

July 2017

## **CANCER PAIN PROCESSES IN THE HOSPICE CARING TRIAD: A GROUNDED THEORY STUDY**

Olga Ehrlich

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**CANCER PAIN PROCESSES IN THE HOSPICE CARING TRIAD:  
A GROUNDED THEORY STUDY**

A Dissertation Presented

by

**OLGA EHRlich**

Submitted to the Graduate School of the  
University of Massachusetts Amherst in partial fulfillment  
of the requirements for the degree of

**DOCTOR OF PHILOSOPHY**

May 2017

College of Nursing

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A GROUNDED THEORY STUDY**

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**OLGA EHRLICH**

Approved as to style and content by:

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## **DEDICATION**

This work is for the all of the hospice patients and families who have allowed me to join in the processes that were certainly heart-wrenching, joyful, and every other emotion imaginable, which comprised their daily lives, as they navigated through personally uncharted territories of living in the face of approaching death. It is because of their grace in allowing my work as a nurse, in the intimate and often uncomfortable moments of living, that I have been inspired to search for solutions, to contribute to improving outcomes for persons coping with end-of-life symptoms.

I would like to further dedicate this dissertation in gratitude for the life-long work of Betty R. Ferrell, whom I respectfully regard as “The Mother of Hospice Nursing Research”.

## ACKNOWLEDGMENTS

I must begin my acknowledgements by offering my deep gratitude to the patients, families, and nurses who gave generously of their time to participate in this study. In the face of a changing unknown occurring every day, they allowed me to visit their homes, interview and observe them, to learn about living at the end stage of incurable cancer. Because of their willingness to talk openly about topics—dying and pain—which too often are brushed aside because of the feelings of discomfort they arouse, their experiences are shared here for others to ponder and learn from. These sharings are invaluable, for all participants offered their de-identified data to be used for secondary analyses and educational purposes beyond this report.

I am also indebted to faculty whose examples and encouragement led me to pursue graduate studies. In the undergraduate nursing program at Arizona State University—Barbara Fargotstein and Kathie Kulikowski for expanding my view of nursing knowledge beyond bedside practice. Bernadette Melnyk introduced me to use of evidence-based practice to improve health outcomes, which lit my spark for researching clinical dilemmas. Here at UMass Amherst, Joan Roche, inspired me to choose a career path of research and teaching. Because of her encouragement I have pursued my deep interest in cancer pain social processes. Cynthia Jacelon, fostered my love of qualitative research methods, especially grounded theory, while providing expert and kind guidance. Rachel Walker, who became my adviser and dissertation chair when Dr. Roche retired, has provided incredible mentoring to me, in many realms of nursing scholarship and research applicable to the doctoral student. It is because of her encouragement, example, and collaboration that I have met milestones of an early stage researcher. I would like to

thank other faculty at UMass Amherst CON who have taught and mentored me in various ways—Annette Wysocki, Donna Zucker, Esther Choi, Ginny Chandler, Linda Lewandowski, and Lisa Chiodo.

I am further indebted to Susan Hankinson, of the UMass Amherst School of Public Health and Health Sciences, and April Vallerand, of the Wayne State University College of Nursing, for the inspiration they have kindled in me, for their expert advice in research design and methods, and for their generosity as sponsors of my proposal for a NINR Ruth L. Kirschstein F31 Predoctoral Fellowship.

The friends and colleagues I have met and worked together with here at the UMass Amherst CON have also been inspiring and bolstered me at times when the workload felt tremendous. I thank you each, and wish you the best!

The most enduring “thank you” must be given to my family, the relatives and friends who have stood by me, giving advice, holding my hand, asking probing questions, and reminding me to follow my heart, even in the darkest of moments.

Lastly, I am grateful to the Beta Zeta At-large Chapter of Sigma Theta Tau International, the Oncology Nursing Society Foundation, the UMass Amherst Graduate School, and the UMass Amherst College of Nursing for the financial support which made this dissertation research study possible.

ABSTRACT

CANCER PAIN PROCESSES IN THE HOSPICE CARING TRIAD: A GROUNDED  
THEORY STUDY

MAY 2017

OLGA EHRLICH, B.S.N., ARIZONA STATE UNIVERSITY

Ph.D., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Rachel K. Walker

The author conducted this constructivist grounded theory study to describe perceptions, behaviors, and communication that hospice caring triads engage in while managing cancer pain, specifically how these social processes can be assessed and used to improve poorly-controlled pain.

Three hospice caring triads comprised of patients, family caregivers, and nurses along with one nurse-patient dyad, were recruited into this longitudinal qualitative study. Each group was observed during nursing visits. Triad and dyad members were individually interviewed. Nurses participated in a focus group and survey. The author used constant comparative methods of data analysis, including line-by-line gerund coding, theoretical codes from cancer pain assessment standards, theoretical sampling of early codes, memo writing, and concept-mapping to raise codes into concepts and domains for a theoretical framework. Study trustworthiness included appropriate methodology to answer research questions, prolonged and repeated participant engagement, triangulation of content across participants, reflexive memos, and use of multiple data sources.



Results were presented in a triadic case study comparing and contrasting the two cancer pain social processes domains related to pain control: *Controlling Cancer Pain* and *Proximity*. The first domain included perceptions of pain control, goals, and efficacy. The second domain included physical and emotional distance between triad members, presence of communication, and level of agreement. When triads were compared, one triad with close emotional and physical proximity had a shared perception of pain meaning and goals for control, and effective communication for pain management behaviors. The other triads had more physical and emotional distance, communication that was vague, and differing perceptions of pain control, pain meaning, or control goals. An important difference for these other triads was a lack of agreement about pain perception and pain severity, as well as vague communication about pain perception, with subsequent impact on pain goals.

*Controlling Cancer Pain* and *Proximity* social processes are inextricable with cancer pain management for hospice caring triads. Assessment tools for proximity-related social processes which measure closeness, communication, and agreement among hospice caring triad members should be developed and tested for improving cases of poorly controlled pain. Development and testing of simple open-ended functional goal assessments is needed.

## TABLE OF CONTENTS

	Page
ACKNOWLEDGMENTS .....	v
ABSTRACT .....	vii
LIST OF TABLES .....	xv
LIST OF FIGURES .....	xvi
CHAPTER	
1. INTRODUCTION: APPROACHING QUESTIONS OF CANCER PAIN SOCIAL PROCESSES .....	1
Background .....	3
Researcher’s Stance .....	5
Hospice Care .....	7
Hospice Caring Triad .....	7
Role of Social Processes .....	8
Study Approach .....	9
Definitions of Pain .....	11
Cancer Pain .....	11
Pain Theory History .....	12
Role of Pain Meaning .....	14
Role of Pain Control .....	15
Conclusion .....	16
Dissertation Format .....	16
2. PAIN AND SOCIAL PROCESSES FOR HOSPICE CANCER PATIENTS: AN INTEGRATIVE REVIEW .....	18
Methods .....	19
Results .....	21
Cancer Pain Meaning .....	22

Role of Pain Meaning .....	22
Pain Meaning for Hospice Patients with Cancer .....	22
Pain Meaning for Family Caregiver and Nurse in Hospice .....	24
Cancer Pain Control .....	25
Role of Pain Control .....	25
Pain Control for Hospice Patients with Cancer .....	25
Pain Control for Family Caregiver and Nurse in Hospice .....	27
Social Processes Concepts Related to Pain.....	27
Affiliation and Attachment .....	28
Social Communication.....	28
Perception and Understanding of Self .....	30
Perception and Understanding of Others .....	31
Discussion.....	32
Pain Meaning .....	32
Pain Control .....	34
Social Processes for Cancer Pain.....	36
Conclusions.....	37
Limitations .....	38
3. AIMS AND METHODS.....	39
Background.....	39
Research Question and Aims .....	40
Methodology: Constructivist Grounded Theory.....	41
Role of Theoretical Frameworks in Grounded Theory.....	42
Study Methods .....	44
Ethical Conduct of Research.....	44
Recruitment and Sampling.....	44
Inclusion-exclusion Criteria.....	45

Recruitment Procedures .....	47
Data Collection .....	52
Observational Visits.....	52
Interviews.....	53
Journals .....	54
Focus Groups .....	55
Methodological Concerns .....	55
Burden of Prolonged Study Engagement.....	55
Challenges to Data Collection .....	56
Data Management .....	57
Data Management Plan .....	57
Participant Note Book.....	57
Study Logistics Spreadsheet .....	58
Theoretical and Reflexive Memos .....	58
Data Analysis .....	59
Use of Line-by-line Method for Early Coding .....	59
Raising of Initial Codes to Conceptual Categories .....	61
Trustworthiness.....	63
Appropriateness of Methodology .....	63
Purposive and Theoretical Sampling .....	64
Prolonged Engagement .....	64
Clarification of Bias .....	65
Audit Trail.....	65
Conclusion .....	66
<b>4. RESULTS: CANCER PAIN CONTROL IN HOME HOSPICE CARE: WHAT ARE THE GOALS, WHO SETS THEM, AND WHAT DOES IT MEAN?.....</b>	<b>68</b>
Introduction.....	68
Background.....	70

What Is a Pain Goal?.....	70
What Does a Pain Goal Mean for the Triad? .....	71
Assessing Pain Severity .....	71
Assessing Function Related to Pain .....	73
Study Design and Methods .....	74
Participants.....	74
Recruitment.....	74
Data Collection .....	75
Data Analysis .....	77
Results.....	78
Domain One: Controlling Cancer Pain .....	78
Who Sets Pain Goals?.....	79
Triad Pain Severity Goals .....	82
Functional Pain Goals.....	83
How are Pain Goals Related to Pain Management Behaviors?.....	84
Pain Perception .....	84
Pain Management Efficacy and Coping Strategies.....	87
Domain Two: Proximity .....	88
Physical-Emotional Distance .....	89
The Loop.....	89
The Page.....	90
How Are Triad Proximities Associated with Controlling Cancer Pain?.....	90
Discussion .....	91
Strengths and Limitations .....	95
Conclusion .....	96
Implications for Nursing.....	96

Implications for Research .....	97
5. RECRUITMENT SUCCESSES AND CHALLENGES IN A GROUNDED THEORY STUDY ABOUT HOSPICE CANCER PAIN .....	98
Abstract .....	98
Introduction.....	100
Study Background.....	102
Findings.....	103
Study Design and Planning.....	103
Ethics of Recruiting Dying Persons .....	105
Target Population and Sample Size .....	107
Recruitment Practices .....	108
Retention.....	110
Implications.....	112
Conclusion .....	113
6. DISCUSSION.....	114
Introduction.....	114
Research Question & Specific Aims.....	115
Summary of Findings.....	116
Specific Aim 1: Describe the meaning of cancer pain and cancer pain management for each member of the hospice caring triad. ....	116
Specific Aim 2: Describe the social processes among the triad members during hospice cancer pain management. ....	117
Specific Aim 3: Propose a framework of and for cancer pain management social processes of the hospice caring triad.....	121
Extension of NIMH Social Processes to Cancer Pain Social Processes.....	121
Related Extant Theories .....	123
Theoretical Framework for Hospice Cancer Pain Processes .....	125
Strengths and Limitations .....	125
Implications for Nursing Theory, Research, and Practice .....	126

Recommendations for Future Research .....	128
APPENDICES .....	130
A. HOSPICE AGENCY MEMORANDUM OF UNDERSTANDING.....	131
B. IRB APPROVAL LETTER .....	132
C. DEMOGRAPHICS STATISTICS AND DATA COLLECTION FORMS....	133
D. RECRUITMENT DOCUMENTS .....	138
E. INTERVIEW AND FOCUS GROUP DOCUMENTS .....	142
F. INFORMED CONSENT FORMS .....	146
G. STUDY LOGISTICS PLAN .....	170
H. SOCIAL PROCESSES FRAMEWORK ELEMENTS .....	171
I. METHODOLOGICAL DOCUMENTS .....	173
BIBLIOGRAPHY.....	178

## LIST OF TABLES

Table	Page
Table 1.1 NIMH Social Processes Definitions .....	10
Table 1.2 Defining Pain Types .....	12
Table 3.1 Recruitment Eligibility Criteria .....	48
Table 3.2 Recruitment Steps and Numbers of Participants Per Triad Role.....	51
Table 3.3 Data Collection Activities by Triad Member Roles .....	53
Table 4.1 Data Collection Points by Type .....	76
Table 4.2 Triad Comparison of The Loop and Pain Goals Categories .....	91
Table 6.1 Current and Proposed Pain Functional Goal Assessments .....	120



## LIST OF FIGURES

Figure	Page
Figure 1.1 World Health Organization Pain Ladder.....	13
Figure 2.1 Study Selection Process.....	21
Figure 3.1 Proposed Study Timeline with Data Collection Activities by Triad Group Member.....	50
Figure 4.1 Numeric Rating Scale.....	72
Figure 4.2 Hospice Caring Triad Social Processes Domains.....	79
Figure 6.1 Social Processes Intersectionality.....	124

# **CHAPTER 1**

## **INTRODUCTION: APPROACHING QUESTIONS OF CANCER PAIN SOCIAL PROCESSES**

In 2014 the Institute of Medicine’s report, “Dying in America” called for increased access to palliative and end-of-life care. It also called for care to be “‘patient-centered’ and ‘family-oriented’ ...designed to meet physical, cognitive, emotional, and spiritual needs...it takes into account culture, traditions, values, beliefs, and language; and it evolves with patient and family needs” (Institute of Medicine, 2014, pp. 1-7). In the United States end-of-life care is increasingly taking place in people’s homes, provided by hospice agencies (National Hospice and Palliative Care Organization [NHPCO], 2014). A key focus of hospice care is management of pain. Persons with end-stage cancers comprise the highest hospice usage group according to diagnosis, at 36.5%, more than twice as high as the next most common hospice diagnosis of dementia (NHPCO, 2014). In 2013, 83.9% of persons receiving hospice care were 65 years of age or older (NHPCO, 2014).

Pain for persons with cancer during and after treatment remains a significant problem (National Cancer Institute, 2014). In their 2007 systematic review, van den Beuken-van Everdingen et al. reported persons with metastatic and advanced cancers experienced pain at rates as high as 64% (CI 58-69), with one third of them reporting moderate-to-severe pain (p. 1439). In a second meta-analysis of cancer pain severity ratings, van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, and Janssen (2016) reported slightly higher rates of poorly-controlled cancer pain for the end stages of disease at 66.4% (95% CI 58.1-74.7) (p. 1076). Strassels, Blough, Hazlet,

Veenstra, and Sullivan (2006) analyzed a national sample of 347,555 hospice patients, 278,044 of whom were over 60 years old, to describe hospice pain demographics in the United States. Pain intensity was scored using an 11 point numeric rating scale, with moderate-to-severe intensity scores ranging from four to ten, with a score of ten identified as the worst pain rating. Of the sample, 180,401 subjects had a primary diagnosis of cancer. For all subjects, 25.9% had scores of moderate-to-severe intensity (scores ranging from four to ten), with 11% of those severe (scores ranging from seven to ten), at admission. A total of 34.7% of subjects had a last reported pain score within the moderate-to-severe range, while 11.5% had a last reported score in the severe range (Strassels et al., 2006). Although hospice is the gold standard for pain and symptom management, these studies demonstrate that the problem of moderate-to-severe cancer pain persists even in the context of hospice care. Effective treatment of cancer pain for older persons receiving hospice care is a critical element of nursing care.

The purpose of this constructivist grounded theory study was to describe the social processes within and among older persons with cancer pain receiving hospice care, their family caregivers, and their hospice nurses, heretofore referred to as the hospice caring triad. Grounded theory methods were used to identify previously unexplored factors that could help to resolve the problem of poorly controlled hospice cancer pain within the caring triad context. The broad purpose of the study was to construct a theory of hospice cancer pain social processes based on the concepts, categories, and proposed relationships interpreted from the data. The researcher hypothesized that important elements of the social processes identified would provide understanding of variables involved in home hospice cancer pain management. The intent of the hospice cancer pain

social processes theory is to inform clinical practice, as well as to develop and test hypotheses to improve patient outcomes in future research studies.

