

Pain Management Concerns from the Family Caregivers' Perspective:
An Exploratory Study and Utility Test of an Educational Tool to Support Pain Management

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Abstract

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Approximately 1.6 to 1.7 million Americans received hospice care in 2014 and about 60% of them received care at their place of residence. Family caregivers play a pivotal role in supporting patient care and symptom management in home hospice care. More than 50% of the patients with terminal illness experience pain and pain is highly undertreated in the end-of-life stage. Pain management has been identified as one of the most challenging tasks for family caregivers and this burden often has a negative impact on family caregivers' well-being and quality of life. There are limited studies focused on exploring family caregivers' concerns regarding pain management in home hospice care and on designing supportive interventions for family caregivers. My dissertation aimed to identify the challenges related to pain management faced by family caregivers in home hospice care and develop an educational tool for healthcare clinicians to support caregivers' pain management. This work is organized in three papers.

In the first paper, I conducted a systematic review to understand family caregivers' pain management in end-of-life care based on a search of CINAHL, Embase, PubMed, and Cochrane Library electronic databases. Fourteen research papers focused on family caregivers' pain management experience and strategies in end-of-life care were included. Nine were observational studies, three were case studies, and two were experimental studies. This review identified themes similar to previous studies on family caregivers of patients with cancer or in palliative care: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with the care team. However, the level of scientific evidence is low and the quantity is scarce. More research is needed to explore family caregivers' pain management in end-of-life care and to design interventions to support

family caregivers in pain management. The first paper has been published in the American Journal of Hospice and Palliative Medicine.

In the second paper, I conducted a secondary data analysis of hospice family caregivers' interviews from a recently completed five-year NIH/NINR R01 (Grant Nr. R01NR012213; PI: Demiris) randomized clinical trial to identify family caregivers' concerns in pain management. The analysis was a theory-driven, deductive content analysis based on an existing hospice pain management framework called "Informal hospice caregiver pain management concerns". The analysis identified most of the themes in the framework and confirmed that family caregivers faced a variety of challenges when managing patients' pain: caregiver-centric issues, caregiver's medication skills and knowledge, communication and teamwork, organizational skill, and patient-centric issues.

In the third paper, I designed an educational tool and conducted an evaluation study to test the utility of the tool. The pain management educational tool consists of five modules and some pain management strategies and assessment scales. Each module includes a clinical scenario of caregivers' challenges in pain management (based on the findings in the second paper) and guidelines (based on the Assessing Caregivers for Team Interventions model) for hospice providers to support family caregivers. The educational tool was vetted through five experts in cancer pain management and caregiving research. Fifteen hospice providers including physicians, nurses, pharmacists, social workers, and chaplains from several hospice agencies in the Seattle were interviewed to solicit their feedback on the utility of the educational tool. The interview data were transcribed verbatim and analyzed using thematic analysis. The hospice providers commented the utility of the tool and suggested improvements of the tool. They commented that the scenarios were realistic and the suggested guidelines were effective. They believed it could be a great reference for hospice providers to use in their clinical practice and a resource for providers' continuing education. They suggested adding additional pain education content and some common pain management challenges into the tool to enhance the utility. They advised creating more than one platform for the tool such as a printed booklet, website, video, or mobile application in order to accommodate different user needs and experiences. The study showed that the educational tool holds promise to be effective and practical in the context of hospice care. The tool also has potential to improve communication in pain management and be integrated into hospice providers' routine care.

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Chapter One

Introduction

The Rapidly Increasing Demand for End-of-Life Care and Family Caregiving

End-of-life care is an important public health issue and national research priority over the last two decades as a result of the rise of an aging population and people with chronic illness.¹ Hospice care aims to provide comfort care, manage patients' pain and symptoms, and support patients and family caregivers' spiritual needs.² It is estimated that 1.2 million deaths in the U.S were under hospice care annually.² An estimated 1.6 to 1.7 million Americans received hospice services in 2014, which is a 20 percent increase compared to the number in 2010.² These statistics demonstrate the quick growth in the hospice population and the importance of building a more comprehensive and structured end-of-life care system for supporting the large number of terminally-ill patients, their family caregivers, and healthcare providers.

About 43.6 million American adults served as family caregivers for patients with chronic conditions.³ In 2014, approximately 60% of the patients received hospice service at their home or place of residence.² Those patients need their family caregivers to assist with their activity of daily living and medical/nursing care at home.² The family caregivers in end-of-life care not only carry complex caregiving tasks but also deal with their grieving process and anticipated loss.

Inadequate Pain Management in End-of-Life Care

Many factors can contribute to pain symptoms in older or dying adults, such as a chronic condition, malignant disease, breakthrough pain, emotional and cognitive state, etc.⁴ Pain is highly prevalent and about 50 % of patients experience pain in end-of-life stage.⁵⁻⁹ A meta-analysis consisting of 52 studies estimated that the prevalence of pain for patients with terminal cancer was 64%.⁵ A systematic review found that the prevalence of undertreated cancer pain was 50%.⁸

Most of the family caregivers do not receive formal training but they are asked to provide pain management. As a result, pain management is the one of the most frequently identified challenges faced by family caregivers in end-of-life care.¹⁰⁻¹² Pain management can negatively affect family caregivers' well-being and quality of life.^{10, 13} The clinical practice guideline of the American College of Physicians suggested that effective symptom management control could not only enhance the patients' outcomes,

but also alleviate the family caregiver's burden.¹⁴ Yet, there is limited research focused on family caregivers' perspectives, and interventions to support hospice family caregivers' pain management.¹⁵⁻¹⁶ Existing literature focuses primarily on patients with advanced cancer. Understanding hospice family caregivers' pain management difficulties and needs would reduce the barriers to effective pain management and improve patients' and their family caregivers' outcomes.

Caregivers' Pain Management Concerns in Home Hospice Care

Previous studies have identified the several factors related to family caregivers' challenges in pain management: inadequate knowledge and skills in pain management,¹⁷⁻¹⁹ concerns about side effects, addiction, and tolerance of pain medications,^{20, 21} discrepancy in perceptions and experience of pain between patients and family,^{22, 23} and poor communication with the healthcare team.^{11, 12, 24} However, the majority of the findings were based on patients with cancer and their family caregivers. There are still limited studies examining challenges related to pain management in end-of-life care for all terminal illnesses from the family caregivers' perspective.

Pain management is a multifaceted process consisting of several steps for family caregivers including pain assessment, medication administration and management (organization, storing, scheduling, and remembering), outcomes evaluation, and communication with healthcare providers.^{17,25,} ²⁶ To explore family caregivers pain management, Lau et al. conducted a qualitative study to propose a theoretical construct of family caregivers' skills in medication management in hospice care: (1) teamwork (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).¹⁹ As medication management is one of the aspects of pain management in end-of-life care, Kelley et al. conducted a literature review and a content analysis to further expand the "Family Caregivers' Skills in Medication Management" framework by Lau et al. to the context of hospice family caregivers' pain management.²⁷ The content analysis included 29 hospice family caregivers of cancer patients from a clinical trial. The major themes in the framework were (1) caregiver-centric issues (e.g., function, cognition, beliefs, self-efficacy); (2) caregiver's medication skills and knowledge (knowledge, medication

administration, pain assessment, personhood issues); (3) end-of-life symptom knowledge; (4) communication and teamwork; (5) organizational skill; and (6) patient-centric issues (e.g., pain assessment congruency, psychological well-being, nutrition and hydration, inability to verbalize pain).²⁷ Kelley's "informal hospice caregiver pain management concerns" framework categorized specific themes regarding caregiver and patient factors.

This framework provided a comprehensive review of hospice family caregivers' concerns in pain management. However, the framework 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 dissertation aimed to identify the challenges related to pain management faced by hospice family caregivers of patients with diverse diagnoses and examine the validity of Kelley's framework.

As family caregivers play an important role in assisting their loved one with pain assessment and pain medication administration, understanding family caregivers' pain management concerns may indeed reduce the barriers to effective pain management and improve patients' and their family caregivers' outcomes. The purpose of this dissertation was to describe in a comprehensive and systematic manner the challenges of pain management reported by hospice family caregivers, and to develop an educational tool to support caregivers, and recommend ways for health care providers to improve existing or design new effective pain management strategies for patients and their family caregivers in end-of-life care.

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Chapter Two

Family Caregivers' Pain Management in End-of-Life Care: A Systematic Review

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Abstract

Context: Pain management was the most identified burden faced by family caregivers in end-of-life caregiving.

Objectives: To synthesize current scientific evidence on family caregivers' experience of pain management in end-of-life care.

Methods: A systematic review was conducted using CINAHL, Embase, PubMed, and Cochrane Library electronic databases. Data were extracted from each included paper and organized into tables to synthesize the findings.

Results: Fourteen research papers focusing on family caregivers' pain management experience and strategies in end-of-life care were included. Nine were observational studies, three were case studies, and two were experimental studies. These studies mainly focused on exploring family caregivers' engagement in pain management and communication with the hospice care team about pain control, family caregivers' knowledge, skills, and self-efficacy in pain management, and family caregivers' concerns and experience of pain management.

Conclusion: This review identified themes similar to previous reviews on family caregivers of patients with cancer or in palliative care: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with the care team. Future research should design educational programs and material for family caregivers to improve their pain management knowledge and skills, communication, and engagement in care. The scientific knowledge on this topic is scarce and level of evidence is low; it is therefore, imperative to have more exploratory studies to expand the quality and quantity of evidence and increase our understanding of family caregivers' needs and barriers to pain management based on larger and more diverse patient and caregiver samples.

Introduction

The Rapidly Increasing Demand for End-of-Life Care and Family Caregiving

The demand for family caregivers is increasing as a result of the rise in the aging population and patients with chronic illnesses. Family caregivers, also referred to as informal caregivers, are unpaid caregivers such as family members, relatives, friends and partners, who take care of their loved ones. They play a key role in delivering care and support services to patients who suffer from a chronic illness or a disabling condition that calls for ongoing assistance with everyday tasks¹. In 2015, the National Alliance for Caregiving and AARP reported that an estimated 43.6 million U.S. adults worked as informal caregivers to provide unpaid care to an adult or a child with or without terminal conditions in the prior 12 months.²

In 2013, approximately 1.5 to 1.6 million patients in the U.S. with terminal illness received hospice care, and about 66% of them received hospice service at their place of residence.^{3, 4} As more people prefer to die at home, many family caregivers provide assistance with daily activities or medical care for the patients who receive palliative or hospice care at home. Palliative and hospice care is patient-centered care involving interdisciplinary team that aims to provide medical care, pain and symptom management, emotional and spiritual support, and improve the quality of life for terminally-ill patients and their families.⁵ Caregiving is essential to the delivery of palliative and hospice care but it may also bring adverse effects on caregivers' health due to physical demands, emotional distress, and expected loss of their loved one.² Some studies have demonstrated that caregiving to patients with terminal illness resulted in more physical burden, higher levels of depression and anxiety, and increased mortality on caregivers.⁶⁻⁹ One of the greatest challenges for caregivers in these cases is to effectively contribute to their loved one's pain management.¹⁰⁻¹² On the other hand, Brown et al. have conducted a national, longitudinal survey of elderly married spouses and found that more than 14-hour caregiving per week is associated with decreased mortality for the family caregivers.¹³

Pain Management in Advanced Disease and End-of-Life Care

Evidence has shown that many factors can contribute to pain symptoms in older or dying adults, such as the presence of chronic conditions, a malignant disease, breakthrough pain, care procedures, emotional/cognitive state, and response of others (denial, distancing, social isolation, miscommunication,

etc.).¹⁴ According to a longitudinal research study funded by the National Institute on Aging, pain is highly prevalent and about 50 % of patients experience pain in end-of-life stage.¹⁵ Van den beuken-van everdingen et al. conducted a meta-analysis consisting of 52 studies published between 1966 and 2002 and estimated that the prevalence rate of pain among the patients characterized as advanced/metastatic/terminal cancer was 64%.¹⁶ Also, more than one-third of the patients graded their pain as moderate or severe.¹⁷

In 2013, the National Institute of Nursing Research (NINR) conducted a large-scale and comprehensive review of end-of-life and palliative care research papers published between 1997 and 2010.¹⁷ A total of 3155 studies were found and 11% of these studies focused on approaches to alleviate patients' pain or symptoms.¹⁷ The NINR reported that the quality of evidence of effective symptom and pain management is still inadequate.¹⁸ In addition, evidence has shown that there are barriers to effective pain management in advanced disease management and end-of-life care including patients' fears and concerns, patients and their family caregivers' reluctance to take pain medicine due to misconceptions about side effects of medications, the physicians' reluctance to prescribe pain medicines, the health care providers' insufficient knowledge and skills in pain and symptom assessment.^{19, 20}

Family Caregivers' Challenges in Pain Management of Advanced Disease and End-of-Life Care

Among the many challenges in end-of-life caregiving, pain management was the most identified burden faced by family caregivers.¹⁰⁻¹² Ward, Berry and Misiewicz conducted one of the earlier studies to examine hospice family caregivers' concepts and concerns about reporting pain and using analgesics for patients with cancer and found that barriers to reporting pain and using analgesics included fears of opioid side effects, addiction or injection, and the belief that increasing pain indicates disease progression.²¹ Ferrell et al. conducted a quasi-experimental study to examine the impacts of pain and pain management education on 231 family caregivers of patients with cancer. The findings demonstrated that patients' pain greatly affected family caregivers' quality of life in the areas of physical, psychological, social, and spiritual well-being.²²

Docherty et al. reviewed the knowledge and information needs of informal caregivers in palliative care, and synthesized 34 clinical trials published from 1994 to 2006.²³ The results stated that barriers to effective pain management among informal caregivers and patients included lack of patient-caregiver

consensus in perceptions and experience of symptoms.²³ Lockett et al. conducted a systematic review related to managing pain caused by cancer, in which they synthesized 65 qualitative studies published between 2000 and 2011.²⁴ This review suggested that family caregivers need adequate pain management knowledge and effective pain management strategies to support their care.²⁴ Meeker et al. synthesized 35 empirical studies published between 1991 and 2007 to explore family caregivers' experience and needs in managing pain induced by cancer.¹¹ The authors concluded that family caregivers need education about pain management, training for problem-solving skills, and recognition from health care providers about their role in pain management.¹¹

The current evidence has shown that barriers to effective pain management exist due to patients and family caregivers' inadequacy of knowledge in pain management, beliefs and attitudes in pain management and pain medications, and communication issues. However, the majority of the review papers or descriptive studies have focused on the perspectives of patients with cancer specifically. In addition, few studies have explored the experience of pain management in end-of-life from the family caregivers' perspective. The understanding of challenges and needs specifically for family caregivers of patients in end-of-life care more broadly (for all terminal illnesses) is limited. Hence, this review aims to synthesize current scientific evidence on family caregivers' experience of pain management in hospice and palliative care.

Methods

Search Strategies

This paper aims to broaden the understanding of family caregivers' experience in pain management and existing strategies to support them in hospice care and palliative care. A systematic review was conducted on April, 2015 using a combination of search terms including end of life, hospice, palliative, pain management, pain control, pain assessment, pain medication, family caregiver, family carer, and informal caregiver in CINAHL, Embase, PubMed, and Cochrane Library electronic databases.

Inclusion and Exclusion Criteria

As there are only limited numbers of studies on this topic and ten-year is a significant span that covers recent literature, we extended our search from the past five years to the past ten years. The studies were included if they were a research paper published in the past ten years and focused on family

caregivers' pain management experience and strategies in palliative and hospice care settings. Studies were excluded if they were not published in English, not studies that described a research, not peer-reviewed articles, not caregiver-focused, and not studies conducted in end-of-life care, palliative care, or hospice care settings.

