Published in final edited form as:

Am J Hosp Palliat Care. 2018 April ; 35(4): 601–611. doi:10.1177/1049909117729477.

Pain Management Concerns From the Hospice Family Caregivers' Perspective

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Abstract

Background: Pain management is a challenging task for family caregivers in home hospice care. However, there are limited studies that examine the challenges regarding pain management in hospice care from family caregivers' perspectives.

Objectives: To identify the challenges related to pain management faced by family caregivers in hospice care and to examine the validity of an existing framework that outlines pain management challenges for hospice family caregivers.

Design: We conducted a theory-driven, deductive content analysis of secondary data obtained from hospice family caregivers' interviews from a randomized clinical trial.

Setting/Participants: We included baseline interviews of 15 hospice caregivers of patients from hospice agencies in the States of Washington. The majority of the participants were white and female caregivers. They were spouse/partner or adult child living with the patient.

Results: The study identified 5 out of the 6 major themes in the original framework and confirmed that hospice family caregivers face a variety of challenges: caregiver-centric issues, caregiver's medication skills and knowledge, communication and teamwork, organizational skill, and patient-centric issues. A couple of the subthemes in the original framework were not present

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Declaration of Conflicting Interests

The authors declared no potential conflict of interest with respect to the research, authorship, and/or publication of this article.

in our findings. We also expanded the original framework by adding 1 subtheme and revised 2 definitions in the original framework.

Conclusion: The study provided an investigation on hospice family caregivers' difficulties in pain management. The results can inform health-care providers and researchers of family caregivers' challenges and provide insights for future designs of educational tools targeting pain management strategies, so that family caregivers can perform pain management effectively at home.

Keywords

pain management; pain medications; family caregivers; carers; hospice care; end-of-life care

Introduction

More than 1.6 million Americans received hospice services in 2014, and about 60% of them received these services at home or place of residence.¹ Hospice care emphasizes the deployment of an interdisciplinary care team to support patients and their family in comfort care, pain control, symptom management, and spiritual needs.¹ Statistics have shown that more than 50% of patients with terminal illness experience pain in the end-of-life stage.^{2–5} Studies also found that the patients' pain in end-of-life care was undertreated.^{6,7} Factors that lead to pain being under-treated include patients and family caregivers' fear and beliefs in pain management and health-care providers' no recognition of pain and fear of doing harm.² Essential to home hospice care are family caregivers who assist patients in their activities of daily living, symptom management, and clinical tasks. Among all the tasks, pain management has been rated as one of the difficult tasks for family caregivers.^{8–10} Pain management makes care-givers felt stressed and frustrated⁸ and affects family caregivers' quality of life.¹¹ Effective pain management would decrease patients' pain and ease family caregivers' burden.¹²

Pain management is a multifaceted process for family care-givers including pain assessment, medication administration and management, outcomes evaluation, and communication with health-care providers.^{13,14} Previous studies have identified family caregivers' barriers to effective pain management including inadequate knowledge and assessment skills in pain management^{13,15,16}; concerns about side effects, addiction, and tolerance of pain medications^{17,18}; discrepancy in perceptions and experience of pain between patients and family^{19,20}; and poor communication with the health-care team.^{9–10,21} However, the majority of the published studies have focused primarily on a cancer population. There are limited studies examining challenges related to pain management in end-of-life care (for all terminal illnesses) from family caregivers' perspectives.

Many patients need medications to relieve pain and symptoms in the end-of-life care. To further understand the medication management skills for family caregivers in hospice care, Lau et al conducted a qualitative study to propose a theoretical construct of family caregivers' skills in medication management in hospice care.¹⁶ The study interviewed hospice providers and family caregivers of older patients in the Chicago metropolitan area to identify effective medication management skills to relieve symptoms including the

following: (1) team-work (coordinate with hospice providers and with other family or hired caregivers), (2) organization (acquire, store, track, and discard medications), (3) symptom knowledge (recognize and interpret common symptoms), (4) medication knowledge (understand the basics of pharmacology and medication administration), and (5) personhood skills (understand and respond to the patient's needs).¹⁶ Lau's framework was validated and further expanded by Tjia and colleagues.²² As medication management is one of the aspects of pain management in end-of-life care, Kelley and colleagues conducted a literature review and a content analysis of hospice caregivers' interviews to expand the "Family Caregivers' Skills in Medication Management" framework by Lau et al to the context of hospice family caregivers' pain management.²³ The content analysis included interviews of 29 hospice family caregivers of patients with cancer from a clinical trial (NINR, Grant Nr. R21 NR010744). The major themes in the framework were (1) caregiver-centric issues (eg, function, cognition, beliefs), (2) caregiver's medication skills and knowledge (eg, knowledge, medication administration, pain assessment), (3) end-of-life symptom knowledge, (4) communication and teamwork, (5) organizational skill, and (6) patient-centric issues (eg, pain assessment congruency, psychological well-being, inability to verbalize pain).²³ In the framework, each major theme contains several subthemes, and each theme has its own definitions and examples (see Table 1). Compared to Lau's "Family Caregivers' Skills in Medication Management" framework, Kelley's "Informal Hospice Caregiver Pain Management Concerns" framework categorized specific themes regarding caregiver and patient factors.

