But that was just because no one was paying any attention.

Finally, there were several examples of issues with medical equipment or the operation of medical equipment. One such instance was shared by a family members (02-0090-0040) who reported:

They scared her to death of the BiPAP machine ... because it was put on her at one night, and it wasn't plugged into the concentrator. So she started smothering. It was horrifying at first. And oh, there were several different incidents like that.

Pain Management

Issues related to the management of pain came from nearly 20% of those discussing end-of-life in the nursing home. One family member (01-0569-0147) expressed frustration about their loved one's pain management because they had to remind nursing home staff to provide pain relief. They reported, "It was basically us going, 'Oh, jeez. It's been 7 hours. Maybe we need to have him just go ahead and try and stay on top of it and give him some more medicine.'" Likewise another son (01-0569-0147) reported concern that his father was not given pain medication when he needed it.

The last few days when we got called in. Dad was not real responsive and was just shaking his head and him moaning. And I know we had asked for--we thought maybe he needed some more of the morphine. And the [nursing home] nurse said, 'Well, let's just wait and see because that will really affect his breathing'.

Positive Experiences

More than a third of those interviewed and discussing end-of-life care in the nursing home reported positive experiences. One family member (01-0108-0039) stated, “I will give much credit to the nursing home in that the administrator sat with her until she passed.” Another daughter (01-0735-0169) proudly shared her positive experience with the collaboration between the hospice and nursing home nurses:

George [name changed] was her [hospice] nurse, and he was just great ... Anytime we needed him 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 Sam [name changed] [nursing home nurse]. And I mean it was just within minutes, we had a reply.

Discussion

The purpose of the study was to explore end-of-life care in the nursing home setting from the experience of family members who received hospice care. Consistent with the hospice philosophy we defined “end-of-life care” broadly to include support for residents’ family members. We examined specific outcomes for family members of hospice patients in the community as well as in the nursing home setting. In addition, to gain a richer understanding of the family members perceptions and experiences of the end-of-life care in the nursing home, we analyzed in-depth interviews conducted with family members of nursing home residents.

It was surprising to find so few differences in clinical outcomes between family members of hospice nursing home residents and family members of community dwelling hospice patients. It appears that the clinical outcomes of having loved ones at the end-of-life are similar, regardless of setting, as evidenced by the similarities in anxiety, depression, perceptions of pain medication and health in both groups.

However, some differences between the groups of family members were identified. These data show that the quality of life of for family members of hospice patients receiving care in the nursing home is better than family members of community dwelling hospice patients. While we did not investigate the reasons for differences between these groups, it is likely that the family members of community dwelling patients are more involved in providing day-to-day hands-on care than their nursing home counterparts. This may have an impact on their quality of life. In addition, this quality of life difference may to some degree represent the impact hospice has for nursing home family members; we can not assume that the quality of life reported by participants in the study reflect the reality of all family members of nursing home residents nearing the end-of-life, particularly those who do not access hospice services. Further, family members commented that hospice, “soothed their worries” and provided oversight, which may also explain some of the differences.

Anxiety, depression, and health outcomes were found to be similar for family members of hospice community dwelling and hospice nursing home residents. While this study did not compare the interview data between these two groups of family members, information

shared by the nursing home families does shed light on the stressors they experience. These family members reported experiencing stress associated with monitoring the care delivered by the nursing home rather than experiencing the stress of delivering the care first hand. Both experiences were found to be associated with similar levels of anxiety, depression, and physical health, challenging the notion that one type of family caregiving arrangement is inherently more taxing than the other.

An unexpected finding was the larger social network reported by the nursing home family members at the point of hospice enrollment. One might expect the lack of a social network to lead to nursing home placement, although many factors undoubtedly play a role. Perhaps the isolation experienced with being at home caring for a loved one explains this finding.