This study was designed to answer the question: In the context of hospice, how do the social processes among the members of the hospice caring triad affect cancer pain management? The following specific aims were addressed:

1. Describe the meaning of cancer pain and cancer pain management for each member of the hospice caring triad

-Expected outcome: Identification of themes for cancer pain meaning and cancer pain management meaning for each member of the hospice caring triad, and critical comparison of themes among the triad members

2. Describe the social processes among the triad members during hospice cancer pain management

-Expected outcome: Identification of social processes occurring for and between each member of the hospice caring triad and development of social processes categories

3. Propose a framework of and for cancer pain management social processes of the hospice caring triad

-Expected outcome: Identification of relationships and processes for and among each member of the hospice caring triad

-Expected outcome: Generate working hypotheses about cancer pain management social processes for the hospice caring triad including barriers and facilitators

### **Background**

Poorly controlled pain persists despite the publication of guidelines for the treatment of cancer pain in the elderly and for end-of-life care (American Pain Society, 2011; Herr et al., 2010; Registered Nurses Association of Ontario [RNAO], 2007; van den Beuken-van Everdingen et al., 2007; van den Beuken-van Everdingen et al., 2016). Identified barriers to cancer pain management include: variations in practice-specific

education for nurses and use of standards or guidelines for management of cancer pain across hospice agencies (Coyle, 2004; Herr et al., 2010); pain meaning perceived negatively (Barkwell, 1991); pain meaning perceived differently by patients, family members, and hospice health professionals (Barkwell, 2005; Ferrell, Taylor, Sattler, Fowler & Cheyney, 1993; Larsson & Wijk, 2007); inappropriate word choices on assessment tools for describing quality of pain for older persons on hospice (Duggleby, 2002); fear and avoidance of pain discussion for hospice patients, nurses, and physicians (Zerwekh, Riddle & Richard, 2002); too few pain management interventions tried and lack of feeling of pain mastery for cancer patients (Byma, Given, Given & You, 2009); lack of pain self-efficacy for patients (Jerant, Franks & Kravitz, 2011); and, myths about use of morphine leading to under-prescription and under-use of it for pain management (Berry & Ward, 1995; Flemming, 2010; Gunnarsdottir, Donovan, & Ward, 2003).

Studies have addressed barriers to and facilitators for cancer pain management for the person experiencing pain, for the person's caregiver, and for the health professionals involved (Beck et al., 2010; Byma et al., 2009; Dawson, Sellers & Spross, 2005; Lau et al., 2010; Lau & Clayman, 2012; van den Beuken-van Everdingen et al., 2016).

Identification of barriers and facilitators is a critical step in the process of developing interventions for health outcomes improvement (diCenso, Ciliska & Guyatt, 2005). There is a gap in the nursing knowledge and research about cancer pain social processes, specifically what they are, how they occur, and how they may facilitate or impede good pain control among members of the hospice caring triad. This study examined a potential source of barriers to effective pain management--the social processes that take place between older cancer patients, their family caregivers, and hospice nurses, in order to fill

this gap in the nursing knowledge. The qualitative method of constructivist grounded theory was used to deeply explore the meaning of cancer pain and interactions persons with cancer pain and their caregiving teams engaged in while managing pain.

### **Researcher's Stance**

The research-relevant context, the life and professional experience, as well as professional and personal cultural beliefs, affect which aspects of a phenomenon the researcher investigates, and the research study questions which are asked (Charmaz, 2010; Miles, Huberman, & Saldana, 2012). The investigator should reveal their stance to readers (Charmaz, 2010). By doing so and by following methods that make procedures and key decisions transparent, study integrity will be maintained.

This study's research-relevant context is nursing, particularly nursing of the person with end-stage cancer. It is grounded in questions which were triggered by the researcher's clinical experiences working with hospice patients experiencing poorly controlled pain, in their homes, along with their family caregivers. Early in her hospice nursing practice, the researcher believed that most pain related to cancer could be well controlled by following evidence-based guidelines, such as the World Health Organization's pain ladder (WHO, 2017). Applying pain management guidelines by teaching their application to persons experiencing pain and their caregivers has been an integral aspect of the hospice nursing care the researcher has provided. However, she has encountered cases where despite nursing application of best practice guidelines, persons experienced poorly controlled pain. The fact that poorly controlled cancer pain continues to be noted in the literature (Strassels et al., 2006; van den Beuken-van Everdingen et al.,

2007) despite the identification of barriers and facilitators to cancer pain control is consistent with the researcher's clinical observations.

The researcher wishes to acknowledge her personal beliefs about pain and their relevance to hospice care in order to engage in reflexivity. Her experience with cancer pain and hospice is solely informed by her clinical practice, as persons close to her have not had hospice care for cancer. She has read the nursing literature about pain from cancer and hospice care for cancer pain extensively, supporting her belief that in most cases application of evidence for assessing and intervening to reduce cancer pain is possible. However, she does believe that the individuality of persons with pain from cancer will influence how they perceive and choose to act on their pain.

Cultural beliefs influencing the researcher's views on cancer pain and hospice are societally and professionally derived. Societal values in the Northeastern United States uniformly identify cancer as an unwanted disease to be fought until there is no hope for cure, at which time hospice services may be beneficial in supporting that person and their family in meeting the challenges of progressive debility and impending death. It is culturally typical to expect that healthcare professionals will provide guidance in navigating the disease experience, and that they have the expertise to do so. There are two dominant approaches to unpleasant symptoms like pain; either people believe that reporting their symptoms promptly to family members and healthcare professionals will result in reduction of unpleasant experiences, or they believe that it is better to tolerate those unpleasant experiences privately, for as long as possible.

Professional cultural beliefs influencing the researcher are based largely on ethics and nursing practice. Nurses are ethically and professionally bound to reduce suffering of

those persons they care for. In fact, when nurses do not have the knowledge or skills to do so they are expected to obtain additional education to provide the standard of care. These cultural expectations have been driving forces in the researcher's ongoing pursuit of knowledge to reduce pain for persons with terminal cancers. It is her belief that suffering from pain is an interfering, unnecessary impediment to quality of life for persons dying from cancer.

### **Hospice Care**

The model for hospice care is provision of services in a person's preferred place of dying, usually their home, with a goal of reducing unpleasant symptoms and improving quality-of-life. Services are provided by an interdisciplinary team in order to assure that care is robust and holistic. This team includes a nurse, medical social worker, spiritual counselor, medical director, home health aide, and volunteer (NHPCO, 2014). Team members visit and provide care in the home in partnership with the patient and their caring partners, such as family members or private pay individuals. Between visits, patients and their caring partners self-manage symptoms. This creates a complex and dynamic environment of care which can be complicated by the progressive and unpredictable nature of end-stage cancer.

### **Hospice Caring Triad**

The hospice caring triad represents the collaboration of the person with cancer receiving hospice care, their family caregiver, and their hospice nurse as they engage in caring, in this case to manage pain. Usually, multiple characters/persons are involved in managing symptoms like pain (Hauser & Kramer, 2004; Lau et al., 2010). Even people who live alone have interactions with neighbors, family, friends, healthcare professionals,



and others whose presence has potential to impact perceptions and behaviors. If an issue to be studied only affects a single character/person involved in the problem, then research directed at only that character/person can yield beneficial results. This research study was designed to examine the complexities involved in an issue rarely affecting only a single person. It was based on the perspective that the next step for understanding poorly controlled cancer pain for persons receiving hospice care necessitated understanding the experiences of each character in relation to one another, in the hospice caring triad context. This approach is consistent with the nursing metaparadigm of person, health, nurse, and environment (Fawcett, 2007). The hospice caring triad fits within the nursing metaparadigm because it includes the person with a health concern, their family caregiver, and their hospice nurse. The home environment is a distinctively unique and variable location for health care processes. A key function of nursing in home hospice is symptom management, which is comprised of social processes. This study examined and identified social processes for pain management to help caring triad members be more effective in reducing pain.

### **Role of Social Processes**

Knowledge of cancer pain management social processes can enhance the hospice nurse's ability to effectively assess and suggest interventions for patient-centered pain management for persons with cancer pain and their family caregivers. See Table 1.1 (p. 10) for social processes and their definitions, which are discussed at length below. Social processes is a complex framework involving cognitive awareness, reflection, behavior, and interactions with others (National Institutes for Mental Health [NIMH], 2012). For hospice cancer pain management, there are many individual processes and

concepts involved. These include the categories of person with cancer pain, family caregiver, and nurse. The NIMH (2012) lists the following concepts for social processes: (a) affiliation and attachment, (b) social communication, (c) perception and understanding of self, and (d) perception and understanding of others.

Because of the complexity of social processes, it is helpful to understand that all persons engage in them constantly in adapting to daily life. They can be pictured as the activities we participate in related to our thoughts, feelings, and situations. Some of these are conscious, and others we take for granted. For the context of pain management, social processes would include how a person in pain perceives and understands the pain, how the person interacts with others because of the pain, and what happens to the pain experience as a result of these actions. An example from Larsson and Wijk's (2007) study is of patients wanting to reveal pain to get help for pain control. Simultaneously, they were worried about reminding their family members of their terminal status and wanted to conceal pain to avoid sadness.

### **Study Approach**

The researcher used grounded theory methodology, a qualitative research approach useful for the study of experiences and processes (DiCenno et al., 2005). Grounded theory has been used for more than 50 years to produce descriptive and explanatory data and propose theoretical relationships for complex phenomena (Charmaz, 2010). The ontology from which grounded theory was developed is the framework of symbolic interaction, or the belief that meaning underpins all behaviors. Social processes are directly related to symbolic interactions.

Table 1.1 NIMH Social Processes Definitions

<b>Affiliation and attachment</b>	<p>“Affiliation is engagement in positive social interactions with other individuals. Attachment is selective affiliation as a consequence of the development of a social bond. Affiliation and Attachment are moderated by social information processing (processing of social cues) and social motivation. Affiliation is a behavioral consequence of social motivation and can manifest itself in social approach behaviors. Affiliation and Attachment require detection of and attention to social cues, as well as social learning and memory associated with the formation of relationships. Affiliation and Attachment include both the positive physiological consequences of social interactions and the behavioral and physiological consequences of disruptions to social relationships. Clinical manifestations of disruptions in Affiliation and Attachment include social withdrawal, social indifference and anhedonia, and over-attachment.” (NIMH, 2012, para. 6)</p>
<b>Social communication</b>	<p>“A dynamic process that includes both receptive and productive aspects used for exchange of socially relevant information. Social communication is essential for the integration and maintenance of the individual in the social environment. This Construct is reciprocal and interactive, and social communication abilities may appear very early in life. Social communication is distinguishable from other cognitive systems (e.g., perception, cognitive control, memory, attention) in that it particularly involves interactions with conspecifics.” (NIMH, 2012, para. 7)</p>
<b>Perception and understanding of self</b>	<p>“The processes and/or representations involved in being aware of, accessing knowledge about, and/or making judgments about the self. These processes/representations can include current cognitive or emotional internal states, traits, and/or abilities, either in isolation or in relationship to others, as well as the mechanisms that support self-awareness, self-monitoring, and self-knowledge. (NIMH, 2012, para. 8)</p>
<b>Perception and understanding of others</b>	<p>“The processes and/or representations involved in being aware of, accessing knowledge about, reasoning about, and/or making judgments about other animate entities, including information about cognitive or emotional states, traits or abilities.” (NIMH, 2012, para. 9)</p>

(National Institute of Mental Health. (2012). *Social processes: Workshop proceedings*. <http://www.nimh.nih.gov/research-priorities/rdoc/social-processes-workshop-proceedings.shtml>)

## **Definitions of Pain**

McCaffery's classic and widely-accepted definition of pain states, "Pain is whatever the experiencing person says it is, existing whenever he says it does" (McCaffery, 1968, p. 95). The International Association for the Study of Pain (IASP) gives the following definition of pain: "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage," and qualifies the definition as follows:

Pain is always subjective...It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience...is always a psychological state, even though we may well appreciate that pain most often has a proximate physical cause. (IASP, 2014, para. 4-5)

## **Cancer Pain**

Pain for persons with cancer can be caused by disease processes or by cancer treatments. Cancer pain can be somatic, visceral, or neuropathic, involving soft tissue, bony structures, and nerves, or combinations of these. Table 1.2 (p. 12) provides descriptions of pain types. Persons with cancer commonly experience break-through pain, or pain that is severe and sudden in onset, and frequently unpredictable (European Oncology Nursing Society [EONS], 2013). Guidelines have been established for the treatment of acute, chronic, and break-through pain. (Caraceni et al., 2013; EONS, 2013; Herr et al., 2010; RNAO, 2007). Nurses have a responsibility to assess the type of pain experienced by persons with cancer. By identifying the type of pain, nurses can advise patients, caregivers, and prescribing providers about interventions likely to be effective for reducing pain severity. There is a strong body of evidence about pain types and the pharmacological interventions known to reduce pain severity (Hanks et al., 2001;

Table 1.2 Defining Pain Types

<b>Somatic Pain</b>	Caused by damage to skin, muscles, bones, joints and connective tissues -common descriptors: <i>localized, aching, throbbing, dull, or sore</i> -for example: <i>pain from skin lesions or bone metastasis</i>
<b>Visceral pain</b>	Pathologic changes to visceral organs -common descriptors: <i>localized or regional, aching, gnawing, cramping, pressure, heaviness</i> -for example: <i>tumors growing in the chest or abdomen</i>
<b>Neuropathic pain</b>	Pain from actual compression or trauma to central or peripheral nerve systems -common descriptors: <i>tingling, pins and needles, burning, shooting, stabbing</i> -for example: <i>tumors applying pressure to nearby nerves, or lesions applying pressure along the spinal cord</i>

(Pasero & McCaffery, 2011)

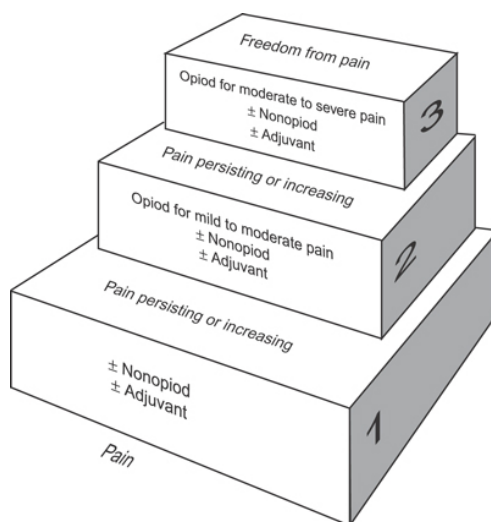
Pasero & McCaffery, 2011; Wiffen & McQuay, 2007). The World Health Organization (2017) created the cancer pain management ladder to assist health professionals in appropriately treating cancer pain according to level of pain severity and known pharmacologic treatments including non-opioids and opioids. See Figure 1.1 (p. 13) to understand how it can easily be applied. The ladder has been widely used and is freely accessible through the internet by searching for ‘cancer pain ladder’. Wilkes (1988) made the claim 27 years ago that in the vast majority of cases, cancer pain could be well managed with the pharmacopeia available at the time, if medications were prescribed and used appropriately.