There are limited studies that focused on pain management in the home hospice care setting. Kelley's framework built on and expanded the previous literature on family caregivers' pain management. The framework provides an overview of potential factors that could impede caregivers' pain management in the hospice setting, but to date has not been validated in any follow-up studies. Also, Kelley's study recruited hospice family caregivers of patients with a diagnosis of cancer. Hence, the present study aimed to identify the challenges related to pain management faced by hospice family caregivers of patients with diverse diagnoses and examine whether Kelley's framework could be applied to hospice caregivers of patients other than a diagnosis of cancer. Participants in the present study were different from Kelley's study and had a variety of diagnoses. In 2014, more than 60% of patients enrolled in an outpatient hospice program had a noncancer diagnosis.¹ As the hospice patient demographics are changing and the number of patients with a noncancer diagnosis is rising, the purpose of this study is to explore family caregivers' challenges when dealing with pain management in hospice care as well as to examine the validity of Kelley's framework as an applicable tool that can be used to better examine and address caregivers' pain management challenges in the hospice setting. Thus, health-care providers and researchers would understand family caregivers' challenges and pursue strategies to ensure that family caregivers can perform pain management accurately and effectively at home.

Methods

Study Design

We conducted a theory-driven, deductive content analysis of secondary data obtained from a recently completed 5-year randomized clinical trial titled “A Problem-Solving Therapy Intervention for Hospice Caregivers.” The original study examined the effects of a problem-solving therapy intervention delivered through technology platforms for hospice family caregivers (NINR, Grant Nr. R01NR012213, principal investigator [PI]: G.D.). The study was approved by the institutional review board at the University of Washington.

Setting and Participants

The original study enrolled 514 hospice caregivers of patients with diverse diagnoses from hospice agencies in the states of Washington. The inclusion criteria were as follows: caregiving for patients enrolled in the outpatient hospice program, ability to speak English, no severe functional or cognitive impairment, and access to a phone line at home. The hospice caregivers were interviewed by experienced hospice researchers with a social worker background following a standardized interview manual to explore caregivers’ most pressing life or caregiving challenges and solve their challenges using problem-solving skills. The caregivers were interviewed several times throughout their study participation, namely, at day 5 postadmission to hospice (baseline), day 11, and day 16. All interviews were audiotaped. Because the median length of hospice service nationally in 2014 was only 17.4 days,¹ the parent study interviewed family caregivers at the early stage of the hospice admission. Although they were in the early stage of the hospice admission, most of the caregivers in the present study had been taking care of their care recipient for more than 1 year (66.6%).

Procedure and Analysis

The purpose of the present study is to identify the challenges related to pain management faced by family caregivers in hospice care and to examine the validity of Kelley’s framework. Therefore, this study only analyzed the baseline (preintervention) interviews of the hospice family caregivers who identified pain management as their major caregiving challenge in the parent study. The inclusion criterion of interview recordings was that family caregivers discussed their pain management difficulties with the interventionist in their baseline interview. The first author (N-C.C.) listened and screened 514 participants’ baseline interview recordings to verify their eligibility. Fifteen family caregivers’ interviews were included and transcribed verbatim by professional transcriptionists of an audio transcription company. The length of all interviews is 540 minutes and 40 seconds, and the mean length of each interview is 38 minutes and 29 seconds.

The interviews were analyzed following Kelley’s “Informal Hospice Caregiver Pain Management Concerns” framework.²³ The analysis process followed a standardized protocol for qualitative content analysis.²⁴ The first author (N-C.C.) listened to and verified all the transcripts. Two authors (N-C.C. and G.D.) perused the themes, definitions, and examples in Kelley’s framework. Two authors (N-C.C. and G.D.) listened to all audio recordings to be familiar with the interviews. In the framework, all major themes and

subthemes have their own definitions and examples (see Table 1). In each transcript, the first author used line-by-line coding in Microsoft Word document to code sentences related to challenges of pain management following Kelley's framework and assigned sentences to their corresponding themes when they fit a particular theme's definition and description in the original framework. All themes, definitions, and quotes were organized into a table and reviewed by 2 authors (N-C.C. and G.D.). The interrater agreement rate was 71%. Two authors (N-C.C. and G.D.) reviewed each theme, definition, and quote iteratively to ensure compatibility and accuracy. The quotes under the same theme were constantly compared to ensure fitness and consistency. Any different decisions between the 2 authors were discussed until reaching 100% consensus during weekly research meetings over 6 months. For sentences that did not fit into any theme and definition in the original framework, the 2 authors created new themes or modified the original themes in the original framework. Two coinvestigators of the parent study also did peer debriefing of the results of the analysis.²⁵

The first author (N-C.C.) verified the transcript before analyzing the data, maintained an audit trail, and asked peer debriefing to protect trustworthiness.²⁵ The second author (G.D.) who had prolonged engagement in hospice research for 15 years was the primary investigator of the parent study and one of the developers of the original framework. He was familiar with the data and the framework and guided the analysis.

