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Informal hospice caregiver pain management concerns: A qualitative study

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Abstract

Background—Informal, unpaid, family caregivers provide much hospice care in the United States. These caregivers suffer physically, psychologically, emotionally, and socially from the burden of caring. The most often identified area of caregiver burden is the management of end-of-life pain. However, little empirical evidence exists of effective interventions to help caregivers manage end-of-life pain, and issues surrounding caregiver pain management remain vague and undefined. Understanding these concerns will inform the design of effective caregiver interventions.

Aim—The purpose of this study was to describe and organize caregiver pain management challenges faced by home hospice caregivers of cancer patients.

Design—A content analysis of secondary data, namely, recordings of caregiver interviews, was conducted to describe pain management issues. These interviews were part of a larger clinical trial.

Setting/participants—Multiple sessions with 29 informal caregivers, of patients dying of cancer, were audio-recorded. Subjects were purposively selected from two hospice programs in the Northwestern United States. Caregivers of noncancer patients were excluded from the study sample.

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Conflict of interest

The authors declare that there is no conflict of interest.

Ethical approval

This study was reviewed and approved by the Human Subjects Division (HSD) Institutional Review Board of the University of Washington (IRB Nr. 33343).

Results—A framework of six major themes with subordinate subthemes was developed through a literature review and peer review. The framework was used to organize the content of 87 caregiver interviews. The six major themes identified in the analysis included Caregiver-Centric Issues, Caregiver Medication Skills and Knowledge Issues, End-of-Life Symptom Knowledge Issues, Communication and Teamwork Issues, Organizational Skill Issues, and *Patient-Centric Issues*.

Conclusion—This analysis clearly articulated and classified caregiver issues surrounding pain management. Future hospice research may benefit from the use of this analysis and framework in the development of tools to alleviate this major cause of caregiver burden.

Keywords

Caregivers; hospice care; pain; pain management; palliative care; end-of-life

Introduction

In the United States, an estimated 1.58 million patients received hospice care in 2010, three times as many patients who received care in 1998.¹ The median length of this end-of-life service, in 2010, was 19.7 days with an average of 67.4 days.¹ Care settings include stand-alone hospice facilities, long-term care facilities, hospitals, and the home. Informal caregivers, usually family members, provide the majority (66.7%) of hospice care in the home.^{1–3} While professional US hospice staff make regular home visits to access the patient and provide additional resources, traditionally, a family member acts as the primary hospice caregiver in the home. In the United States, these caregivers are referred to as the informal caregiver.¹ These unpaid, informal caregivers suffer physically, psychologically, emotionally, and socially from the burden of caring.^{4–5} The most often identified area of burden for caregivers is the management of their loved one's pain.^{6–9} While central themes of hospice include management of pain and symptoms as well as informal caregiver support,^{2,10} little empirical evidence exists of efficacious caregiver interventions to meet these goals.^{11–16} Moreover, even less research exists concerning interventions tailored to informal caregivers' concerns about managing pain at the end of life.^{17–19}

In the past three decades, several meta-analyses,^{14,15} including one Cochrane review,¹⁷ have illuminated this lack of efficacy and effectiveness of interventions in support of informal caregivers. Several informative literature reviews have also addressed the ineffectiveness of intervention in decreasing the burden of caregiving.^{7,12} Additionally, poor study quality and rigor has delayed effective interventions.^{7,12–18}