### **Pain Theory History**

The most prominent theory about pain cited in the nursing and medical literature is Melzack and Wall’s classic 1965 work, the Gate Control Theory. This theory brought together the previously opposing concepts of pain perception described by the line and specificity theories of pain. Pain had long been studied

and debated, with the early references acknowledging it as a multidimensional experience (Moayedi & Davis, 2012). As with much of the body of medical

Figure 1.1 World Health Organization Pain Ladder



(WHO. 2017. <http://www.who.int/cancer/palliative/painladder/en/>)

research carried out in the empirical tradition, these theories focused on pain as a mechanistic process involving a stimulus and behavior, without considering related emotional or mental aspects. Melzack and Casey expanded pain theory to include three dimensions, the sensory-discriminative, affective-motivational, and cognitive-evaluative (Moayedi & Davis, 2012). The third category considers individual responses to pain stimulus based on context.

The hospice movement for caring at end-of-life was based on Dame Cicely Saunders' theory of total pain, developed in the 1960s when she nursed the dying in a British hospital. Her multidimensionality of pain extended beyond the three dimensions proposed by Melzack and Casey. She observed that her patients were experiencing needless suffering that was not just physical, but also involved emotional, mental, social,

and spiritual dimensions (Saunders, 1978). Although it is common in hospice care to hear discussion of the physical, social, emotional, and spiritual aspects of total pain, Saunders' theory has not been extensively developed and applied in the nursing research, perhaps because of its complexity. At the heart of total pain theory is the precept that physical pain is often worsened by unresolved emotional, psychological and spiritual issues (Clark, 1999).

### **Role of Pain Meaning**

Munhall's (2012) view of nursing science would compel nursing researchers to explore Saunders's multidimensionality of pain. She identified nursing as a human science that differentiates it from natural sciences (Munhall, 2012). She states, "...*the natural sciences investigate objects from the outside to the inside, whereas the human sciences depend on a perspective from the inside to the outside.* The most important concern of the human sciences is meaning" (Munhall, 2012, p. 11). Effective nursing assessment and management interventions for pain therefore should be rooted in the meaning of pain (Ferrell et al., 1993). One element of meaning is the situated context, which is comprised of an individual's unique circumstances, how the person interprets those, and how they are integrated into a social construct unique to that person's self. Meaning is critical for understanding how and when change may occur (Munhall, 2012). The lived experience of cancer will necessarily vary for each person. Therefore interpretation of and adaptation to symptoms such as pain will also be unique for individuals. Because meaning of cancer pain occurs within a social context, it is important to examine not just the meaning of pain for the person with cancer, but how meaning is interpreted by family caregivers and nurses.

## **Role of Pain Control**

One aspect of meaning for cancer pain is whether or not a person feels in control of their pain. In an early study of control Lewis (1982) found that end-stage cancer patients who had experienced feelings of control over their lives were more likely to have higher quality-of-life than those who had not. Purpose in life was significantly related to perceived control of health (Lewis, 1982). Control can refer to an individual's sense of ability to cope, and the lack of perceived coping ability can prevent adequate pain management (APS, 2005; Byma et al., 2009). Control may be related to how an individual appraises their circumstances and chooses to act. Appraisal occurs in the context of meaning. Byma et al. (2009) report that control of symptoms for patients with cancer can be affected by cognitive behavioral interventions like mastery. Nurses use cognitive behavioral interventions, which like other pain management strategies fall within the context of social processes. Vallerand and Ferrell (1995) encouraged nurses to collaborate with patients to develop pain management strategies that promote patient control, while acknowledging and supporting the needs of family caregivers. Pain control can be viewed through the perspectives of all members of the hospice caring triad, which are not always congruent (Ehrlich, 2014, podium paper; Vallerand & Ferrell, 1995). The concept of pain control usually has different meanings for healthcare professionals than the persons they care for (Barkwell, 2005; Ferrell et al., 1993). Pain control as a concept can refer to an acceptable level of pain severity which is considered an end-point, a functional goal, a facilitator, a method, or a challenge (Barkwell, 2005; Chen, 1999; Ehrlich, 2014, podium paper; Vallerand & Ferrell, 1995).



## **Conclusion**

In summary, this dissertation study used constructivist grounded theory methods to identify theoretical concepts and constructs about cancer pain social processes for the hospice caring triad. This is an area of pain management which has had little research, none of which has had the goal of creating a structural framework or theory to identify the social processes and their relationships. At this time, there are no theories that adequately describe how patients, caregivers, and their hospice nurses work together to manage pain. In this study, preliminary elements of pain management and the relationships among them have been identified, described and defined. By engaging in this theory-building process, new propositions for improving cancer pain management for persons receiving hospice care have been identified. Subsequent research studies can examine the nature of the framework relationships, and develop and test interventions for improving pain.

Early in the processes of data collection and analysis, several themes became apparent to the researcher as possible domains for the cancer pain social processes theory. While the end goal of this research study remained the construction of the theory, within this dissertation, the focus is specifically on a case study analysis of the hospice caring triad and the domains of Cancer Pain Control goals and the sharing of information through verbal or nonverbal means, which the researcher labelled as being 'in-the-loop' or 'out-of-the-loop'.

## **Dissertation Format**

The dissertation is structured as chapters comprising this first introductory chapter, a chapter presenting aims and methods, three manuscripts about the study written

for publication, and a concluding chapter. In Chapter Two, the first of the manuscripts, the literature review informing the researcher about known and unknown cancer pain social processes issues is presented. This integrative literature review, “Pain and social processes for hospice cancer patients”, was published in the *European Journal of Oncology Nursing* in October of 2016. Chapter Three presents the study aims and methods. In Chapter Four, results of the triadic case study analysis are presented, introducing the theoretical domains, *Controlling Cancer Pain*, and *Proximity*. Chapter Five presents a discussion of issues related to study recruitment and retention, intended for submission to *Journal of Nursing Research*. Chapter Six presents a summary of the dissertation study and suggests directions for refining pain management theory.

## CHAPTER 2

### PAIN AND SOCIAL PROCESSES FOR HOSPICE CANCER PATIENTS: AN INTEGRATIVE REVIEW

**Manuscript 1: Previously published as: Ehrlich, O., & Walker, R. K. (2016). Pain and social processes for hospice cancer patients. *European Journal of Oncology Nursing*, 83-89. DOI: 10.1016/j.ejon.2016.10.001.**

Relief of suffering, especially physical pain, is a primary function of hospice care (National Hospice and Palliative Care Organization, 2016). Rates of pain in patients with metastatic and advanced cancer are as high as 64%, with one third of patients reporting moderate to severe pain (van den Beuken-van Everdingen et al., 2007). The problem of poorly controlled pain persists despite the publication of guidelines for the treatment of cancer pain, and pain in adults and older people (American Pain Society, 2011; Herr et al., 2010; RNAO, 2013). While hospice and palliative care programs strive to stay at the forefront of pain control, hospice nurses' clinical practice and use of these evidence-based guidelines varies widely (Coyle, 2004; Herr et al., 2010).

Hospice care usually takes place in the dynamic setting of people's homes, where a constellation of factors affect outcomes of cancer pain management (Lau et al., 2010). However, barriers to and facilitators of excellent cancer pain control in the context of home hospice care have yet to be fully described and integrated into theory to guide nursing practice, especially social processes. Social processes is a complex framework involving cognitive awareness, reflection, behavior, and interactions with others. The purpose of this integrative review is to identify and describe factors impacting

management of cancer pain in the home hospice setting, using a social processes framework to organize and interpret current research. We chose a social processes framework as a theoretical lens to guide this review because the experience and meaning of pain for the person with hospice care, and how the family caregiver and nurse relate to and interpret this experience is not well understood. The following questions guide the literature review and synthesis:

- 1) What is the experience of pain for the person with cancer?
- 2) What is the experience of the family caregiver in regards to the person's pain?
- 3) What is the experience of the hospice nurse in regards to the person's pain?
- 4) Which social processes related to hospice cancer pain have been identified?

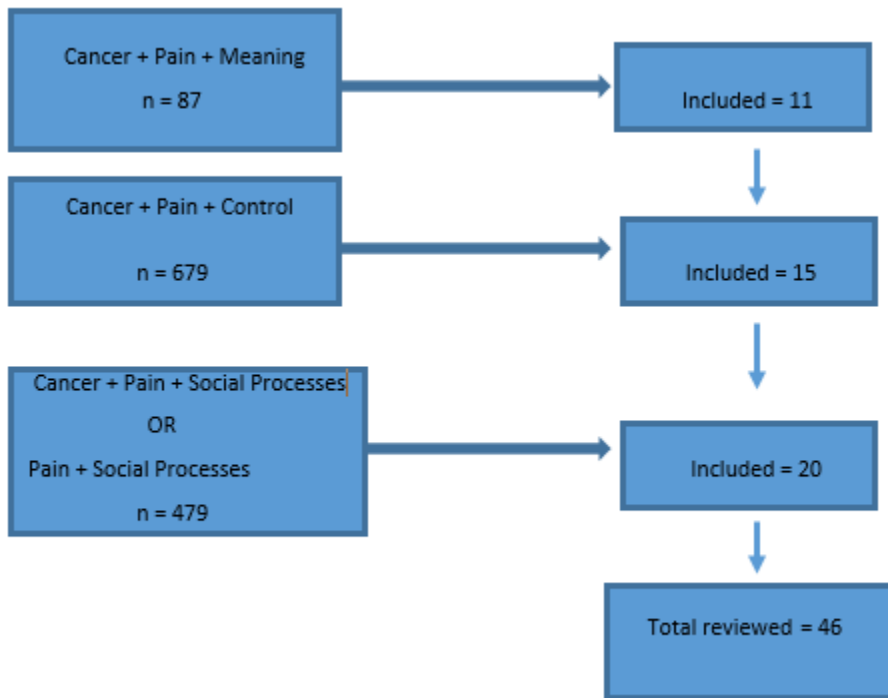
Symbolic interactionism is at the root of social processes, explaining how people create meaning as a result of thoughts, behaviors, and communications (Charmaz, 2010). The social processes framework we have adopted from the National Institute of Mental Health (NIMH) (2012) for the purpose of this review, involves a complex combination of cognitive awareness, reflection, behavior, and interactions with others. How social processes may be impacting pain experience is an area relevant for clinical practice when pain from cancer is poorly controlled. By categorizing and summarizing pain social processes studied so far, we point out considerations for clinicians to address and gaps in understanding of poorly controlled pain.

### **Methods**

Integrative review methods were used according to published best practices (Whittemore & Knafl, 2005). Author one searched Cumulative Index of Nursing and Allied Health Literature (CINAHL) and PubMed for peer-reviewed journal articles using

the following search terms singly and combined: cancer pain, pain, meaning, goals, control, processes, hospice, palliative care, patient experience of pain, end-of-life suffering, end-of-life pain, cancer pain relief, hospice nurse, and hospice caregiver. To identify studies of pain meaning and experience, the search also included methodological keywords, such as qualitative research and grounded theory. Early searching located only a few studies about all three concepts guiding this review (cancer, pain, and social processes). Because of this, after journal article titles and abstracts had been read, the authors agreed to include two studies about persons with pain from end-stage cancer receiving treatment in both the home and outpatient settings in other countries. The data reported contributed to the pain social processes lens, and it is likely that these same two samples would have been receiving hospice care if in the United States. Studies that focused solely on children, pain meaning not related to cancer, and studies not published in English were excluded. No publication date limits were set. Author one identified 46 articles after eliminating duplicates and including articles identified by hand searching of bibliographies. After reading the studies completely, another 25 studies did not fit the criteria because they focused on chronic non-cancer pain, laboratory studies inducing pain in healthy volunteers, or cancer patients who were not receiving hospice care. A total of 21 articles, including one from a text book, were included in the final review. Figure 2.1 (p. 21) illustrates the search steps. Based on nursing theory, the authors agreed to categorize studies under the broad headings of pain control and pain meaning, and the subcategories of social roles within the hospice triad—person with pain, caregiver, and hospice nurse.

Figure 2.1 Study Selection Process



## Results

Most of the literature reviewed was about the cancer pain management experiences of clinicians, particularly studies about controlling pain. Some articles presented the perspectives of persons with pain from cancer, and people supporting them. These studies tended to explore the value of having support, or the personal effects of being a caregiver for a person with cancer pain. We present our findings under the major categories of cancer pain meaning and cancer pain control, discussed from the perspectives of each: person with pain, caregiver, and hospice nurse. Then, we further explore the literature within the social processes context.

## **Cancer Pain Meaning**

### **Role of Pain Meaning**

Munhall (2012) identified nursing as a human science differentiated from natural sciences by its focus on meaning. Effective nursing assessment and management interventions for pain therefore should be rooted in the meaning of pain. One element of meaning is the situated context, which is comprised of an individual's unique circumstances, how the person interprets those, and how they are integrated into a social construct unique to that person's self. Meaning is critical for understanding how and when change may occur (Munhall, 2012). The lived experience of cancer will necessarily vary for each person. Therefore how that individual interprets and adapts to symptoms such as pain from cancer will also be unique. Because meaning of cancer pain occurs within a social context, it is important to examine not just the meaning of pain for the person with cancer, but how meaning is interpreted by family caregivers and nurses.

### **Pain Meaning for Hospice Patients with Cancer**

Pain has been identified as a challenge for hospice patients with cancer. Barkwell (1991) conducted a mixed methods study examining correlations between patient-identified pain meaning, coping strategies, depression levels and pain levels based on Melzak and Wall's gate control theory, Lipowski's meanings of illness, and Lazarus' psychology of coping framework. Two groups of 50 patients with terminal cancer diagnoses either receiving home care or hospice care were asked to rank their pain meaning within preset categories. Challenge was the most relatable meaning of pain (36%), with punishment ranked second most relatable (23%), and enemy third (20%). There were significant correlations between assigned meaning of pain as a challenge,

coping strategy, and depression levels. Individuals in both groups who considered their pain to be a challenge were more likely to have higher coping scores and lower pain levels than those who labelled their pain as punishment or an enemy (Barkwell, 1991).

Two studies using phenomenology to explore cancer pain experience also found that pain was a challenge for hospice patients (Ferrell, Taylor, Sattler, Fowler, & Cheyney, 1993; Larsson & Wijk, 2007). The challenge was that although pain meant suffering it indicated vitality (Ferrell et al., 1993). Larsson and Wijk's (2007) pilot study of three cancer patients who used intrathecal pain pumps for relief found a similar challenge. These patients shared feelings of wanting to reveal pain so that they could receive help for pain control to be conflicting with feelings of wanting to conceal pain to avoid reminding family members that they were suffering or dying.

Sometimes the meaning of pain is inextricable from the meaning of having cancer (Barkwell, 2005). In a grounded theory study of Ojibway beliefs related to cancer, there were differences in how cancer pain was perceived by the participants, their families, and healers versus the nurses and doctors. For patients and family members the terms pain and cancer were inseparable. Therefore, physical pain was interconnected with thoughts, feelings, and intuition, as well as social and spiritual aspects of their lives (Barkwell, 2005).

Duggleby (2002) found that elderly hospice patients used different words to describe their pain than those listed on the McGill Pain Questionnaire and Memorial Pain Assessment Card. She reviewed charts to identify which words the patients used. Patient participants were also interviewed to ask what words or terms they would apply to describe their pain. They only used 30% of the word choices available in the tools,



indicating that assessment tools used as best practice were not meaningful to over half of her sample.

### **Pain Meaning for Family Caregiver and Nurse in Hospice**

Hospice nurses may ascribe different meaning to cancer pain than patients do. Ferrell et al. (1993) in their phenomenological study which sought to explain the roles of patient, carer, and nurse found that how nurses perceive the patient pain experience affects their practice. Whereas patients viewed the pain experience as a conflict between attaining comfort and knowing that they were alive, nurses viewed the patient's pain as a symptom for which they had provided relief. They defined the ultimate roles of the nurse as helping the patient and carer dyad find shared meaning for the pain.

A grounded theory study was conducted at five hospice agencies in Florida to examine constraints faced by nurses in relation to use of opioids for pain relief (Zerwekh, Riddell, & Richard, 2002). Themes of fear and avoidance played significant roles in underutilization of opioid medication use for hospice patients. Nurses reported that they had encountered fear and avoidance from doctors, patients, carers, and other nurses.