Results

Fifteen family caregivers' interviews were analyzed in our study. The majority of the participants were white (93.3%), female (53.3%), married (80%), and had a college degree (60%). Most of them were spouse/partner (40%) or adult children (33.3%) living with their loved one and had provided caregiving for more than 20 hours weekly (86.7%). They provided caregiving for less than 1 year (33%), 1 to 3 years (33.3%), or more than 3 years (33.3%). Caregivers' demographics are listed in Table 2 and individual caregiver's profiles in Table 3.

There were 6 major themes and 35 subthemes in Kelley's framework (see Table 1). This analysis identified 5 out of the 6 major themes in the original framework, except for end-of-life symptom management. Some subthemes in the original framework were not present in our data: caregivers' cognition, culture, pain medication side effects, caregivers' medication administration, patient-caregiver communication, caregiver-family communication, tracking and recording medication, patients' psychological well-being, patients' beliefs, and patient's nutrition and hydration. We also updated the framework based on the findings which added 1 new subtheme "physical well-being issues" into the patient-centric issues and expanded the definitions of 2 subthemes, caregivers' functional issues and caregiver support network (see Table 4 for updated framework, definitions, and exemplars). The findings are summarized below.

Major Theme: Caregiver-Centric Issues

This theme addressed issues related to family caregivers that might interfere with the caregiver's ability to manage, treat, assess, and attend to the patient's pain.²³ The major theme included subthemes: function, cognition, culture, belief system, self-efficacy, duration

of caregiving and proximity to death, previous life experiences, and concurrent responsibilities.²³

The analysis identified most of the subthemes under this major theme except caregivers' cognitive and cultural issues. These two subthemes were not identified in our analysis because of the inclusion criteria of the study, which were family caregivers who had no severe functional or cognitive impairment and spoke English. Among identified themes, family caregivers frequently mentioned their functional issues (n = 4) and beliefs (n = 8) affected their pain management strategies for patients.

Functional issue was defined as family caregivers' physical and/or psychological limitations that hinder them from adequately managing a patient's pain.²³ In this analysis, some caregivers claimed that the difficulty of pain management coupled with the burden from caregiving caused them to feel physically and psychologically exhausted, which interfered with their ability to manage the patient's care and pain. One caregiver shared her experience: "Just physical and mental exhaustion on all of [the family members were overwhelming] ... I over-medicated [my husband]. I didn't care at that point." The caregiver also described her situation, "I was getting so little sleep. I'm not sure if I could make a rational decision." (P1) Hence, we revised the definition of the functional issues as "physical and/or psychological caregiver limitations, *burden, or exhaustion* preventing adequate management of patient's pain."

Belief system included caregiver's religious/moral/ethical beliefs, mythical belief, or fear which might influence care-givers' philosophy in managing patients' pain.²³ One daughter caregiver struggled with the belief that pain medication might hasten her mother's death, "I wanted my mother to die, [but] I really didn't want to be giving that pain medication to her out of a desire to have her die. That idea felt really awful to me and felt like an intent to do something that wasn't OK ... It was a real moral dilemma." (P12)

Some caregivers feared the potential side effects of morphine, so they were hesitant in giving patients morphine. One caregiver stated that she would not want to give her care recipient pain medications, "I'm not looking forward to giving him morphine and things like that to make him more comfortable and dope him up. [Pain medications] are going to make him not so coherent. I'm going to feel like I'm assisting him in dying." (P5)

Major Theme: Caregiver's Medication Skills and Knowledge

This theme pertained to caregivers' knowledge of medication and skills to assess pain.²³ The subthemes were caregivers' pharmacology knowledge issues (polypharmacy issues and pain medication side effect issues), medication administration issues, pain assessment issues, and personhood issues.²³ The analysis identified most of the subthemes but not pain medication side effect issues and medication administration issues. Among the subthemes, pharmacological knowledge (n = 2) and pain assessment (n = 5) was most frequently addressed by participants.