In trying to understand the experience of family members of nursing home residents in particular, the Saltz and Schaefer model for family participation in health care teams, provides a useful approach. We readily identified all four elements in the model (context, structure, process, and outcomes) can be identified in our qualitative data. Family members' feedback demonstrates how context, structure, and process can affect outcomes in nursing home care at the end-of-life. For instance, in the final example provided above, the daughter of a nursing home resident explained how effective collaboration between the hospice and nursing home nurse resulted in timely and responsive care for her father. This example illustrates how the nursing home environment (context) created a role for the family member (structure) who felt free to communicate needs (process) with confidence that both the hospice and nursing home nurse would follow through. As a result, their perceived outcome of the care at their loved one's end-of-life was positive. In contrast, the family members' feedback on the experience regarding the BiPAP machine (02-0090-0040) describes the environment of the nursing home as scary and nonresponsive (context). The nursing home staff did not recognize family members' role as an expert (structure) and thus their communication was not acknowledged (process) and they were forced to go to the administrator to provide feedback (outcome). The experience was therefore negative, as the family did not feel their patient received appropriate care in the facility.

During their interviews, family members identified a multitude of barriers to quality end-of-life care in the nursing home setting and emphasized that support for family members is an essential part of quality end-of-life care for residents.²⁴ To provide needed support and fully engage family in the care of their loved one, the family members' capacity to participate in care must be assessed. Family assessment is already recognized as important to pre-nursing home practice settings,²⁵ and we suggest that such assessment is also important within nursing home settings. Without an assessment of family needs and goals, encouragement and support for their involvement is not feasible.

While this study is limited by experiences with residents enrolled with four hospices, it does represent several nursing facilities served by these hospice programs. Additionally, like all qualitative studies, these data should not be generalized to every nursing facility. The results, however, are consistent with findings in the literature.^{5,6} Interview data are also limited as a secondary analysis of data gathered for another purpose. Specific interview questions and follow-up probes regarding the nursing home were not asked; rather these data

were in response to questions regarding their experience in care planning with the hospice team. Because the focus of this study was on end-of-life care in the nursing home setting, researchers analyzed only the interview data that made specific reference to care in the nursing home, not the care provided by hospice, except as it was presented in terms of collaboration between the two providers.

Existing regulations require hospice providers to coordinate care related to the terminal illness, even in the nursing home setting. Given the comments from these interviews it is clear that this coordination is not always successful. For example, concerns regarding pain management would be a hospice directed care concern. The father who was reported to be moaning in pain the final days of his life was either not receiving effective pain management from the hospice (through appropriate pain medication orders), or the nursing home was not implementing the plan of care as directed. Likewise, the challenges reported by the family member in the pain management example provided in Table 4 indicate that the hospice's coordination of the plan of care was falling through the cracks between nursing home staff shifts. It is not clear from our data if these situations were reported to the hospice and if any action was taken by the hospice to improve the situation in the future. This situation illustrates that, even with hospice involved, the family must make sure that breakdowns in care are communicated to the hospice providers who are charged with the coordination of that care.

These data reveal that interventions in nursing homes that improve end-of-life care are needed. The ability for loved ones to participate in nursing home care holds promise as one way to actively engage family members in decision making and care planning. While this study used data from one such intervention, there are many residents who are not enrolled in hospice care at the end-of-life and would benefit from being an active participant in the care planning process.^{4,26,27} Additionally, interventions that engage family members earlier in the process have the potential to ease the last minute complications that arise when family members come to visit from distant places and do not understand or have not been involved in the care decisions for their loved one.

Conclusion

This study suggests that nursing homes should embrace the opportunity to involve families in the care planning process. This requires that nursing homes create a structure to support this involvement, recognize the expertise of family members in decision-making, and view feedback from family members as an opportunity to improve care given at the end-of-life. Further research into the benefits of family involvement in nursing home care should be increased and assessment tools and interventions should be designed and tested to improve the long-standing problems associated with end-of-life care in this setting.