While there is little research into the perceived meanings of cancer pain for family caregivers, what is known consistently reflects potential differences between their meanings and those of nurses and loved ones (Ferrell et al., 1993; Zerwekh et al., 2002). Barkwell's (2005) results similarly reflected differences in how cancer pain was perceived by the participants, their families and healers, versus the nurses and doctors. For the healthcare professionals, cancer was viewed as separate from pain, for example they did not expect every type of cancer to be associated with pain, while family caregivers expected both cancer and pain.

## **Cancer Pain Control**

### **Role of Pain Control**

Control can refer to an individual's sense of ability to cope, and the lack of perceived coping ability can prevent adequate pain management (Byma et al., 2009). Control may be related to how an individual appraises their circumstances and chooses to act. Appraisal occurs in the context of meaning. Byma et al. (2009) report that control of symptoms for patients with cancer can be affected by cognitive behavioral interventions like mastery. Therefore, meaning and control are necessarily intertwined social processes relative to the person with pain and others engaged in pain management activities.

The term pain control is ambiguous, having multiple meanings. In reviewing the studies, we categorized meanings as: end-point, challenge, facilitator, method, or context. For nurses, physicians, and researchers, pain control is frequently an end-point to be achieved, like a reduced pain severity rating, which is facilitated with an intervention (Ahmedzai, 1997; Jho, Myung, Chang, Kim, & Ko, 2013; Minson, et al., 2012; Rustoen, Torbjorn, Padilla, Paul, & Miaskowski, 2005). Pain control as a method could be an intentional intervention from the perspective of the nurse (Ahmedzai, 1997; Ferrell et al., 1993; Jho et al., 2013; Minson et al., 2012; Rustoen et al., 2005). For people with pain from cancer, pain control is more often relevant as a challenge, a facilitator, or a context (Ehrlich, unpublished study, 2014).

### **Pain Control for Hospice Patients with Cancer**

Use of pain control as an end-point for hospice patients is evident in the literature. Middleton-Green (2008) applied the gate control theory of pain, in a case study analysis to explain how hospice agencies could better achieve patient-centered pain control. She

recommended that the patient might have had more effective pain control if offered early interventions to identify preferences for analgesic use. A study in Sweden assessed the participant-reported impacts of receiving hospice care. Pain control was one of two significantly improved end-points used to measure efficacy of hospice care. All aspects of pain management were significantly improved after starting hospice (Bostrom, Sandh, Lundberg, & Fridlund, 2004). A systematic review of four randomized controlled studies focused on patient-related outcomes, in which educational interventions for cancer patients with pain had significant impacts on the reduction of pain intensity and pain interference (Ling, Lui, & So, 2012).

Pain control as a facilitator for patient quality of life (QOL) was studied by Redinbaugh et al. (2002). Their descriptive study of 31 patient-carer dyads served by two non-profit hospice agencies in southeastern Pennsylvania reported that QOL was significantly negatively correlated with patient pain ratings ( $t=-4.9, p<.01$ ). Bostrom et al. (2004) also studied pain control as a facilitator. Pain control was statistically significantly correlated with feeling secure, having continuity of care, and knowing who to call.

Pain control can be perceived as a method, which is similar to the concept of pain control as a facilitator. Vallerand, Saunders, and Anthony (2007) carried out a phenomenological study about the role of perceived control in relationship to pain of 10 cancer patients receiving home hospice care and their caregivers. They identified six themes common to patients: pain was hungry, they felt desperate, robbed of the most simple tasks and pleasures, and pain was winning. Perceived control was associated with feelings of comfort.

## **Pain Control for Family Caregiver and Nurse in Hospice**

In reviewing the few studies about pain control for caregivers, we identified context as the most common concept. This was evidenced by the potential effect of caregivers' perceptions about pain and pain relief interventions on patients' levels of physical suffering. Redinbaugh et al. (2002) found that caregivers consistently rated patient pain higher than patients which led to higher stress levels for both of them, and lower QOL ratings for both. Flemming's (2010) systematic review also found that caregiver beliefs about the symbolism of morphine, addiction, and tolerance influenced patient use of morphine. Vallerand et al. (2007) asked caregivers about the meaning and impact of pain control. Caregivers felt as though they were observers to the pain processes patients experienced, with little ability to influence pain control, and that this caused emotional distress. In summary, the studies described how the context within which caregivers applied pain control influenced of their roles in pain management activities.

Many studies about hospice pain address pain control from the nursing perspective of an end point or outcome. We located only one study about a different meaning of pain control for hospice nurses. Ferrell et al. (1993) identified the need to control the pain of the cancer patients that nurses cared for as a challenge. The challenge was the moral and professional obligation to control pain.

### **Social Processes Concepts Related to Pain**

Besides organizing research study themes and findings under the pain meaning and pain control categories, we further searched for social processes concepts related to hospice cancer pain for the members of the caring triad. The theoretical lens of social

processes as outlined and defined by the NIMH (2012) was applied. These included: (a) affiliation and attachment, (b) social communication, (c) perception and understanding of self, and (d) perception and understanding of others. Each concept is defined in Table 2.1, below and includes a summary of study concepts for each hospice triad role. Discussion regarding their application to cancer pain follows.

### **Affiliation and Attachment**

Affiliation and attachment can be behaviors that each or all individuals involved in the caring triad engage in. While affiliation does not rely on conscious choosing, attachment does. However, affiliation potentiates attachment (NIMH, 2012). For example, a person may report pain to their caregiver or nurse because of a previous positive experience when reporting of pain severity resulted in assistance with medication and consequent pain relief. The type of social bond selected by the person with pain may vary depending on the caregiver or nurse's responses to pain reporting.

All triad members were represented in research relating to affiliation and attachment. Studies included: communication and pain reporting for the person with pain; ability to administer medications, assertiveness, accepting responsibility, and communication for the caregiver; and partnering communication for the nurse (Lau et al., 2010; Larsson & Wjik, 2007; Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Redinbaugh et al., 2002). One study found that people chose not to report pain to caregivers because doing so caused emotional distress to the other (Redinbaugh et al., 2002).

### **Social Communication**

By its very nature of including a team approach to care management, hospice necessitates social communication. Two studies included all three triad members

Table 2.1 Social Processes Definitions and Related Researched Concepts

Definition	Triad Member Concepts		
	Patient	Caregiver	Nurse
<i>Affiliation &amp; Attachment:</i> "...engagement in positive social interactions with other individuals. Attachment is selective affiliation as a consequence of the development of a social bond." <sup>1</sup>	Communication Pain reporting	Cognitive empathy Able to administer meds Assertiveness Accepting responsibility Communication	Partnering communication
<i>Social Communication:</i> "[a] dynamic process that includes both receptive and productive aspects used for exchange of socially relevant information. Social communication is essential for the integration and maintenance of the individual in the social environment." <sup>1</sup>	Gender Social support Communication Pain reporting	Information seeking Communication Literacy Mimicry and feedback Cognitive impairment Physical impairment Social support	Partnering for communication Social support
<i>Perception &amp; Understanding of Self:</i> "The processes and/or representations involved in being aware of, accessing knowledge about, and/or making judgements about the self [including] current cognitive or emotional internal states, traits, and/or abilities, either in isolation or in relationship to others." <sup>1</sup>	Psychological distress Suffering Relief of suffering Motivation to find meaning Communication Social support	Experiences of suffering Relief of suffering for self Negative emotional state Cognitive impairment Assertiveness-accepting responsibility Self-efficacy for suffering relief Skills needs Core knowledge Knowing symptoms Able to manage meds	Pain Self-reflection
<i>Perception &amp; Understanding of Others:</i> "The processes and/or representations involved in being aware of, accessing knowledge about, reasoning about, and/or making judgements about other animate entities, including information about cognitive or emotional states, traits, or abilities." <sup>1</sup>	Communication Pain reporting	Pain assessment Information seeking Perspective-taking Knowing patient preferences Cognitive impairment Suffering	Pain perception

National Institute of Mental Health. *Social processes: workshop proceedings*. 2012. <http://www.nimh.nih.gov/research-priorities/rdoc/social-processes-workshop-proceedings.shtml>.

(Ellington, Reblin, Clayton, Berry, & Mooney, 2012; Ferrell et al., 1993). Concepts from the literature that fall under this construct include social support, communication, and pain reporting for the person with pain; information seeking, communication, literacy, cognitive impairment, physical impairment, and social support for the caregiver; and partnering for communication as well as social support for the nurse (Ellington et al., 2012; Ferrell et al., 1993; Ferrell, Ferrell, Ahn, & Tran, 1994; Larsson & Wjik, 2007; Lau et al., 2010).

Ellington et al.'s (2012) study of communication patterns at hospice nursing visits found that of different coded forms of talking at the visits, patients engaged in 31% physical care talk, while caregivers and nurses did so at 15% and 22% respectively. Lau et al.'s (2010) qualitative study of factors influencing hospice caregivers' ability to successfully manage patient medications at home found that factors identified by caregivers and providers included literacy, quality of communication between caregiver and patient, competing caregiver responsibilities, cognitive or physical impairments of caregivers, caregiver confidence, caregiver life experience, and caregiver emotional state. Ferrell et al.'s (1994) study of an educational intervention for cancer patients and their caregivers found that after the intervention, use of prescribed pain medications as well as non-medication interventions increased.

### **Perception and Understanding of Self**

In seeking to understand what pain meaning is for any member of the caring triad, and that individual's role in pain management some degree of knowledge, choices, and feelings inform thoughts and behaviors. Most of the literature concepts falling under perception and understanding of self were associated with the caregiver. These were:

cognitive impairment, assertiveness-accepting responsibility, self-efficacy for suffering relief, skills needs, core knowledge, ability to recognize symptoms, and ability to store, organize, and administer medications (Ellington et al., 2012; Ferrell et al., 1995; Lau et al., 2010; Ling et al., 2012; McCaffrey et al., 2011). Variables for the person with pain were: psychological distress, suffering and relief of suffering, motivation to find meaning, communication, and social support (Ferrell et al., 1993; Larsson & Wjik, 2007; Lau et al., 2010; Ling et al., 2012; Vallerand et al., 2007).

Perception of self could impact family caregivers' capacities to assist spouses experiencing pain. Lau et al. (2010) found that caregivers identified high confidence, good communication, life experience, and background knowledge as facilitators to medication management for hospice patients. They identified barriers as negative emotional states, competing responsibilities, complex medication regimens, cognitive or physical impairments, and negative emotional state. Redinbaugh et al. (2002) found that caregivers' perception of their stress affected their caregiving abilities. Vallerand et al. (2007) reported that nurses should assess caregivers' self-efficacy and gear interventions for patient pain control toward caregiver self-efficacy.

### **Perception and Understanding of Others**

This concept is very similar to perception and understanding of self when applied within the hospice caring triad because of the social nature of pain management. There was one study about this concept related to the caregiver that addressed information seeking, knowing patient preferences, and cognitive impairment (Redinbaugh et al., 2002). Other studies included the variables for persons with pain of communication and



pain reporting, and for the nurse, pain perception and barriers to use of opioids (Ferrell et al., 1993; Larsson & Wjik, 2007; Zerwekh et al., 2002).

In their descriptive study of persons receiving hospice and their caregivers, Redinbaugh et al. (2002) found that caregivers' ability to assess patient pain was inaccurate and usually resulted in higher severity ratings than reported by the persons experiencing the pain. In turn this contributed to decreased QOL for both. Ferrell et al. (1993) reported that nurses' pain perceptions affected their pain practice for hospice cancer patients. For patients, reporting of pain was significant for their willingness to engage in doing so because of the relationship already discussed between caregiver pain knowledge and potential suffering.

### **Discussion**

The overarching question guiding this review is: In the context of hospice, how do the social processes among the members of the hospice caring triad affect cancer pain management? Elements of social processes and pain management for the hospice caring triad members have been examined in individual research studies. Most studies did not have identification or clarification of social processes concepts as goals of the study. Pain meaning and pain control for various triad members in the context of improving pain outcomes and QOL were key concepts in the studies reviewed.

### **Pain Meaning**

For persons with cancer receiving hospice care, pain meaning has been identified as a challenge, punishment, and enemy (Barkwell, 1991; Ferrell et al., 1993; Larsson & Wjik, 2007). Pain was also identified as a cause of suffering which reminded participants that they were still alive or as a reminder to loved ones of suffering or as impending

death. Studies of persons with cancer not receiving hospice care, found that pain can mean loss, threat, challenge, or spiritual awareness (Chen, 1999). Some ways that non-hospice patients with cancer specified their pain meaning were being challenged by God or by feelings of wanting death to come (Coyle, 2004). One study found that patients who took morphine for pain relief felt as though death was impending (Flemming, 2010). For those people, as for participants in a study of pain related to breast cancer, the meaning of pain was considered to be related to worsening disease (Bender et al., 2008).

Comparing and contrasting pain meaning for cancer patients receiving hospice care or other outpatient care demonstrates the wide range of possible pain meanings. Clinicians should consider that any of these pain meanings could be impacting poorly controlled pain when best practices for cancer pain management have previously been used with patients and caregivers to intervene. Chen (1999) conducted a quantitative study with Taiwanese cancer patients. She tested six scales of the Perceived Meanings of Cancer Pain Inventory (PMCPPI) with a sample of 200 people. Four meanings of the scales had good construct validity in this population: loss (Cronbach's alpha .82), threat (Cronbach's alpha .88), challenge (Cronbach's alpha .74), and spiritual awareness (Cronbach's alpha .72), whereas blame-other and blame-self did not. The loss and threat scales described negative views of pain, for instance: "loss of life enjoyment" or "pain may develop to a degree that no medication can control" (1999, p. 349). The challenge and spiritual awareness scales contained statements which indicated positive views: "can control the pain by my own will or methods" and "rethink the meaning of life" (1999, p. 349). Gaps remain in understanding when and how hospice clinicians should explore

such factors in the context of pain management. Studies which explore similar scales of meaning, or replicate Chen's (1999) work for American hospice patients are needed.

Some cultures may consider pain and cancer inseparable despite contrary beliefs held by their healthcare professionals (Barkwell, 2005). This difference between perception of pain meaning between people with cancer pain and those caring for them was also found in a study showing that older persons infrequently used words listed in common pain assessment tools (Duggleby, 2002). Studies examining differing pain meaning perceptions among hospice caring triad members are needed to understand if and when patients, caregivers or nurses believe that pain and cancer are inseparable. Although no guidelines exist for hospice nurses to use in understanding pain perception, nurses should consider the possibility of individual beliefs related to pain inevitability, and language choices used to describe pain, in the face of poorly controlled pain.

### **Pain Control**

For persons with cancer receiving hospice care, pain control as an end-point has been researched and has demonstrated the efficacy of hospice care (Bostrom et al., 2004). A case study analysis found that end-of-life cancer pain relief could be better achieved through early interventions for all symptoms, not just pain (Middleton-Green, 2008). Also, a systematic review of RCTs showed that educational interventions for achieving reduced pain intensity could be effective (Ling et al., 2012). Hospice nurses can familiarize themselves with resources available to help them apply cancer pain management best practices such as the Cancer Pain Practices Index (Herr et al., 2010) and Pasero and McCaffery's (2010) text, "Pain Assessment and Pharmacologic Management".

Control of pain itself can be a method for improving the functional status of those suffering from cancer pain (Vallerand et al., 2007). In a study of non-hospice cancer patients, Yang et al. (2012) found significant relationships between pain severity and quality of life, where reduced pain correlated with higher QOL. Another study found that for participants who journaled about their cancer pain, those with high emotional disclosure had significantly reduced pain intensity (Cepeda et al., 2008). Findings indicate that study participants who used few interventions for pain relief also had little belief in their ability to control their pain (Arraras, Wright, Jusue, Tejedor, & Calvo, 2002). Some people with cancer indicated uncertainty about who to turn to for pain management assistance, a desire to be informed about pain and management options before it occurs, and wanted to understand the meaning of pain in relation to disease progression (Bender et al., 2008). Although such nursing interventions need to be studied in the hospice context to determine how and when they should be applied, nurses can encourage journaling with emotional disclosure, engage in ongoing assessment of QOL goals for patients and caregivers, and introduce the idea that patients may have improved pain control by trying multiple interventions over time rather than giving up.