Pharmacological knowledge referred to caregivers' knowledge of medications and the basic understanding of how medications work.²³ Some caregivers felt that they were not confident

and did not have adequate medication knowledge to manage pain. One caregiver recalled that sometimes she had to call hospice nurses for instructions on how to administer additional pain medication, “the nurse told me, No, you can’t give him morphine. Because morphine and whatever it is, they’re similar. Just give one more oxycodone.” (P3)

Pain assessment issues dealt with caregivers’ skills to assess and treat pain adequately. Several caregivers discussed the challenge in assessing pain accurately, especially for patients who cannot express their own pain. One daughter caregiver described it was very difficult to assess pain for her mother with dementia, “[My mother] could be tired, have a muscle ache, or have anything. It’s hard to know whether she really had pain or not.” (P7)

Major Theme: Communication and Teamwork Issues

This theme dealt with issues surrounding teamwork and communication among patients, family caregivers, and health-care providers that may make pain management difficult for the caregiver. The subthemes were caregiver–patient communication, caregiver–family communication, caregiver–health-care system communication, and caregiver support network communication issues.²³ The family caregivers in the analysis identified 2 subthemes: caregiver–health-care system issues (n = 4) and caregiver support network communication issues (n = 3).

Caregiver–health-care system communication addressed communication issues between health-care team and family caregivers.²³ The communication between health-care team and caregivers sometimes was not timely or efficient, which might affect effective pain management. A couple of caregivers stated that they did not obtain sufficient and timely pain management guidance from health-care providers. One caregiver described her experience when the patient experienced breakthrough pain, and she really needed pain medication guidance from health-care providers: “[Health-care providers] were taking forever to call me back. And I thought, ‘[the patient] is in pain.’ I think I was pestering them. A half an hour is a long time to wait when you are in pain and it hurts you.” (P3)

Caregiver support network communication issues addressed caregivers’ need for a support network. Caregivers’ lack of social support could negatively affect caregivers’ ability to manage pain. The family caregivers in this study highlighted that they lacked the necessary support and needed self-care and personal time, so we revised the definition as “caregivers lack adequate support network and *need self-care and personal time*.”

Major Theme: Organizational Skill Issues

The major theme dealt with caregivers’ skills to track and record pain medications as well as safely store and discard pain medications.²³ The subthemes were tracking and recording issues and safety issues.²³

Our family caregivers only identified safety issues (n = 1). The inability to store or discard medications safely could cause medication safety issues. One caregiver mentioned that they did not know how to discard excess morphine: “We went to 3 large drugstores and a police station, and they wouldn’t take [morphine] ... My daughter took all the labels off and put [morphine] into 4 different trash cans.” (P6)

Major Theme: Patient-Centric Issues

Patients' well-being and beliefs toward end-of-life care and pain management can affect caregivers in assessing and managing patients' pain effectively. The subthemes included pain assessment congruency, psychological well-being, inability to verbalize pain, negative existential view of life, and patients' beliefs.²³

The family caregivers in this study identified most of the subthemes under this major theme except patients' psychological well-being, nutrition and hydration, and patients' beliefs. Patients' inability to verbalize pain is the most discussed topic (n = 5). Cognitively impaired patients had limited ability to express their pain. Some caregivers may be unable to assess pain based on patients' nonverbal cues, so the pain may be overtreated or undertreated. One caregiver used a 10-point pain scale to assess his wife's pain, but it was still difficult, "I asked 'Which number?' [My wife] hesitated because she couldn't say or pinpoint a number [on a 10-point pain scale]." (P13)

The family caregivers also expressed that patients' physical deterioration might increase the levels of pain and make the family caregiver difficult to manage pain effectively. One caregiver described that her husband suffered multiple chronic conditions for years and was physically and psychologically exhausted, "He was in severe pain and up all the time. He wanted me to kill him." (P1) This caregiver sometimes over-medicated her husband because she was tired and did not want the patient suffering. We added "patients' physical well-being" as a subtheme into this major theme. The definition of this subtheme was "A patient's physical deterioration might increase the levels of pain and make the family caregiver difficult to manage pain effectively."

Discussion

The study is the first study to examine the validity of Kelley's framework. The data validated the applicability and relevance of Kelley's overall framework and confirmed that hospice family caregivers faced a wide variety of issues that interfered with pain management. The original study included hospice family caregivers of patients with a diagnosis of cancer, but our study recruited family caregivers of patients with several diagnoses. Some of the subthemes were not identified in the present analysis because of a small and homogenous sample and the inclusion criteria (caregivers have no severe cognitive impairment and speak English). Future study can conduct a longitudinal investigation and include a large sample size of family care-givers and patients with more diverse backgrounds to examine the applicability of the original framework.

Previous studies have demonstrated that caregivers' knowledge, beliefs, experience, and self-efficacy could interfere with family caregivers' pain management for patients.^{8,26,27} Relatively, few studies discussed caregiver-centric issues such as caregivers' function, cognition, concurrent responsibilities, and patient-centric issues.^{14,16} The study confirmed Kelley's framework that caregiver-centric and patient-centric issues can affect effective pain management. The study provides insights to health-care providers and researchers that family caregivers encounter a number of challenges, and there is a need to develop guidelines or educational tools to support family care-givers, ensuring that family caregivers

can manage patients' pain effectively at home. Issues most frequently raised by the family caregivers in this study were caregiver's functional issues, caregiver's beliefs, pain assessment issues, caregiver-health-care system communication, and patients' inability to verbalize pain.