The initial search yielded 648 articles. After excluding 62 duplicated articles, 291 articles that were not published in English or not published between April, 2005 and April, 2015 were removed. Two hundred ninety-five remaining articles' abstracts were reviewed and applied the inclusion and exclusion criteria. Two hundred and seventy-six articles were further excluded because they were not describing a research study (n=8), not focusing on pain management issues (n=216), not caregiver-focused (n=29), and not conducted in end-of-life care settings (n=23). Nineteen full-text articles were assessed for eligibility. Five studies were excluded because they did not describe a research (n=1), not focus on pain management issue (n=2), or not focus on family caregiver (n=2). A total of fourteen studies were identified and included in this review (See Figure1).

Data Extraction and Management

To synthesize the results among included studies, the following data were extracted from each paper and organized into tables: authors, published year and country, journal, purpose, sample size and characteristics, study setting, study design, theoretical framework, measure for caregivers, data collection, caregivers' outcomes, and limitations. In order to synthesize the current scientific evidence, we also evaluated the quality of evidence. Each article was scored for the strength of the findings by using the Oxford Centre for Evidence-based Medicine framework. This framework consists of ten levels of strength and evaluates a study based on its study design. Lower scores indicate higher strength of evidence (1a: Meta-analysis; 1b: Individual randomized controlled trial (RCT); 1c: Non-RCT; 2a: Systematic reviews of cohort studies; 2b: Individual cohort study; 2c: Outcomes Research; 3a: Systematic review of case-control studies; 3b: Individual case-control study; 4: Case-series; 5: Expert opinion without explicit critical appraisal).²⁵

Results

Authors, Published Journal, Study Countries, and Settings

Fifteen studies were published in 11 journals covering diverse scientific areas including palliative

and hospice medicine, symptom and pain management, oncology, and clinical practice areas. The majority of the studies were conducted in the U.S. (64%), followed by Canada (21%), Spain (7%), and Taiwan (7%). The most frequent study setting was the patients' home (78%), while some studies took place at hospital inpatient settings (21%) and patients' institutional living arrangement (nursing home and long-term care facility) (7%).

Sample Size and Characteristics

Nine studies included only family caregivers (64%), while five studies included both patients and family caregivers (35%). Two studies included above 100 participants (14%), three included participants ranging from 50 to 100 (21%), six included participants ranging from 10 to 50 (42%), and three case studies included only one case (21%).

All the studies included family caregivers in palliative or hospice care, and 12 studies among them specifically focused on family caregivers of patients with cancer (85%). The family caregivers in these studies had a mean age ranged from 52 to 70 years old. Thirteen studies had more than 70% to 80% female family caregivers (92%), six studies had more than 70% Caucasian family caregivers (42%), and eight studies primary family caregivers mostly were the patients' spouse/partner (57%).

Study Design

Nine were observational studies (64%), three were case studies (21%), and two were experimental studies (14%). According to the Oxford Centre for Evidence-based Medicine framework,²⁵ the strength of evidence for these studies was moderate to low. There is an increasing volume of research on end-of-life care. However, the quality of evidence is still limited. There are many challenges in doing an end-of-life care study such as the difficulty in conducting longitudinal studies that cover longer segments before patients' death; unclear definition of dying; and the neglect of the distinctions among quality of life, quality of death, and quality of end-of-life care.²⁶

Study Focus

Five studies focused on family caregivers' engagement in pain management and communication with the hospice care team about pain control. Five studies explored family caregivers' knowledge, skills, and self-efficacy in pain management. Four studies discovered family caregivers' concerns and experience of pain management.

(1) *Engagement and Communication*

Family Caregivers' Engagement in Care and Participation in Interdisciplinary Team

Meetings. Parker Oliver et al. conducted a pilot, non-randomized, sequential mixed method study to test the feasibility of family caregivers' participation in hospice interdisciplinary team meetings via videophone.²⁷ The goal was to improve family caregivers' outcomes (quality of life and communication anxiety) and perceptions of pain medication. This intervention was designed based on Saltz and Schaefer's framework "family participation of health care teams."²⁸ A total of 68 family caregivers were involved in this study, and 32 of them attended via video 89 hospice interdisciplinary team meetings. The family caregivers who participated in the meetings showed improvements in their perceptions of pain medication. The author concluded that the limitations of small sample size, non-randomization design, missing data, and high attrition rate (40%) might affect the ability to detect more positive outcomes.²⁷

Parker Oliver et al. conducted a mixed-method study to understand the current practice of hospice assessment and collaboration on informal caregiver issues related to pain management.¹² This study included 30 hospice caregiver-patient dyads from one rural hospice agency. In the first phase, 87% of caregivers indicated concern with at least one question on the Caregiver Pain Medicine questionnaire. In the second phase, due to the patients' death or transfer, only 23 hospice caregiver-patient dyads were able to participate in the hospice interdisciplinary team and were recorded over nine months for a total of 86 sessions. During the 86 hospice interdisciplinary team meetings, 38% of the discussions involved patient-related issues and 20% of the discussions were about patients' pain complaints, but only one discussion focused on family caregiver' concerns about patients' pain. The authors suggested that there is a need to increase assessment and interventions for family caregivers' pain management in hospice care.¹²

Kirk presented a case study of a 74-year-old white male patient with primary end-stage colon cancer receiving home hospice.²⁹ His wife was the primary family caregiver. The patient in this case showed increased signs of pain and agitation but his wife, the primary family caregiver, continued to insist on administering long-term analgesics to the patient. The hospice nurse was frustrated during home visits. As hospice care involves patients and their family, the hospice nurse has significant moral obligations to this case and his family caregiver. The author developed an action plan for the hospice care

providers for engaging family caregivers on a home hospice service: 1) establish common goals; investigate disparities; 2) establish shared perceptions; investigate disparities; 3) establish shared beliefs; investigate disparities; and 4) establish shared action/behaviors; investigate disparities.²⁹

Building Trust and Cooperative Relationship. Baldwin conducted semi-structured bereavement interviews with a female African American family caregiver of her 81-year-old mother with cancer living in a nursing home.³⁰ This study aimed to explore the hospice caregiver's experience with pain management. The family caregiver expressed dissatisfaction with hospice care as her observations of poor communication between the hospice staff and the nursing home staff and neglected concerns about overmedicating her mother. The authors found that poor communication among staff contributed to this family caregiver's lack of trust in hospice care.³⁰ The authors suggested that building trust and a cooperative relationship among health care professionals and family caregivers is essential for successful pain management. In addition, the authors discussed that highly educated family caregivers may have higher health literacy, but this does not equal to higher understanding of and comfort with pain management.³⁰

Understanding of and Communicating with Family Caregivers. Reddy et al. presented a case study in which an African-American mother denied her daughter, who had terminal cancer, adequate pain management and hospice care.³¹ This patient was conscious and complained of severe pain associated with bladder spasms, crying, and screaming. The patient continued to refuse pain medication in spite of health care providers' recommendations because her mother advised her not to use pain medications as the mother assumed that pain medications would interfere with the patient's cognition, function, and treatment.³¹

(2) Knowledge, Skills, and Self-efficacy

Tailored educational intervention. Cagle et al. conducted a pilot, cluster RCT to test the preliminary efficacy of a tailored educational intervention for family caregivers in four hospice agencies.³² This study included 126 family caregivers (55 interventions and 71 controls). For the family caregivers in the intervention group, the trained hospice staff would screen the family caregivers' barriers to pain management at admission and discuss misunderstandings regarding pain management with the family caregivers and the patients. The intervention was based on the cognitive behavioral framework.³³ When

outcomes were evaluated at two weeks and three month, family caregivers in the intervention group showed greater knowledge of pain and pain management and lower pain management barriers – despite the fact that was a high patient mortality between data collection intervals (63%). Another finding in this study related to racial differences. Compared to Caucasian caregivers at baseline, African-American caregivers had more self-efficacy, more concern about addiction, and less knowledge about pain management at admission.³² The intervention also appeared to be especially beneficial for African-Americans at reducing stigma.

Perceptual congruence of patients' pain between patients and family caregiver.

Tu and Chiou conducted a pilot, cross-sectional study to explore the differences in perceptual congruence of patients' pain and quality of life between the patients with cancer and their family caregivers.³⁴ Fifty-eight patients and their family caregivers completed the demographic data, disease profile, bio-psycho-social factor questionnaire, and the quality-of-life questionnaire within ten days after the patients' hospice inpatient admission. The trained hospice nurses also rated the patients' pain. The results showed that patients' self-reported pain was higher than hospice nurses' and their family caregivers' rating of the patients' pain, and the patients' rating of the quality of life was lower than their family caregivers' rating.³⁴

Family caregivers' self-efficacy for managing pain. Byrne et al. analyzed the survey data of 50 parent-child dyads from a multi-site, cross-sectional study. The goal of the study was to explore the role of parents' self-efficacy related to pain management for terminally ill children and adolescents.³⁵ The parents in the study had more negative moods and less vigor than adults in a normative sample, as well as higher levels of pain management self-efficacy than previous reports on family caregivers of adult patients.³⁵ The parents' strain and mood states (mood disturbance, anger, and fatigue) inversely correlated with pain management self-efficacy.³⁵ The limitation of this study was secondary analysis of self-reported data, but the findings will advance future interventions to improve family caregivers' self-efficacy on pain management.

Family caregivers' assessment and management of patients' pain. Mehta et al. interviewed 24 family caregivers of patients with advanced cancer receiving palliative care at home. This study aimed to describe the types of pain experienced by the patients and how family caregivers assessed and mitigated the pain.³⁶ Interviewed data were analyzed by open, axial, and selective coding following the Puzzle of

Pain Management Model.³⁷ The authors found that not all family caregivers were able to distinguish between the different types of pains and choose the appropriate strategies for the patients, which caused poor pain management and family caregivers' frustration.³⁶

Knowledge about opioid treatment. García-Toyos et al. conducted a qualitative study to understand the patients and their family caregivers' preferences and knowledge about opioid treatment.³⁸ Twenty-two patients with advanced cancer receiving hospice care (either at home or hospital) and 20 family caregivers were included in this study to participate in individual interviews. The results showed that less than one-third of the participants recognized the term opioid.³⁸ Among these participants, they had false beliefs of these drugs including addiction, increased risks of cognitive impairment and premature death, and exclusive use in end-of-life care. The information of opioid treatment the patients and family caregivers received was very general, and they expressed interest in receiving more information and participating in therapeutic decision making.³⁸

(3) *Barriers to Effective Pain Management*

Kelley et al. analyzed interviews with 29 family caregivers of patients with cancer receiving home hospice care from a mixed-methods clinical trial.³⁹ The interview data were analyzed using content analysis and organized to describe the pain management challenges faced by the hospice family caregivers. The barriers to effectively managing patients' pain caused by cancer for the family caregivers included caregivers' knowledge and skills in symptom and medication management, communication issues, patient-centric issues (pain assessment congruency between patients and family caregivers, well-being, mythical/religious/ethical/moral beliefs about pain control, inability to verbalize pain, etc.), and caregiver-centric issues (function, cognition, mythical/religious/ethical/moral beliefs about pain control, self-efficacy in pain management, concurrent responsibility, etc.).³⁹

McPherson et al. used a qualitative descriptive approach with thematic analysis to explore the cancer pain perceptions and experience of older adults and their family caregivers.⁴⁰ Eighteen older adults with advanced cancer receiving palliative care at home and 15 family caregivers participated in semi-structured interviews to express their experience of patients' pain. Three emerging themes from the interviews were: sensation of pain caused by cancer (the sensory aspects of the pain, origin of the pain, and meaning of the pain), reaction to pain caused by cancer (behavioral, cognitive, and emotional

reactions), and living with pain caused by cancer (patients' functioning with cancer pain, caregiving issues, cancer pain in the relationship). Some family caregivers expressed that patients' pain and pain management had impacted their physical and psychological health and the relationship with the patients.⁴⁰

Parker Oliver et al. conducted interviews with 38 hospice family caregivers of patients receiving home hospice and explored the hospice caregivers' experience about pain management.⁴¹ The family caregivers participated in interviews between 14 to 30 days after the patients' death. The family caregivers expressed that the challenges included 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.⁴¹

Mehta, Chan, and Cohen conduct a secondary analysis⁴² of interview data with 24 family caregivers from a grounded theory study.³⁷ This secondary analysis explored family caregivers' distress experience when managing pain for patients with advanced cancer receiving palliative care at home. The family caregivers expressed that the overwhelming responsibility "made them feel like being in a prison"; they felt like "flying blind and unprepared"; they didn't get enough support and felt as they were "lambs to the slaughter"; they felt hurt to witness their loved one suffering in pain and when pain crisis invoked thoughts of death.⁴² The family caregivers who take the pain management tasks are at risk of psychosocial distress.

Discussion

Study Settings, Sample Size, and Sample Characteristics

The National Hospice and Palliative Care Organization (NHPCO) reported that about 66% of people received hospice services at their place of residence.³ In this review, 78% of the studies' study setting was at the patients' home and 7% was at a nursing home. Besides the three case studies with a sample of one each, the rest of the studies included relatively large samples, especially considering the known challenges of conducting end-of-life research. Sixty-four percent of the studies were designed specifically for family caregivers. These strengths would enhance the generalizability of the results to many family caregivers in end-of-life care.

The majority of the studies in this review included the family caregivers of patients with only

primary cancer diagnosis. According to the NHPCO, 63% of patients enrolled in hospice services had a non-cancer diagnosis (dementia, heart disease, lung disease, stroke, kidney disease, liver disease, and others), and cancer only accounted for 36% hospice admission in 2012.³ As the demographics of patients change, the current sample in research is not representative of today's majority of patients and family caregivers in end-of-life care. Many patients at their end-of-life stage experience pain, not only patients with cancer, which results in family caregivers identifying pain management as the most difficult task. Pain and pain management concerns may differ dramatically depending on the patients' primary diagnosis. More exploratory studies are needed to understand the family caregivers of patients with a diagnosis other than cancer.

In the U.S., eighty percent of the patients enrolled in hospice services were Caucasian, 8.6% were African Americans, and 2.8% were Asian, Hawaiian, and Other Pacific Islander.³ The national statistics recently showed that the majority of the U.S. family caregivers were old and female.² In this review, the majority of the participants were older, female, and Caucasian family caregivers who were the patients' spouse or partner, which was similar to the national hospice family caregivers' profile. However, 40% of the U.S family caregivers are male and 60% of the family caregivers are employed, and limited research has been done with these populations. In order to meet the caregiving demands, approximately 70% of the family caregivers that are working reported that they have to make changes to their work situation. It is challenging for them to balance caregiving tasks with their work and life. As a result, family caregivers who work full-time have reported poorer physical health.^{2, 43}

One exploratory study have shown that family caregivers with different characteristics had different levels of concerns and difficulties in pain management. Male, employed, less educated, blue-collar, and retired family caregivers had greater concerns about pain management, which resulted in less control of the patients' pain.⁴⁴ More subgroup analyses are needed to understand the association between pain management issues and family caregivers' background, and more interventions tailored to meet family caregivers' needs are also required.