One meta-analysis¹⁵ of 78 studies from 1982 to 2001 was conducted to determine the effectiveness of interventions for family caregivers during end-of-life care. Outcome variables of interest in the studies included subjective well-being, sources of satisfaction from caregiving, ability/knowledge, symptoms of care receivers, depression, and burden. While several studies, in this meta-analysis, addressed respite care/adult day care and patient symptoms, no study dealt directly with caregiver pain management issues. Intervention characteristics varied greatly, variables were not consistent, and the study limitations were great. Another meta-analysis¹⁴ of 29 randomized clinical trials, conducted from 1983 to 2009, analyzed the efficacy of three types of caregiver interventions: psycho-educational, skills training, and therapeutic counseling. Most interventions were delivered to the patient-caregiver dyad but addressed only patient care directly. Intervention content for caregiver self-care was a secondary focus. In a Cochrane review,¹⁷ researchers attempted to assess the effects of interventions designed to improve the psychological and physical health of caregivers. Of 11 randomized clinical trials involving 1836 caregivers from 1984 to 2008,

only 9 interventions focused directly on the caregivers. There was only low-quality evidence to indicate that direct support of caregivers reduces psychological distress. Study limitations were unclear due to all trials underreporting research methodology. Additionally, the generalizability of the findings was limited due to small sample sizes. The authors concluded, as did researchers in another meta-analysis,¹⁵ that practitioners should inquire about specific caregiver concerns and address those concerns directly.

Only one study,¹⁹ from the above meta-analyses, addressed caregiver pain management concerns. In this study,¹⁹ researchers conducted a double-blinded, randomized controlled trial of 82 dying patients, and their caregivers, to evaluate the efficacy of a caregiver-guided pain management intervention. The intervention integrated educational information about cancer pain with a cognitive-behavioral pain coping strategy. While caregiver self-efficacy for helping patients manage pain significantly increased, patient pain levels were not significantly changed. Caregivers thought that they were managing pain better but, in fact, were not. The study protocol included teaching the coping strategy to both patients and caregivers for use in patient pain management; however, clear and specific caregiver pain management concerns were not incorporated in the caregiver intervention nor evaluated.

In one of very few empirical studies available, Oliver et al.²⁰ addressed caregiver perceptions of pain management as discussed in hospice interdisciplinary team (IDT) meetings. As active participants in team meetings with hospice staff, caregivers asked many questions about pain control. With caregivers present, over one-third of the team discussion focused on pain management. Without the caregivers present, no discussion of pain management took place.

Ineffective caregiver interventions and failure to address caregiver pain management concerns become especially challenging for caregivers of cancer patients as moderate to severe cancer pain is common, affecting 80%–93% of patients with advanced disease.^{21–23} Since cancer is the largest hospice admission diagnosis category (35.6%), with heart disease (14.3%) and unspecified debility (13%) a distant second and third,³ and with nearly half of these cancer patients suffering without adequate pain relief,²⁴ the pain management concerns contributing to caregiver burden are real and dominant.

Understanding and organizing issues surrounding this burden may help clarify caregiver needs and increase the effectiveness of interventions. To date, effective strategies and strong empirical research have been elusive. The purpose of this study was to describe and organize informal (family) caregiver pain management concerns during home hospice care of cancer patients in an attempt to clarify informal caregiver needs.

Methods

Design

A content analysis of data was conducted to describe pain management issues as discussed by 29 informal caregivers of cancer patients during home hospice care. The data were obtained from a mixed-methods clinical trial^{25–27} that explored the value of problem-solving therapy for hospice caregivers. In the parent study, three to four intervention sessions and exit interviews were conducted by trained research staff interventionists (nurse and social worker) and were audio-recorded. Caregivers were asked semistructured questions to identify the most pressing problems. These problems were then used for the problem-solving therapy. As the majority of caregivers identified pain as one of their top three concerns, this data set offered an opportunity to explore caregiver pain management issues in more depth. Detailed parent study methodology and results have been previously published.^{25–27}

Setting/participants

In the parent study, investigators purposively enrolled informal hospice caregivers from two home hospice programs in the Pacific Northwest area of the United States. Caregivers, referred to the primary study,^{25–27} met the following criteria: a family/informal caregiver of a patient enrolled in the outpatient hospice program, able to speak and read English, 18 years or older, without functional hearing loss or with a hearing aid that allows the participant to conduct conversations, access to a standard telephone line at home, mild or no cognitive impairment, and with at least a sixth-grade education. De-identified audio files from caregivers participating in the parent study,^{25–27} were used for this analysis. Caregivers of noncancer patients were excluded from the study sample.