Caregivers' Functional Issues

Caregivers expressed that fatigue caused by caregiving coupled with pain management burden deteriorated their own physical and psychological well-being, which affected their ability to take care of their care recipient or perform concurrent responsibilities. The finding was similar to one of Lau' studies that caregivers' fatigue impeded their ability to make thoughtful decisions and give correct dosages of pain medications.¹⁴ In this study, most of the caregivers lived with their care recipient and provided more than 20 hours of caregiving per week for more than 1 year. This finding demonstrated the importance of providing respite care information or resources to family care-givers to decrease their caregiving burden. During each visit, health-care providers may observe or ask family caregivers the impact of caregiving on their health, personal life, and work. As the goal of hospice care is to support patients and their family caregivers as a whole,¹ caregivers need to be cared for as well. When needed, health-care providers can refer the care-giver to a social worker, a volunteer coordinator, a counselor, or a financial assistance program.

Caregivers' Beliefs

Caregivers' fears and beliefs of pain medications were one of the main issues that hindered effective pain management. Some caregivers viewed administering pain medications as assisted suicide or hastening death, so they were unwilling to administer pain medications to their care recipient. Some caregivers preferred their care recipient alert rather than painless and sedated. The findings were consistent with previous studies that care-givers' fears of medication addictions and side effects can affect caregivers' pain management.^{13,15,17} The findings suggested that it is critical to have an open and early discussion pertaining to patients' end-of-life wishes and goals of pain management among stakeholders. At the same time, the health-care providers can explore caregivers and patients' acceptance of the use of pain medications and dispel any misconceptions about pain management in early stages of the discussion. Furthermore, health-care providers can express willingness to support patients and caregivers in carrying out patients' expectations of end-of-life care. The findings showed that the general public's stigma of morphine and other opiates associating addiction and death still remains. Opioids are an essential part of symptom management in end-of-life care to treat nonmalignant and neuropathic pain and ease shortness of breath.^{28,29} Opiate addiction and hastening death only happen in opiate abuse and overdose. Future study can propose strategies to increase the awareness of the benefits of opiates use in end-of-life care and reduce the stigma of opiates.

Caregiver–Health-Care System Communication

Another issue identified in our study was the delayed assistance provided by hospice services. Some family caregivers tried to ask for hospice professionals' advice via 24-hour hospice service, but the help was not timely or clear enough to solve their problems. Effective and open communication with health-care providers is a major challenge in end-of-

life care, and there is a need to create more efficient communication avenues for family caregivers. One way to solve this issue is to provide adequate pain management education during each visit, so the need to call for help is diminished. Also, hospice agencies can be proactive and schedule after-hour check-in calls for family caregivers who are struggling with pain medications to ensure that family caregivers get the support they need. Other strategies include creating a plan for breakthrough pain in advance for patients and family caregivers, inviting family caregivers to join interdisciplinary team meeting,² and using video or other telehealth technology to remotely assess patients' condition.³⁰

Pain Management Knowledge and Pain Assessment Skills

For some caregivers, their insufficient medication skills and knowledge impeded them from managing pain effectively. Some participants claimed that they sometimes had to call hospice providers to confirm the correct medications and dosage before giving pain medications. Health-care providers follow pain management guidelines to manage pain, and it is necessary for health-care providers to ensure that family care-givers are able to perform and follow the same guidelines. Health-care providers can provide family caregivers written educational materials, ask family caregivers to take notes and repeat those instructions, and follow up on family caregivers' pain management progress.

Face-to-face pain management education sessions could improve caregivers' knowledge, belief, and outcomes and reduce patients' pain.^{31–34} Cagle and colleagues conducted a pilot study to test the efficacy of a tailored educational brochure for family caregivers and patients.³⁵ The results found that caregivers had better knowledge and fewer concerns about pain and pain medications and lower pain in patients.³⁵ Cape-well et al conducted a feasibility study to examine a 6-minute DVD-based educational intervention for patients with cancer and their caregivers in palliative care.³⁶ The results showed that the DVD-based educational intervention improved patients' pain most significantly in the first week, but no further improvements were shown at the fourth week.³⁵ Future research is need to focus on examining the long-term effects and efficient ways to deliver educational materials to patients and their family caregivers.³⁶

Patients' poor quality of life, fears, or beliefs can complicate caregiving and pain management. Some patients in end-of-life care experienced a rapid decline in their physical and psychological health as evidenced by distress, malnutrition, dehydration, and inability to verbalize pain, which augmented the challenges of pain management for family caregivers. Health-care providers need to constantly evaluate a patient's physical and psychological changes and adjusted pain medication regimen accordingly. Family caregivers had no clear guidance on how to assess pain by nonverbal cues or adjust medication dose based on a patient's condition. In addition to providing the 10-point and facial pain scales, health-care providers can introduce appropriate tools based on a patient's condition for family caregivers to assess pain from a patient's words, facial expressions, behaviors, emotion, movement, and positioning,^{37,38} especially for a patient with dementia or other types of cognitive impariment.²⁹ Furthermore, health-care providers can demonstrate how to assess pain using validated scales and ask family caregivers to teach back.