Ethnic minority patients and families are less likely to choose hospice care at end-of-life stage, and there are disparities in access to end-of-life care and quality of care between races. The minority of patients and their family caregivers' perceptions, needs, and challenges of end-of-life care were less

discussed in the research and literature. In this review, four studies discussed the differences in pain management between different ethnic groups. The subgroup analysis of Cagle's cluster RCT found that African-American family caregivers had more self-efficacy, more concern about addiction, and less knowledge about pain management than Caucasian family caregivers, and the educational intervention had a greater effect on African-American family caregivers in terms of improving stigma.³⁰ Baldwin's case study found that a highly educated African-American family caregiver had low understanding and comfort with her mother's pain control in hospice care.²⁸ Reddy' case study showed that an African-American mother' fears and misassumptions of pain medications led to the patient's suffering from severe pain at end-of-life.²⁹ Some cultural beliefs and beliefs about medical care might be potential barriers to effective pain management. Some family caregivers might need greater levels of monitoring, education, and support. Future studies are needed to explore their beliefs and perspectives about pain management in end-of-life care. Also, it is imperative to understand, and address patients and family caregivers' fears regarding pain medications, and the necessity to design an integrated approach including patients, family caregivers, and a multidisciplinary provider team (from oncology and end-of-life care), and to facilitate early referrals to palliative care.

Study Design and Focus

The current body of literature about family caregivers' pain management in end-of-life is scarce. Among 14 included studies, only two studies in this review had designed and tested interventions to enhance the family caregivers' perspectives and knowledge on pain management in end-of-life care. The strength of evidence in this review was moderate to low as the majority of the study designs were observational studies and case studies. However, these studies provided preliminary understanding and in-depth analyses on this issue for clinical practitioners and future interventional studies.

Three main domains discussed across the studies were family caregivers' engagement in pain management and communication with the hospice care team about pain control, family caregivers' knowledge, skills, and self-efficacy in pain management, and barriers to effective pain management.

Five studies discussed family caregivers' engagement in patients' pain management and communication with the care team. The goal of hospice and palliative care is to improve patients' and their family members' symptom and pain management and quality of life. However, the findings showed

that the family caregivers in many cases had limited engagement in pain management and poor communication with and trust in the care team, which caused disparities of pain management expectations among the family caregivers and the care team. The majorities of the patients live with their family caregivers or need family caregivers to assist with medical care. However, the current hospice and palliative practice doesn't always take into account family caregiver' concerns and challenges in pain management. Parker Oliver et al. found that family caregivers' pain management issues were rarely discussed or even mentioned in the hospice team meeting. Parker Oliver's study also showed that family caregivers who were invited to participate in the hospice team meeting had improved perceptions of pain medication.¹² Inviting family caregivers to the hospice team meeting is a promising strategy to improve family caregivers' participation in pain management and building trust and a cooperative relationship between the care team and family caregivers. Kirk suggested that health care providers should invite family caregivers into patients' care, investigate and understand family' beliefs, and establish common goal and behaviors.²⁷ Future studies should explore health care providers' perceptions about communication issues and family caregivers' role in end-of-life care, and design effective interventions to enhance family caregivers' engagement in care and communication with care teams.

Five studies revealed that family caregivers had inadequate knowledge, assessment ability, skills, and self-efficacy in pain medications and management. Another four studies found that the family caregivers' most common concerns about pain management were the risks of addiction and side effects from pain medications to impact on the patients' treatment plan, cognition, and function. They also found that the most frequent challenges faced by family caregivers were pain assessment and pain medications administration due to limited knowledge and skills and inadequate supports from the care team. Tu and Chiou' study found that there was incongruence between patient reported pain and proxy reported pain in end-of-life care. The patients' self-reported pain was greater than the nurses' and their family caregivers' evaluation, which led to poor pain management.³⁴ Pain is a subjective experience and it is hard to be described and measured. Some family caregivers felt extremely overwhelmed and stressed out to assist with the patients' pain control. Family caregivers in end-of-life not only take on their concurrent responsibilities (working or take care of other family members), but are also learning the caregiving tasks and how to assess and manage the patients' pain and symptoms. Symptom and pain management is one

of the major goals for hospice and palliative care. Although the hospice care team would visit and provide care to the patients to assure adequate pain control, the family caregivers are the ones assisting with assessing patients' pain and administering pain medication, especially for the terminally ill patients who cannot communicate or speak for themselves. As most of family caregivers do not have formal clinical training, it is crucial to develop a structured educational manual that provides family caregivers knowledge, skill training, guide book, and consultation service regarding pain assessment and management in end-of-life care. In this review, Cagle's cluster RCT demonstrated that a tailored educational intervention targeted the patients and their family caregivers' needs and misunderstanding on pain management could improve their knowledge of pain management and decrease pain management barriers.³⁰

Conclusion

This review synthesized the current understandings of family caregivers' pain management in end-of-life care. The patients in end-of-life care are suffering from inadequate pain control and their family caregivers are overwhelmed by the pain management task. The family caregivers in this review had limited knowledge, skills, and training in pain management, and insufficient support and communication with the care team. The family caregivers need formal and structured training on pain management and the tools to be empowered to actively and effectively cooperate with the care team to support the informal caregiver' role. Future research should design educational programs and material for family caregivers to improve their pain management knowledge and skills, communication, and engagement in care. It is also critical to investigate health care providers' perceptions about palliative and hospice pain management and their cooperation and communication with family caregivers.

There is limited evidence on palliative and hospice caregivers' pain management needs and practices. This review identified themes similar to these of previous reviews on family caregivers of patients with cancer or in palliative care: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with the care team.^{11,20,22} However, one of the major limitations of this present review was that most of the studies included female, Caucasian family caregivers of patients with cancer from a geographic area, which limited the generalizability of the results to family caregivers with different background. As the number of hospice

patients is growing and demographics of patients are changing, more studies including a representative sample will help understand this issue. Another limitation of this review was the study design. Most of the studies were observational study, secondary analysis, and case study. Secondary analysis might restrict the ability to know family caregivers' needs, and case study would have limited generalizability of the results to other family caregivers. The scientific knowledge on this topic is scarce and level of evidence is low; it is therefore, imperative to have more exploratory studies to expand the quality and quantity of evidence and understanding of family caregivers' needs and barriers to pain management from larger and diverse samples studies such as family caregivers of patients with diverse ethnic backgrounds, diagnoses, literacy and health literacy and overall educational level. Such investigation will advance interventional studies to develop and test appropriate strategies for family caregivers in end-of-life care to be more effective and efficient in pain management.

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Figure1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of review process.

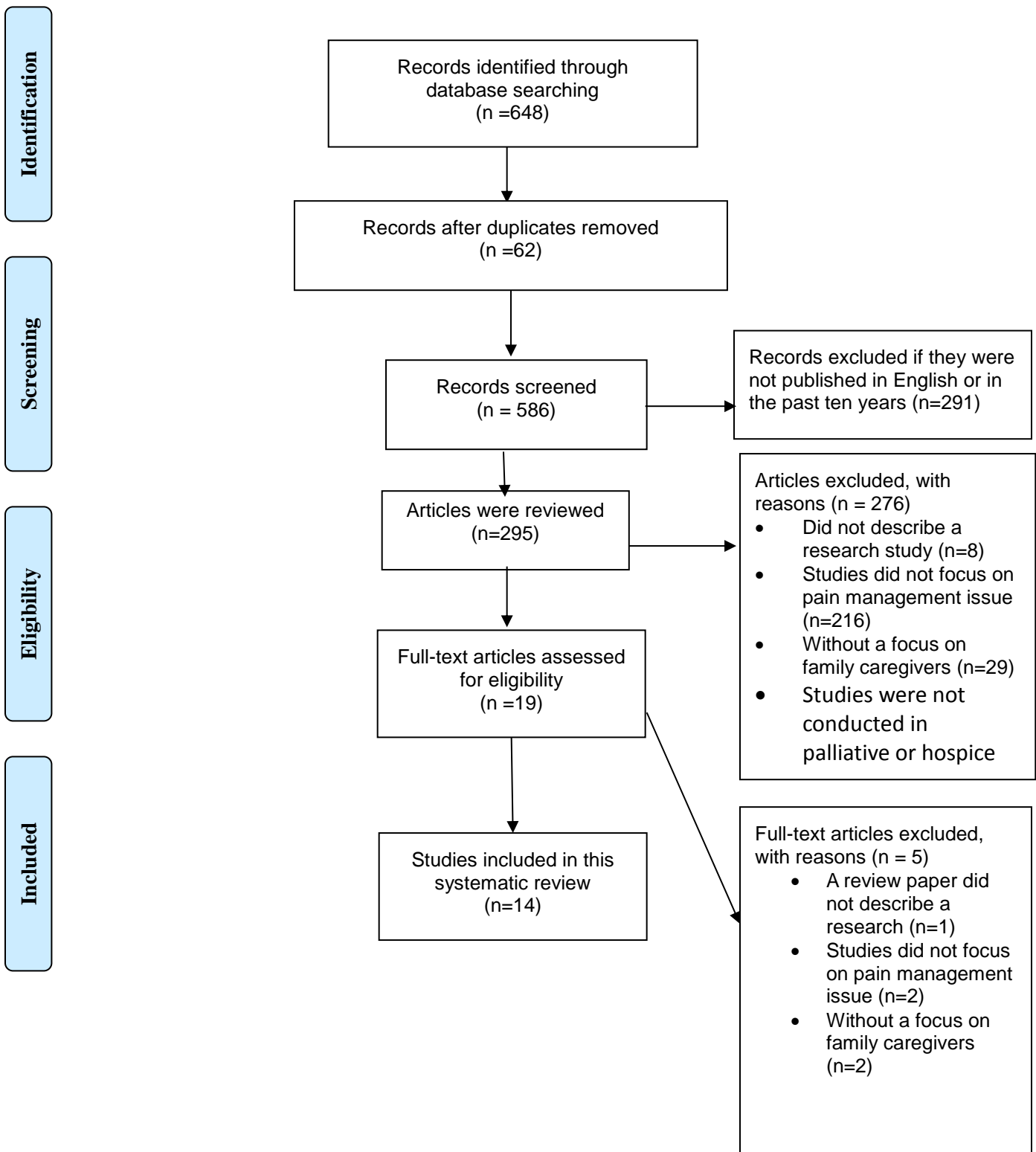


Table1-Characteristics of included studies: Experimental design

Patient=Pt; Caregiver=CG; End of life=EOL; Quality of life=QOL; Randomized controlled trial=RCT; Intervention group=I; Control group=C

Author /Year /Country /Journal	Purpose	Sample/ Setting	Study Design /Theoretical framework	Measures for CG Data collection	CG Outcomes	Limitations
Parker Oliver 2010, USA American Journal of Hospice and Palliative Medicine	To improve pain management through including CG participation in interdisciplinary team meeting via videophone	-68 CGs (38 in phase 1- control group and 30 in phase 2- videophone team meeting group) from two rural hospice programs -CG: mean age 58, 77% female, 97% white, 85% care their loved one at home, more than half were CG of pt with cancer	-Pilot, non-randomized, sequential mixed method 2-phase design -Framework: Family participation on health care teams of Saltz and Schaefer	-Compared the perceptions of pain medicine, QOL, anxiety between control group and videophone team meeting intervention group -All meetings were video recorded -Participants in the intervention group and staff also participated in interviews at end of research	-CG participation in the care planning change CGs' perceptions of pain medication, potentially improving pain management for Pts	-Small sample size -Non-randomization design -High attrition rate (greater than 40%)
Cagle 2015, USA Journal of Pain and Symptom Management	Describe the prevalence of CG barriers to pain management on admission to hospice and examine the preliminary efficacy of EMPOWER	-126 CGs of Pt receiving home hospice from four agencies (I:C=55:71) -CG: mean age 58.2, 59% CGs of Pt with cancer, 70% white, 25% African American,	-Pilot, cluster RCT -Framework: Cognitive behavioral framework	-The CGs in the interventional groups received: staff screening of barriers to pain management at admission, and discussion about misunderstandings regarding pain management After two week, CG were measured: -The Caregiver Pain	-When outcomes were evaluated at two weeks and three month, family CGs in the intervention group showed greater knowledge of pain and pain management and lower pain management barriers -The intervention appeared to be especially beneficial for American Americans at	-Collected data from medical chart and CG self-reported data -Small sample size -High patient mortality (63%) between two weeks and three months so this study only focused on the results at two weeks

	intervention	78% female, 40% spouse, 34% adult children, 30% full-time, 10% part-time, 33% retired, 22% unemployed		Medicine Questionnaire (CPMQ) -The Caregiver Self-Efficacy in Pain Management (CSE) -The Family Pain Questionnaire (FPQ) Knowledge Subscale -Patient Pain 10-point scale -The EMPOWER Pain Barriers Measure	reducing stigma	
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Table2- Characteristics of included studies: Descriptive design

Patient=Pt; Caregiver=CG; End of life=EOL; Quality of life=QOL; Randomized controlled trial=RCT; Intervention group=I; Control group=C

Author /Year /Country /Journal	Purpose	Sample/ Setting	Study Design /Theoretical framework	Measures for CG Data collection	CG Outcomes	Limitations
Tu 2007, Taiwan International Journal of Clinical Practice	Research the differences in perceptual congruence of Pts with cancer and CGs when assessing Pts' pain and QOL	-58 Pt-CG dyads from one hospice inpatient unit -All Pts with a diagnosis of cancer -CG: mean age 48.7, 77.6% female, 48.3% spouse, 32.8% children, 22.4% education above college, 84.5% married	A pilot, cross-sectional study	Pts and CGs completed demographic data, disease profiles, bio-psycho-social factors (including pain rating), and QOL questionnaires within ten days after the patients' admission. The trained hospice nurse also rated the patients' pain	-Pts' self-reported pain was higher than CG's and hospice nurses' rating -Pts' rating of QOL was lower than CG's rating -Biological pain, religion, and gender were independent variables for Pts' pain	-Low participation and high dropout rates (because of patients' terminal illness and poor condition) -Generalizability (results from one institution)
Parker Oliver 2008, USA Journal of Pain and Symptom Management	Understand the current practice of hospice assessment and collaboration on CG issues related to pain management	-30 Pt-CG dyads -Pts receive home hospice, most of Pts with a diagnosis of cancer -CG: mean age 60, 100% white, 87% female, 71% married, 90% education above high school, 39% adult children, 32% spouse	Mixed methods	This is part of a 2-phase mixed method study. This study analyzed hospice pain perception via questionnaire and interdisciplinary team meeting via qualitative analysis -Caregiver Pain Medicine Questionnaire (CPMQ) -Interdisciplinary team discussions from 23 dyads in 86 sessions	-87% of CGs indicated concern with at least one question on the Caregiver Pain Medicine Questionnaire -Only one discussion of caregiver pain-related concerns during the hospice team meeting	-Small sample size -Homogenous sample (100% Caucasian) -Generalizability (results from one hospice program)
Byrne 2011, USA	Explore the role of parent self-	-50 parent-children dyads -Children and	Secondary analysis	The study analyzed the surveys that participating parents filled out for a multi-	-The parents reported more negative moods and less vigor than adults	-Secondary data and cross-sectional design