Pain control was identified as a challenge to persons with pain because well-controlled pain left some participants feeling as though they had surrendered to the cancer (Author one, unpublished study, 2014; Ferrell et al., 1993). For caregivers and nurses, challenges included feelings of helplessness, increased stress for caregiver and patient because of difference in pain severity ratings, and myths about morphine affecting pain treatment caring behaviors (Flemming, 2010; Redinbaugh et al., 2002; Vallerand et

al., 2007). How to overcome these particular challenges related to pain control is an area needing further research.

### **Social Processes for Cancer Pain**

Social processes related to cancer pain management for hospice care will usually overlap, involving some complex interplays which may be difficult for nurses to pick apart. However, for patients with poorly controlled pain, it is possible that applying an understanding of known pain social processes can help with planning care. For example, the role of attachment in pain management behaviors of the family caregiver and person with cancer can influence how communication about pain occurs. The type and nature of the attachment could influence ineffective communication, increased pain, and increased suffering for both persons (Monin & Bohulz, 2009). However, clinicians should note that affiliation and attachment can have positive or negative influences on pain, depending on the meaning of pain for all persons involved in caregiving. Educational interventions for family caregivers and people with cancer pain are one way that nurses can promote social processes with the positive outcomes of increased use of prescribed pain medications and non-pharmacological treatments (Ferrell et al., 1994). For non-hospice caregivers, learning to imagine the symptom from the point of view of the patient has improved outcomes by preventing the distress for both people that occurs when the caregiver overestimates symptom severity (Lobchuk & Vorauer, 2003), an example of the interplay between self-perception and perception of other.

How nurses perceive experiences of those they care for affects their hospice practice because of their professional and ethical obligation to provide symptom relief (Ferrell et al. 1993). Some hospice nurses also associate pain meaning with fear and

avoidance from the patients they care for, as well as from healthcare professionals (Zerwekh et al., 2002). While nursing education programs commonly use self-reflection to help students develop critical thinking and analysis skills, use of reflection upon one's own illness experiences generally is not practiced. Nay and Fetherstonough (2012) described a method practicing nurses can use in order to understand how their own pain experiences might influence those they provide care for. The role of how such reflective practices for hospice nurses could impact their pain management practices has not been studied.

### **Conclusions**

The central objectives of this critical review of the literature were to establish what is known about pain meaning and pain control for older persons with cancer, the family caregiver, and the hospice nurse, in the context of social processes involved in pain management. In this integrative review we have provided a conceptual and empirical foundation for the design and conduct of research to address important gaps in the knowledge of social processes in hospice cancer pain management (see Table 2.1, p. 29). We have also made evidence-based recommendations for nurses to consider when pain from cancer appears poorly controlled.

The likelihood or fear of experiencing pain during cancer is real (van den Beuken-van Everdingen et al., 2007). Pain is one of the most prevalent and troubling symptoms of cancer (Coyle, 2004; Herr et al., 2010). When viewing pain management for the hospice caring triad through a social processes lens, it is difficult to separate out each meaning, role or context of control, and their relationships to the individual social processes themselves. Pain as a complex phenomenon is not a new idea. However, in the context of

poorly controlled pain, hospice nurses may be able to better assist patients and caregivers when having a familiarity with the literature.

Changes in delivery of healthcare have increasingly moved in the direction of self-management of symptoms like pain by those experiencing it and their family caregivers, at home between visits with practitioners. In order to provide patient-centered pain assessments and interventions for people living in the community, hospice nurses must know how to investigate pain meaning and patient-directed goals. To do so consistently, in accordance with best practice, assessment tools for pain meaning and patient-directed pain control goals must be developed. Clinicians need assessment tools to help them identify other sensitive barriers and facilitators related to cancer pain social processes for pain management to be effective.

### **Limitations**

This review's primary purpose was to summarize themes and categories to establish a lens through which pain social processes can be acknowledged and researched. Therefore, we did not critically evaluate each research study's methodologies, nor did we undertake an exhaustive search of the literature. Because of the many different methodologies used in hospice cancer pain research, and the various instruments and scales implemented, it is difficult to compare results from these studies. Readers should consider these points when searching for evidence from which to base clinical practice and for purposes of designing research studies.

## CHAPTER 3

### AIMS AND METHODS

#### Background

Reports on pain in end-stage cancers indicate that pain control can be problematic for a significant number of people (Strassels et al., 2006; van den Beuken-van Everdingen et al., 2007; van den Beuken-van Everdingen et al., 2016). Much has been studied about effective pharmacological solutions for cancer pain (Hanks et al., 2001; Pasero & McCaffery, 2011; Wiffen, Wee, & Moore, 2016) and barriers to their use, including inappropriate pain medication prescribing by providers, lack of cancer pain best practices knowledge in nurses and physicians, as well as fear (Zerwekh et al., 2002), and the ongoing myth of opioid addiction in healthcare professionals and the public (Flemming, 2010; Institute of Medicine, 2011). Studies have identified different interpretations of the cancer pain meaning for patients and caregivers (Barkwell, 2005; Chen, 1999; Ehrlich, 2014, podium paper; Ferrell et al., 1993; Flemming, 2010; Larsson & Wijk, 2007; Redinbaugh et al., 2002; Vallerand & Ferrell, 1995). Hospice care is the delivery model for persons with terminal end-stage cancers, and is usually provided in the home setting. The caring triad is an integral part of hospice care, consisting of the patient, a caregiver, and the nurse. Little is known about how variables such as cancer pain meaning, pain control behaviors (for example use of medications, or communication about pain), and other social influences interact to affect pain control outcomes for the hospice caring triad (Ehrlich & Walker, 2016). Each person in the triad brings lived experience, knowledge, values, and beliefs to their shared interactions, which can be discussed as a framework of social processes. These social processes include communication, awareness of self and



others, and the nature of personal relationships (see Table 2.1, p. 29). The interplay of social processes undergirds pain management for persons with cancer because symptom management is never conducted solely by one person (IPRCC, 2016). A systematic search of prior research for hospice caring triad social processes while managing pain pointed to gaps. While there has been considerable focus on how individual patients or caregivers manage pain in the home hospice setting, there has been little research on how patients, family caregivers, and hospice nurses work together to do so. Specifically the interplay of social processes for all triad members had not been examined, and further, social processes which had been examined within a triadic context were not done so with the goal of identifying a pain management social processes theory to be used for guiding practice (Ehrlich & Walker, 2016).

### **Research Question and Aims**

The overarching question of this study is: In the context of home hospice, how do perceptions, meanings, and interactions among the members of the hospice caring triad affect cancer pain management? Based upon the complexities of studying multiple persons in caring groups, along with the likelihood of dynamic social processes at play, the author used aims to focus the study. The aims of this research study were:

1. Describe the meaning of cancer pain and cancer pain management for each member of the hospice caring triad.
2. Describe the social processes among the triad members during hospice cancer pain management.
3. Propose a framework of and for cancer pain management social processes of the hospice caring triad.

### **Methodology: Constructivist Grounded Theory**

The researcher chose the constructivist grounded theory (CGT) methodology because of its strength for revealing values and facts crucial to social processes (Charmaz, 2010). Grounded theory (GT) as a research methodology was developed in 1967 to demonstrate that qualitative research could be rigorous and reliable. Glaser and Strauss were first to employ the methodology, based on immersive ethnography, as they studied the meaning of dying in hospitals from a sociology perspective (Munhall, 2012). Specifically, GT was used initially to develop strong middle-range theories grounded in the data. The strength of these emerging theories relied on the rigor of the methods used (Strauss & Corbin, 1990). Key aspects of GT include the goal of discovering theory, inductive data analysis, constant comparative analysis of data, identification of concepts within the data set, and relationships leading to theory (Strauss & Corbin, 1990; Streubert & Carpenter, 2011). The philosophy of pragmatism influenced Strauss's contribution to GT. Pragmatism acknowledges context, with the value to society considered to be of primary importance (Corbin & Strauss, 2008; Wuest, 2012). Another foundational philosophy is symbolic interactionism. The symbolic interactionism lens views human behaviors as comprised of reactions to other people based on thoughts and creation of context. According to this view, there are meanings underlying people's thoughts and actions, and they are inseparable. Corbin and Strauss stated that theoretical knowledge derived from GT may often be "precipitated by a problematic situation, where one can't just act automatically or habitually" (2008, pp. 2-3). Grounded theory methods rely on careful observation and recording of conversations and behaviors related to a problem, whereby the researcher follows key coded data from analysis back into the field and so

on, in a recursive process of constant comparison of data newly collected and previously coded, where meanings can be identified and explored in greater depth.

Constructivist grounded theory has foundations in traditional grounded theory. Kathy Charmaz, credited with popularizing CGT, was a student of Glaser and Strauss. A constructivist grounded theorist acknowledges the personal experiences, values, and beliefs that she or he holds. Taking these into account, the researcher constructs concepts, themes, and knowledge from the raw data. However, Charmaz (2010) believes that forms of data besides observational notes can be analyzed using CGT methods. She encourages the use of CGT methods to give researchers a theoretical view of their study data, even if they are not setting out to construct theory. One of the strengths of CGT is that early gerund coding, theoretical sampling, and free-writing help the researcher to hone in on both factual and value-laden data, both of which are critical elements of social processes. By examining multiple dimensions of social processes Charmaz (2010) states that CGT data collection and analysis can help the researcher construct theoretical domains, cases, or variables for use in future research. Constructivist grounded theory methods were appropriate for examining the value-laden (subjective) symptom of pain and related beliefs of the hospice patient, caregiver, and nurse. Also, CGT methods of field observation and interviewing of triad participants enabled the researcher to differentiate social processes based upon factual behaviors from social processes based upon beliefs and assumptions.

### **Role of Theoretical Frameworks in Grounded Theory**

Use of theoretical frameworks helps nurses conducting research to produce results that are clinically relevant (Roy, 1994). Traditional grounded theorists may collect and

begin analyzing data prior to reviewing literature and without a previous framework (Corbin & Strauss, 2008). The claim is that the literature should be studied in order to verify or compare findings rather than influence them. Researchers utilizing constructivist grounded theory methods may choose to view some literature prior to beginning data collection, and may even base their inquiry upon an existing theoretical framework. In fact, Charmaz (2010) states that all researchers decide upon topics to study because of previous knowledge and expertise in their fields. Her stance is that researchers should acknowledge what they know, and on an individual basis may choose to further sensitize themselves to relevant issues or topics prior to collecting data. For this study, pragmatism, symbolic interactionism, and the NIMH social processes were important sensitizing frameworks for the author to consider when categorizing research concepts in the formal review of literature, developing interview questions, and aggregating codes into concepts and domains, although none of the NIMH social processes categories were used as discreet themes in final data analysis.

The NIMH (2012) social processes concepts are based upon reflective and interactive behaviors that involve thought processes, assigning of meaning, and conscious or unconscious behaviors, all of which occur during hospice cancer pain management. The researcher chose this framework because of its congruency with the pragmatist and symbolic interactionist underpinnings of grounded theory. The NIMH social processes include affiliation and attachment (the types and nature of roles people take on); perception and understanding of the self and others; and social communication. Because cancer pain management is inherently social, especially within a caring triad context,

these framework domains were helpful to the researcher as she extracted meanings, patterns, and categories from complex observational and interview data.

## **Study Methods**

### **Ethical Conduct of Research**

Guidelines for the ethical conduct of research have been established at UMass Amherst and other institutions to protect participants from harm. After designing the study and consulting with administrators at the cooperating hospice agency, the researcher applied for and obtained institutional review board (IRB) approval from UMass Amherst IRB. The agency requested this in a memorandum of understanding which was submitted during the IRB process. The hospice director was supportive of the study goals and offered use of agency meeting rooms for interviews and focus groups. The researcher was known to the hospice agency staff as a nurse employed there for five years prior to beginning the study. Substantive discussion of procedures that the researcher and her advisement committee used for ethical conduct of research is presented in Chapter Five of this dissertation.

### **Recruitment and Sampling**

Based on consultation with a GT research expert (C. Jacelon, March 13, 2015, personal communication), a sample of at least five triads was desired to increase the likelihood of reaching saturation. Saturation is the point at which rich description of the dimensions of coded concepts has been achieved, and a sufficient number of concepts have been identified to establish meaningful interrelationships. As CGT data analysis began with the first collection of data (the joint introductory, observational visit in this case), theoretical sampling was also used to explore dimensions of themes which the

researcher interpreted from the data (Charmaz, 2010; Streubert & Carpenter, 2011). The researcher used two types of theoretical sampling. First, she intentionally recruited persons with the expertise necessary to accurately describe the phenomenon of cancer pain in the hospice caring triad. Second, she sought out data at subsequent collection points to enhance descriptions and understanding of the emerging themes by asking follow-up questions at interviews, a focus group, and via an email survey to nurses. Three triads and one dyad were recruited into the study. Saturation was determined by sufficient data from the triads to describe key social process domains related to cancer pain control. As an acknowledgement of their contribution to the study, each participant was offered a gift card from a local business at termination of participation.

### **Inclusion-exclusion Criteria**

To recruit persons who were most knowledgeable about hospice caring triad cancer pain, the researcher established criteria for each of three groups within the caring triads: patient, family caregiver, and nurse, for data collection and analysis purposes.

The first group recruited were nurses, who in turn would recruit patients. Nurse eligibility was based upon sampling nurses with hospice pain management expertise, who also would be providing full care to potential patient participants as their case managers. Participants had to be registered nurses in Massachusetts, had to have met with the researcher and signed an informed consent agreement, had to have worked at least two days per week as a hospice nurse over the previous 12 months, and been able to converse in English. Hospice nurses who were not providing care for a potential patient participant, did not converse freely in English, had not worked in hospice care at least

one year prior to study recruitment, and who had worked less than two days per week in hospice over the previous twelve months were not eligible to participate.

The patient group was the second to be recruited. For the hospice patient group, participants had to be 60 years of age or older, have had a hospice admitting diagnosis of cancer which they verbalized to the researcher (in lieu of access to patient health records), had been able to engage in conversation in English as determined by discussion between them and the researcher about the informed consent, and had a hospice nurse participating in the study. One nurse and patient wished to participate in the study although there was no caregiver involved. The researcher and adviser agreed that participation was appropriate since a gap in qualitative data about hospice cancer pain social processes had been identified, as well as the dyad data serving as a contrast case (Ehrlich & Walker, 2016). Other inclusion criteria for patients involved age limits because the study focused on the social processes of older persons. Patients younger than 60 years of age were not eligible to participate. This age cut point was selected based on definitions of old age from a global health perspective (WHO, 2015). The researcher assessed for cognitive impairment at the time of obtaining informed consent per previously established and IRB-approved protocols. After the potential participant had time to read through the informed consent agreement, the researcher asked the person to summarize their understanding of the study in several sentences. All potential participants who met with the researcher to discuss the consent were able to do so, and thus were considered not to be cognitively impaired for study purposes. Ongoing assessment of cognitive impairment, which is one sign of worsening disease for some persons with cancer, occurred informally prior to beginning interviews. No participants were unable to

engage in meaningful conversation with the researcher over the course of participation, although several experienced short term memory loss.