Data analysis

For this content analysis, a peer-reviewed framework guided coding of audio-recorded caregiver discussions about problems related to pain management. The coding framework was designed by expanding a construct described by Lau and colleagues,^{28,29} and using topics identified in a literature review. The construct described by Lau and colleagues^{28,29} identified themes associated with caregivers and medication management. However, medication management is only one aspect of pain management during end-of-life care. Therefore, to include all aspects of caregiver pain management, we searched electronic databases, including MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, and Cochrane Database of Systematic Reviews, from 1980 to present. Terms searched singularly and in combination included pain, pain management, cancer, palliative care, caregiver, family caregiver, informal caregiver, end-of-life, EOL, hospice, opioid, medication, and barriers. Following citations in articles and snowballing identified other pertinent literature. Abstracts were reviewed, and appropriate studies were examined in full for empirical rigor.

Based on Lau and colleagues'^{28,29} construct, and research identified in the literature review, mutually exclusive themes and subthemes were identified, organized, and operationalized in the form of a codebook. Along with theme definitions, the codebook included inclusion criteria, exclusion criteria, and example quotes. Peer review and debriefing of the codebook ensured theme completeness and discreteness, while enhancing credibility and confirmability of the themes through external validation.

The qualitative software program, NVivo9, was used to code and analyze the audio recordings. Field notes collected from the primary study were part of the analysis and helped provide context for caregivers' pain management issues and helped with data triangulation.

Several techniques helped maximize study trustworthiness. To ensure intercoder reliability,^{30,31} four coders independently coded 18% of the audio recordings. Differences in coding were resolved through discussion, and 100% agreement was reached. This type of investigator triangulation helped ensure thematic validity, discreteness, and reliability. To ensure intracoder reliability (the consistent manner in which the primary researcher codes),^{32,33} the first author (M.K.) coded all the audio recordings and then recoded 28% of the audio recordings at a later time. Codes from the initial coding were compared with codes from the recoding. Only one discrepancy was identified and resolved in this process. An audit trail also helped enhance trustworthiness. A methodological decisions journal, documenting research decisions and justifications, and a self-reflective journal were kept as part of this audit trail. Memos, notes, and date and time stamps within the NVivo9 software were also a part of the audit trail.

Results

Demographics are summarized in Table 1. Caregivers' average age was 52 years, with the majority (58%) of caregivers between the ages of 51 and 70 years. Most caregivers were married, White, female, and living with the patient at the time of the study. Most had at least some college education, and several had masters or doctoral degrees. About half of the caregivers worked outside the home (55%), with seven caregivers (24%) retired. Patients' average age was 68 years. Patients ranged in age from 40 to 89 years, with over half of the patients older than 71 years. All patients identified race as White/Caucasian with the exception of one who identified as multiracial.

Twenty-nine caregivers generated 87 audio recordings, each between 20 and 60 min in length. Results were organized under six major themes. Subordinated themes (sub-themes) were associated with each of these major themes (Table 2). Twenty-eight of the 29 caregivers identified at least one pain management concern or theme. The majority of caregivers identified many themes. Thematic data saturation was achieved after coding 77 audio recordings. Two major themes, *Caregiver-Centric Issues* and *Communication and Teamwork Issues*, were most prevalent in the data with several subthemes identified more frequently than others were. These subthemes included Functional Issues, Concurrent Responsibilities, Caregiver Fears, and *Caregiver-Family Communication Issues*. Findings by themes are discussed in the following.