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Table 1

Summary of Family Characteristics by Hospice Patient's Residence

Demographic Characteristic	Community Dwelling (N=267)	Nursing Home (N=175)	<i>p</i> -value*
Family Sex			
Female	206 (77.2%)	142 (81.1%)	.32
Male	61 (22.9%)	33 (18.9%)	
Family Age (years)			
Mean (standard deviation)	59.4 (13.5)	60.0 (11.6)	.60
21–50 years	64 (24.0)	30 (17.1)	.25
51–60 years	73 (27.3)	57 (32.6)	
61–70 years	72 (27.0)	57 (32.6)	
71 or more years	55 (20.6)	29 (16.6)	
Unknown	3 (1.1)	2 (1.1)	
Family Race			
Caucasian	243 (91.0%)	162 (92.6%)	.64
African American	16 (6.0%)	7 (4.0%)	
Other	8 (3.0%)	6 (3.4%)	
Family Education			
Less than high school	23 (8.6%)	13 (7.4%)	.20
High school/GED	74 (27.7%)	32 (18.3%)	
Some college/trade school	69 (25.8%)	55 (31.4%)	
College/grad/profess degree	94 (35.2%)	69 (39.4%)	
Other/unknown	7 (2.6%)	6 (3.4%)	
Family Marital status			
Married	186 (69.7%)	124 (70.9%)	.022
Divorced	32 (12.0%)	23 (13.1%)	
Widowed	11 (4.1%)	16 (9.1%)	
Other	38 (14.2%)	12 (6.9%)	
Family Relationship to resident			
Spouse	92 (34.5%)	16 (9.1%)	<.0001
Adult child	113 (42.3%)	124 (70.9%)	
Other relative	42 (15.7%)	26 (14.9%)	
Other/unknown	20 (7.5%)	9 (5.1%)	
Family employment			
Full time	74 (27.7%)	60 (34.3%)	.13
Part time	30 (11.2%)	17 (9.7%)	
Retired	89 (33.3%)	65 (37.1%)	
Not employed	37 (13.9%)	12 (6.9%)	
Other	37 (13.9%)	21 (12.0%)	
Family income			
< \$20,000	66 (24.7%)	24 (13.7%)	.0004
\$20,001–40,000	85 (31.8%)	42 (24.0%)	

Demographic Characteristic	Community Dwelling (N=267)	Nursing Home (N=175)	p -value*
\$40,001–70,000	44 (16.5%)	54 (30.9%)	
Over \$70,000	46 (17.2%)	40 (22.9%)	
Unknown/not reported	26 (9.7%)	15 (8.6%)	
Family Reside with patient			
Yes	180 (67.4)	0 (0.0)	<.0001
No	87 (32.6)	175 (100.0)	

* Chi-square analysis for categorical variables, *t*-test for mean age.

Table 2

Summary of Hospice Patient Characteristics by Residence

Demographic Characteristic	Community Dwelling (N=246)	Nursing Home (N= 166)*	<i>p</i> -value**
Patient Sex			
Female	136 (55.3%)	122 (73.5%)	.0002
Male	110 (44.7%)	44 (26.5%)	
Patient Age (years)			
Mean (standard deviation)	76.2 (13.7)	86.0 (9.8)	<.0001
21–50 years	7 (2.9)	0 (0)	<.0001
51–60 years	29 (11.8)	5 (3.0)	
61–70 years	54 (22.0)	6 (3.6)	
71 or more years	154 (62.6)	154 (92.8)	
Unknown	2 (.8)	1 (.6)	
Patient Race			
Caucasian	223 (90.7%)	156 (94.0%)	.36
African American	17 (4.3%)	6 (3.6%)	
Other	6 (2.4%)	4 (2.4%)	
Patient Education			
Less than high school	47 (19.1%)	42 (25.3%)	.16
High school/GED	76 (30.9%)	60 (36.1%)	
Some college/trade school	56 (22.8%)	32 (19.3%)	
College/graduate/professional degree	46 (18.7%)	19 (11.5%)	
Other/unknown	1 (8.5%)	13 (7.8%)	
Patient Marital status			
Married	114 (46.3%)	30 (18.1%)	<.0001
Divorced	34 (13.8%)	23 (13.9%)	
Widowed	78 (31.7%)	108 (65.0%)	
Other	20 (8.1%)	5 (3.0%)	
Patient Primary diagnosis			
Cancer	103 (41.9%)	19 (11.5%)	<.0001
Dementia	14 (5.7%)	18 (10.8%)	
Other	129 (52.4%)	129 (77.7%)	
Patient PPS at study enrollment[†]			
Mean (standard deviation)	43.8 (11.3)	37.7 (7.93)	<.0001

* 8 Residents who transferred into or out of a nursing home during their study enrollment were excluded from both groups.

** Chi-square analysis for categorical variables, *t*-test for mean age.

[†] Palliative Performance Scale

Table 3

First and Last Available Measures of Family Members' Quality of Life, Anxiety, Social Support, Depression, and Health [Mean and (Standard Deviation)] by Hospice Patient's Residence.

