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Hospice Caregivers' Experiences With Pain Management: "I'm Not a Doctor, and I Don't Know If I Helped Her Go Faster or Slower"

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Abstract

Context—Those caring for their loved ones in hospice experience tremendous stress, being faced with numerous decisions as they work to manage the pain experienced by their loved one. Although hospice care teams create pain management strategies, it is the role of the caregiver to implement these plans.

Objectives—The purpose of this study was to further understand the hospice caregiver experience relating to pain management.

Methods—Semi-structured interviews with 146 caregivers provided data for the study. Responses to seven questions asking for a ranking of end-of-life pain management indicated a less than ideal experience. Available narratives from 38 caregivers were analyzed for themes related to further understanding the concerns.

Results—Five themes were identified in the data including difficulty with administration of pain medicines, concerns about side effects of medications, insecurity with pain assessment, frustrations with communication among health care team members, and memories of unrelieved pain.

Conclusion—These findings should raise concern among hospice professionals, whose commitment is to the management of pain, including emotional pain, with a focus on both the patient and the family as a unit of care. These data clearly suggest hospice providers have an opportunity to be sensitive to perceptions held by caregivers regarding pain management.

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Effective planning for pain control must incorporate the values and beliefs not only of each patient, but also of the family caregiver.

Keywords

hospice; caregivers; pain

Introduction

The prevalence of pain at the end of life and associated challenges with pain management are well documented. An Institute of Medicine report (1) suggests that 40% of those at the end of life have severe, unrelieved pain. Patients say barriers to effective pain management include communication problems with providers, structural problems in the health care system (difficulty obtaining medications), fears related to addiction, and personal attitudes, beliefs, and values (2–4). Similarly, health care providers find patient adherence with pain medication regimens to be problematic (5, 6).

Hospice in the U.S. is largely a home-based service and the majority of the care is provided in patients' homes by an informal, unpaid caregiver, often a family member of the dying patient. Nearly 70% of hospice deaths occur in the patient's place of residence (7). Distressing pain and symptoms have been documented to affect 76%–90% of hospice patients (8, 9). The home of a dying patient has been compared with a hospital unit in which informal caregivers are expected to manage all aspects of patient care; those lacking formal education are left anxious, exhausted, and burdened (10). Caregivers have been found to experience anxiety, depression, and physical symptoms (11–16). Difficulty managing pain is significant, especially among older informal caregivers. The combination of dealing with the emotional distress from the expected loss of a loved one, the physical demands of caregiving, and the biological vulnerability brought on by age combine to increase the risk for their own health problems and early death (17, 18).

Pain is one of the most common and challenging symptoms to manage, especially when caring for a loved one. Research has shown that age, fears, beliefs, lack of assessment skills, burden and strain are barriers to managing pain effectively (19–24). Despite lack of training, informal caregivers must assess the severity of pain, and make choices about how to administer medication to treat it. Hospice patients have complicated medication schedules, particularly regarding administration of opioids. It is a challenge for the caregiver to assess pain and bring into play "extra" opioid pain relief "as needed" (PRN) for "breakthrough" pain. It is often frightening to shoulder the responsibility of keeping a loved one comfortable by using a controlled medication (25). And yet, hospice patients and staff alike rely heavily on informal caregivers to do just that. A confident, skilled, and trusting family member is often their best ally in preventing pain and implementing feasible management strategies (26). Hospice teams spend as much as 38% of their time focusing on pain control during care planning meetings, yet typically do not include discussion about the challenges experienced by caregivers (4).

Globally, support services in hospice and palliative care do not include programs aimed at training caregivers about pain management or systematic assessment of the caregivers' needs (27, 28). In some countries, death and dying remain taboo topics despite a preference for truthtelling among patients and caregivers; thus, pain management is never discussed (29). In Italy, for example, providers commonly provide diagnosis and prognosis information to the caregiver who then makes a decision about disclosure while simultaneously overseeing the management of care at the end of life (30). Caregivers worldwide report a lack of psychosocial and emotional support while providing hospice and palliative care (28, 31). Less than 5% of all European caregivers have access to services aimed at addressing the psychological needs of caregivers; these services are particularly rare in Italy, Poland, and Greece (27). Better pain control was reported among bereaved family members in the U.K. compared with those who provided home care (32).