Major theme 1: Caregiver-Centric Issues

This major theme included issues interfering with the caregivers' ability to manage, treat, assess, and attend to a patient's pain. This theme contained the largest number of subthemes, and was identified by the most caregivers. *Functional Issues*, *Concurrent Responsibilities*, and *Caregiver Fears* were prominent subthemes identified under this major theme. The subtheme *Functional Issues* included physical and psychological limitations, preventing caregivers from adequately managing a patient's pain. For example, a caregiver suffering from arthritis found it difficult to open pain medication bottles. Depression was a *Functional Issue* that prevented several caregivers from managing loved one's pain. A young single mother, caring for her dying mother, as well as her active young child, articulated thoughts about depression. While her child was crying in the background, and through her own tears, she whispered,

I get kind of sad because I feel depressed all the time. I try to work out what I can do to feel better. But I don't know what to do. I just want to cry all the time cause my mom is sick. When I feel depressed, I just want to cry and I don't want to live. I want to die ...

Exhaustion was also noted by several caregivers as a *Functional Issue*. One caregiver admitted,

... you can't help when she gets up and it's 11:30 and you just got to bed and you're trying to sleep and you're awake and she gets up and it's 1:00 am and you're awake, and she gets up and it's 2:30 am and you're awake you know. I haven't done much work, I was going to go in today, but it became really difficult for me to just, I don't want to leave her alone either and she's not comfortable being with anybody else.

Another caregiver noted,

I was just exhausted. I couldn't hear him [the patient] call. I didn't know he needed more [pain] medicine.

Concurrent Responsibility Issues was also a subtheme under the *Caregiver-Centric Issues* major theme. This sub-theme recognized that caregivers had other ongoing responsibilities interfering with their ability to manage their loved one's pain. Responsibilities included work outside the home; family responsibilities, such as childcare; caring for other chronically ill family members; and financial responsibilities. Financial responsibilities prevented caregivers from affording pain treatments or medications. One caregiver of an older sibling dying of lung cancer best described the issue:

Well that's it ... it's not fair. I was ready to start screaming at people. I felt I was almost in tears ... he needs this stuff [pain medicine] ... and I don't have any money ... Dealing with insurance companies and different medicines the insurance company don't cover. But we had to get an appeal form from the insurance company and the appeal process takes 3 or 4 weeks to complete ... by that time, you know ... [his brother would be dead].

A different caregiver noted, crying,

I just can't do it, I just can't. I was up all night with [the patient] then worked all day and then was up all night the again. I just can't ...

Caregivers also identified their *Fear* as a subtheme under the *Caregiver-Centric Issues* major theme. *Caregiver Fear* of overmedicating or undermedicating was mentioned on many occasions. One elderly caregiver described his issues in the following way:

It is overwhelming ... And the moment I needed the morphine [for the patient] was the moment I realized we ran out. We had another morphine bottle, but it was in a different container, uhm, I couldn't find it and then it was in a different dispenser, it was an eyedropper thing and I never really used an eyedropper. And the level in the eyedropper kept going up and down and I didn't want to give her too much or too little. That was part of the call to hospice to determine how I was supposed to read the dropper.

Later in the audio tape, the caregiver admitted,

I panicked. I tried to figure out how to solve the problem, looking at one thing at a time. I ran around like a chicken with it's head cut off.

Another caregiver expressed *Fear* using the eyedropper to administer morphine:

She (dying loved-one) has chronic pain ... the morphine was in an unusual bottle and I was afraid to give her too much or too little and the dropper wasn't working. It was very scary.

Major theme 2: Medication Skills and Knowledge Issues

This major theme dealt with the caregiver's knowledge of medications, including pharmacology, polypharmacy, and drug side effects. For one exhausted caregiver, medication knowledge was inadequate. He was having difficulty sleeping, and wanted to solve the problem by taking some of the patient's Lorazepam:

We have a veritable trove of drugs here and one that I thought I could try is one half Lorazepam ... a sleep medication that I have never tried but it doesn't leave you with ill effects in the morning so I thought I might try that ...

Lorazepam is a treatment for anxiety not insomnia, not to mention the issue of taking another person's prescription medication. Another caregiver had difficulty identifying her mother's pain level and with the side effects of morphine:

It is difficult trying to identify a person's pain level when they have dementia. I ... sometimes don't know and then kind of wait and then, of course, when the nurse comes she says just give it [morphine] every 4 hours. I felt like I was sort of drugging her ... you know when you give somebody something and you see their tongue go to the side and you're not a nurse? That kinda stressed me out a bit, but I just watched her.