Measure	Enrollment measure			Last available measure		
	Community-dwelling	Nursing home	p-value	Community-dwelling	Nursing home	p-value
Caregiver Perceptions of Pain Medicine Questionnaire (CPMQ)	61.7 (9.29)	62.7 (9.72)	.25	63.4 (9.5)	64.6 (9.38)	.23
Caregiver Quality of Life (CQLFR)						
Emotional	7.30 (2.11)	7.30 (2.18)	.99	6.83 (2.19)	7.37 (1.88)	.014
Financial	6.43 (2.92)	6.99 (2.53)	.034	6.37 (2.76)	7.01 (2.37)	.02
Physical	6.95 (2.18)	7.42 (1.98)	.023	6.55 (2.23)	7.08 (2.02)	.022
Social	6.98 (2.64)	7.69 (2.12)	.002	6.40 (2.71)	7.21 (2.30)	.003
Generalized Anxiety Disorder (GAD-7) score	5.92 (5.21)	6.36 (5.26)	.45	6.36 (5.87)	5.07 (5.19)	.071
Lubben Social Network Scale (LSNS-6)	18.1 (5.94)	19.3 (5.56)	.05	17.2 (6.45)	18.3 (5.95)	.10
Patient Health Questionnaire (PHQ-9) depression score	6.24 (5.16)	6.02 (5.11)	.70	6.52 (5.57)	5.39 (5.52)	.11
SF12 Health Survey						
General health	63.1 (24.5)	63.5 (25.8)	.93	56.0 (26.4)	64.0 (25.7)	.062
Mental health	59.7 (21.6)	60.9 (19.9)	.71	58.2 (23.9)	62.5 (19.6)	.24
Physical health	72.8 (32.1)	72.4 (33.1)	.94	75.0 (86.4)	72.7 (34.2)	.82

Table 4
Coding Categories, Definitions, and Narrative Examples from Exit Interviews of Family Members of Hospice Patients Living in Nursing Homes

Code	Definition	Example
Communication	Communication between nursing home staff or nursing home and family (not hospice related communication)	<i>I sat down with the head of the nursing home, [staff name], at [nursing home name], and I said "it's like your staff doesn't know from one shift to the next shift. If you have an employee that works two days a week, how many days out of the nursing home, they don't know what's on the floor, what's not on the floor. They don't know what's changed and what's not changed. I don't know if there's some way you can come up with a piece of paper, that says these patients now get this and they need to read that before they go on their shift, or what. But it's like, the helpers don't know. And in a week's time, the nursing home can vastly change if you're only going to have a girl work two days a week or three days a week ... you need to make sure that they understand what a patient can do and what it can't do, and how to handle the patient". 02-0468-0203</i>
Pain Management	Pain management issue that was related to the nursing home setting	<i>But, in the absence of consistent caregivers, and that's one of the problems we had out there, having three different caregivers a day and on a weekly basis, you know possibly twenty caregivers of people who didn't know what my mom had been given the night before and what pain level she was having. 02-0252-0115</i>
Hospice Collaboration	Comments made pertaining to hospice involvement in the nursing home. Positive and negative comments related to collaboration between nursing home and hospice.	<i>At any time, when we talked with hospice employees, we were able to get what we felt was the right plan of action. 01-0261-0085</i>
Positive Comment	A positive statement related to end of life care in the nursing home	<i>I mean anything she wanted that the [care facility] people tried to provide to her. If it was not something that they could do, they would just call and say, "She would like to have whatever." It was usually liverwurst or some disgusting thing. 01-0104-033</i>
Family Expectation and information needs	Family holds and expectation and points blame/praise specifically identifying what should/was or should not/was not done	<i>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 caregiver know that they're adjusting medication, oxygen, whatever. And honestly, that's just for somebody that's involved. If they've got a caregiver that doesn't care, they probably don't want to know the medication. But I did. 02-0458-0198</i>
Resident care issues	Instances brought up describing poor care by the nursing home.	<i>...the nursing home was still trying to give mom pills. And she wasn't able to swallow or anything and they were just sitting in her mouth. 01-753-0174</i>