Given the lack of caregiver support for pain management, the purpose of this study was to further understand the hospice caregiver experience relating to pain management. Specifically, the research questions guiding this study were: 1) How do hospice caregivers rate the experience with the pain management for their loved ones? 2) What are the concerns of hospice caregivers about their loved one's pain and its management?

Methods

Interviews of hospice caregivers from an ongoing randomized clinical trial funded by the National Institute of Nursing Research (R01NR011472) were used for the study. Details on the larger project are available elsewhere (33). All study participants were designated caregivers of enrolled hospice patients, over 18 years of age, English-speaking, and active participants in managing the pain of their loved ones. This project was approved by the institutional review board of the supporting university.

Semi-structured interviews were conducted with hospice caregivers from two Midwestern U.S. hospices 14–30 days following the death of their loved one. The purpose of the interviews was to collect data on the experience with the larger intervention study and the caregiving experience in general. All interviews were audio-recorded and transcribed verbatim for analysis. The interview guide for both the usual care and intervention participants had some unique and some common questions. The common set of questions related to pain provided data for this study (Table 1). Interviewers also prompted caregivers to provide explanatory narrative regarding their answers. Eighty-one individuals chose to share additional narrative when prompted, and 38 individuals shared specific narratives that were related to pain control or pain management issues.

Data Analysis

The seven structured interview questions were entered into SAS for Windows v9.3 (SAS Institute Inc., Cary, NC) to generate descriptive statistics. We also generated simple counts on the narratives to determine how often caregivers mentioned specific concerns. The interview guide asked caregivers to rate their experiences with pain management on a scale of 0–10 (0 reflecting the most negative and 10 the most positive). Open-ended responses and shared narratives beyond the numerical rating were treated as qualitative data because they provided further clarification of the descriptive statistics. Only a subsample of participants from the larger study elaborated on their rating scores with detailed narratives.

Transcripts for caregivers with response narratives about pain were selected as a subset for qualitative analysis to identify and understand concerns related to pain management. Three members of the research team coded transcripts and used thematic consensus coding to identify emergent themes. Transcripts were read three times by all three coders. In the first review of the transcripts, themes were identified as all coders discussed each narrative together. All coders did a second reading of all transcripts and themes were combined, refined and finalized by consensus. Finally, transcripts were read for a third time as a final check.

Results

Descriptive statistics were generated on 146 caregivers who had completed final interviews during the first two years of the project. As of November 9, 2012, this represented 70% of the total 210 caregivers whose patient had died while in the trial. Fifty-six caregivers were lost to follow-up as we were unable to reach them following the death of their loved one or they were unwilling to be interviewed after the study. Eight interviews were not yet completed at the time of the analysis. Table 2 summarizes the demographics of both the total sample and the subsample used in the qualitative analysis.

To explore caregiver pain management concerns, we summarized caregiver ratings of their experiences with pain management between all caregivers and the subsample of caregivers who provided narrative comments regarding their pain management experiences (Table 3). On average, caregivers' mean rating of their personal knowledge and skills at the end of the hospice experience, their level of understanding and comfort with pain medications, rating of their loved ones' pain, and overall satisfaction with hospice management of the patient ranged between 7.5 and 9.0. Similarly, when asked to rate if they felt their loved one was at peace with dying, if they felt their loved one kept their dignity and self-respect, and the quality of death for their loved one, responses averaged between 8.0 and 8.7.

Understanding the Experiences

Eighty-one caregivers responded to questions with additional narratives related to pain management. A review of the narratives yielded 38 (47%) with clearly stated concerns about pain management. Analysis of the narratives for the 38 caregivers reflected five themes. Caregiver concerns included a) difficulties with the administration of medications, b) concerns regarding side effects of pain medications, c) insecurity with assessing pain, d) frustrations with poor communication among health care providers, and e) memories of unrelieved pain of loved ones. Table 4 summarizes each theme, its definition, frequency, and narratives supporting the theme.