Major theme 3: End-of-Life Symptom Knowledge Issues

Under this major theme, common end-of-life symptoms were misperceived by caregivers as dire, requiring emergency treatment. This domain also included the caregiver's inability to treat end-of-life symptoms that increased the patient's pain load (*End-of-life Symptom Assessment Issues* subtheme). One caregiver, caring for a loved one with metastatic cancer, stated,

But even getting up to go to the bathroom she gets short of breath and then she starts to panic and we have to give her lorazepam to try to calm her down. And so now, like, a week ago it wasn't that big of a deal. But this weekend everything just changed.

Major theme 4: Communication and Teamwork Issues

Communication problems between caregivers and others, including family, friends, or health-care delivery systems were the hallmark of this domain. Many caregivers identified the subtheme *Caregiver–Family Communication Issues*. One caregiver had difficulty giving her dying mother pain medication because her father (patient's husband) kept interfering. They were barely speaking. She admitted,

I hate my father with a passion ... [he] screamed and yelled at me last night ... But, if he wasn't there, her [the patient] life would be so much easier. It could be such a better experience than what she will go through. At least I could give her the pain pills without sneaking them to her ... But the bigger picture is why would he let her suffer like this. Why keep her in this kind of agony. And his explanation, when I asked him was, well, I want to save them for when it is really bad and then we will give drugs.

Another caregiver described issues communicating with the *Healthcare Delivery System*:

For example, one of his [the patient's] meds is not covered by hospice, so we have to go to the pharmacy, the pharmacy had a problem with the insurance company, they were all calling the doctor, da dah, da dah, da dah, ... everyone was going crazy and I need this medicine for [the patient]. And they wanted to give us something else. It took us a month to get this right medicine ... it helps him sleep all night ... and so I'm just starting to pop! ... I can just see myself screaming at a lot of different people. I actually tried to call. Someone called from the agency, left a name and a number. I called them back and got bounced around to seven different people and finally I got to someone completely unrelated to the problem. I said, I cannot handle that!

Major theme 5: Organizational Skill Issues

A caregiver's lack of organizational skills may cause pain management problems particularly if the caregiver cannot remember when or how much pain medication was given (*Tracking/Recording Issues* subtheme). Additionally, the inability to store medications safely, away from children or in the refrigerator to protect medication potency, may cause issues. Failure to discard out-of-date medications may also create problems for patients as some

medications have toxic effects if used after expiration (*Safety Issues* sub-theme). As an example of the *Tracking/Recording Issues* subtheme, a mother caring for her dying adult daughter expressed frustration about the medication schedule:

When things were [getting bad], I had to get [my daughter] up at 7 a.m. to take her one pill before her 8 o'clock meds. She had to take some of them on an empty stomach, some of them with food, and there was a bunch of other stuff going on [vomiting] ... and so everything got cockeyed.

Another caregiver was having difficulty dosing the morphine to meet the pain needs of her father. She did not have a record of how much morphine she had given and was not sure how to explain to the nurse that she had been giving more than the nurse had suggested. She stated,

The nurse said "what you are giving him should be fine, give him 5 mgs of morphine and then 5 mgs more every half hour," I don't know how much we can give him but I would start out with 10 mgs ... and sometimes give over 20 mgs but over the course of what time? I guess that is a question we need to ask. Is that too much? It would be nice to have some endpoint parameters.

The *Safety Issue* subtheme addressed caregiver's inability to safely store and discard medication. This subtheme included medications being stolen, abused, or misused. It also included improper storage and disposal of equipment (e.g. syringes). After a crisis in identifying medications late at night, another caregiver stated,

We name everything in the bottles by what it does; instead of trying to remember a 42 letter medical name. We have a label maker so we put the label on the bottle. And then we put all the bottles in a box and if we move to another part of the house, we just take the whole box with us.