Palliative and Supportive Care	efficacy related to pain management	adolescents with terminal illness -Parents: 60% white, 26% Hispanic/Latino, 30% education above college		site, multi-method, cross-sectional study. -The Chronic Pain Self-Efficacy Scale (CPSS) -Caregiver Strain Index -The Profile of Mood States (POMS) -Symptom Rating Scale (SRS)	in a normative sample -The parents had higher levels self-efficacy than previous reports average than reported previously by family caregivers of adult patients -The parents' strain and mood states (mood disturbance, anger, and fatigue) inversely correlated with pain management self-efficacy	-No measures of pre-illness general parent self-efficacy -Self-reported data -Selection bias: Recruit participants who speak English
Mehta 2011, Canada Oncology Nursing Forum	Describe the types of pain patients in palliative care at home experience and how CG assess them and intervene	-24 CGs of Pt with advanced cancer receiving palliative care at home -CG: mean age 69, 66% female, 66% spouse, diverse ethnicity	Qualitative grounded theory method -Framework: the Puzzle of Pain Management	Semi-structured interviews	Family were asking their pain management experience: Not all CGs were able to distinguish between the different pains afflicting patients and select the most appropriate interventions. This often led to poorly managed pain and frustrated CGs.	-Generalizability (recruit only CGs of Pts with cancer receiving palliative care in the home environment) -CGs who did agree to participate may have had more concerns related to pain, poor pain management, and uncontrolled pain than those who did not participate
Kelley 2013, USA Palliative Medicine	Describe and organize CG pain management challenges	-29 CGs of Pt with cancer receive home hospice service -CG: mean age 52, most were married, White, female, college education and living with the patient at the	Secondary analysis -Framework: informal caregiving in medication management for home hospice patients	Semi-structured interviews	-Six major themes: CG-centric issues(functional issues, concurrent responsibilities, and fears), CG inadequate medication skills and knowledge issues (pharmacology, polypharmacy, and drug side effects), end-of-life symptom knowledge	-Secondary data analysis -Small sample size -Sample homogeneity -The lack of the Pt's and professional hospice workers' perspectives

		time			issues, communication and teamwork issues, organizational skill issues, and Pt-centric issues	
McPherson, 2013 Canada Pain Research & Management	Explore the cancer pain perceptions and experiences of older adults with advanced cancer and their CGs	-18 older adults with advanced cancer receiving palliative care at home and 15 their family CGs -CG: mean age 70, 73%female, Canadian or European, 73% partner, 20%adult children, 86% residing with Pt	Qualitative descriptive study	Semi-structured interviews	Three themes of experiencing pain: -Feeling cancer pain: Sensory aspects of pain, origin of the pain, and meaning of cancer pain -Reacting to cancer pain: Behavioral, cognitive and emotional reactions -Living with cancer pain: functioning with cancer pain, caring for a family member with cancer pain, cancer pain in the relationship	-Small sample size -Sample homogeneity (female CG) -The lack of the professional hospice workers' perspectives
Parker Oliver 2013, USA Journal of Pain and Symptom Management	Understand the hospice CGs experience relating to pain management	-38 CGs of Pts receive home hospice -CG: 76.3% female, 53% > 60 years old, 94.7% White, 68.5% > college education, 79% married, 50% adult child, 21% spouse, 52.6% living with Pts	Qualitative descriptive study	Semi-structured interviews	Five themes: 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.	-Generalizability (results from one area)
García-Toyos 2014, Spain Pain Medicine	Identify the values and preferences of terminal Pts and CGs regarding treatment	-22 Pts with advanced cancer receiving home hospice care at home or hospital and 20 CGs	Qualitative descriptive study	Semi-structured interviews	-Less than one-third of participants recognized the term opioid. Among these, they had false beliefs of these drugs including addiction, risks of cognitive impairment	-Selection bias: The absence of patients who had rejected the treatment. Recruited Pt with high adherence to treatment.

	with opioids	-CG: mean age 53.9, 80% female			and premature death, and exclusive use in end-of-life care -The information received was very general on the opioid treatment -They expressed interest in receiving more information and participating in therapeutic decision making	-Generalizability
Mehta 2011, Canada Journal of Psychosocial Oncology	Highlight the sources of distress experienced by family CGs managing pain at home	-24 CGs of Pt with advanced cancer receiving palliative care at home -CG: mean age 69, 66% female, 66% spouse, diverse ethnicity	Secondary analysis	Semi-structured interviews Family CGs' were interviewed to ask their thoughts, feelings and concerns around pain management	Major themes: -Like being in a prison: overwhelmingly responsible -Flying blind: unprepared -Lambs to the slaughter: unsupported -It hurts to watch somebody you love suffer	-Secondary data analysis -Small sample size

Table3- Characteristics of included studies: Case study design

Patient=Pt; Caregiver=CG; End of life=EOL; Quality of life=QOL; Randomized controlled trial=RCT; Intervention group=I; Control group=C

Author /Year /Country /Journal	Purpose	Sample/ Setting	Study Design	Results	Discussion
Kirk 2007, USA Pain Management Nursing	Presents a case study, moral analysis, and an evidence-based, practical plan of action for engaging family members on a home hospice service	A 74-year-old white male with end-stage cancer receiving home hospice and her wife is the primary family CG	Case description and discussion	-The family CG failed to provide sufficient pain management to the Pt -The author developed plan of action for hospice nurses to engage family caregivers on care: 1) Establish common goals; investigate disparities 2) Establish shared perceptions; investigate disparities 3) Establish shared beliefs; investigate disparities 4) Establish shared action/behaviors; investigate disparities	-Not all family CGs are able to provide adequate care and support to their loved ones -The author created action plan for hospice nurse to guide, educate, and support family CGs. The author want to open more discussion on this topic and generate alternative plan of action for other hospice professionals in the future
Baldwin 2012, USA American Journal of Hospice and Palliative Medicine	Explore African American CG's experience with hospice pain management	A 54-year-old CG (married, full-time professor) of a 81-year-old mother with stomach cancer receiving hospice care in a long-term care facility	Semi-structured bereavement interviews with the family CG	-CG's dissatisfaction with and distrust of hospice owing to her observations of poor communication between the hospice staff and the nursing home staff and neglected concerns about overmedicating her mother. -This family CG rated her personal knowledge and skills of pain management as moderate, satisfaction with the hospice care and the hospice team's pain management as moderate, and the quality of her mother's death as moderate high, but rated her understanding and comfort with her mother's pain medication as low	-Building trust and cooperation relationship among health care professionals and family caregivers is essential -High educated family CGs doesn't mean that they have higher understanding of and comfort with pain management -African American cultural beliefs and beliefs about medical care might be potential factors to create barriers to effective pain management
Reddy 2013, USA	Describe a mother prevents	A middle-aged African American woman with T-	Case description and	-The mother advised the patient not to use any pain medications as they would interfere with her cognition and	-A patient can make decisions with autonomy but may be influenced by external factors such as family

Journal of Palliative Medicine	the daughter from receiving adequate pain management at the end of life (in hospital)	cell lymphoblastic leukemia in her end-of-life stage and her mother was the primary family CG	discussion	function and would prevent her from receiving any further chemotherapy -The patient complained of severe pain (10/10) associated with bladder spasms, crying, and screaming, yet she continued to refuse pain medication. And the patient deferred all decisions to her mother -The family CG prevented the patient from receiving adequate pain management and hospice care despite interdepartmental and interdisciplinary efforts (end-of-life discussion, consultation, education)	coercion -This case highlighted the importance of understanding and addressing fears regarding opioid use and implementing an integrated approach including oncologists and palliative care physicians, along with early referrals to palliative care -Future studies should focus on understanding barriers to adequate pain management and the role of patient and family education regarding the use of opioids as a tool for overcoming such barriers
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Chapter Three

Pain Management Concerns from the Family Caregivers' Perspective: Validation of a Framework Outlining Pain Management Challenges in End-of-life Care

Abstract

Background: In end-of-life care, family caregivers are often asked to support pain management and administer pain medications at home. Pain management is one of the most challenging tasks for family caregivers. However, there are limited studies that examine the challenges related to pain management in end-of-life care (for all terminal illnesses) from family caregivers' perspectives.

Objectives: The purpose of this study was to identify the challenges related to pain management faced by family caregivers in hospice care and 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 recently completed five-year randomized clinical trial. The major themes in the "informal hospice caregiver pain management concerns" framework include caregiver-centric issues, caregiver's medication skills and knowledge, end-of-life symptom knowledge, communication and teamwork, organizational skill, and patient-centric issues.

Setting/participants: We included baseline interviews of 15 hospice caregivers of patients with diverse diagnoses from hospice agencies in the States of Washington. The majority of the participants were White, female, married, and had a college degree. Most of them were spouse/partner or adult child living with the patient.

Results: The study identified five out the six major themes in the original framework and that hospice family caregivers face a wide variety of challenges including 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 in our findings. We also expanded the original framework by adding one subtheme and revised two definitions.

Conclusions: The study provided an investigation on hospice family caregivers' difficulties in pain management. The results confirmed most of the themes and subthemes in the original framework, as well

as expanded the original framework. The results can inform healthcare providers and researchers of family caregivers' challenges and provide insights for future designs of educational materials targeting pain management strategies, so that family caregivers can perform pain management effectively at home.

Introduction

More than 1.6 million Americans with a terminal illness received hospice services in 2014, and about 60 percent 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 pain in the end-of-life care was undertreated.⁶⁻⁷ Factors that lead to pain being undertreated include patients and family caregivers' fear and beliefs in pain management, and healthcare 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, or medical and nursing tasks. Among all the tasks, pain management has been rated as one of the difficult tasks for family caregivers.⁸⁻¹⁰ Pain management make caregivers felt stressful and frustrated⁸, and affect 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 caregivers including pain assessment, medication administration and management, outcomes evaluation, and communication with healthcare 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 healthcare team.^{9-10, 21} Although the evidence on this topic is growing, the majority of the published studies have focused primarily on challenges in managing pain suffered by patients with cancer and their family caregivers. 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 22 hospice providers and 23 family caregivers of older patients in the Chicago Metropolitan area to identify effective medication management skills to

relieve symptoms including: (1) teamwork (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 Tjia and colleagues conducted secondary data analysis of 18 interviews of home hospice visits to assess the applicability of Lau's framework in home hospice care in the greater urban area of the Rocky Mountain West.²² All the patients had a diagnosis of cancer. The results supported the "Family Caregivers' Skills in Medication Management" proposed by Lau et al and the authors also updated the framework by adding two subthemes into personhood skills.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 29 hospice family caregivers of cancer patients' interviews from a clinical trial (NINR, Grant Nr. R21 NR010744). The major themes in the framework were (1) caregiver-centric issues (function, cognition, beliefs, self-efficacy, etc.); (2) caregiver's medication skills and knowledge (knowledge, medication administration, pain assessment, personhood issues); (3) end-of-life symptom knowledge; (4) communication and teamwork; (5) organizational skill; and (6) patient-centric issues (pain assessment congruency, psychological well-being, nutrition and hydration, inability to verbalize pain, etc.).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 text, 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. The participants in the present study were different from Kelley's study and had diverse diagnoses including dementia, heart failure, stroke, pulmonary, etc. In 2014, more than 60% of patients enrolled in an outpatient hospice program had a non-cancer diagnosis such as heart disease and dementia.¹ As the hospice patient demographics are changing and the number of patients with a non-cancer 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 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, healthcare 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 five-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, PI: Demiris). The study was approved by the Institutional Review Board at the University of Washington.

Settings and Participants

The original study enrolled 514 hospice caregivers of patients with diverse diagnoses from hospice agencies in the States of Washington, U.S. The inclusion criteria were: 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 their 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 post admission 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 their care recipient for more than one 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 (pre-intervention) interviews of the hospice family caregivers who identified pain management as their major caregiving challenge in the parent study. The first author (NC) listened and screened 514 participants' baseline interview recordings to verify their eligibility. The inclusion criterion of interview recordings was that family caregivers discussed their pain management difficulties with the interventionist in their baseline interview. Fifteen family caregivers' interviews were included and transcribed verbatim by professional transcriptionists of an audio transcription company.

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 (NC) listened to and verified all the transcripts. Two authors (NC, GD) perused the themes, definitions, and examples in Kelley's framework. Two authors (NC, GD) listened to all audio recordings to be familiar with the interviews. In the framework, all major themes and subthemes has their own definitions and examples (See Table 1). In each transcript, the first author used line-by-line coding to code sentences related to challenges of pain managements 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, quotes were organized into a table and reviewed by two authors (NC, GD). The inter-rater agreement rate was 71%. Two authors (NC, GD) 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 disagreement between two authors was discussed until reaching 100% consensus during weekly research meetings over six months. For sentences that did not fit into any theme and definition in the original framework, the two authors created new themes or modified the original themes in the original framework. Two co-investigators of the parent

study also did peer debriefing of the results of the analysis.²⁵

The first author (NC) verified the transcript before analyzing the data, maintained an audit trail, and asked peer debriefing to protect trustworthiness.²⁵ The second author (GD) who had prolonged engagement in hospice research for 15 years was the primary investigator of the parent study and one of the co-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 one to three years (33.3%) or more than three years (33.3%). Caregivers' demographics were listed in Table 2 and individual caregiver's profiles in Table 3.

There were six major themes and 35 subthemes in Kellye's framework (See Table 1) or the major themes, the analysis identified five out of the six major themes in Kelley's framework except for end-of-life symptom management. Some subthemes in the original framework were not present in our data: caregivers' cognition, caregivers' 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: added one new sub-theme "physical well-being issues" into the patient-centric issues and expanded the definitions of two sub-themes: caregivers' functional issues and caregiver support network (Table 4. updated framework, definitions, and exemplars). Our 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 several subthemes: functional issues, cognitive issues, cultural issues, belief system, self-efficacy/ optimism/ self-confidence, duration/extent of caregiving and proximity to death, previous life experiences, and

concurrent responsibilities.²³

The analysis identified most of the subthemes under the major theme of caregiver-centric issues except caregivers' cognitive issues and cultural issues. The results can be explained partly by that inclusion criteria 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) that affected their pain management strategies for patients.

Functional issue is 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 commented that she was too exhausted to provide care so she overmedicated her husband: "Just physical and mental exhaustion on all of [the family members were overwhelming]... I over-medicated him. 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 caregivers' philosophy in managing patients' pain.²³ One daughter caregiver struggled with the belief that pain medication was hastening 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." This caregiver also wondered about the meaning of pain control, "I believe that Western medicine is so frightened of pain that we think of dignity as being painless and being medicated out of our minds when we're in pain." (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 pain medications to her care recipient, "I'm not looking forward to giving him pain medication of 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. I just don't want to do that." (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 subthemes, pharmacological knowledge (n=2) and pain assessment (n=5) was the most common issues.

Pharmacological knowledge referred to caregivers' working 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 [the patient] 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 healthcare providers that may make pain management difficult for the caregiver. The subthemes were caregiver-patient communication, caregiver-family communication, caregiver-healthcare system communication, and caregiver support network communication issues.²³ The family caregivers in the analysis identified two subthemes: caregiver-healthcare system issues (n=4) and caregiver support network communication issues (n=3).