Difficulties with Administration of Pain Medications—Nearly one-half of caregivers with concerns shared challenges they faced administering pain medication. These difficulties included problems finding the most effective medication, determining the correct dose, or struggling with scheduling or the delivery method (intravenous, sublingual, pills, patch, etc.). One caregiver reported:

> … it was more of like a trial and error. It probably is for a lot of people trial and error. But um, you know just talking to the nurses after, you know going through some series, we kind of found a method that worked the best. But I think in hindsight you always look back and say I wish I would have known that a little bit sooner. CG1-0208

Additionally, difficulties in administering medication often involved a patient's refusal or reluctance to take medications. One caregiver shared:

> … he just refused to take his medicine. They asked him and he said no. So they asked him again, I guess they thought he probably didn't remember the first time, and he said, I told you politely that I will not take that medicine. So he didn't take it. CG2-0201

Concerns Regarding Side Effects of Medication—The second most frequently discussed concern involved the side effects of pain medications. Drowsiness, confusion, sleep, and even a feeling that the medications hastened death were mentioned as concerns. One daughter discussed her worry about the sedating effects of morphine:

> And my Mom was also quite concerned about the start of morphine and stuff like that. I tend to have to agree with her. It's very hard for the person who is receiving the morphine to function. It's kind of like you are sedating them. Well, you ARE sedating them in a way. CG1-0327

Likewise, the confusion brought on by the pain medication concerned another caregiver:

> Well I, I never was very comfortable with that Roxanol because it made her, um, confused. And … if she got confused, too confused and stayed confused she'd have to go to the nursing home and I didn't want her to do that. CG2-0054

A few caregivers also shared concerns that the medication may have hastened the death of their loved one. One son stated it this way:

> … I’m not a doctor, and I don’t know if I helped her go faster or slower or what, hell I don’t know. CG2-0164

Another caregiver questioned the timing of her mother’s death and the use of morphine:

> It seemed like when we gave her morphine it made her sleep better, and then it took her on out…if I didn't give her that, what would happen? You understand what I'm trying to say? Would she still have died right off then? CG1-0026

Insecurity Assessing Pain—Several caregivers made statements indicating they were unsure of how to assess pain and were thus unable to know if their loved one experienced it. When asked if her loved one’s pain seemed to be controlled, one caregiver replied:

> How in the world would he be able to tell us if he was suffering any negative side effects, if it was causing him pain, if it was causing him headaches, if it was causing him to think that beetles were crawling up his legs? He had no, he had no speech ability--how can he tell us? CG1-0005

Caregivers were surprised by how the hospice staff could assess pain, especially in patients who were unable to communicate. A wife caring for her husband explained:

> It was amazing to me, the last day that the lady [nurse] was there. And she says, “He is not comfortable.” And so she was on the phone, letting the doctor know, “This isn't working. What else can we do?” And … she was telling me what she was seeing that made her realize that he was still in pain. He didn't talk to us at all, you know. Just visually … it's just a matter of knowledge. You gain it in time. CG2-0110

Communication Problems Among Providers—Caregivers expressed frustrations related to communication about pain management among their providers. This included hospice nurses, physicians, and nursing home nurses. Several talked about challenges in obtaining physician orders for medications or problems with communicating needs between themselves and a nurse or physician. One such example was a caregiver who stated:

> I told [the nurses], “If you are telling me that you cannot get hold of her doctor to get the medicines that she needs, I will call him personally.” “Oh, no, no, we will take care of it.” And so it would be in the morning that [the nurses] said they would take care of it and by afternoon I’m calling going “What have we found out?” And even prior to that when she would be hurting, [the nurses] would reorder medicine, and it would be a day or two before it would get here. And I’m going, you know, that’s a long time period. CG1-0093