Major theme 6: Patient-Centric Issues

Most of the subthemes under this major theme are similar to those found under *Caregiver-Centric Issues* (major theme 1) with one difference: the inclusion of the subtheme *Pain Assessment Congruency Issues*. This subtheme involved caregivers either underestimating or overestimating pain as the patient perceived it. All examples of *Pain Assessment Congruency Issues* in the data had to do with patients hiding pain from caregivers. One daughter, caring for her mother, described the situation:

... she [dying mother] won't really talk about pain with us. And if she is in any pain she never tells us. She kinda suffers through it ... later on if we go to the doctors appt. then she'll say "oh yea, I was in a lot of pain," and we will say well why didn't you say anything? We couldn't help you? We'll ask her if she wants something [for pain] and she'll say no. Then she gets up and gets it [pain medication] and takes it ... [I feel] kinda helpless, how can I help her if she (inaudible and crying) won't let me help her?

Discussion

Family caregivers, of hospice cancer patients, described concerns surrounding their loved one's end-of-life pain management. Four subthemes, Functional Issues, Concurrent Responsibilities, Caregiver–Family Communication Issues, and *Caregiver Fears*, were the primary issues for caregivers as they struggled to provide effective pain management for their loved ones. *Functional Issues* and *Concurrent Responsibilities* were understandable in that the majority of caregivers were working women with other family responsibilities. Additionally, the majority of caregivers were older than 50 years, increasing the likelihood

of age-related functional impairments. While these themes were discussed most often and by the most caregivers, five subthemes were not mentioned in the data set.

Subthemes without representation included (1) Cognitive Literacy or Education-Level Issues, (2) English as a Second Language (ESL) Issues, (3) Cultural/Ethnic Norm Issues, (4) Personhood Issues–Medication Skills, and (5) Patient Mythical Belief Issues. Several reasons may account for these findings. The demographic distribution of the study sample was homogeneous in terms of race, culture, and ethnic distribution and mirrored the current national demographic distribution in hospice care.^{7,34} Given this homogeneity, ESL and cultural themes were not identified nor expected. Additionally, the caregivers enrolled in the parent study had to meet the inclusion criteria of being able to speak and read English, making ESL and Cultural/Ethnic Norm Issues even less likely. Since the majority of caregivers had at least a high school education, and a primary study inclusion criterion was mild or no cognitive impairment, Cognitive Literacy/Education-Level Issues were not identified.

The lack of patient input and feedback limits this study's findings. This may account for the underrepresentation of themes dependent on the patient's perspective as in the case of the *Medication Personhood* and *Patient Mythical Belief* subthemes. These two subthemes were concerned with patients' belief systems about pain and pain medicine. Without patients' input or feedback, identification of both issues proved difficult. Of note, the subthemes identified by the fewest number of caregivers were those in "Major theme 6: Patient-Centric Issues." Perhaps, lack of interview-specific questions about the patient and their pain experience, or lack of the patients' perspective contributed to underrepresentation of these themes.

Study limitations included the restrictions of a secondary data analysis (e.g. lack of subject validation and/or feedback), the relatively small sample size, and the lack of the patients' and professional hospice workers' perspectives. This study was also limited by sample homogeneity. Although reflective of the current US hospice caregiver population, this homogeneity prevents extrapolation of the findings to other ethnic or minority groups. Future research is needed to validate these themes and subthemes in ethnically and culturally diverse populations as well as other more heterogeneous populations. Construct validation in other cultures as well as with feedback and validation from caregivers, patients, and hospice professionals is a necessary next step.

Implications

Before health-care and hospice providers can meet the goal of helping caregivers with end-of-life pain management,^{6–9} the issues surrounding pain management must be clearly identified, described, and articulated. The framework we developed to organize these caregivers' experiences highlights the complex challenges that caregivers face and may be relevant, regardless of demographics or culture, as pain is a universal challenge in end-of-life cancer care. With further validation and testing, this construct may be useful in future caregiver education and training as well as in the individualization of that education. As identified in the meta-analysis by Sorensen et al.¹⁵ and a Cochrane review by Candy et al.,¹⁷ caregiver concerns should be identified first and then dealt with on an individual basis. Sorensen et al.¹⁵ also noted that the most effective way to address caregivers concerns was through increasing knowledge and ability.