Caregiver-healthcare system communication addressed issues about ineffective communication between healthcare team and family caregivers.²³ The communication between

healthcare 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 healthcare providers. One caregiver described her experience when the patient experienced breakthrough pain, and she really needed pain medication guidance from healthcare providers: “[Healthcare 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*.” One caregiver felt she was the only person who knew how to provide care for her mom and alleviate her mom’s pain. She could not find other people to stay with her mom. This caregiver was sick and her physician suggested her to receive care or join support groups. The caregiver said she would not consider joining a support group presently because that she wanted to have personal time. (P11)

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 three large drugstores and a police station, and they wouldn’t take [morphine]. We made five attempts to get rid of morphine...So my daughter took all the labels off and put [morphine] into four different trash cans.” (P6)

Major Theme: Patient-Centric Issues

Patients’ well-being and beliefs towards 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' non-verbal cues, so the pain maybe over-treated or under-treated. 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 pinpoint a number." (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 overmedicated her husband because she 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

Our 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. Kelley's 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 sample size and the inclusion criteria (caregivers have no severe cognitive impairment and speak English). The caregivers' characteristics can explain why family caregivers did not identify issues related to caregivers' cognition, culture, medication administration, and tracking and recording medications issues. Also, this study did not include patients, so patients' beliefs and nutrition and hydration issues were not present in the study. Furthermore, the family caregivers were included in the

parent study in the early stage of hospice admission, so they did not discuss the challenges of dealing with end-of-life symptoms. Future study can conduct a longitudinal investigation from hospice admission and bereavement stage and include a large sample size of family caregivers 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 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 healthcare 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 caregivers, 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-healthcare 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' fatigues impeded their ability to make thoughtful decisions and give correct dosages of pain medications.¹⁴ In our study, most of the caregivers lived with their care recipient (80%) and provided more than 20 hours of caregiving per week (86.7%) for more than one year (66.6%). This finding demonstrated the importance of providing respite care information or resources to family caregivers to decrease their caregiving burden. During each visit, healthcare 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 as well. When needed, healthcare providers can refer the case to a social worker, a volunteer coordinator, a counselor, or a financial assistance program.

Caregivers' Beliefs

Caregivers' fears and mythical beliefs of pain medications were the main issues that hindered effective pain management. Some caregivers viewed administering pain medications as assisted suicide, hastening death, or sedation 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 caregivers' fears of medication addictions and side effects.^{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 patients, family caregivers, and healthcare providers. At the same time, the healthcare 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, healthcare 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} Opiates 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 for the general public.

Caregiver-healthcare 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 healthcare 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 meeting² and using video or other telehealth technology to remotely assess patients' condition³².

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. Healthcare providers follow pain management guidelines to manage pain, and it is necessary for healthcare providers to ensure that family caregivers are able to perform and follow the same guidelines. Healthcare 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.³³⁻³⁶ Cagle and colleagues conducted a pilot randomized clinical trial to test the efficacy of interventions consisting of hospice staff education, screening of barriers to pain management, and an educational brochure discussing misunderstandings of pain management for family caregivers and patients.³⁷ The results found that caregivers had better knowledge and fewer concerns about pain and pain medications, and lower pain in patients.³⁷ Capewell et al. conducted a feasibility study to examine a 6-minute DVD-based educational intervention for cancer patients and their caregivers in palliative care.³⁸ 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.³⁷ More future research is needed to focus on examine the long-term effective and efficient way to deliver educational materials to patients and their family caregivers.³⁸

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. Healthcare 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 a 10-point pain scale and a facial pain scale, healthcare 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,^{30,31} especially for a patient with dementia or other types of cognitive impairment.²⁹ Furthermore, healthcare providers can demonstrate how to assess pain, administer pain medications, keep records of pain medication usage, and ask family caregivers to teach back.

Pain Medication Dispose Issues

Pain medication 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 (FDA) 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 Healthcare providers should 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 healthcare 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 caregivers; about 10%) described that they faced pain management challenges at their baseline questionnaires. However, when they were asked to deal with their most pressing life event or caregiving challenge using problem-solving strategies in their baseline interviews, many caregivers decided to tackle other issues such as work accommodation, financial constraints, etc. 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, a lack of patients' perspective, some subthemes identified 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.

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Table 1. Kelley “Informal Hospice Caregiver Pain Management Concerns” Framework”²³

Major themes and sub-themes	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/	Caregiver’s negative self-efficacy in making decisions correlates with inability to manage pain.

Self-Confidence	
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.
<ul style="list-style-type: none"> ● Polypharmacy Issues 	Complex medication interactions may inhibit pain management. Lack of working knowledge and skill with medicines may inhibit pain management.
<ul style="list-style-type: none"> ● 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 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 (i.e. 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 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	A caregiver under-estimates or over-estimates 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.
<ul style="list-style-type: none"> ● Patient's Mythical Beliefs 	Patient's beliefs not based on facts or scientific evidence.
<ul style="list-style-type: none"> ● Patient's Religious/Ethical/ ● Moral Beliefs 	Patient's religious, moral, or ethical beliefs are at odds with caregiver's beliefs or hospice philosophy.
<ul style="list-style-type: none"> ● Patient's Fears 	Patient's fears surrounding EOL or pain that may interfere with pain management.

Table 2. Caregivers' Demographics (N = 15)

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 or part-time)	7 (46.7%)
Caregiving > 20 hours/week	13 (86.7%)
Duration of Caregiving	
● < 6 months	3 (20%)
● 6 months – < 1 year	2 (13.3%)
● 1 year – < 3 years	5 (33.3%)
● > 3 years	5 (33.3%)

Notes. N, (%) unless otherwise noted.

Table 3. Individual Caregiver's Profiles

Participant ID	Age	Relationship with patient	Patient's diagnosis
P1	81	Spouse/partner	Dementia
P2	68	Spouse/partner	Diabetes
P3	38	Other	Cancer
P4	42	Spouse/paww22a12rtner	Amyotrophic lateral sclerosis
P5	54	Other	Heart failure
P6	82	Spouse/partner	Cancer
P7	60	Adult child	Dementia
P8	61	Adult child	Unknown
P9	82	Other	Cancer
P10	67	Other	Stroke
P11	56	Adult child	Pulmonary disease
P12	62	adult child	Cancer
P13	79	Spouse/partner	Cancer
P14	60	Adult child	Leukemia
P15	45	Spouse/partner	Cancer

Table 4. Updated “Informal Hospice Caregiver Pain Management Concerns” Framework”

Major themes and sub-themes	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)	Revised definitions: Physical and/or psychological caregiver limitations, burden, or exhaustion preventing adequate management of patient’s pain (physical, psychological, social, and/or spiritual).	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.	
<ul style="list-style-type: none"> 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)
<ul style="list-style-type: none"> Mythical Beliefs (n=1) 	Caregiver’s beliefs not based in scientific evidence.	Pain doesn't kill you. You don't die from pain. (P15)
<ul style="list-style-type: none"> 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 totally 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	Duration of care and requirements, as well as proximity to death may	A total of 15 days, [my wife] has no sense at all. But

Proximity to Death (n=2)	interfere with pain management.	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)
<ul style="list-style-type: none"> ● 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 decisions 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	Because of our desire for quality of life to have her

	caregiver refuses to act in accordance with those wishes.	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 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 Health-Care Delivery System Communication Issues (n=4)	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)	New definition: 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.	We went to three large drugstores and a police station, and they wouldn't take [morphine]. We made five attempts to get rid of morphine...So 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 under-estimates or over-estimates 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)

Chapter Four

Testing the Utility of a Pain Management Education Tool for Hospice Care Providers

Abstract

Context: Pain management is a challenging task for family caregivers. Few studies explored the design of educational interventions that could be integrated into the hospice routine care and support family caregivers.

Objectives: To design an educational tool for hospice providers to support family caregivers in pain management as well as test the perceived utility of the educational tool and other recommendations by hospice providers.

Methods: We designed an educational tool based on the Assessing Caregivers for Team Interventions framework and a secondary analysis of interview data obtained from a clinical trial with hospice caregivers. The educational tool was structured into five modules, each organized into two parts: (1) A description of the common clinical pain management scenarios that were identified in analyses of the caregiver interviews; and (2) A list of questions and strategies for hospice providers to assess and support family caregivers in pain management. Some pain management strategies and pain assessment tools were organized as an appendix in the tool for providers to teach caregivers. The content of each scenario was vetted through two experts in cancer pain management and three experts in hospice caregiver research. After multiple revisions, the final version of the educational tool was evaluated for utility by 15 hospice providers including physicians, nurses, pharmacists, social workers, and chaplains from the Seattle metropolitan area.

Results: The hospice providers found the scenarios realistic and strategies to be effective. Participants believed that the educational tool could be a reminder and reference in hospice care, and a material for orientation and continuing education for hospice providers. They suggested adding additional pain education content and some further common pain management challenges into the tool to enhance the utility. Participants advised creating more than one platform for the tool such as a printed booklet, website, video, or mobile application in order to accommodate different user needs and experiences.

Conclusions: The study showed that the educational tool holds promise to be effective and practical in the context of hospice care. The tool also has potential to improve communication in pain

management, and could be integrated into hospice providers' routine care. Future research can translate the educational tool to several platforms and test its effectiveness on hospice providers', family caregivers', and patients' outcomes.

Introduction

Pain is a common symptom for patients with a terminal illness such as cancer, dementia, heart disease, and lung disease due to patients' physical deterioration, disease progress, treatment, and distress.¹⁻³ More than 50% of patients experienced pain in end-of-life care.³⁻⁸ A nationally representative longitudinal survey of symptom prevalence among community-dwelling residents in the U.S. showed that the prevalence of pain during the last year of the residents' life increased from 54.3% in 1998 to 60.8% in 2010.⁹ However, pain was undertreated. A systematic review determined that the prevalence of undertreated cancer pain was about 50%.¹⁰ A nationally retrospective survey reported that 16% of the decedents who died between 2010 and 2013 in the U.S. had unmet needs in pain management during the end-of-life care.¹¹

Hospice services focus on supporting patients and their family caregivers in comfort care, symptom management, and addressing their emotional and spiritual needs.¹² More than 1.6 million Americans enrolled in hospice services in 2014.¹² Among these patients, 58.9% of them received outpatient hospice services at their place of residence or home while 31.8% of them lived in an inpatient facility.¹² Hence, for a patient receiving hospice services at home, their family caregiver (informal caregiver) is the key person who carries out clinical tasks and symptom management.¹³

Pain management is a difficult task for family caregivers because it requires a combination of skills including pain assessment, medication management and administration, and organization skills.^{14, 15} Studies showed that pain management could cause negative consequences to family caregivers' well-being (e.g., fatigue, exhaustion, and anxiety) and quality of life.^{16, 17} In the last two decades, a number of studies explored factors interfering with family caregivers' effective pain management: a lack of knowledge and assessment skills in pain management;^{14, 18, 19} fears of potential side effects of pain medications;²⁰⁻²¹ incongruent pain assessment between patients and family;^{22, 23} and ineffective communication with healthcare providers.²⁴⁻²⁶ Kelley and colleagues developed a framework that described family caregivers' concerns in hospice care.²⁷ The framework addressed factors that can affect caregivers' pain management including caregiver-centric issues, caregiver's medication skills and knowledge, caregivers' end-of-life symptom knowledge, communication and teamwork, organizational skill, and patient-centric issues.²⁷ In a survey study, hospice providers agreed that three approaches

were critical to support family caregivers in managing medications for patients' symptoms: teaching to increase knowledge, supporting medication management process, and counseling to overcome attitudinal barriers.²⁸ However, only 6% of the hospice providers reported they used all of the three approaches and 47% believed that providers would benefit from additional resources to help caregivers.²⁸

Corresponding to these issues, some studies designed pain management training programs to support family caregivers in pain management, but mostly focused on a cancer population.²⁹⁻³⁴ Ferrell et al. conducted one of the earliest nurse-led educational programs for family caregivers of patients with cancer.²⁹ The program consisted of three face-to-face sessions: pain assessment, pharmacological treatment management, and nonpharmacological strategies. Keefe and colleague designed a face-to-face program included pain management and pain coping skills delivered by a nurse educator for hospice cancer patients and their family caregivers.³⁰ Both studies enhanced caregivers' knowledge and attitude in pain management²⁹ or self-efficacy in pain control.³⁰

A recently published systematic review synthesized interventions to support family caregiver managing pain medications for advanced cancer.³⁵ Eight studies were identified and the interventions included one to three face-to-face educational sessions delivered by trained healthcare providers or researchers.³⁵ Few interventions were designed to be integrated into clinical practice or involved providers in the development process.³⁵ For pain management interventions to become successful and ultimately adapted in clinical practice, the intervention needs to address their translation and applicability into real life patient scenarios throughout the design and testing phases of the intervention. Such efforts include ongoing involvement of stakeholders in these phases.

Pain management is a multidimensional process and requires efforts and contributions from patients, family caregivers, and healthcare providers; thus, these stakeholders need to provide feedback to any educational intervention addressing pain management. Additionally, such interventions in the hospice setting need to be comprehensive (addressing various pain types and challenges) but also focus on other diagnoses not just cancer. In 2014, 63.4% of patients enrolled in the hospice services had a non-cancer diagnosis (e.g., dementia, heart disease, lung disease).¹² In order to support family caregivers in home hospice care, there is a need to design an effective and practical educational tool for hospice providers to support or instruct family caregivers during home visits. The purpose of this study was to (1) design a pain management educational tool for hospice

providers to assist family caregivers better manage pain that is meant for all diagnoses in hospice care; (2) test the perceived utility of the educational tool and other recommendations by hospice providers; and (3) understand how to best implement the educational tool as well as further refine it.

Methods

Development of an Educational Tool

A secondary data analysis of a recently completed randomized clinical trial with hospice caregivers (NINR, Grant Nr. R01NR012213, PI: Demiris) was conducted to identify hospice family caregivers' challenges in pain management. In the secondary analysis, we reviewed 514 hospice family caregivers' baseline interviews and only included the interviews in which family caregivers discussed their challenges in pain management. The analysis identified several challenges that caregivers faced when trying to manage pain for their care recipient including caregiver-centric issues (e.g., function, beliefs, fears), caregiver's medication skills and knowledge (e.g., pain assessment issues), communication and teamwork, organizational skill, and patient-centric issues (e.g., pain assessment congruency, inability to verbalize pain). A more detailed description of the content analysis of these interviews can be found elsewhere.³⁶ For each challenge, we recorded the numbers of family caregivers who encountered and discussed their experience with the challenge. We selected the five most frequently mentioned issues raised by participating family caregivers that hindered an effective pain management for their care recipient: (1) Caregivers' physical and psychological burden (n=4); (2) Caregivers' fear of side effects of pain medications (n=3); (3) Caregivers' beliefs (n=4); (4) Caregivers' inability to accurately assess pain (n=5); and (5) Caregiver and healthcare delivery communication and teamwork issues (n=4).

Based on the results, we developed an educational tool consisting of five scenarios along with strategies for hospice providers to support family caregivers in pain management. The tool aimed to help hospice providers to recognize challenges of pain management faced by family caregivers and support family caregivers in pain management.

The educational tool consists of five modules and an appendix that contains several pain management strategies, pain assessment scales, pain medication tracking table, and some pain management and caregiving resources for providers to use and instruct family caregivers of their

use. Each module was organized into two parts: (1) a description of the common pain management scenarios that were identified in analyses of the caregiver interviews and included direct quotes from the study participants; and (2) A list of assessment questions, strategies, and follow-up questions for providers to use when interacting with family caregivers. The suggested questions and strategies were developed based on the Assessing Caregivers for Team Interventions model (ACT model)³⁷ (See Figure1).