Caregivers were likewise challenged by communication between nurses and physicians. A daughter shared her frustration:

> She [loved one] was still having quite a bit of pain, especially in her face, and uh, we kept increasing the morphine and we had talked to, to the nurses about getting the fentanyl patch, and the doctor didn't want to do it. And finally, we just had to … The doctor didn't want to do it, so the last couple days we had to continue to increase the morphine, and we got to where we were administering it every hour on the hour, and it was very difficult to get her to…then she [loved one] was reaching for her face and her hands. [She] was just sinking because she was in such pain… And we didn't get that stopped until we put on the fentanyl patch. CG2-0045

Memories of Unrelieved Pain—When asked about their loved one’s pain, 11% of concerned caregivers believed they were in pain when they died. The witnessing of this suffering, despite efforts to manage it, were disturbing memories for caregivers who felt unable to help. One caregiver described it this way:

> She was not at peace. Her eyes were closed. She didn't open them, but there were rapid eye movement underneath. So I know she was in pain. 01-0144

Similarly, a daughter who was caring for her mother remembered:

> I kept her in almost a drug-induced coma. But we would have to change her Depends and do different things like that and she literally would scream in pain and throw her arms up and her eyes would come right open. That's a very, very difficult thing to watch. 01-0286

Discussion

This study explores caregivers’ experience with pain in the hospice setting. Although hospice and palliative medicine have made significant advances in treating pain, managing it continues to be one of the most difficult challenges for both hospice and hospice caregivers (4, 34). The urgency of this challenge is reflected by the fact that more than one-third of hospice families have concerns about the amount of information they received regarding what to expect when the patient was dying (35) and that informal caregivers (46–94%) have concerns about reporting pain and using analgesics to manage pain (20, 34). The caregiver experiences described in this study indicate fears, knowledge gaps, inaccurate beliefs surrounding pain management, and unrelieved pain, all of which have the potential to impact caregiver satisfaction with hospice. In one study, 92% of caregivers were reported as agreeing with at least one statement that was considered a barrier to pain management (4).

The concerns voiced by these informal caregivers are similar in many ways to those of professional health care providers. Studies have shown that even trained, licensed health care professionals struggle with pain management, including fear of causing harm, challenges with assessment, and a lack of education (36). Therefore, it is not surprising that informal caregivers would experience similar concerns, as noted from these narratives.

Although statistical differences between the total sample and subsample were not found, the ratings indicate that the subsample had a somewhat more negative experience with pain management than the total sample. Overall, they rated their pain management knowledge and skills as less than desirable, with a mean of only 7.8 of 10 and their understanding of pain medications at 8.5. They also rated their knowledge and skills with pain management the lowest and their satisfaction with the hospice team pain management of their loved one as the highest. The second lowest mean rating was their understanding of pain medications followed by the overall rating of pain control. In comparing the total sample with the subsample of caregivers who shared narratives regarding their concerns, mean ratings on all questions were 0.3 to 0.7 points lower for caregivers who discussed pain. In the subsample, the lowest mean rating was also in response to caregiver knowledge and skill with pain management at the end of hospice, but the highest average rating was the response to their loved ones' dignity and self-respect. The second lowest average rating was in response to "if the loved one's pain was controlled."

Consistent with the literature, the additional narratives of the subsample provided examples of difficulties administering pain medication, including challenges in determining the correct type, dose, and delivery method (24, 37, 38). They also were concerned with many side effects, some questioning if the pain medication had hastened the end of life. Another challenge was evident in the insecurity shown in descriptions requiring the assessment of pain.

Additionally, caregivers reported frustrations when witnessing communication problems among various health professionals. This included struggles to obtain doctor's orders, change orders, or coordinate various pain management strategies. Finally, there were caregivers who shared difficult memories of their loved one's pain not being controlled, and more importantly, witnessing suffering.