Pain Medication Disposal Issues

Proper disposal of prescribed pain medication was another issue family caregivers raised. Few studies discussed pain medication safety issues.^{14,16} Actually, each state and institution has different regulations or policies on how to discard opioids and controlled substances. The US Food and Drug Administration initiated Medicine Take-Back Programs nationally.³⁹ If there are any unused or expired medications, family caregivers can find medications collection sites near them through the US Drug Enforcement Administration website.⁴⁰ Health-care providers can instruct family caregivers on proper disposal of pain medications to avoid any undesirable outcomes.

Some of our findings were consistent with the previous studies but provided a more comprehensive evaluation of challenges from the family caregivers' perspective. Our findings suggested that there is a need to develop an effective educational tool to support family caregivers in managing pain. The tool should provide information about potential challenges or misperceptions about pain management, instruction in pain assessment and medication administration, storage and disposal, and basic pharmacological knowledge. This educational tool can be helpful for health-care providers to identify caregivers' concerns and instruct family caregivers in pain management strategies.

Limitations

A small sample size is a limitation to our study. In the parent study, more than 50 family caregivers (out of 514 family care-givers; about 10%) described that they faced pain management challenges at their baseline questionnaires. However, when they were asked to deal with one of the most pressing life events or caregiving challenges using problem-solving strategies in their baseline interviews, many caregivers decided to tackle other issues such as work accommodation, financial constraints, and others. Only 15 family caregivers who chose to deal with pain management as the priority issue in their baseline interviews were included in this study. There were still many family caregivers in the parent study who had pain management difficulties. A secondary data analysis limited the ability to further explore participants' issues.

The majority of the participants were older, highly educated white family caregivers who provided long-term and higher-hour caregiving to their loved one. The homogenous sample in a geographic area might limit the generalizability of the results. Due to the participants' backgrounds, research inclusion criteria, a small sample size, and a lack of patients' perspective, some subthemes related to caregivers' cognition and culture and patients' issues in Kelley's framework were not present in the analysis. Future research should include a larger and more diverse sample of patients and family caregivers and explore pain management concerns of different ethnicity and culture.

Conclusion

Our study showed that "Informal Hospice Caregiver Pain Management Concerns" framework is an applicable framework and provided a comprehensive investigation on hospice family caregivers' difficulties in pain management. The results of this study can

inform providers and researchers of caregivers' challenges and provide insights for future designs of educational materials targeting pain management strategies, ensuring that caregivers can manage patients' pain effectively at home.

Acknowledgments

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported in part by the NIH/National Institute for Nursing Research Grant Nr. R01NR012213 (PI: G.D.), Sigma Theta Tau International (Psi-at-Large Chapter) Small Grant (PI: N-C.C.), Hester McLaws Nursing Scholarship Fund at University of Washington (PI: N-C.C.), and Technologies Incubation Scholarship, Taiwan Ministry of Education (PI: N-C.C.).

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Table 1.

Kelley “Informal Hospice Caregiver Pain Management Concerns” Framework.”²³

Major Themes and Subthemes	Description
Major theme: Caregiver-centric issues	This theme includes issues concerning the caregiver that might interfere with the caregiver's ability to manage, treat, assess, and attend to the patient's pain
Functional issues	Physical and/or psychological caregiver limitations and preventing adequate management of patient's pain (physical, psychological, social, and/or spiritual)
Cognitive issues	This theme deals with issues of memory, language, thinking, and judgment. The theme includes normal age-related cognitive changes as well as any pathologic changes
• 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
Culture issues	This theme deals with issues that might interfere with a caregiver's ability to understand directions due to a language barrier which may negatively influence the caregiver's ability to manage the patient's pain. This theme also includes cultural or ethnic norms interfering with pain management
• English as second language 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	This theme includes fears, myths, and religious beliefs that interfere with the caregiver's ability to manage pain
• 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
Major theme: Caregiver's medication skills and knowledge	This major theme deals with the caregiver's knowledge of medications, including pharmacology, polypharmacy, and drug side effects
Pharmacology knowledge issues	This theme deals with the working knowledge of medications including: pharmacology and basic understanding of how medications work, issues related to polypharmacy and drug interactions, side effects of medications, and assessments and outcomes of pain management therapy
• 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