The ACT model was originally developed by Pearlin et al. but modified by Demiris et al. to fit into the hospice caregiving context.³⁷ The ACT model explains how caregivers' background context (e.g., support services, and employment) and caregivers' stressors (e.g., physical exhaustion, lack of time for self-care, disruption in caregivers' life, financial concerns, myths, role identity, and role mastery) affect family caregivers' outcomes of the hospice experience (e.g., caregivers' quality of life, anxiety, satisfaction with hospice, and perceptions of patients' outcomes). For each scenario, we created questions for hospice providers to assess the elements in caregivers' background context and stressors relevant to the scenario and strategies that hospice providers can use to ease caregivers' stressors in pain management and advance their pain management skills. For example, if a caregiver has misbeliefs about morphine, the questions can help hospice providers further explore caregivers' belief about morphine and role identity in pain management. The strategies can help hospice providers support caregivers' role in pain management and find resources and social support for caregivers. The follow-up questions help hospice providers to evaluate the outcomes of the assessment and strategies on family caregivers. Below is an example of one module:

SCENARIO: CAREGIVERS' BELIEF-ETHNIC DILEMMA

For two years, Bob has been taking care of his 70-year-old wife who has heart disease and shortness of breath which requires that he administer morphine to make her comfortable. As his wife's pain is getting worse, the dosage of morphine keeps increasing. Bob says that he is concerned about a medication overdose which might hasten his wife's death. Bob says, "Assisted suicide is what [my wife] would have gone for, if there would have been enough time for her to lucidly go that direction." But Bob tells the nurse, "It is a real moral dilemma for me."

WHAT TO ASK FAMILY CAREGIVERS IN SIMILAR SITUATION:

Role identity

What are [care recipient's name] expectations/wishes of end-of-life care?

What are your expectations of end-of-life care?

How [care recipient's name] feel about the side effects of morphine?

Role mastery

How comfortable are you with administering morphine?

How do you know if [care recipient's name] is in pain?

Beliefs and myths

How does morphine fit in the goal of care?

What, if anything, worries you about giving morphine?

What do you believe about using morphine?

What is your and the patient's experience with pain and morphine?

Explore caregivers' belief in morphine, "People often feel morphine would hasten patients' death.

How do you think?"

WHAT TO DO FOR FAMILY CAREGIVERS:

Role mastery

Explain the purpose of using morphine.

Beliefs and myths

Clarify that use of morphine to treat a patient's pain is not assisted death.

Clarify that it is common to increase the dosage of pain medication over time as patients develop tolerance, which is not overdose.

Clarify that the patient will die from the disease, not morphine.

Support services and social support

Validate caregivers' feelings with a statement such as, "Giving pain medicine is difficult for many caregivers."

Encourage caregivers to express the way they prefer to relieve the patient's pain.

Schedule, if acceptable to the caregiver, meetings among the patient, family members, and hospice care team to discuss the patient's wishes or needs in end-of-life care.

Refer the case to a social worker, counselor, hospice chaplain, or local clergy if needed.

FOLLOW-UP WITH FAMILY CAREGIVERS:

Role mastery

What do you think about the current medication regimen?

Beliefs and myths

Do you feel less conflicted when administering morphine?

Support services and social support

How was the discussion regarding the goal of pain management among family members?

The content of each module was vetted through two experts in cancer pain management and three experts in hospice caregiving research. Experts provided feedback in terms of expanding the

scenarios, re-writing or clarifying questions, and enriching the details of each of the scenarios. After multiple revisions, the final version of the educational tool was evaluated for its utility by hospice providers.

Evaluation of the Educational Tool

We conducted an evaluation study to test the utility of the education tool for hospice providers. Participants were interviewed to seek their feedback on the education tool (and more specifically, their views on how this tool could be used or improved, and any challenges or other considerations associated with its use). Care providers across disciplines and spiritual counselors in the hospice care team, including medical directors, physicians, nurses, pharmacists, social workers, and chaplains were recruited because they all support patients and family caregivers in pain management. Participants were recruited from the Seattle metropolitan area through posting flyers in several hospice agencies, sending research invitation via emails to hospice agencies and hospice providers' networking groups, and snowball sampling. The inclusion criteria for participants were that they are healthcare providers who have experience in home hospice care and deal with pain management for patients and family caregivers. The exclusion criterion was unwilling to be audio-recorded. All of the potential participants contacted the first author (NC), who assessed them for their study eligibility. The study was approved by the Institutional Review Board of the University of Washington. All included participants signed a consent form before the interview.

All participants took part in a one-time, face-to-face, individual, semi-structured interview conducted by the first author (NC) at their workplace or other setting of their choice between February 2017 and April 2017. Before the interview, participants completed a demographic information form (assessing age, gender, race, type of profession, and years of work experience). During the interview, the participants were asked to read the educational tool first, then they were asked for their feedback following an interview guide (Table 1. The Interview Guide). The interview guide consisted of 12 questions regarding the realism of the scenarios based on their experience, perceived effectiveness of the strategies, suggestions for any improvement, other frequent challenges the providers encountered in their clinical practice, utilization of the tool in their clinical practice, and preferred platforms of the tool.

Data Analysis

Participants' demographic data were entered into a spread sheet to conduct basic descriptive

statistics.

Braun and Clarke's thematic analysis steps were employed to analyze the participants' interview data.³⁸ Thematic analysis is to search for and identify common threads across the interview data for specific research questions following systematic and standardized steps.³⁹ Six steps were followed: (1) Familiarizing of the data: the first author read all the transcripts and listened to the audio recordings to validate the accuracy of the transcripts. The three authors (NC, SH, GD) then read all the transcripts to become familiar with the data. (2) Generating initial codes: Three authors discussed and created an initial codebook with initial codes and definitions. The coding unit is the sentences with a complete idea. This study's investigator and another member of the research team of the parent study analyzed the interview data line-by-line independently using Track changes in Word. The two authors coded the first five transcripts first, compared the coding results, resolved the conflicts codes, and revised the codebook. The inter-coder agreement rate of the first five transcripts was 72%. The revised codebook was used to code the next 10 transcripts. The codebook was expanded and refined along the coding process. The inter-coder agreement rate of the next 10 transcripts was 77.1%. (3) Searching for the themes: all codes and coding units were grouped into tables to review and redefine iteratively to ensure its accuracy and consistency by the three authors. Similar codes were grouped together to develop themes. (4) Reviewing themes: The themes, codes, and definitions were reviewed and refined iteratively by the three authors to ensure its compatibility and consistency. (5) Defining and naming themes and domains: The theme were generated and refined to represent the analysis. Similar topics of themes were grouped to develop higher levels of domains. (6) Producing the report: The first author reviewed the final analysis and selected compelling examples to report in this paper.

There were several strategies to protect the trustworthiness. The verification of transcripts, prolonged engagement in hospice research, established audit trail, and peer debriefing was used to enhance the trustworthiness. The transcripts were verified by the first author (NC) who interviewed the participants. The third author (GD) had more than 15 years of hospice research experience to guide the interview and analysis procedures. Two coders (NC, SH) coded data separately, discussed constantly, and asked for peer debriefing during weekly research team meetings.⁴⁰

Results

Sixteen hospice providers contacted the first author and met the inclusion criteria. One provider started the interview but did not finish the entire interview process due to an urgent family call. A total

of 15 hospice providers' demographics and interview sessions were analyzed.

We recruited 8 nurses (53.3%), 2 physicians (13.3%), 2 social workers (13.3%), 2 chaplains (13.3%), and 1 pharmacist (6.6%) from 5 hospice agencies and 2 hospitals in the Seattle metropolitan area. All participants were employed at the time of the study (86.6%) or had work experience (13.3%) in home hospice care. The majority of them were White (93.3%), female (86.6%), and had home hospice working experience more than 10 years (60%) (Table 2. Providers' Demographics). All interviews were transcribed verbatim. The length of interviews ranged from 17 minutes to 52 minutes with an average of 32 minutes (\pm Standard Deviation 11.3 minutes).

Participants were asked questions about the utility of the tool (Table 1. The Interview Guide). The responses were analyzed by each scenario but the responses to each scenario had many overlaps. Hence, the results were synthesized by combining answers from each of the scenarios. Table 3 lists the domains and themes, codes, and exemplars of the themes.

Domain 1: The Utility of the Educational Tool

Realism of Scenarios

The theme refers to the extent providers recognize the scenarios and find them to be realistic based on their own clinical experience. For all scenarios, all providers (100%) found them to describe very common cases and characterized them as realistic as they were quite familiar to them from their practice. One social worker noted that the scenarios were "*Extremely realistic. They were very reasonable and realistic, and it sounds very familiar to what I do and what I see.*" One physician shared his feedback, "*I was thinking how hard it is for families and patients to manage when they have multiple pain medications, like what to give and when. It's really hard. I definitely recognize that.*"

Effectiveness of Questions and Strategies

This theme refers to the effectiveness of the assessment questions and strategies linked to each of the scenarios. All of the participants (100%) agreed that these strategies were effective and helpful for them to ask family caregivers.

Coverage. For each scenario, we developed assessment questions, actions, and follow-up questions for providers to ask and do for family caregivers. Some providers (n=4; 26.6%) concluded that the assessment and follow-up questions were very thorough, and the strategies to support family caregivers covered everything relevant they could think of. The strategies included referrals of

patients and caregivers to a social worker, chaplain, financial program, or volunteer coordinator if needed. One physician stated that the strategies were expansive and cover many aspects, "I think it's pretty effective. I think a lot of the issues are not so much related to medicine but related to the social support and the financial issues."

Reminder Function. As participants stated, providers oftentimes focus solely on patients, so they neglect to assess the needs of family caregivers. Some providers believed the tool would be a good reminder for providers to make an effort to specifically address caregivers' needs (n=5; 33.3%). One social worker also commented that the questions and strategies in the tool reminded her to assess family caregivers more because the tool demonstrated that pain management impacted family caregivers on so many levels. One chaplain mentioned that the follow-up questions in the tool helped him to assess follow-up and outcomes, "*In hospice, the landscape changes very quickly. It is great with the initial discussion, but forget to come back to it subsequently and to make sure that the discussion was helpful.*"

Facilitating Pain Management Education and Discussion. Two providers (13.3%) agreed that it was effective for the tool to include discussion of pain management knowledge and common concerns in pain medications such as addiction and tolerance. One nurse described how that the questions would be helpful for providers to identify what caregivers already knew and what needed to be taught. One physician also commented, "*That is good to clarify and to talk about tolerance versus addiction. We talk about that quite often because people are commonly worried about addiction. It is good to discuss why the use of pain medications.*"

Exploring Patients' Wishes. Some assessment questions in the tool suggested that providers should facilitate discussion regarding patients' wishes in end-of-life care and pain management among providers, patients, and caregivers. Three providers (20%) remarked that the questions would remind providers to explore and honor patients' end-of-life wishes. One chaplain stated, "*I thought they were good and trying to get at what their [patients'] expectations and wishes were. It's important to remember it's a patient-centered care. It's not our decision.*" One nurse thought these questions also directed caregivers to think about the wishes of the patient instead of only their own wishes.

Effective Forms of Communication. Five providers (33.3%) found that the form of questions can facilitate effective communication and support family caregivers: open-ended questions and validation of caregivers' efforts. One chaplain mentioned, "*I think it's great that a lot of them are open-*

ended and fairly nonjudgmental.” One physician noted, “Validation is really important because there’s not really any way to make this easy for anyone.”

Benefits for Providers

The theme refers to how providers can benefit from using this tool in their clinical practice. All providers (100%) agreed that providers would benefit from the tool. The tool was conceptualized by some as a reference book for providers to ensure a comprehensive assessment of pain management (33.3%), and as material for continuing education or orientation (53.3%). A nurse manager explained how she would use the tool, *“It’d be nice to do an orientation and refresher in-services to talk about that communication that happens [in the scenarios] and just give staff those scripted type of conversations because sometimes they don’t know how to delve down. I think that’s nice to reinforce [nurses] how to use the pain scale with your families and caregivers, how to use your medication sheets.”*

Domain 2: Proposed Enhancements for the Educational Tool

Level of Details and Clarity

Participants suggested ideas to improve the overall clarity of the scenarios. Four providers (26.6%) commented that some scenarios should be described more clearly. One nurse advised that each scenario should address the causes of pain and types of pain, otherwise hospice providers would not know how to treat the pain appropriately and handle the situation. The fourth scenario discussed a caregiver’s challenge in assess pain for her father with dementia, and two providers advised that it is necessary to address the cause of the patient’s confusion and which stage of dementia. That would help providers to decide how to manage the pain and choose pain scales. In these cases, the recommendations focused on adding details and clarifying aspects of the scenarios to improve overall clarity.

Incorporating Additional Strategies

Participants believed the strategies included in the tool were effective and they also shared a number of additional strategies that could be added into the tool.

Reviewing Pain Medication Regimens. As participants pointed out, sometimes it is challenging for caregivers to manage pain because the regimen is too complicated or not successful in treating a patients’ pain. Two providers (13.3%) suggested including recommendations or strategies to review or

re-address patients' pain medicine regimens to ensure that they were still appropriate to treat the pain. One nurse practitioner stated, *"It could be common in this scenario that the pain medicine regimen is not right."*

Creating a Breakthrough Pain Plan in Advance. Family caregivers sometimes face the difficult situation where they have to call providers when patients need additional medications for their breakthrough pain. Four providers (20.6%) advised to include recommendations on creating and writing down a breakthrough pain plan in advance for patients. Caregivers can follow the instructions when patients experience a breakthrough pain. One nurse shared her strategy, *"You know that they're gonna have a pain crisis. You come up with an emergency plan that they can refer to so they don't feel like they're calling for help. Because it might not be possible for them to talk to the nurse immediately."*

Including More Pain Management Education. Providers also believed that it was helpful for family caregivers to manage pain effectively if they can acquire more pain management and medication knowledge. Providers recommended adding additional pain management education resources into the tool to support family caregivers (60%): explaining the current pain management regimen (26.6%); talking about the use of medications (26.6%); providing pain assessment scales (26.6%), demonstrating pain assessment skills (6.6%); and using teach back strategies (6.6%).

A couple of providers liked to share with caregivers the pain medications protocol to determine the dose of pain medication and let caregivers understand that the dose of pain medication could be titrated without hurting patients. Also, some providers explained the reason why they used morphine and make caregiver more comfortable with giving morphine. Morphine is one of the most common medications used in end-of-life care because it not only alleviates patients' pain but also helps with shortness of breath. One chaplain said that he would let caregivers understand there was additional benefits of morphine, *"Morphine is actually helping the patient breathe and making them more comfortable; not just alleviating pain."*

Several providers also recommended including not only 10-point pain scale and facial pain scales, but also non-verbal pain assessment scales in the tool. Hence, providers can demonstrate to caregivers how to assess pain by using scales. One clinical nurse specialist advised, *"I would suggest adding specific pain scales for assessing pain in the patient with dementia. When they don't have the cognitive ability to understand the question about how much pain they're in on a scale of 0 to 10."*

Teaching the caregiver how to look for other signs and how to come up with a number, so that she can compare from time-to-time.”

Exploring Patients’ and Caregivers’ Experiences, Beliefs, and Concerns. Six providers (40%) described that some caregivers hesitate to give pain medications, especially morphine, because patients and families have had a bad experience with pain medication or have their own beliefs on pain and the role of pain medication. If patients had a bad experience with morphine such as experiencing sedation, providers would like to discuss and adjust the dose of medications for patients. Regarding belief issues, providers thought it was critical to explore caregivers’ and patients’ beliefs. One chaplain described his experience, *“I like exploring the beliefs around morphine. People often have a misconception of what morphine does. That’s often a cultural thing. It can be used in TV and film, and people immediately associate it with death.”* Participants felt that adding the strategies to explore patients’ and caregivers’ experience and concerns could provide an opportunity for providers to clarify some misperceptions about pain medications or discuss strategies to support patients and caregivers in pain management.