These caregiver experiences demonstrate the important role they play in pain management and frustrations encountered as they attempt to care for a loved one. The lack of communication with members of the hospice and health care teams and a lack of education and understanding regarding pain medications highlight areas in need of improvement in hospice care (6). Many of these narratives illustrate an underlying voice of the caregivers as they manage the pain experienced by loved ones. This voice presents itself across themes pointing out that as caregivers focus on the physical pain of another, they themselves experience emotional pain requiring management as well (37). Fear, confusion, and guilt have a definite impact on their ability and willingness to comply with hospice pain management strategies. Emotional pain should be addressed both as a psychosocial issue and a medical challenge.

Although hospice is considered the gold standard of pain management, it is important to note that there is opportunity for improvement in managing, educating, and communicating about pain. Caregivers in this study reflected a concern, either real or perceived, that hospice patients were overmedicated, and in some cases that death may have been hastened by the use of pain medication. Findings from this study should challenge hospice providers to review the pain management of their patients as well as to examine the communication and education of hospice caregivers. Prior research has focused on barriers and challenges to caregiver education about pain management (39) and little work has examined systematic and professional barriers that may inhibit proper caregiver education. For example, this study suggests that communication among the hospice team and with other clinicians may impede the pain management process, leaving caregivers feeling helpless and unsure about quality pain management for their loved one.

The perception of how patient pain is managed may impact caregiver satisfaction with hospice care and the quality of their bereavement (28). If a bereaved caregiver believes their loved one's death was facilitated by overmedication, the caregiver is left to feel either guilt for having given too much medication or frustrated with the kind of care received. In either case, neither the caregiver nor the hospice are served well by these perceptions. Likewise, negative pain management experiences are carried forward and when the caregiver is again faced with the death of yet another loved one, these negative experiences and misperceptions could impact their ability to manage pain in the future.

One of the challenges for hospice programs may be identifying, understanding, and addressing the underlying beliefs misperceptions, and former experiences of caregivers that may impact compliance with pain control strategies and perceptions of pain. Without a formal assessment of caregiver beliefs and values, hospice providers may assume that caregivers are implementing the pain management plan and trusting in nurse and physician orders, when in fact that may not be the case. Although there is one instrument that measures caregiver perceptions of pain management (20), the psychometrics have not been extensively tested and its usefulness in practice is unknown.

Interviews were based on caregivers' perspectives and, therefore, are specifically limited to their personal experiences. Caution should be used when generalizing these findings to all hospice caregivers. Similarly, these findings may not be generalized to countries where hospice is largely an inpatient service as many of these respondents received care in their home. Diversity in hospice care populations continues to be a challenge; therefore, applying these findings to a more diverse population is problematic. Additionally, diversity in individual hospice programs and staff approaches to patient and caregiver education prevents generalization, as the effect of these varied efforts is unknown. Despite these limitations regarding generalization, these findings lend valuable insight into the hospice caregiving experience and its many challenges specific to pain management.

Implications

Confirming many recent findings regarding the struggles of caregivers in managing their loved ones pain (4, 40), these data lend specific examples to those struggles and have implications for hospice teams. The first implication is the importance of interdisciplinary communication and collaboration within the hospice team (6), including health care team members who are not part of the core hospice team, such as the attending physician and nursing home staff. Whereas each team member has a unique role, conflicts in these roles and in communication can impact caregiver and patient trust (6).

A second implication of this study is the impact that caregiver perceptions of pain can have on hospice satisfaction. These data provide examples of both positive and negative experiences with pain management and the caregivers discussion of hospice in relation to those experiences may be a clue into their future use of the service. Especially frustrating or guilt-laden memories may impact decisions regarding pain management in the future, should these caregivers find themselves in similar situations.

Finally, these data should be a challenge to hospices to screen and assess both caregiver and patient goals for care, including pain management. Although hospice caregivers and patients are treated as one unit of care, the assumptions made that both agree on goals of pain management may not be accurate. Without an understanding of both stakeholders' goals, the pain management may disappoint either the patient or the caregiver. Part of the role of the interdisciplinary team is to moderate these conflicts and facilitate a plan of care that is mutually agreeable within the family. This again speaks to the value of an interdisciplinary team for pain management.