Major Themes and Subthemes	Description
Major theme: End-of-life symptom knowledge issues	This theme encompasses issues of common end-of-life symptoms or assessments which caregiver's misperceive as needing emergency treatment. This theme also includes caregivers' inability to address any symptoms that may increase the patient's pain load
Common end-of-life symptom management	Expected events in hospice are not considered crisis by hospice personnel but may be perceived as such by caregivers
Symptom assessment issues	A caregiver lacks the skill to assess, treat, monitor, and reassess end-of-life symptoms
Personhood issues	Caregiver understands patient's wishes but refuses to act in accordance with those wishes
Major theme: Communication and teamwork issues	This theme deals with all issues surrounding teamwork and communication that may make pain management difficult for the caregiver
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	A caregiver lacks adequate support network (ie, respite care not available)
Major theme: Organizational skill issues	This theme is concerned with caregiver's lack of organizational skills, which may cause problems with patient pain management. It includes tracking and recording treatments, assessments, medications, and outcomes
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
Major theme: Patient-centric issues	This theme deals with the patient's total pain, also known as the pain load. Pain and suffering occur in 4 distinct yet intersecting domains: physical, psychological, social, and spiritual. This theme also includes fears, myths, and religious beliefs that affect the patient's pain management
Pain assessment congruency issues	A caregiver underestimates or overestimates pain as the patient perceives it
Psychological well-being issues	A patient's negative psychological well-being may cloud the patient's ability to report pain and respond to pain management
Nutrition and hydration issues	Dehydration, decreased BMI, and overall wasting may alter a patient's absorption, metabolism, and excretion of medication and negatively affect pain management
Inability to verbalize pain	A patient's inability to verbalize pain makes pain assessment difficult for a caregiver
Negative existential view of life	A patient with a negative view of their overall life or current quality of life may affect the interaction with the caregiver and the conversation about end-of-life wishes
• Patient's belief system issues	A patient's fears, myths, and religious beliefs that interfere with pain management
• 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 end of life or pain that may interfere with pain management

Abbreviations: BMI, body mass index; EOL, end of life.

Table 2.Caregivers' Demographics.^{a,b}

Characteristic	Caregivers
Age, mean (SD)	62.5 (14.3)
Female	8 (53.3%)
White	14 (93.3%)
Relationship to patient	
• Adult child	5 (33.3%)
• Spouse or partner	6 (40.0%)
• Other	4 (26.7%)
Married	12 (80%)
College degree	9 (60%)
Lives with patient	12 (80%)
Employed (full-time or part-time)	7 (46.7%)
Caregiving >20 h/wk	13 (86.7%)
Duration of caregiving	
• <6 months	3 (20%)
• 6 months to <1 year	2 (13.3%)
• 1 year to <3 years	5 (33.3%)
• >3 years	5 (33.3%)

^aN = 15.^bValues are n (%) unless otherwise noted.

Table 3.

Individual Caregiver's Profiles.

Participant ID	Relationship With Patient	Patient's Diagnosis
P1	Spouse/partner	Dementia
P2	Spouse/partner	Diabetes
P3	Other	Cancer
P4	Spouse/partner	Amyotrophic lateral sclerosis
P5	Other	Heart failure
P6	Spouse/partner	Cancer
P7	Adult child	Dementia
P8	Adult child	Unknown
P9	Other	Cancer
P10	Other	Stroke
P11	Adult child	Pulmonary disease
P12	Adult child	Cancer
P13	Spouse/partner	Cancer
P14	Adult child	Leukemia
P15	Spouse/partner	Cancer

Table 4.

Updated “Informal Hospice Caregiver Pain Management Concerns” Framework.