Addressing Misalignment between Patients’ and Caregivers’ Expectations. In one scenario, a patient suffering intolerable pain asked to be anesthetized but the caregivers felt that giving pain medications could sedate the patient which caregivers felt was not desirable. Providers agreed that it is necessary to have a conversation to explore both patients’ wishes and caregivers’ expectations because the reasons behind withholding pain medications could be that caregivers do not realize patients’ disease prognosis, are afraid of losing the patient, experience. Nine providers (60%) suggested adding some strategies to reduce the discrepancy of expectations between patients and caregivers: holding a family conversation, discussing patients’ disease prognosis, and talking about physician’s orders for life-sustaining treatment form (PLOST) to explore patients’ wishes.

Giving Options. To make pain management more effective, four providers (26.6%) suggested expanding the tool to recommend giving treatment options and let patients and caregivers formulate a decision in pain management plan: giving options in pain medications, providing complementary therapy, and talking about the benefit versus the burden of any interventions. One nurse gave an example, *“I like to have a conversation about the benefit versus the burden of any intervention...Is it worth the burden of being more sedated in order to have the pain more controlled? Let them know that it’s their choice ultimately. We lay out the options. Then let them determine which works the best*

for them.”

Adding Additional Concerns

Some participants recommended including additional scenarios of caregivers' pain management concerns in the tool. Although the five scenarios in the tool were common and realistic, seven providers claimed that there were some other frequent family caregivers' concerns related to pain management they encountered: undertreated pain in adult family home and nursing home (13.3%); the difficulty in distinguishing pain among anxiety and agitation (especially for patients with dementia or Parkinson's disease) (13.3%); the difficulty in discriminating among medication side effects, disease symptoms, and dying (6.6%), the different expectations regarding pain management among family members (6.6%), and fear of overdosing or giving the last dose of medications to patients (6.6%).

Providers suggested that these concerns could be created as one or more scenarios and added into the tool. Specifically in terms of the adult family home setting, two participants discussed conflicts that may arise between paid and family caregivers as some paid caregivers in adult family homes and nursing homes did not want to give prescribed pain medications to patients due to their own personal beliefs or other reasons. Providers also commented that it was very challenging to assess pain and other symptoms for patients who can't verbalize their pain. Furthermore, providers highlighted the importance of talking about patients dying from the disease, not symptoms or medications. A nurse demonstrated an example, *“People cannot discriminate between medication side effect and disease symptoms and dying. It's important to talk about that. You could come up with a scenario where the person is saying the side effects or the person is actively dying, and the family says, 'Well, they're dying because of the side effect of the drug. I feel bad about that.' In actual fact, they're dying because they have cancer.”*

Domain 3: Platforms for the Delivery of the Educational Tool

Preferred Platforms to Maximize the Utility

During the interviews participants identified various platforms that they felt would be most appropriate to maximize the utility of the educational tool.

Multiple Platforms. Many participants (60%) advised creating more than one platforms to accommodate different user needs and experiences (with a combination of at least two of the

available platforms, namely a written form, website, video, and mobile application).

A Written Form. Most of the providers (73.3%) preferred a written brochure, booklet, or handout because they could use it as a reference to read when they need it or show caregivers various pain assessment tools. They also suggested a separate concise list of suggested questions and actions for providers to use on site.

A web-based platform. Several providers (60%) liked the content to be read on a website as a part of continuing education. Hospice providers usually bring their laptop when they do home visits so a website is convenient for showing caregivers pain management tools.

Videos. Many providers (53.3%) felt that a video would be a powerful tool to help people internalize the scenarios and disseminate the tool more effectively since people were already online looking for information. One nurse stated, *“If you were training agency caregivers, it would be really effective to show this is what you see and demonstrate how the team asks the questions.”*

Videoconferencing/videotaping. Three providers (20%) commented that the use of technology such as videoconferencing or videotaping would enable providers to see patients’ conditions, talk to family caregivers, or assist caregivers with treating difficult pain, especially for caregivers living in rural areas.

A mobile Application. Some providers (40%) recommended that the tool could be developed as a pain management mobile application because all material including scenarios, management strategies, pain assessment scales, medication administration alarms, and tracking pain medication use and pain scores could be integrated into one app that may even be accessible to both providers and caregivers.

Discussion

The Utility of the Educational Tool

The American Society for Pain Management Nursing Position Statement described that the factors leading to an ineffective pain management in end-of-life included patients and families’ fears and beliefs in pain medications and healthcare providers’ non-recognition of pain, fear of doing harm, and exclusion of other non-pharmacological therapy.⁸ It is critical to create a tool that can minimize these barriers. Previous studies found that structured educational programs improved homecare nurses’ knowledge and attitude about pain management and decreased barriers to pain management.^{41, 42} Several studies delivered structured educational programs to support pain

management for cancer family caregivers, and those participants showed significant improvement in caregivers' knowledge, beliefs, and self-efficacy.²⁹⁻³³ These training sessions were effective but required valuable resources and personnel. Few of the programs were developed based on a theoretical framework, user-centered, or evaluated family caregivers' needs using a systematic approach. There is a need to have an effective and efficient tool for providers to use in hospice routine care to ensure that family caregivers can manage patients' pain following pain management regimens at home.

The study tested the utility of an educational tool for hospice care providers to support family caregivers in pain management. The tool comprised five scenarios using cancer, dementia, and heart failure cases to address family caregivers' physical and psychological burden, fear of side effects of pain medication, beliefs, inability to accurately assess pain, and communication with hospice providers. The design was based on an evidence based approach, as the cases and stakeholders presented (and even the direct quotes) were extracted from real cases part of a large repository of caregiver interviews as part of a completed hospice clinical trial. The evaluation of the tool demonstrated that hospice providers found the educational tool to contain realistic scenarios and effective strategies. The scenarios helped hospice providers to recognize family caregivers' concerns. The assessment questions and strategies assisted hospice providers in organizing pain management strategies, giving guidance in pain management and assessment, clarifying common misperceptions about pain medication, exploring patients' and caregivers' expectations in pain management, and providing social and spiritual supports. Participants noted that the tool covered many aspects of pain management including pain and medication management, and social and spiritual supports for family caregivers. The tool reminded providers to assess caregivers' well-being and needs and providers resources to family caregivers. Hence, hospice providers across disciplines can use and benefit from the tool, which corresponded to the goal of hospice care to provide holistic care by an interdisciplinary team.¹² Participants argued that the educational tool could be used as a reminder for hospice providers to assess family caregivers' needs and discuss patients' wishes during home visits, and as appropriate material for hospice providers' orientation and continuing education. Participants also mentioned that inadequate pain management was frequently an issue in nursing home, adult family home, or long-term care facilities. This educational tool has the potential to support paid caregivers' pain management in long-term care institutions.

Lau and colleagues investigated key approaches that hospice providers (nurses, physicians, and social workers) used to support family caregivers in managing medications to relieve patients' symptoms including: establishing trust, providing information, promoting self-confidence, offering relief, and assessing understanding and performance.⁴³ The authors suggested that there is a need to develop a standardized, validated clinical tool to educate and assess caregivers' ability in managing medications efficiently.⁴⁴ Our educational tool included similar components to these key approaches and could be a useful clinical tool for all types of providers to systematically assess and support family caregivers in pain management and medication management.

Enhancements for the Tool

The hospice providers gave several constructive recommendations to enhance the utility of the educational tool. They suggested creating a breakthrough pain plan in advance, adding more pain management strategies and resources, and adding additional common challenges in pain management into the educational tool to accommodate the needs of diverse cases in hospice care.

Breakthrough pain was defined as "transitory exacerbations of pain that occur on a background of stable pain otherwise adequately controlled by around-the-clock opioid therapy."^{44, 45} Breakthrough pain commonly occurs in patients with terminal illness.^{45, 46} Hence, it is important for providers to explain to family caregivers what may happen and how to give additional medication to deal with a breakthrough pain.⁴⁶

Pain is a common symptom in end-of-life care but presentations of pain are not the same for each diagnosis group. About 50% of patients with dementia experienced pain.⁴⁷⁻⁴⁹ Pain in patients with dementia associated with their neuropsychiatric symptoms, deterioration of cognitive functioning, and performance of activities of daily living.⁴⁹⁻⁵¹ The decline of cognitive functioning make it difficult for patients with dementia to verbalize their pain⁵⁰ so they may express their pain through their body language. The original tool included a 10-point pain scale and a facial pain scale. Participants suggested adding the Pain Assessment in Advanced Dementia (PAINAD) Scale⁵² into to the tool so providers can teach family caregivers on how to use body language, facial expression, and vocalization to assess patients' pain. Patients' pain could be better treated. Participants recommended incorporating additional content to teach family caregivers how to discern pain, anxiety, and agitation symptoms. Dyspnea is a common symptom for patients with cancer and advanced heart or lung disease.⁵³ The use of opiates such as morphine can ease patients' pain and make patients breathe

smoothly.^{53, 54} In addition to clarifying common misperceptions about morphine, providers also suggested explaining the reasons and additional benefits of using morphine, which might increase caregivers' understanding and acceptance of administering opiates to patients.

Pain management is a major complement of hospice services. Patients of dementia and heart disease make up a large part of the population in hospice enrollment but their pain was treated inadequately.⁵⁴⁻⁵⁷ Although a family caregiver is the key person managing their patient's pain at home, there are often no clear guidelines for them to follow. The future pain educational material for hospice care needs to be expanded and tailored to meet the needs of pain management for diverse populations and their family caregivers.

Future Platforms for the Delivery of the Educational Tool

Participants advised creating several formats of the education tool to increase the dissemination and usability of the tool for different users: a written form, a web-based platform, videos, videoconferencing, and a mobile application. A brochure or booklet was convenient to use and review. Cagle and colleagues tested the efficacy of a tailored pain management brochure for family caregivers and their patients.³⁵ The caregivers reported they had improved knowledge about pain and fewer concerns about pain and medications at two weeks.³⁴

Participants liked multimedia platforms such as a website or video because these platforms are efficient and effective to demonstrate the scenarios and strategies for patients and family caregivers, and a larger population on the internet. Youtube has been found as a promising tool for healthcare providers to share pain management education with caregivers.⁵⁸ Capewell et al. tested a feasibility of a combination of a 6-minute DVD and a booklet that addressed the importance of cancer pain assessment and the use of strong opioids.⁵⁹ The feasibility study showed improvement in the patients' pain most significantly in the first week, but no further improvements were shown at the fourth week.⁵⁹ Future research should examine the long-term effects of educational interventions delivered through multimedia platforms on patients and their family caregivers.

Some providers believed that the use of videophone technology can support family caregivers in communicating with hospice providers in pain management. Parker Oliver et al. tested a videophone intervention to enable family caregivers and patients to participate in hospice interdisciplinary team meeting and found that the intervention changed family caregivers' perceptions of pain medication.⁶⁰ The use of telehealth technology in healthcare can facilitate communication among stakeholders,

engage family caregivers and patients in decision making process, and benefit family caregivers and caregivers who live in rural areas.

Furthermore, some smartphone applications for pain management are available to address pain management skills and education, self-monitoring, and relaxation training.⁶¹ But most of them did not involve healthcare providers during the development process and lacked authority, validity, and reliability of the content. Future mobile application design can create more comprehensive usage including pain scenario videos, pain management education, pain assessment scales, pain mediation alarm and tracking, and accessibility of patients, caregivers, providers to provide a better pain management.

There are limited pragmatic interventions for hospice providers to use to support pain management in hospice routine care.^{35, 62} This educational tool is caregiver-centered and grounded in extensive qualitative data involving caregivers, and could be integrated in hospice care for all types of hospice providers. Some studies showed that giving pain management intervention via multimedia platforms can improve family caregivers' and patients' outcomes.^{34, 59, 60} Future research can translate this educational tool into different platforms and examine the most cost-effective platform for hospice providers to use in their clinical practice.

Limitations

The small sample size of hospice providers from one geographic area limited the extent of findings. Also, the tool design and testing process did not include the patients' perspective that might limit the utility of the tool in managing patients' pain comprehensively. Future design should include patients, family caregivers, and healthcare providers in the tool design process.

Conclusions

Study results showed that the educational tool holds promise as an effective and practical guide for hospice care providers. The participating providers reported that the tool could serve as a reminder and reference in their clinical practice and material for orientation or continuing education. Providers recommended adding more educational content and additional common concerns for pain management into the tool to enhance the tool's utility. Participants also suggested developing for use in more than one platform in order to accommodate different users' needs and experiences.

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Figure1. Assessing Caregivers for Team Interventions Model (ACT)³⁷

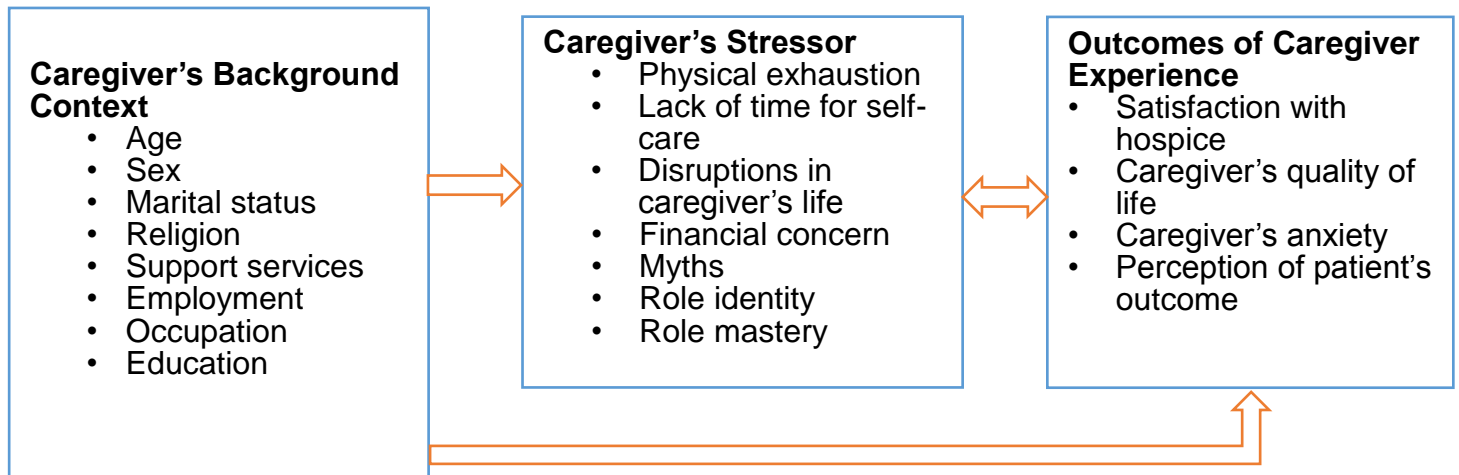


Table 1. Semi-structured Interview Guide

Interview questions for each scenario along with its strategies:
<ol style="list-style-type: none"> 1. Do you recognize the scenario discussed in the tool from your own experience/ practice? How realistic is the scenario? 2. What do you think about the effectiveness of the strategies? 3. Do you have other strategies that you have found to be effective for this scenario? 4. Are there any edits/ changes you would propose for this scenario?
Overall evaluation on the educational tool:
<ol style="list-style-type: none"> 1. Are there other frequent challenges that were not mentioned in the tool that you think would advance pain management? 2. How would you use the tool in your practice? 3. Would this tool be beneficial to you and your colleagues in your agency? 4. Which hospice provider group may benefit most from this tool? 5. Are there other stakeholder groups (e.g. patients, families) that could benefit from this or a similar tool? 6. What do you think is an effective platform for the delivery of the content of this tool? Please explain why. 7. Anything you would like to suggest to improve this tool? 8. What is your overall opinion of this educational tool?