Early identification of caregiver concerns and individualization of help for the family unit in managing end-of-life pain will be more important than ever in the coming years. As the baby boomers age, most with multiple complex disease comorbidities, more and more pressure will be put on the hospice system. Add to that the lack of adequately trained

hospice and palliative care providers,³⁵ workforce shortages,³⁶ and the high costs associated with end-of-life care,³⁷ a perfect storm will exist for deleterious effects on quality of hospice care and burden to family caregivers.

Family members caring for loved one's dying of cancer suffer from the burden of this care through the continuum of the death and dying process. A direct consequence of this caregiving role is the increased risk for physical and mental morbidity. Often, the psychological distress of the caregiver eclipses that of the dying loved one.³⁸ This distress may have a negative effect on the care provided and thus the well-being of the patient.³⁸ In a recent Provisional Clinical Opinion issued by the American Society of Clinical Oncology,³⁹ researchers acknowledged the continuous nature of caregiving and the caregiver burden. They called for early integration of palliative care into standard oncology care in an effort to reduce caregiver burden, improve quality of life, and increase patient satisfaction. This research clearly describes issues paramount to the increased burden of caregivers' experience and with further study may be extrapolated across the entire continuum of care to positively affect caregiver and patient.

Conclusion

This content analysis was conducted to illuminate the most often identified cause of caregiver burden: patient pain management issues. We identified Functional Issues, Concurrent Responsibilities, Caregiver Fears, and *Caregiver–Family Communication Issues* as the primary issues informal family caregivers contended with as they struggled to provide care for their dying loved ones. The comprehensive framework that we developed clearly articulated and classified caregiver issues surrounding pain management. The framework will need further validation and testing for future use in clinical settings to help individualize treatment and education. Once validated, hospice initiatives and future research may benefit from use of this framework in the design and implementation of tools to alleviate this major cause of caregiver burden.

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Table 1

Demographics—caregiver and patient.

Variable	Caregiver (n = 29)	Patient (n = 29)
Sex		
Male	11	9
Female	18	20
Race		
White/Caucasian	28	27
Missing data	1	1
Multiracial	NA	1
Ethnicity		
Hispanic	2	1
Non-Hispanic	27	27
Marital status		
Never married	4	2
Divorced	1	3
Married	24	19
Widowed	0	5
Age range		
50 years or less	6	4
51-70 years	17	10
71 years or greater	6	15
Mean Age	52	68
Residence		
Lives with patient	21	NA
Does not live with patient	8	NA
Primary study		
Withdrew	NA	1
Completed	NA	22
Death	NA	6
Education		
High school	4	NA
Some college	14	NA
Undergraduate	6	NA
Graduate	4	NA
Unknown	1	NA
Employment		
None outside home	2	NA
Full time	15	NA
Part time	1	NA
Retired	7	NA
Relationship with patient		

Variable	Caregiver (<i>n</i> = 29)	Patient (<i>n</i> = 29)
Spouse/partner	12	NA
Adult child	12	NA
Sibling	1	NA
Parent	3	NA
Other	1	NA

Table 2

Major themes and subthemes comprising content analysis coding.