The third group to be recruited into the study was family caregivers. Inclusion criteria were: having a patient who had self-identified as a family member and had elected to participate in the study, a hospice nurse who was providing care to the patient who had elected to participate in the study, having been at least 18 years old, having lived with or provided care to the person with cancer pain at least two days per week, and having been able to engage in meaningful conversation in English. People younger than 18 years old, not considered a family member by the patient participant, not able to converse in English, with cognitive impairment preventing them from understanding or answering the study questions, or not having provided care to the patient participant at least two days per week were not eligible to participate in the study. Inclusion and exclusion criteria for the three triad roles are summarized in Table 3.1 (p. 48).

### **Recruitment Procedures**

The first step in recruitment was an informational meeting held for the nurses at their workplace to facilitate participation. The researcher invited all hospice nurses to attend via letters placed in their office mailboxes and voicemail messages left in the nurse group answering service. At the informational meeting the researcher presented a scripted talk with PowerPoint (Microsoft, 2013) slides that had been approved by the IRB, describing the study's purpose, procedures and timeline. The meeting lasted approximately 20 minutes, including time for questions. After the researcher left the meeting, a sign-up sheet was circulated by the hospice manager so that nurses wanting more information, or to volunteer for participation could provide their information



Table 3.1 Recruitment Eligibility Criteria

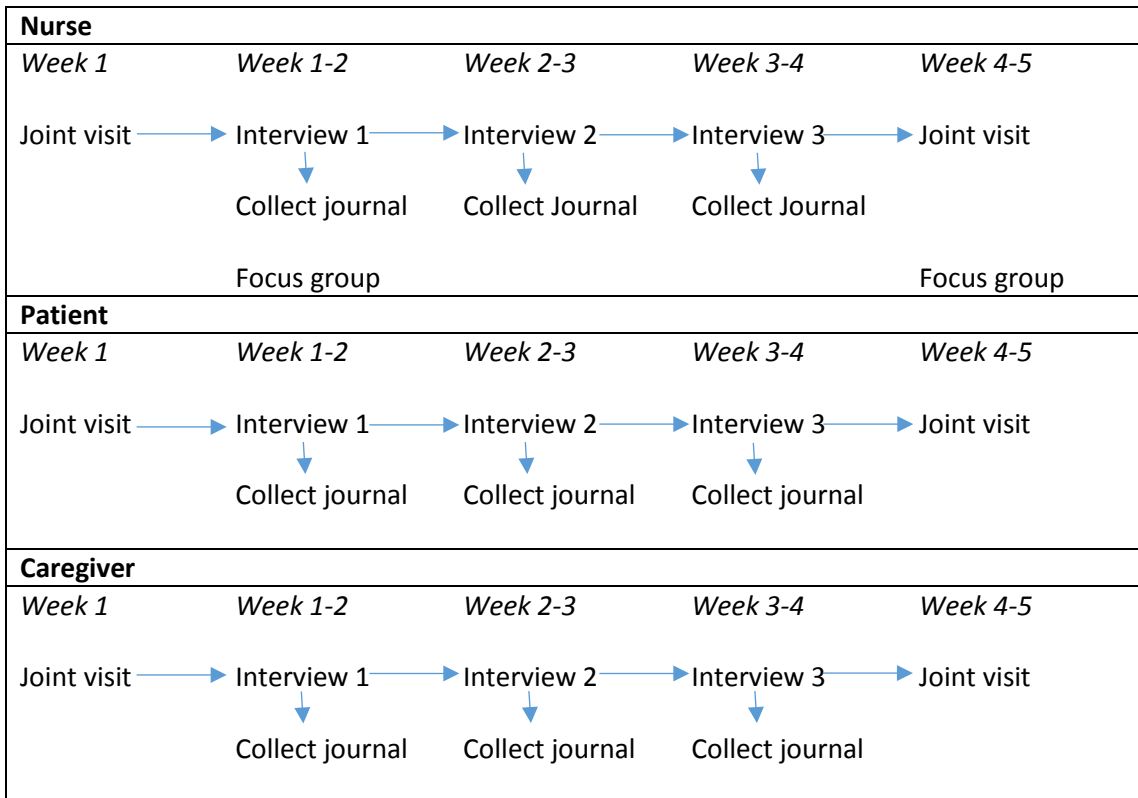
ROLE	ELIGIBILITY CRITERIA
<b>Nurse</b>	<p><b>Inclusion:</b>  Registered Nurse license  Met with researcher to sign informed consent agreement  Able to converse in English  Providing care to a potential group P participant  Had worked at least two days per week as a hospice nurse over the past 12 months</p> <p><b>Exclusion:</b>  Not providing care for a potential group P participant  Had not worked in hospice care for least 12 months in the year prior to study recruitment  Had worked less than two days per week in hospice over the past 12 months</p>
<b>Patient</b>	<p><b>Inclusion:</b>  60 years of age or older  Had a hospice admitting diagnosis of cancer verbalized by participant  Met with researcher to sign informed consent agreement  No cognitive impairment impeding ability to understand and discuss IC  Able to converse in English  Had a hospice nurse and caregiver participating in the study</p> <p><b>Exclusion:</b>  Younger than 60 years of age  Hospice patient without primary cancer diagnosis  Unable to engage in meaningful discussion because of cognitive impairment  Unable to converse in English  No nurse and caregiver willing to participate</p>
<b>Family Caregiver</b>	<p><b>Inclusion:</b>  18 years of age or older  Met with researcher to sign informed consent agreement  No cognitive impairment impeding ability to understand and discuss IC  Able to converse in English  Caring for a patient participating in the study  Living with or providing care to the person with cancer pain at least twice a week</p> <p><b>Exclusion:</b>  Younger than 18 years of age  Not considered a caregiver by the patient participant  Unable to converse in English  Unable to engage in meaningful discussion because of cognitive impairment  Not providing care to the person with cancer pain at least twice a week</p>

without feeling pressured by the researcher’s presence and their existing professional relationship. Two nurses immediately requested information and were contacted via telephone. After discussing the study, the researcher arranged meetings with them for obtaining written consent. Over the year-long data collection period, a total of five nurses participated in the study.

Participating nurses recruited patient and family caregiver participants. At the nurse consent meeting, the researcher had provided each nurse with inclusion and exclusion criteria. These nurses agreed to read a brief recruitment statement to any patient meeting the criteria. Potential patient participants either gave their name and contact information to the recruiting nurse who passed it along to the researcher, or they declined to be contacted. The nurse contacted the researcher via email, text or phone call to inform her that a potential participant had opted in or out. The researcher was not provided with identifiers for those who opted out, other than the date of contact and the name of the nurse who had made the contact. Nurses asked those opting in to provide their preferred means of contact, related contact information (e.g. email address or phone number), and time they preferred for contact. The researcher then made contact with any interested potential participants to explain the study. At that time, she asked if they had a family caregiver who would want to join the study. Family caregivers were approached initially for study participation by either the patient or the nurse.

During these contacts with potential patient participants, the researcher set up meetings to review and obtain written consent. Some family caregiver participants joined these meetings, whereas others met privately with the researcher at their request, to discuss participation and give consent. The meetings took place in the location of the participant's choice. At the consent meetings, a visual study timeline was presented to explain the anticipated duration of participation and the chronological order of data collection activities. The researcher used it to explain the anticipated observational visits, interviews, and focus groups. See Figure 3.1 below.

Figure 3.1 Proposed Study Timeline with Data Collection Activities by Triad Group Member



All nurses except for one chose to review and sign consent in a private meeting room at their workplace, individually. The other nurse requested a meeting at her home for this. The researcher obtained verbal and written consent from all patient participants in their homes. One family caregiver had a joint consent meeting with the patient in the patient’s home. Another family caregiver asked to be consented at the hospice office in a private meeting room. The third family caregiver invited the researcher to a private business office for review and signing of consent. One of the participating nurses who had recruited several potential participants who had either died or become cognitively impaired between the time of phone contact with the researcher and their scheduled

consent meetings, asked about participation for a patient who had no caregiver. It was decided to include the patient and nurse in the study as a dyad, because of the patient's desire to participate and the opportunity to explore a contrasting experience of living alone and managing pain with the help of a nurse.

Over the course of the study, the researcher recorded de-identified data about all participants who met eligibility criteria and were approached for participation on a spreadsheet using ordered, coded alphanumeric pseudonyms. When a potential participant gave the recruiting nurse verbal consent for the researcher to contact them, she did so to answer questions, obtain verbal consent, and make an appointment for the first visit. At this visit, the researcher then obtained written consent. She also obtained ongoing verbal consent at each meeting and reminded participants that they could leave the study at any time without providing an explanation. A total study sample of 22 potential participants spoke with the researcher. The final sample comprised 12 participants, and Table 3.2 includes the recruitment statistics for the sample.

Table 3.2 Recruitment Steps and Numbers of Participants per Triad Role

<b>Role</b>			
<i>Recruitment Step</i>	<b>Nurse</b>	<b>Patient</b>	<b>Caregiver</b>
Asked for contact with researcher	5	12	5
Verbal consent	5	9	5
Written consent	5	4	3
Unable to participate [reason]	0	8 [had illness status change or died prior to 1 <sup>st</sup> meeting]	2 [related patients died prior to 1 <sup>st</sup> meeting]

## **Data Collection**

The researcher had planned a number of data collection activities in order to ensure a robust body of data from which to develop theoretical concepts, constructs and relationships. These included observational visits of the triads and dyad, individual interviews, a focus group, and the opportunity to journal. Each participant was observed engaging in pain management with their caring group and was interviewed multiple times with the exception of one participant. Besides obtaining a rich body of data, the researcher anticipated that prolonged engagement with study participants would increase the likelihood that their experiences were recorded and analyzed as accurately as possible through member-checking, purposive and theoretical sampling, and triangulation. Table 3.3 on page 53 contains numbers and types of data collection activities.

### **Observational Visits**

To obtain observational data about the social processes occurring between the triad and dyad members, the researcher joined each group for a regularly planned nursing visit at least once and, when possible, two times during their participation. At these visits she sat in the room, near the groups, and observed but did not actively participate in conversation. To capture salient quotes and notable details, the researcher made field notes during the observation. In her car, immediately upon leaving the participants' homes, she continued to make notes or audio-recorded memos. Some participants opted to be interviewed on the day of these observational visits, prior to the caring team observation. Those who chose not to, made appointments for other times, at their convenience and in their locations of choice. Nurses also scheduled private interviews according to participant scheduling and location needs.

Table 3.3 Data Collection Activities by Triad Member Roles

	Nurse 1	Nurse 2	Nurse 3	Nurse 4	Nurse 5
<b>Data collection method</b>					
Observational Visit 1	x	x	x	x	
Observational Visit 2	x	x	x		
Interview 1	x	x	x	x	x
Interview 2	x	x	x	x	
Interview 3	x	x	x		
Interview 4	x	x			
Focus group	x	x	x		
Online survey	x	x	x	x	x
	Patient 1	Patient 2	Patient 3	Patient 4	
Observational Visit 1	x	x	x	x	
Observational Visit 2	x	x	x		
Interview 1	x	x	x	x	
Interview 2	x	x	x	x	
Interview 3	x	x	x		
Journal	x	x			
		Caregiver 2	Caregiver 3	Caregiver 4	
Observational Visit 1		x	x	x	
Observational Visit 2			x		
Interview 1		x	x	x	
Interview 2		x	x		
Interview 3		x	x		

### **Interviews**

The study's primary form of data collection consisted of semi-structured interviews with each triad member. Prior to beginning each interview appointment, verbal consent was again obtained. The researcher audio-recorded all interviews using a

SONY ICD-LX30 digital recorder. Three of the patient participants completed all three interviews, and one completed two interviews prior to dying, while enrolled in the study. Two of the three family caregivers were interviewed three times, while one opted for a single interview during enrollment, stating that she did not feel she had anything more to share. The fourth patient participant did not have a family caregiver. Nurses participated in from one to five interviews. Four of the nurses gave interviews instead of the final focus group, which was cancelled because nurses were unable to attend. Interview schedules and some follow up questions used in theoretical sampling are included in Appendix E (p. 142).

### **Journals**

All participants were offered the opportunity to journal about their pain experiences related to the person with cancer beginning at the time of the first interview, and were given notebooks and pens if they opted to do so. The researcher anticipated participants might wish to record thoughts or experiences related to pain management contemplatively between interviews, or that they might feel more comfortable writing privately, even with the intent of sharing it later. Each journal included a slip of paper with prompts to record any thoughts or feelings about pain meaning and management related to their experience, or that of the other triad members participating in the study with them. Three patient participants took notebooks for journaling. Two of them used it to record pain-related experiences, and one did not. One person did not share the writings with the researcher and the other did. No other study participants took journals, stating that they likely would not have time to engage in this activity.

## **Focus Groups**

In order to seek out common themes among the nurses, to provide the opportunity for them to share perceptions about the social processes with other nurses, and for the researcher to triangulate codes and themes emerging during data analysis, all participating nurses were invited to take part in two focus groups. The first focus group was held ten months into the study, and the second was scheduled for the end of the twelfth month. Attendance of all five nurses at either focus group turned out to be untenable due to time and schedule constraints. Therefore, only the first focus group was held, and there were three nurses in attendance. The second focus group was cancelled the day it was to be held, when two of the three planned attendees were unable to come at the last moment. The researcher conducted the single focus group, which included operation of audio and video recording devices, posing open-ended questions, (see Appendix E for examples), and following up with spontaneous probe questions for clarification and expansion. Data from the focus group included both audio and video recordings to capture body language, facial expressions, and verbal exchanges in real time.

## **Methodological Concerns**

### **Burden of Prolonged Study Engagement**

Because of the potential for adding emotional or physical burden to the lives of persons with end-stage cancer pain, and their caregivers, the researcher periodically asked the participants if they felt well enough to continue with the interviews, and obtained ongoing verbal consent at each data collection meeting for the same reason. She



conducted all data collection activities, as an experienced hospice nurse, which increased her sensitivity to fatigue, pain, anxiety, or other reasons that it would have been appropriate to terminate data collection. Participants and the researcher together decided when interview content discussed at the session had reached a natural saturation point, and the participant was ready to stop. The researcher encouraged all participants to phone or email her if they wished to change the dates and times of scheduled interviews or observational visits. Some participants from each group did request changes, all of which were accommodated. Institutional review board approval had included plans to provide support and access to needed nursing, other hospice team, or community agency interventions should they be required during data collection sessions.

### **Challenges to Data Collection**

The average hospice length of stay is now close to 70 days (National Hospice and Palliative Care Organization, 2014) and median length of stay at around 17 days (medpac, 2016). Therefore in planning the study, data collection challenges related to changes in patient status and attrition were anticipated. For patients, there were challenges related to rapid disease progression from time of hospice admission. As discussed earlier and summarized in Table 3.2 (p. 51), eight of twelve potential patient participants over the year-long data collection phase either had rapid changes or died between time of first recruitment contact and the first scheduled meeting. Another difficulty in collecting data was the researcher's availability to visit with participants when they felt well enough to talk. Also, there was the need for frequent last-minute cancellations due to patients not feeling well. Challenges for nurse data collection were the time delay between deciding to enroll and actual enrollment for half of the five

eligible nurses. This resulted in limited opportunities for patient recruitment for the nurse who was last to enroll, meaning she was not able to be part of a caring group for the study. Also, it meant a smaller window of availability for focus group dates and interviews.

The researcher made changes to her personal schedule as one way of compensating for challenges. This gave her greater availability to meet with participants to collect data. As a result she was able to meet the scheduling needs of the groups' participants every time, except in the case of unpredictable disease progression and death.

### **Data Management**

#### **Data Management Plan**

Data management entails how data is stored and has been used during collection and analysis, and after the study has been completed. The researcher developed the data management plan with guidance from members of the dissertation committee and approval of the UMass IRB. The plan included provisions for privacy protections of participants, storage of data sources, and sharing of data sources.