Table 2. Providers' Demographics (N = 15)

Characteristic	Providers
Age range, mean \pm SD	34-62 (51.6 \pm 10.41)
Female	13 (86.6%)
Race	
● White	14 (93.3%)
● Asian	1 (6.6%)
Types of Profession	
● Physician	2 (13.3%)
● Nurse	8 (53.3%)
■ Registered Nurse	■ 6 (40%)
■ Clinical Nurse Specialist	■ 1 (6.6%)
■ Nurse Practitioner	■ 1 (6.6%)
● Pharmacist	1 (6.6%)
● Social Worker	2 (13.3%)
● Chaplain	2 (13.3%)
Years of Working Experience	
● 1 to 3 years	1 (6.6%)
● 3 to 5 years	4 (26.6%)
● 6 to 10 years	1 (6.6%)
● >10 years	9 (60%)

Notes. N, (%) unless otherwise noted.

Table3. Results: Domains, Themes, Codes, Definitions, and Exemplars

Domain 1: The Utility of the Educational Tool			
Major Theme and Subtheme	Code	Definition	Exemplar
Realism of scenarios (100%)	Recognizability and familiarity of the scenarios; realism of scenario	The extent to which providers recognize the scenarios and find them to be realistic based on their own clinical experience.	<ul style="list-style-type: none"> ● It's amazingly realistic because it's very common.
Effectiveness of questions and strategies (100%)	Good questions and effective strategies	The effectiveness of the assessment questions and strategies linked to each scenario.	<ul style="list-style-type: none"> ● I think these questions, the follow-up question things are very good to address that concern.
<ul style="list-style-type: none"> ● Coverage (26.6%) 	Covered many aspects; thorough questions and strategies	Questions and strategies are thorough and cover many aspects of pain management.	<ul style="list-style-type: none"> ● I think they covered almost everything.
<ul style="list-style-type: none"> ● Reminder function (33%) 	Being a good reminder	Questions and strategies remind providers to assess and support family caregivers.	<ul style="list-style-type: none"> ● We're so focused on the patient, so I think it's a good reminder for us to be asking caregivers.
<ul style="list-style-type: none"> ● Facilitating pain management education and discussion (13%) 	Talking about pain management knowledge; discussing concerns	Questions and strategies help providers educate caregivers about pain management and discuss concerns.	<ul style="list-style-type: none"> ● I really liked them [questions and strategies]. Just trying to help the nurse to understand how family is doing, so she can teach whatever needs to teach.
<ul style="list-style-type: none"> ● Exploring patients' wishes (20%) 	Discussing patients' wishes and expectation	Questions and strategies help providers explore patients' wishes and expectations in pain management or end-of-life care.	<ul style="list-style-type: none"> ● I think that it's really good that it starts out with getting to what the wife would've wanted and understanding her wishes because it might help clarify for her husband why he's giving pain medication. I think that's really good. Probably a good nice neutral place to start.
<ul style="list-style-type: none"> ● Effective forms of communication (30%) 	Asking open-ended questions; validating caregivers' feelings and concerns	The forms of question can facilitate effective communication and support family caregivers.	<ul style="list-style-type: none"> ● I appreciated the validate caregiver's concerns with a statement...I thought that was great.

Benefits for Providers (100%)	The utility of the tool for providers	How providers can benefit from using this tool in their clinical practice.	<ul style="list-style-type: none"> I think everybody benefits from that.
<ul style="list-style-type: none"> A reference book (33.3%) 	Being a reference	The tool can be a reference for providers to ensure a comprehensive assessment of pain management.	<ul style="list-style-type: none"> It's reference tool and a guidebook. It's not just informational. That's how I would use this: I would look at it more as this is my workbook. Before I go into a visit, if they're having an issue I might look at this. I would use it and think again what they need help.
<ul style="list-style-type: none"> A material for continuing education or orientation (53.3%). 	Using for continuing education; orientation; training	The tool can be a material for continuing education or orientation.	<ul style="list-style-type: none"> This could be used for continuing education, the new nurses or other education, so people coming on board to understand this. Again, the cases as well as appendix stuff I think could be very helpful.
Domain 2: Proposed Enhancements for the Educational Tool			
Level of details and clarity (26.6%)	Insufficient or unclear scenarios; ideas to improve the scenarios	Suggesting ideas to improve the overall clarity of the scenarios.	<ul style="list-style-type: none"> The only thing that's missing here is [a caregiver] is taking care of her 75-year-old father with dementia who's in a great deal of pain. Why has he got pain? Again, you need to know why he's having the pain to know how to best manage the pain.
Incorporating additional strategies	Additional strategies; suggestions to improve strategies	Including additional strategies into the tool.	
<ul style="list-style-type: none"> Reviewing pain medication regimens (13.3%) 	Reviewing medication regimens	Including strategies to review or re-address patients' pain medicine regimens.	<ul style="list-style-type: none"> What I would say is, "Well, let's sit down and take a look at what this is. Maybe we need to readdress the regimen."
<ul style="list-style-type: none"> Creating a breakthrough pain plan in advance (20.6%) 	Making a breakthrough/crisis plan	Including strategies to make a plan for family caregiver on how to deal with a breakthrough pain.	<ul style="list-style-type: none"> I think doing a collaborative planning and writing out a plan for caregiver. There are the crises that could happen and what do you do in these situations.
<ul style="list-style-type: none"> Including more pain management education (60%) 	Explaining the current pain management regimen; talking about the use of medication; providing pain assessment scales; demonstrating pain	Adding additional pain management education resources into the tool.	<ul style="list-style-type: none"> Under what to do, with the role mastery explaining the current pain management regimen, then I would go into explaining how doses are initiated, and how we determine how to increase the dose.

	assessment skills; using teach back strategies		
● Exploring patients' and caregivers' experiences, beliefs, and concerns (40%)	Exploring history; exploring beliefs and concerns in pain and pain medications	Including strategies to explore patients' and caregivers' experience, beliefs, and concerns in pain and pain medications.	● I would ask "Have you had any experience with morphine, or has your mom had any experience? What's your experience with morphine," and then I would say, "What's your experience with it? Tell me what makes you nervous about it," and then after that, I would go into the education.
● Addressing misalignment between patients' and caregivers' expectations (60%)	Having family conversation; discussing patients' disease prognosis; talking about PLOST form to explore patients' wishes	Including strategies to address misalignment between patients and caregivers' expectations.	● To have the conversation with the patient and the caregiver together because it sounds like [the patient] is being asked to be put out. [The caregiver] is having the struggle, so I often find that when you have a caregiver who is maybe at odds with the patient that you end up talking to them separately. If there's a way to just have the conversation with the patient and the caregiver together.
● Giving options (26.6%)	Providing options; talking about the benefit versus the burden of any interventions; giving complementary therapy options	Including strategies to explain and provide treatment options for patients and caregivers.	● We certainly can provide massage therapy. Some hospices might provide acupuncture or reiki. Because if the wife is concerned about giving the pain medications and feeling like there is no other choice. Providing alternatives can help with that.
Adding additional concerns (46.6%)	Adding other common concerns and challenges	Including additional scenarios of common caregivers' pain management concerns in the tool.	● To be able to identify symptoms: Is this pain or is this anxiety or is it something else? Is it constipation? That can be very, very difficult, so that's another challenge for caregivers that we see often.
Domain 3: Platform for the Delivery of the Educational Tool			
Preferred platforms to maximize the utility	Platform for delivery the content; multiple platforms; website; videos; mobile applications	Identifying platform to maximize the utility of the educational tool.	
● Multiple platforms (60%)	Multiple platforms	Creating more than one platforms to accommodate different user needs and experiences.	● I think [the platform] needs to be multiple. Maybe having a couple different options so that they can say, "Oh, I prefer to read this by myself," or, "I need a video."

● A Written form (73.3%)	booklet; brochure; handout	Creating a written form for users who prefer to read.	● I think that for a lot of people the written handout is helpful. Because they can refer to it later.
● A web-based platform (60%)	A Web-based platform	Creating a website for users who prefer to read information on a website.	● That would be really nice if it is web based and then you could ask your new employees to go online and do this, read this tool and watch the little videos, and answer some questions.
● Videos (53.3%)	Videos	Creating videos for users who like watching videos.	● I think you could put them on YouTube. If you have really good family conversations, it would be an amazing thing for them to be on YouTube. People could go to them because they Google everything.
● Videoconferencing/videotaping (20%)	Videoconferencing; videotaping	Using videoconferencing or videotaping enables providers to support family caregivers in pain management.	● Videoconferencing would be perfect. Even videotaping with the phones or something, saying, "This is what's happening. When he gets up in the morning, he's in terrible pain and the nurse isn't there in the morning to be able to do that."
● A mobile application (40%)	A mobile application	Creating a mobile application to integrate all information and resources.	● You can make an app that incorporates all of these resources together. I think people use their phones for all these things now.

Chapter Five

Conclusion

Summary of the Findings

This dissertation explored and identified the challenges related to pain management faced by family caregivers in home hospice care, developed an educational tool for hospice providers to support family caregivers' efforts in pain management, and tested its utility with hospice providers.

In the first paper, a systematic review was conducted to synthesize current scientific evidence on family caregivers' experience of pain management in end-of-life care. The systematic review included 14 studies published between 2005 and 2015. Most of them were observational studies and 2 were interventional studies designed specifically for hospice family caregivers. The review identified family caregivers' challenges in pain management in end-of-life care, which included limited engagement in pain management decision, ineffective communication with the healthcare providers, inadequate knowledge, assessment skills, and self-efficacy in pain management, and misperceptions of pain medications.

In the second paper, a theory-driven, deductive content analysis of secondary data of hospice family caregivers' interviews was conducted. Fifteen hospice family caregivers' interviews were analyzed using Kelley's "informal hospice caregiver pain management concerns" framework. The study identified most of the themes in the original framework and confirmed that hospice family caregivers face a variety of challenges including caregiver-centric issues, caregiver's medication skills and knowledge, communication and teamwork issues, organizational skill, and patient-centric issues.

In the third paper, we describe the development and testing of an educational tool based on the findings of the second paper. The educational tool consisted of five scenarios and suggested guidelines for hospice providers to support family caregivers in pain management. Fifteen hospice providers from the Seattle metropolitan area were interviewed to test the perceived utility of the tool. The hospice providers found the scenarios to be realistic and the strategies to be effective. Participants believed that the educational tool could be a reference and material for orientation and continuing education for hospice providers in end-of-life care.

Taking care of patients in end-of-life stage can have a negative impact on family caregivers' well-being and quality of life, and pain management is one of the most challenging issues for

caregivers in end-of-life care. Effective pain management can benefit patients' and family caregivers' outcomes. Although there are existing studies that discussed family caregivers' pain management issues and designed educational programs for family caregivers, most of them focused on cancer population and did not involve stakeholders in the design and testing process. There are limited studies and interventions that focused on home hospice family caregivers. In 2014, about 60% of patients enrolled in hospice services received their care at home and needed their family caregivers to support their clinical tasks and symptom management. Also, 63.4% of patients enrolled in hospice services had a non-cancer diagnosis in 2014. In order to better support family caregivers, more studies need to explore family caregivers' needs in home hospice care and design pragmatic and cost-effective interventions to support their caregiving role.

Limitations

The limitation of the first systematic review paper was introduced by the participant samples of the included studies. Most of the participants in the studies were female, White family caregivers of patients with cancer. Hence, the results might not be generalizable to family caregivers with different gender, ethnicity, and backgrounds. Most of the included studies were observational studies and the quantity and quality of the evidence were limited.

The limitations of the second paper were that it described a secondary data analysis, and it had a small and homogenous sample (n=15). Although the participating family caregivers took care of patients with diverse diagnoses (cancer, dementia, heart disease, lung disease, etc.), most of them were older, highly educated, and White family caregivers. In the parent study, more than 50 hospice family caregivers claimed that they had a pain management related concern but they ultimately chose to deal with other higher-priority life or caregiving issues with the interventionist in the. A secondary data analysis method limited the ability to further explore those participants' pain management issues. Hence, some themes of caregivers' pain management concerns in the original framework were not present in the study due to its small and homogenous sample.

The limitations of the third study were that it had a small sample size of hospice providers from one geographic area which limited the extent of the findings. The educational tool design and testing process did not include the patients' perspective, which might restrict the utility of the educational tool in managing patients' pain comprehensively.

Implications for Clinical Practice

This dissertation determined that hospice family caregivers face a variety of challenges when they manage care recipients' pain at home. Family caregivers need assistance and guidance in pain management from hospice providers in order to be able to perform pain management effectively at home for their patients. When teaching family caregivers pain management strategies, hospice providers can use a validated educational tool, demonstrate how to use verbal and non-verbal pain assessment scales, and provide medications and complementary options.

Besides knowledge of pain management and assessment skills, patient-centered and caregiver-centered issues can interfere with caregivers' ability to manage pain. Hospice providers need to constantly evaluate patients' and caregivers' well-being and needs as well as adjust the pain medication regimen accordingly. It is important to have an open and early discussion among stakeholders to explore and honor patients' end-of-life wishes and discover any barriers and concerns from patients and their families. Family caregivers are the ones who support patients' pain management and patient care at home, so they need to participate in the decision making process. Hospice providers should provide necessary recourses for caregivers or refer them to other hospice team members to meet their social and spiritual needs.

Implications for Future Research

Most of the caregiver participants in this dissertation were female, White, spousal caregivers of patients with cancer. Minorities' needs and preferences in end-of-life care are inadequately explored. Future studies should explore the needs, preferences, and beliefs of end-of-life care for cultural and ethnic minorities. Also, the roles of informal caregivers such as adult children caregivers, employed caregivers, male caregivers, paid caregivers in a nursing home and adult family home may have different caregiving and pain management challenges. More subgroup analyses or larger-scale studies need to understand the association between pain management issues and family caregivers' backgrounds.

The demographics in hospice care are shifting. More patients in hospice services have a non-cancer diagnosis and receive care at home. Future research can conduct a longitudinal investigation of family caregivers' needs and concerns in pain and symptom management throughout the entire illness trajectory and include a larger sample size of hospice family caregivers and patients with more diverse backgrounds.

Pain and many other symptoms still are undertreated in end-of-life care. The mechanism of pain,

association with other end-of-life symptoms, validated measurements of pain, related factors of effective pain management still need to be explored through rigorous and longitudinal investigations. The first systematic review identified a limited quantity and quality of exploratory and interventional studies in issues related to hospice pain management. To better support pain management in home hospice services, future research should expand on the current knowledge in pain management, and more exploratory studies should be done to understand the issues in pain management from larger and more diverse patient and family caregiver populations. The educational tool and intervention design should base on a theoretical framework to outline causes and measurable outcome. Future interventional designs should include patients, family caregivers, and hospice providers' involvement during development and testing process to make it practical and be able to integrate into routine care.

The educational tool in this dissertation demonstrated its potential for hospice providers to support family caregivers' pain management in clinical practice. Future research should conduct a pre-post intervention study to examine the effectiveness of the tool as well as examine effective platforms (e.g., website, mobile app, paper brochure, combination of these) for hospice providers to access this information readily and effectively support family caregivers in pain management.

Technology holds promise for supporting end-of-life care. Future study can use technology-enhanced interventions to facilitate discussions on pain management in end-of-life care, increase engagement among stakeholders and improve the quality of end-of-life care. More cost-effectiveness analyses need to be conducted to find effective ways to support patients and family caregivers in needs.