Conclusion

Although the mean ratings computed for caregiver responses scored between 7 and 8, it should be noted that when it comes to something as important as pain management, the goal should be a 10. If nearly one in four, or one in five is having difficulty, there is room for improvement. It is also noteworthy that scores are clustered together, indicating that perceptions of caregivers on pain-related questions are consistent and similar. The narratives provide insight to and highlight the significance of concerns; this is particularly the case with regard to the emotional stress reported by caregivers. These findings should raise concern among hospice professionals, whose commitment is to the management of pain, including emotional pain, with a focus on both the patient and the family as the unit of care. These data clearly suggest hospice providers need to be more sensitive to perceptions held by caregivers regarding pain management. Effective planning for pain control must incorporate the values and beliefs not only of each patient, but also of the family caregiver. Additionally, recognizing emotional pain experienced by a caregiver who is asked to make an assessment of their loved one and administer an opioid medication accurately, while dealing with the sometimes overwhelming grief and accumulating losses in the relationship, needs specific attention and support from the hospice team. The treatment of what Cecily Saunders termed “total pain” must focus on the patient and the family, the physical and the emotional, and the spiritual and psychological pain.

Early in the admission while the patient is more likely to be able to communicate coherently, hospice staff would be well served to facilitate family discussions between caregivers and patients as part of the pain control plan. Likewise, hospices should systematically assess a caregiver’s perceptions and understanding of pain and provide structured education to assure that each medication’s dosage, potential side effects, and method of administration are clearly comprehended by the person responsible for implementing the pain strategy. Hospice staff members are advised to be aware of distress when communication fails between providers and work to improve relationships and shelter families from disagreements or frustrations so as not to fracture the delicate trust families need. Finally, staff should acknowledge the caregiver’s emotional stress related to pain management and intervene with support. Assessment tools evaluating patient and caregiver pain goals, as well as understanding perceptions related to pain management, would be a helpful addition to the hospice care toolkit.

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Table 1

Interview Guide

1. On a scale of 0–10 with 10 being the best possible situation, how would you rate your personal knowledge and skills related to pain management by the end of your service with hospice?

Prompt: Can you share an example of why you gave yourself this rating? A time when you feel you had sufficient knowledge, or perhaps a situation when you did not know something that you wish you had known?

2. On a scale of 0–10 with 10 being the best possible situation, how would you rate your understanding and comfort with your patient's pain medications by the end of your service with hospice?

Prompt: Which medications did you feel made you the most comfortable and which the least comfortable?

3. On a scale of 0–10 with 10 being the best possible situation, how would you rate your overall satisfaction with the hospice team's pain management of your patient by the end of your service with hospice?

Prompt: Can you share an example of how the hospice team focused on your loved ones pain?

4. Do you have any other thoughts or suggestions that might help us improve this experience for hospice patients or caregivers?

5. On a scale where 0 is not at all controlled and 10 is almost perfectly controlled, overall, did your loved one's pain appear to be controlled?

Prompt: Can you share a time when your loved ones pain was out of control, what was that like and how did it get resolved?

6. On a scale where 0 is not at all and 10 is almost perfectly at peace, overall, did your loved one appear to be at peace with dying?

Prompt: Was there anything in particular that led you to believe they were or not at peace?

7. On a scale where 0 is not at all and 10 is almost perfect, overall, did your loved one appear to keep his/her dignity and self-respect?

Prompt: Can you give an example?

8. On a scale where 0 is terrible and 10 is almost perfect, overall, how would you rate your loved one's quality of death?

Prompt: What observations or examples of how things went lead you to feel this way?