Major Themes and Subthemes	Description	Exemplar
Major theme: Caregiver-centric issues	This theme includes issues concerning the caregiver that might interfere with the caregiver's ability to manage, treat, assess, and attend to the patient's pain.	
Functional issues (n = 4)	Physical and/or psychological caregiver limitations, burden, or exhaustion preventing adequate management of patient's pain.	I am exhausted so there was a strong desire to have my mother die, and I didn't want to be coming from that place, administering medication to her.” (P12)
Belief system	This theme includes fears, myths, and religious beliefs that interfere with the caregiver's ability to manage pain.	
• Religious/ethical/moral beliefs (n = 4)	Caregiver's religious, moral, or ethical beliefs which are at odds with patient's beliefs or hospice philosophy.	I believed that my mother had a right to do whatever she chose with her own death. Even if it wouldn't be my way. What my dilemma was whether or not I was going to administer that pain medication myself. (P12)
• Mythical beliefs (n = 1)	Caregiver's beliefs not based in scientific evidence.	Pain doesn't kill you. You don't die from pain. (P15)
• Caregiver fears (n = 3)	Caregiver's worries and fears may prevent caregiver from acting in a prudent and timely manner to relieve patient's pain.	I had a huge fear that somehow in giving [the patient] morphine that we were depriving of her ability to communicate. (P5)
Caregiver self-efficacy/optimism/self-confidence (n = 2)	Caregiver's negative self-efficacy in making decisions correlates with inability to manage pain. The converse is true. Feeling of self-efficacy correlate positively with caregivers' ability to manage pain adequately.	I'm so efficient because I'm so used to it... When I move her or put her to bed, I know how to adjust and put the pillows exactly. Because she's in excruciating pain in certain positions. (P11)
Duration/extent of caregiving and proximity to death (n = 2)	Duration of care and requirements, as well as proximity to death may interfere with pain management.	A total of 15 days, [my wife] has no sense at all. But we're ready. She was in so much pain. We're just giving her more pain medications. (P2)
Previous life experiences (n = 2)	Experience or lack of experience with pain management.	It was good to have [my father] home with hospice care, the medicines, and stuff. I want my mom having the same kind of comfort... I don't want my mom to be miserable. I'd rather have her drugged. (P11)
Concurrent responsibilities (n = 1)	Caregiver's other ongoing responsibilities including work, family, and financial responsibilities.	I can't leave her alone now for more than a half-hour. (P11)
Major theme: Caregiver's medication skills and knowledge	This major theme dealt with the caregiver's knowledge of medications, including pharmacology, polypharmacy, and drug side effects.	
Pharmacology knowledge issues (n = 2)	This theme deals with the working knowledge of medications including: pharmacology and basic understanding of how medications work, issues related to polypharmacy and drug interactions, side effects of medications, and assessments and outcomes of pain management therapy.	My concern is Are we doing the right thing? Do we have the right protocol? I think I need more work on that with some other professional people about the usage of pain meds. (P2)
• Polypharmacy issues (n = 1)	Complex medication interactions may inhibit pain management. Lack of working knowledge and skill with medicines may inhibit pain management.	I would say personal apprehension of using so many pain medications. (P2)
Pain assessment issues (n = 5)	Caregiver's inability to adequately monitor, assess, treat, and reassess pain.	The day-to-day decision is how much medicine do I give her? She made me promise I wouldn't give her too much and we give her just enough to keep her comfortable. That gets to be kinda tough sometimes. (P13)
Personhood issues (n = 2)	Ability to understand patient's medication management wishes but caregiver refuses to act in accordance with those wishes.	Because of our desire for quality of life to have her more alert. I know at times when pain gets really bad, she asks to be put out. So maybe the thing is for her to always be the one in control. I don't know if I could let that go. (P2)

Major Themes and Subthemes	Description	Exemplar
Major theme: Communication and teamwork issues Caregiver health-care delivery system communication issues (n = 4)	This theme deals with all issues surrounding teamwork and communication that may make pain management difficult for the caregiver. Communication and teamwork breakdown between caregiver and hired help, hospice providers, pharmacist, primary provider, insurance company, equipment delivery service, and so on.	We weren't getting any medical help. (P1)
Caregiver support network communication issues (n = 3)	Caregivers lack adequate support network and need self-care and personal time.	I should have get respite care. (P1)
Major theme: Organizational skill issues	This theme is concerned with caregiver's lack of organizational skills, which may cause problems with patient pain management. It includes tracking and recording treatments, assessments, medications, and outcomes.	
Safety issues (n = 1)	Caregiver's inability to safely store and discard medication, equipment, and so on to prevent theft or misuse.	My daughter took all the labels off and put [morphine] into four different trash cans. (P6)
Major theme: Patient-centric issues	This theme deals with the patient's total pain also known as the pain load. Pain and suffering occur in four distinct yet intersecting domains: physical, psychological, social, and spiritual. This theme also includes fears, myths, and religious beliefs that affect the patient's pain management.	
Pain assessment congruency issues (n = 2)	A caregiver underestimates or overestimates pain as the patient perceives it.	She doesn't report pain. (P13)
Physical well-being issues (n = 2)	A patient's physical deterioration might increase the levels of pain and make the family caregiver difficult to manage pain effectively.	It's neuropathy pain from her knees down through her feet. The erratic nature of the illness is very difficult to resolve. What we're doing is we're using pain medication to override what her body's trying to do. It's getting more and more complicated. (P2)
Inability to verbalize pain (n = 5)	A patient's inability to verbalize pain makes pain assessment difficult for a caregiver.	It sucked to have to make a choice about the amount of medicine that we were giving her without her input. (P12)
Negative existential view of life (n = 1)	A patient with a negative view of their overall life or current quality of life may affect the interaction with the caregiver and the conversation about end-of-life wishes.	[My husband] is totally paralyzed from the belly button down. He is in bed and gets out of bed every other day. He has been so much pain and really wants to die...he refused all the treatment and medications. (P15)