Major themes and subthemes	Description
<i>Caregiver-Centric Issues</i>	
Functional Issues	Physical and/or psychological caregiver limitations and preventing adequate management of patient's pain (physical, psychological, social, and/or spiritual).
Cognitive Issues	
Cognitive Pathology Issues	Age-related as well as disease-related issues of memory, language, thinking, and judgment.
Cognitive Literacy or Education-Level Issues	Caregiver's formal education or lack thereof.
Cultural Issues	
ESL Issues	Inability of caregiver to communicate with patient, family, or health-care delivery system because of language barrier.
Cultural and Ethnic Norms	Cultural or ethnic norms that interfere with pain management during EOL care
Belief System Issues	
Religious/Ethical/Moral Beliefs	Caregiver's religious, moral, or ethical beliefs which are at odds with patient's beliefs or hospice philosophy.
Mythical Beliefs	Caregiver's beliefs not based in scientific evidence.
Caregiver Fears	Caregiver's worries and fears may prevent caregiver from acting in a prudent and timely manner to relieve patient's pain.
Caregiver Self-efficacy/Optimism/Self-Confidence	Caregiver's negative self-efficacy in making decisions correlates with inability to manage pain.
Duration/Extent of Caregiving and Proximity to Death	Duration of care and requirements, as well as proximity to death may interfere with pain management.
Previous Life Experiences	Negative or lack of experience with pain management.
Concurrent Responsibilities	Caregiver's other ongoing responsibilities including work, family, and financial responsibilities.
<i>Caregiver Medication Skills and Knowledge Issues</i>	
Pharmacology Knowledge Issues	
Polypharmacy Issues	Complex medication interactions may inhibit pain management. Lack of working knowledge and skill with medicines may inhibit pain management.
Pain Medication Side Effect Issues	Side effects of pain medications and the potential for caregiver to change pain management based on these side effects.
Medication Administration Issues	Caregiver's inability to administer different forms of medicines in safe manner: pill, liquid, sublingual, transdermal, and so on.
Pain Assessment Issues	Caregiver's inability to adequately monitor, assess, treat, and reassess pain.
Personhood Issues	Ability to understand patient's medication management wishes but caregiver refuses to act in accordance with those wishes.
<i>EOL Symptom Knowledge Issues</i>	
Common EOL Symptom Management	Expected events in hospice are not considered crisis by hospice personnel but may be perceived as such by caregivers.
Symptom Assessment Issues	Caregiver lacks skill to assess, treat, monitor, and reassess EOL symptoms.
Personhood Issues	Caregiver understands patient's wishes but refuses to act in accordance with those wishes.
<i>Communication and Teamwork Issues</i>	

Major themes and subthemes	Description
Caregiver Patient Communication Issues	Breakdown in communication and teamwork between caregiver and patient.
Caregiver Health-Care Delivery System Communication Issues	Communication and teamwork breakdown between caregiver and hired help, hospice providers, pharmacist, primary provider, insurance company, equipment delivery service, and so on.
Caregiver-Family Communication Issues	Caregiver has communication/teamwork conflicts with other family members taking time and attention away from pain management.
Caregiver Support Network Communication Issues	Caregiver lacks adequate support network (i.e. respite care not available).
<i>Organizational Skill Issues</i>	
Tracking and Recording Issues	Caregiver's inability to track and/or record medications or treatments.
Safety Issues	Caregiver's inability to safely store and discard medication, equipment, and so on to prevent theft or misuse.
<i>Patient-Centric Issues</i>	
Pain Assessment Congruency Issues	Caregiver overestimates or underestimates patient's pain
Psychological Well-Being Issues	Patient's negative psychological health influences pain reporting.
Nutrition and Hydration Issues	Dehydration, decreased BMI, and overall wasting affects pain management.
Inability to Verbalize Pain	Patient unable to verbalize pain makes pain assessment difficult for caregivers.
Negative Existential View of Life	Patient has overall negative view of life as well as negative daily quality of life.
<i>Patient's Belief System Issues</i>	
Patient's Mythical Beliefs	Patient's beliefs not based on facts or scientific evidence.
Patient's Religious/Ethical/Moral Beliefs	Patient's religious, moral, or ethical beliefs are at odds with caregiver's beliefs or hospice philosophy.
Patient's Fears	Patient's fears surrounding EOL or pain that may interfere with pain management.

EOL: end-of-life; BMI: body mass index; ESL: English as a Second Language.