Table 2

Summary Caregiver Demographics

	Study Participants (N=146)		Subsample That Discussed Pain Concerns (N=38)	
Demographic Characteristic	***n***	***n*(%)**	***n***	***n*(%)**
Sex	146		38	
Female		113 (77.4%)		29 (76.3%)
Male		33 (22.6%)		9 (23.7%)
Age	142		38	
21–50 years		31 (21.8%)		7 (18.4%)
51–60 years		39 (27.5%)		11 (29.0%)
61–70 years		40 (28.2%)		10 (26.3%)
71 or more years		32 (22.5%)		10 (26.3%)
Race	146		38	
Caucasian		137 (93.8%)		36 (94.7%)
African American		7 (4.8%)		2 (5.3%)
Other		2 (1.3%)		0 (0.0%)
Education	144		38	
Less than high school		14 (9.7%)		2 (5.3%)
High school/GED		37 (25.7%)		8 (21.1%)
Some college/Trade school		31 (21.5%)		6 (15.8%)
Undergraduate degree		29 (20.1%)		8 (21.1%)
Graduate/Professional degree		28 (19.4%)		12 (31.6%)
Other/unknown		5 (3.5%)		2 (5.3%)
Marital Status	145		38	
Never married		9 (6.2%)		2 (5.3%)
Married		112 (77.2%)		30 (79.0%)
Separated		3 (2.1%)		2 (5.3%)
Divorced		12 (8.3%)		3 (7.9%)
Widowed		8 (5.5%)		1 (2.6%)
Other		1 (.7%)		
Relationship to Patient	146		38	
Spouse		43 (29.5%)		8 (21.1%)
Adult child		70 (47.9%)		19 (50.0%)
Sibling		5 (3.4%)		2 (5.3%)
In-law		10 (6.9%)		3 (7.9%)
Non- relative		5 (3.4%)		3 (7.9%)
Other-relative		8 (5.5%)		2 (5.3%)
Other/unknown		5 (3.4%)		1 (2.6%)
Caregiver Employment	140		37	
Full-time		35 (25.0%)		13 (35.2%)
Part-time		19 (13.6%)		4 (10.8%)

	Study Participants (N=146)		Subsample That Discussed Pain Concerns (N=38)	
Demographic Characteristic	***n***	***n*(%)**	***n***	***n*(%)**
Retired		53 (37.9%)		15 (40.5%)
Not employed		14 (10.0%)		2 (5.4%)
Other		19 (13.6%)		3 (8.1%)
Patient's Residence	146		38	
Patient's home		85 (58.2%)		20 (52.6%)
Nursing home		58 (39.7%)		17 (44.7%)
Other		3(2.1%)		1 (2.6%)
Resided with patient	146		38	
Yes		66 (45.2%)		14 (36.8%)
No		80 (54.8%)		24 (63.1%)

Table 3

Response to Close-Ended Questions Regarding the Hospice Pain Experience[a]

Question	All Participants n	Mean (SD)	Subsample n	Mean (SD)
How would you rate your personal knowledge and skills related to pain management by the end of your service with hospice?	145	7.8 (2.25)	38	7.7 (2.30)
How would you rate your understanding and comfort with your patient's pain medications by the end of your service with hospice?	144	8.5 (2.03)	38	7.9 (2.31)
How would you rate your overall satisfaction with the hospice team's pain management of your patient by the end of your service with hospice?	145	9.0 (1.90)	38	8.4 (1.94)
Overall did your loved one's pain appear to be controlled?	140	8.6 (1.92)	38	7.9 (2.20)
Overall, did your loved one appear to be at peace with dying?	136	8.7 (2.15)	37	8.0 (2.52)
Overall, did your loved one appear to keep his/her dignity and self-respect?	137	8.9 (1.63)	37	8.6 (1.89)
Overall, how would you rate your loved one's quality of death?	134	8.7 (2.06)	37	8.2 (2.30)

[a] All items were rated on a 0–10 scale, where 0=worst possible experience and 10=best possible experience.