#### **Participant Note Book**

One of the initial steps taken in managing data was to create a note book for tracking participant identification for use during data collection and analysis. This notebook was kept separately from all other study data. It included the participants' names and contact information, along with assigned pseudonyms to be used in place of real names during data gathering, analysis, and dissemination of study results. Although the chair of the dissertation committee did have access to the study note book upon request, only the researcher used it. The note book has been kept in a locked cabinet in

the researcher's office, where it will remain for safe keeping, and per UMass IRB and participant consent, may be used by the researcher to contact surviving participants for secondary data analyses conducted in the future.

### **Study Logistics Spreadsheet**

In order to track data collection and study processes the researcher kept operational memos about day-to-day logistics involved in conducting the research study in a hand-written journal. This journal was locked in her office, separately from the study note book. She created a data spread sheet containing the de-identified potential and actual participants and dates of contact with recruiting nurses and/or the researcher, which was secured on a password-protected personal computer.

### **Theoretical and Reflexive Memos**

The researcher wrote and audio-recorded theoretical memos about how and why she named codes; thoughts and ideas about codes; and how and why codes evolved into concepts, categories, theoretical domains, and their interrelationships. These memos provided an outlet for her to express feelings about engaging in the research processes, reflect on these impressions, and consider how they might impact her views of the data. To expand her reflexive thinking, she shared and discussed samples of each type of memo with her dissertation adviser. All such memos had no personal health information identifiers for any of the participants whose experiences they related to. These journals and audio recordings were kept in the researcher's locked office, and will remain locked in a cabinet there per IRB approved protocols.

## Data Analysis

### **Use of Line-by-line Method for Early Coding**

Data analysis began with the CGT method of coding from the first data collection point which is a part of the constant comparative process. Prior to beginning coding, the researcher transcribed audio-recorded interviews. As she continued early data collection and analysis, she transcribed nine interviews using NVivo 11 Pro for Students software (QSR International Pty Ltd, 2014). An additional six interviews were transcribed by the UMass Amherst Translation Center's transcription services, and the remaining interviews were transcribed by VerbalInk, an industry transcription service. The researcher coded data using the review function of a computer word processing program by typing codes into notes in the transcript margin, and by using the node function of NVivo 11 Pro for Students software (QSR International Pty Ltd, 2014).

Charmaz's (2010) method for CGT coding begins with line-by-line description of actions and experiences in transcribed data. Coding in CGT is an iterative process which begins as soon as data have been collected and "compares data with data" (Charmaz, July 22-23, 2013, p. 6). Charmaz encourages the use of gerunds when coding as they capture actions and behaviors, as opposed to topics (July 22-23, 2013, p. 6). Some examples have been provided from data collected during interviews below to illustrate these processes. The data cited below were not used in the results reporting of this dissertation. An example of line-by-line gerund coding is the following description by the daughter of a parent with cancer (gerund codes in brackets):

'I can't keep doing this. I'm exhausted.' But that's just somebody venting. She didn't mean it like that. But she was burnt [*Being burnt out by caregiving*]. And

she was very depressed after [*Experiencing depression at loss*]. She became a hermit [*Becoming a hermit after husband's death*].

Line-by-line coding resulted in the identification of many more codes than might have emerged using other non-CGT coding methods. These numerous codes provided the researcher with a multitude of emerging issues.

By using a constant comparative process for coding, she was able to work quickly in identifying initial codes. She then used theoretical sampling as an additional phase in data gathering to follow up on coded content which had been mentioned multiple times by participants, or things participants had said with particular emphasis in order to explore them further. Where other types of qualitative data-gathering might rely on use of saturation and large numbers for a rich corpus of data, CGT also utilizes theoretical sampling based on early-identified codes. Because each participant was observed and interviewed over a period of no less than two weeks and up to six months, the researcher had a prolonged period during which to revisit codes and themes with individual participants, across participants within roles, and across roles and participants. This ongoing engagement allowed her to check ideas about emerging codes and themes with participants, a critical part of describing participant experiences accurately (Charmaz, July 22-23, 2013, p. 4). For instance, within one triad, she interviewed all participants about the in vivo code, *my dilemma*, which was introduced by a patient participant at her first interview. The patient spoke of multiple dilemmas she felt challenged by. For example:

So, I don't know, it's, it's a dilemma whether to still keep or go on a higher level of the Fentanyl patch. I might not really want to. You know, I think pain is a normal part of life that is talking to you.

The patient's caregiver spoke of the dilemma in this way:

I think that for her...what her personality is she thinks it will change her, she doesn't want to go into that grabbing at cats and seeing things, hallucinating. I think she's afraid of that. Whereas we just don't want to see her in pain.

And the nurse had this to say about the patient's dilemma:

I've been talking to her for weeks about it because I've been seeing her struggle to get up and her walking is so different than it had been and I just have really felt like she could be more comfortable here. But want, you know, not wanting to overwhelm her.

By asking directly and indirectly, it became clear over the course of the study that a number of participants had dilemmas stemming from different issues, but which could stand in the way of understanding one another or achieving better pain control.

### **Raising of Initial Codes to Conceptual Categories**

Codes which appear to have significance in initial coding are then "raised" and examined further as selected or focused codes (Charmaz, July 22-23, 2013, p. 5). In this case, the researcher evaluated the codes which she had identified initially by writing memos and discussing early emerging codes with her adviser, or by mapping out groups of codes. She selected codes which stood out during line-by-line coding, or embodied concepts of interest to participants. Because of the large number of codes which she identified across participants, she had to make choices about which to advance into themes for purposes of keeping the construction of theoretical concepts manageable. Therefore, data analyses reported in this dissertation were focused on two triad pain management social processes deemed significant, *cancer pain control goals* and *the loop*.

Another method used in the process of creating concepts from emerging codes occurs as the result of analytical memos the researcher writes (Charmaz, 2010; Corbin & Strauss, 2008; Groenewald, 2008). These are notes to oneself which capture thoughts about research study processes, why a code name is chosen, how codes seem to represent

meaning emerging from the data, or anything the researcher wants to remember and be able to refer back to in order to rigorously describe the processes involved in concept development, and later on theory development as relationships between concepts are explored and described (Corbin & Strauss, 2008; Groenewald, 2008). Charmaz is frank about the subjectivity of the researcher in deciding which codes to raise, however she points out that rigorous CGT will be always be supported by a rich body of data in which codes are grounded (Charmaz, July 22-23, 2013). Memo-ing serves the purpose of helping to clarify initial codes and then through comparative memo writing, codes which are significant are developed further (Charmaz, July 22-23, 2013, p. 18).

As with coding, memo-ing began early in this research study, with audio-recorded memos made upon leaving each interview. In these memos, the researcher described behaviors or postures not captured by the audio of the interviews, her immediate thoughts about possible meanings of topics covered, and comparing of those to previous interviewees' data. She also made notes and mapped out ideas in a journal while transcribing and coding interviews and focus group content. She used these processes for moving codes "upward to theoretical categories" (Charmaz, 2010, p. 73). She used free-writing to analyze and interpret significant social processes throughout the course of the study, with the goal of focusing these data-driven ideas into theoretical concepts. Besides memo-ing, the researcher discussed her memos and shared data with the dissertation committee members for reflexive checking. Together, these procedures contributed to the study's trustworthiness and credibility, which is discussed in depth later in this chapter.

Once data collection was completed, based on theoretical saturation, the researcher continued data analysis by listening to interviews again, revisiting codes, rereading memos, revising and writing new memos, additional raising of codes into theoretical domains or concepts, and describing the relationships apparent among the concepts in free-writing and mapping. She created diagrams as well as memos to examine and illustrate theoretical relationships (Corbin & Strauss, 2008; Groenewald, 2008). Several significant themes with potential for inclusion in a cancer pain social processes theory emerged during data analysis. The breadth of codes and concepts identified during data analysis resulted in content which can be explored in future construction of the theory. Two significant theoretical domains are described and discussed in Chapter Four of this dissertation, in the form of a publishable journal manuscript.

### **Trustworthiness**

One hallmark of qualitative research is the demonstration of trustworthiness, which is akin to the concept of reliability in quantitative research (Groenewald, 2008). There is consensus among qualitative researchers about the importance of maintaining integrity to methodology and discovery, however scholars debate how qualitative research should be evaluated (Corbin & Strauss, 2008; Mackey, 2012). Corbin believes that regardless of methodology, qualitative research should be judged by both its science and creativity (Corbin & Strauss, 2008).

### **Appropriateness of Methodology**

Trustworthiness is generally agreed upon as a measure of the scientific validity of qualitative research which is inherently different from validity as it is used in quantitative methodologies (Creswell, 2009). It can be evaluated by a number of criteria (Creswell,



2009; Charmaz, 2010; Corbin & Strauss, 2008; Groenewald, 2008; Streubert & Carpenter, 2011). The first thing to be evaluated is use of the appropriate methodology to answer the research question (Creswell, 2009; Streubert & Carpenter, 2011). In the case of this research study, CGT methods allowed the researcher to explore the issue of concern, poorly controlled pain, by describing the experiences of the individuals involved, particularly their social processes, which grounded theory views through a lens of symbolic interaction (Charmaz, 2010; Strauss & Corbin, 1990).

### **Purposive and Theoretical Sampling**

Trustworthiness can also be assessed in sampling methods. In this case, purposive and theoretical sampling were used. The researcher recruited the participants most knowledgeable about the phenomenon to be studied for the sample, which is one way of employing purposive sampling. She used theoretical sampling to re-examine data and memos as she constructed emerging categories. Further, triangulation of data during analysis allowed confirmation of codes and categories over time with additional interviews of the same and other participants, as well as other sources (Creswell, 2008). These included journal entries, focus group data, and scientific literature.

### **Prolonged Engagement**

Another way that the qualitative researcher can increase trustworthiness is through prolonged engagement with participants and the body of data (Creswell, 2009; Corbin & Strauss, 2008). Prolonged engagement can increase the researcher's sensitivity to both emerging codes and subtleties which demand clarification. It increases opportunities for triangulation. In conducting this study, the researcher incorporated

prolonged engagement by use of multiple interviews with the same participants over time, and analyzing data from all participating triads over the course of a year.

### **Clarification of Bias**

One criteria useful in evaluating trustworthiness is clarification of the researcher's bias (Charmaz, 2010; Creswell, 2009). During this dissertation research work the researcher engaged in reflexive activities to identify the effect of her own beliefs and experiences while collecting and analyzing data. She did this by journaling about her thoughts and feelings related to the study processes, as well as by discussing these with the chair of her committee. The dissertation advisor's experience as an oncology nurse who has cared for patients and families experiencing end-of-life provided additional reflection. The researcher also took care to clearly identify her role to study participants and readers as that of both a nurse researcher and hospice nurse clinician at the agency from which recruitment occurred, and described her stance in undertaking this study (see Chapter One).

### **Audit Trail**

The researcher maintained a clear audit trail to demonstrate the study's methods and decision-making processes to the committee members and readers. This has included rich descriptions of study methods used in writing up the study results and this dissertation chapter, use of computer software for organizing and managing data, creation of the study book for internal review, writing of code definitions for study consistency, obtaining the ethical oversight for study procedures by the IRB, demonstrating her clinical expertise with the study population and knowledge of the literature, use of established coding methods including open and constant-comparative; use of gerund

coding to describe social processes, and the writing of memos over the course of data collection and analysis. She tracked de-identified participant demographics and data collection activities on a computer-generated spread sheet. Her consultation with a committee member who is an expert in grounded theory, Dr. Cynthia Jacelon, and her attendance at courses taught by Dr. Cathy Charmaz, the CGT expert, strengthened the study design and methods.

### **Conclusion**

In summary, by conducting this qualitative research study using constructivist grounded theory methodology, the researcher has been able to answer the question: In the context of hospice, how do the social processes among the older person with cancer pain, their family caregiver, and nurse (the hospice caring triad) affect cancer pain management? The question was deemed to be of value for improving pain management for hospice patients by conducting a review of the literature and taking into consideration the researcher's clinical expertise, both of which were discussed with and known to the doctoral dissertation committee, and with expert consultants as the study was designed. Previous research about cancer pain management in hospice has not specifically sought to outline the social processes among all three members of the caring triad, or a theory describing these. Careful consideration of the methods most appropriate for answering the question was given in the selection of the methodology and methods in order to increase the study's trustworthiness and value to society. The researcher used outcomes from this study to construct domains for a theory about cancer pain management social processes for hospice. These will be used in future research studies to define hospice cancer pain management social processes concepts further and operationalize them.

Besides helping clinicians and the persons receiving their care to better understand how to effectively manage pain, the theory has identified variables important in improving pain management that will be tested in future search studies.

## CHAPTER 4

### **RESULTS: CANCER PAIN CONTROL IN HOME HOSPICE CARE: WHAT ARE THE GOALS, WHO SETS THEM, AND WHAT DOES IT MEAN?**

**Manuscript 2: To be submitted to *Journal of Hospice and Palliative Nursing***

#### **Introduction**

Studies about cancer pain management best practices for hospice care have suggested that setting goals for the reduction of pain and individualized plans should be a part of cancer pain management (Herr et al., 2010; Pasero & McCaffery, 2011; Zylla et al., 2016). Pain frequently occurs for persons with end-stage cancers (Foley, 1985; van den Beuken-van Everdingen et al., 2016) and when uncontrolled can result in physical and emotional suffering for patients, psychosocial distress for families (Kelley, Demeris, Nguyen, Oliver, & Wittenberg-Lyles, 2013), ethical dilemmas for healthcare providers, increased monetary costs to patients and healthcare agencies, and perpetuation of the myth that dying from cancer is innately painful (Herr et al., 2010; Hjermstad, Fainsinger, & Kaasa, 2009). Pain at the end-of-life is frequently managed by a hospice team, and hospice nurses are expected to have the knowledge and skills to relieve pain in the dying. Because pain is subjective in nature, hospice nurses must clearly understand each patient's personal objectives for comfort to provide person-centered assessment, intervention and evaluation (Ehrlich & Walker, 2016; Sanders et al., 2013). Interventions can then be based on setting specific, measurable, and realistic goals. There is a gap in the literature however, as to how nurses should assess patient pain goals.

Family members of persons on hospice are often involved in pain management. They too should know what their significant others value and hope to achieve by attaining pain relief, so that their assistance reduces suffering, instead of unintentionally adding emotional or physical symptom burden. The hospice patient, caregiver, and nurse comprise a hospice caring triad, whose members collaborate to assess and control cancer pain on a day-to-day basis. This collaboration involves thoughts, feelings, and behaviors which can be viewed from a theoretical framework of social processes, occurring for and amongst the caring triad members. The role of the hospice nurse within the caring triad is defined by professional and ethical standards. However, the roles of the patient and family are dependent upon individual and collective historical factors, largely unknown to nurses. Nurses may be better equipped to help patients and caregivers set pain goals and develop care plans based upon triad member needs if they understand how pain management fits into a social processes framework.

The author has constructed triadic cases viewed through a social processes lens to describe goal-setting for pain control within the hospice caring triad. This interpretation of the data is intended not simply to explain the caring triad goal-setting issues, but to assist nurses in comprehending the complex factors involved in pain goal setting. Areas discussed in the triad context are: how pain control goals were determined, what criteria were used in setting goals, and how associations between perception of pain control and goal-setting could be explained.

Typical cancer pain assessments used by hospice nurses may not include probing questions to explore underlying social processes that affect pain management, including determining a patient's or family's goals for cancer pain control (Herr et al., 2010;

Hjermstad et al., 2009). These triadic cases were constructed during data analysis for a grounded theory study with rural, home-dwelling hospice patients for creating a cancer pain social processes framework.

## **Background**

### **What Is a Pain Goal?**

Setting goals for care is a standard for nursing, however there is little specific guidance on setting patient-centered pain goals at the end-of-life, or for persons with cancer. Pasero and McCaffery (2011) provide evidence-based practices for setting numeric pain goals, in order to easily reassess a person's response to a pain intervention. They advise asking a person with pain to provide a number between zero and ten which would allow them to function normally. Studies about numeric pain goals have provided clinically useful evidence about how much of a decrease in the severity rating is correlated with increased function (Pasero & McCaffery, 2011; Twycross, Harcourt, & Bergl, 1996).