Table 4

Final Themes, Definitions, Frequency in Subsample, and Examples of Narratives (*N*=38)

Theme	Definition	Frequency	Examples of Narratives
Difficulty in Administration	The narratives described various difficulties with the administration of pain medications. Examples included problems in finding the most effective medication, determining the correct doses, or struggling with scheduling or the delivery method (intravenous, sublingual, pills, patch, etc.). They also included difficulties related to psychosocial issues such as fatigue and a patient's refusal to comply.	18 (47%)	*Within an hour and a half he had received 3 doses of 3 different pain medicines… which were doubled…he thought it was sweet but he never woke up either. CG2 0314* *My sisters and I would stay [awake] and make sure she had pain control. We'd be up every hour. We slept in the bed with her sometimes …. When she knew we were there, we'd just lay down with her and go to sleep because it was any sleep. CG1-0286* *His own stubbornness caused him more pain than anything because he didn't want to take [pain medications] . 02-0314-0149*
Side Effects	Narratives discussed concerns about the side effects of medications, including drowsiness, confusion, sleep, or a feeling that the medications hastened the death of their loved one.	15 (37%)	*They say, make them comfortable But I think you have to prepare the family for the fact that by making them comfortable sometimes that means they're no longer able to respond and you have to weigh those things. CG1-0327* *I always felt like I never got to say goodbye to him. Like he was talking to me one day and the next day they started that [morphine] and he was gone. And that could have been a function of what was happening to him, but I think a lot of it was the morphine they, every 20 minutes, that they were giving him. CG2-0252* *I was told by the hospice that you're prepping the body for death But for the people who are living it's very disconcerting because it's almost like assisted suicide; the person's body sort of shuts down CG1-0327*
Communication	Narratives related to communication about pain management between providers including examples of conflict between providers and lapses in communication.	11 (29%)	*We had a doctor that didn't work with us so well. So in that sense [patient name] did not have the comfort that I felt he should have had, but it wasn't the hospice nurse. She was trying…I guess her side of it she did everything she could, but the doctor didn't. CG1 249* *But the nursing home staff didn't feel like they could [administer pain medication] without the permission of the hospice people And that took a day. And when we did finally get it, then they somehow didn't give it to he*

Theme	Definition	Frequency	Examples of Narratives
			Tuesday night. CG1-0014 *And so she called the doctor and suggested [another pain medication]. And he said, "Well the morphine will work if we get a high enough dose." And which they did, and it didn't work! But and maybe it's very expensive. I don't know. I don't want him to be using the most expensive drug in the world. But it may have been more expensive. I don't know why the doctor had that idea "Morphine will work." Because there are some people, morphine just doesn't work that well with And it certainly didn't work with him the first day. And so that was my only thing was that I felt like the doctor wasn't listening to the nurse very much. CG2-0110*
Pain Assessment	Statements indicated caregivers were unsure of how to assess their loved one's pain and were thus unable to know if their loved one experienced pain.	15 (37%)	*And once she was close to being comatose, you don't really have any sense of whether she was in pain or not. CG2-0252* *Once the medication was started, I think that he was probably in more pain than we realized sooner. And again, because he may not have been able to tell us about the pain and maybe he wasn't seen by his regular nurse right at first there might have been some problem … because, when I would ask him, he would say he was not in pain, but his actions indicated, the nurse was able to determine he was in pain. CG1-0281* *That last day, from that last 2 hours really, every 30 minutes they were giving him double doses of everything. You know, I just felt like that was kinda much … He didn't even know if he had any pain at that point. I mean seriously he didn't know where he was, he didn't know who he was. CG2 0314*
Unrelieved Pain	Narratives sharing memories of their loved one as in pain when they died or near their time of death.	4 (11%)	*She was still suffering with her back and her stomach right up to the very end. CG1-0142* *Well, I'll tell you what happened Three days before the day that it all started, she could no longer get out of bed and so she was bedbound, which meant to me that she was uncomfortable -- probably from laying around. And every time we moved her she would holler out, so we started giving her the morphine every hour around the clock. And then I suggested a fentanyl patch or something, and I was kind of told it would take too long to take effect [but] she lived three days after that, so 12 hours to take effect was appropriate*

Theme	Definition	Frequency	Examples of Narratives
			CG1-0286 *[Medication] controlled her pain so she wasn't moving, but if anybody moved her … then it was horrible pain. CG2-0195*