Current pain assessment tools for functional goal setting ask patients to set a tolerable numeric or severity rating (for instance, a scale with faces showing different emotions could also be used) or ask patients to report on what pain interferes with. Pain interference is usually measured with dichotomous questions asking if pain affects activities, mood, appetite, sleep, or relationships. Some tools for measuring pain interference, such as the Brief Pain Inventory, ask patients to use a Likert-type scale to rate the degree of interference (Pasero & McCaffery, 2011). These assessments rely on the clinician to make the jump from an assessment item that indicates interference to identifying and prioritizing functional pain goals. Zylla et al. (2017) created a quality

improvement project which rather than using statistical evidence to help cancer patients set these numeric pain goals, simply asked them to declare the number at which their pain was controlled. The critical difference was that the patient, rather than the data was setting the pain goal. Asking patients to set their pain goals seems consistent with the values supporting patient-centered care. To this author's knowledge, however, no established tools asking patients to report open-ended functional goals exist. Nor does there appear to be guidance in the clinical literature about best practices for assessing or setting functional goals for persons with cancer pain on hospice. This is significant because due to limited time, energy, and capacity, persons dying from cancer may have very specific functional goals which cannot be inferred from interference questionnaires.

### **What Does a Pain Goal Mean for the Triad?**

In the context of cancer pain, goals should be discussed and clearly outlined per standards of care. Goal setting is a key exercise in the planning of nursing interventions and for evaluating their efficacy. For triad members to successfully manage pain, goals should be set by the patient and shared within the triad. Having a shared pain goal means that all triad members can assess pain severity and whether or not pain is interfering with accomplishing functional pain goals. It also facilitates nurse collaboration with triad members and medical providers to assure that medication regimens are personalized and appropriate for facilitating the goals.

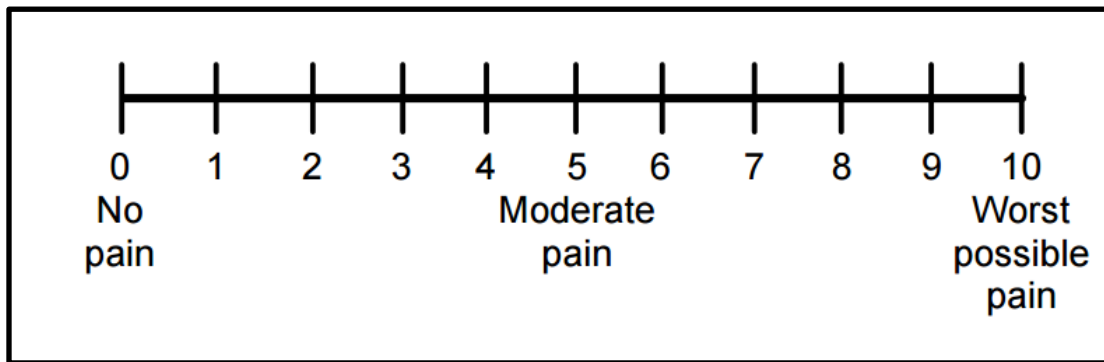
### **Assessing Pain Severity**

One way that pain goals are set is by asking for a subjective pain intensity rating which can be used to help a patient decide what a tolerable pain intensity would be (Pasero & McCaffery, 2011). Current hospice nursing standards call for nurses to



routinely assess pain at nursing visits (Fink & Gates, 2010; Herr et al., 2010; Paice, 2010). Typically, pain severity is assessed by asking patients or caregivers to rate how intense their pain feels. One of the most widely used assessment tools for cancer pain severity is the numeric rating scale (Pasero & McCaffery, 2011). Persons with pain are asked to give a number rating their pain from zero to ten, using the anchor phrases “no pain” and “the worst possible pain” (see Figure 4.1). The value of this pain scale is its

Figure 4.1 Numeric Rating Scale



(Pasero & McCaffery, 2011, p. 56)

reliability for capturing snapshots of pain intensity at given moments in time. These snapshots can then be compared across a time frame. The numeric rating scale (NRS) is a subjective pain assessment tool, with good validity and reliability in a variety of populations (Jensen & Karoly, 1992), including older adults (Ware et al., 2006).

However, it represents only a single element of pain assessment (Herr et al., 2010; Kaasa et al., 2011). It is critical for clinicians using the NRS and other similar pain intensity assessment tools to acknowledge this *important but limited role*. In order for cancer pain to be maximally treated, a range of pain-related elements must be assessed, including whether that pain is acute, chronic, or both, and what an individual patient hopes to

achieve once pain is reduced to a tolerable intensity (Pasero & McCaffery, 2011). For comfort goal-setting, nurses can use the NRS to quickly assess pain severity and collaborate with the patient and other healthcare team members to intervene and reduce pain. One role of the nurse in hospice caring triad pain management is education of patients and family members in using a pain severity assessment tool like the NRS to evaluate pain intensity. Patients and caregivers can then be taught how to use that intensity rating to choose an appropriate pain intervention in the nurse's absence. For those interventions to be patient-centered, they should be based upon patient-stated goals for pain severity.

### **Assessing Function Related to Pain**

Because maintaining functional capacity has been identified as a key element for quality-of-life (Ferrell, 2004) it would seem logical for hospice patients to choose pain management interventions based on achieving or maintaining functional pain goals. In chronic non-cancer pain, assessing functionality and pain interference with daily life is best practice (Pasero & McCaffery, 2011). While there are key differences between cancer and non-cancer pain, because the ongoing nature of cancer pain implies interference, assessing function should be included in the management of chronic end-of-life cancer pain. Pain assessment tools like the Brief Pain Inventory (BPI) (Pasero & McCaffery, 2011) ask patients to rate pain interference using a Likert-type scale to understand how pain affects regular functioning. By the time many patients with cancer opt for hospice care, their functional capacities may be limited to the extent that they are no longer able to work or engage independently in activities of daily living, the types of functional activities assessed by the BPI. Therefore the BPI and similar scales for

functional interference with pain, are not appropriate for many hospice patients. It is unclear to what extent hospice nurses and electronic documentation systems have incorporated the assessment of function into pain management tools. The development and testing of such hospice-specific functional pain goals assessment tools is needed.

### **Study Design and Methods**

In order to capture the constellation of factors involved in pain management across a caring triad, a case study design was chosen for illustrating cancer pain goal social processes. Philosophical and analytic principles underlying constructivist grounded theory guided data generation and analysis. Grounded theory methods were used because of their focus on the meanings underpinning behaviors (Charmaz, 2010). The broader study from which this triadic case study analysis was drawn had the goal of identifying and relating cancer pain management social processes within a framework for hospice care. By using case studies as the unit of analysis and description here, the author compared and contrasted data categories across the triads, in a constant comparative manner (Sandelowski & Leeman, 2012; Miles, Huberman, & Saldana, 2012). The author clarified like and un-like social processes that the triad members engaged in to evaluate whether social processes impeded or facilitated pain control, specifically in the context of using goals.

### **Participants**

#### **Recruitment**

A strength of grounded theory methodology is sampling of data from persons with expertise about the research topic (Charmaz, 2010). For this study, the population which could provide the best data about how cancer pain is managed for hospice patients at

home was the caring triad members. Participant recruitment began after obtaining institutional review board approval from the researcher's university. Hospice nurses in full-time practice, with at least one calendar year of hospice experience at a single, small rural hospice agency in New England, were invited to an informational meeting about the study. Nurses who wished to participate then contacted the researcher to discuss the study. Over the one year recruitment period, all five agency nurses who were eligible elected to participate. These nurses then recruited patient participants from their individual caseloads. Hospice patients 60 years and older with a primary cancer diagnosis verbally confirmed by all caring triad members, a history of using pain medication since beginning hospice care, and able to converse in English were eligible to participate. At routine home visits, the nurses read a brief statement describing the study and asked if the patients would like the researcher to contact them. Twelve eligible patients were approached. Of those, four declined to join the study after speaking with the researcher over the phone, and four died in the time between the phone discussion and their scheduled first meeting. The deaths occurred between four and 23 days of first contact with the researcher. Four other patients participated in the study. Three of the patients also had a participating family caregiver, and it is the data of these three caring triads which were examined for this study.

### **Data Collection**

To provide the richest data representing the lived experiences of the caring triad members, the author used different data collection activities, to occur over weeks or months for each triad. Because the context of caring was the homes of the hospice patients, a majority of the data collection activities were conducted there. Data collection

began with a brief demographic questionnaire at the first visit (see Appendix C for the questionnaires and table with demographics, p. 133). Each triad had observational visits during which the researcher watched interactions about pain management between the nurse and patient, and when possible the family caregiver. At the observational visits, the author took notes describing triad member behaviors, discussion topics, types of questions asked by the various individuals, as well as environmental factors like physical and emotional proximity to one another (see Appendix I for an illustration of physical and emotional proximity based upon field notes, p. 173). All participants were interviewed by the author beginning with a set of predetermined questions which were followed up with probes to clarify interview content (see Appendix E for interview schedules, and probe examples, p. 142). To explore emerging topics from a nursing perspective, nurses were invited to participate in a focus group and a follow-up email survey about cancer pain goals. This resulted in the collection of 43 different data sources, presented in Table 4.1 below.

Table 4.1 Data Collection Points by Type

<b>TRIAD ROLE</b>	<b>Observational Visit</b>	<b>Private Interview</b>	<b>Journal</b>	<b>Focus Group</b>	<b>All</b>
<i>Nurse</i>	6	17		1 (3 participants)	
<i>Patient</i>	6	11	2		
<i>Caregiver</i>	5	7			
<b>ALL DATA COLLECTION POINTS BY TYPE</b>	6 (each visit included all triad/dyad members)	35	1 (one journal could be collected prior to end of participation)	1 (3 participants)	
<b>TOTAL DATA COLLECTION POINTS</b>					43

Pseudonyms chosen by the author were used in all data collection and transcription activities to protect confidentiality.

### **Data Analysis**

To answer questions about which meanings and perceptions underpinned cancer pain management processes, the author sought sources of data revealing triad members' lived experiences. Rich first person accounts, in the form of audio-recorded and transcribed interviews, provided the author with data that could be analyzed for patterns, and salient participant statements. The author used data analysis methods typical for grounded theory in which original sources may be read or listened to multiple times while interpreting meaning and behaviors. Data analysis began with listening to digital audio recordings of interviews and researcher memos, as they were transcribed by the author. She then coded data sources within a software system (NVivo 11 Pro for Students, QSR International Pty Ltd, 2014), using line-by-line gerund coding, whereby codes interpret actions associated with processes (Charmaz, 2010). As more observational visits and interviews were conducted with the same and new participants, the author made new notes and memos, and re-read others written while coding, as part of a constant comparison of findings through multiple stages of analysis (Charmaz, 2010; Miles et al., 2014). Additional field interviews were conducted with follow-up probes about codes and themes identified across data sources. The author then compared codes across data collection visits as well as across triads, and individual triad roles. As concepts and patterns were identified, the author used theoretical data sampling to explore these in greater depth (see Appendix I see for examples of initial codes, concepts and categories). Finally, concept-mapping and free-writing were used to process these emerging themes

and codes (Charmaz, 2010; Miles et al., 2014). Then the author condensed them into two pain social processes theoretical constructs: *Controlling Cancer Pain* and *Proximity*. Related concepts included: pain perception, pain severity goal, functional pain goal, and pain efficacy, physical-emotional distance, *The Loop*, and *The Page* (Appendix H, p. 171). The *Controlling Cancer Pain* concepts were linked to questions that all triad members were asked during the interviews about their understanding of pain-related concerns for the patient in the triad. *Proximity* was based on process code concepts which included participant beliefs, values, and interactions (Charmaz, 2010; Miles et al., 2014). *Proximity* describes interpersonal relationship processes for relationship closeness, communication, and agreement associated with the domain of *Controlling Cancer Pain* (see Figure 4.2, p. 79).

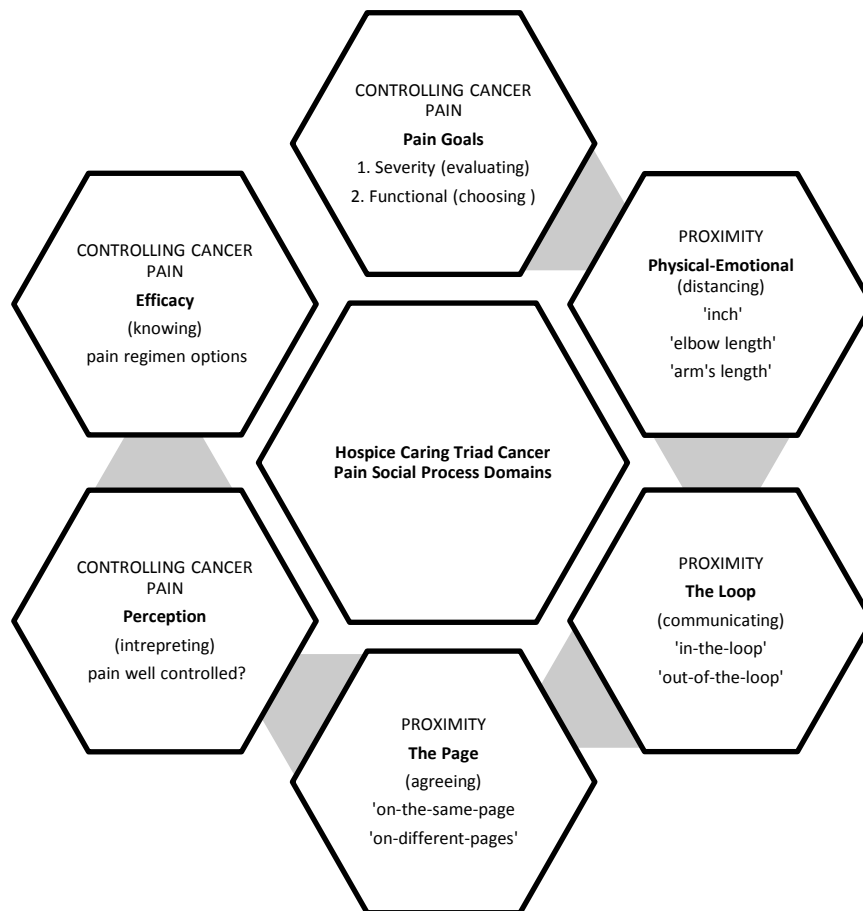
## **Results**

During analysis, processes associated with pain goals emerged as a central organizing construct. Triadic case studies were interpreted by the author according to two schema: (a) congruence across triad members about pain goals, and (b) collaboration in pain goal-related activities, over time. These were organized within the domains of *Controlling Cancer Pain* and *Proximity*.

### **Domain One: Controlling Cancer Pain**

To describe the domain, *Controlling Cancer Pain*, the author used a framework of usual hospice nursing practices like pain severity assessment and interference, perception of pain as tolerable or discomforting, care planning to reduce unwanted pain, and patients' and caregivers' knowledge about which medications or other interventions they could have used to reduce or control pain (see Figure 4.2, p. 79).

Figure 4.2 Hospice Caring Triad Social Processes Domains



### Who Sets Pain Goals?

For most triad members, there had been no clear indication of explicit pain goal setting. One family member had stated, “Now that she's on hospice, my goal is to keep ahead of the pain and make it so she doesn't experience pain as opposed to reacting to it.” The triad nurse had not asked for a pain goal during the observed visit. In an interview, she had explained that she usually inferred pain goals through indirect questions like, “What is it that you were planning to do but could not do? Is the medicine making you too sleepy to do that?” She had assumed that the patient’s goal was the thing she was



unable to do, or that she did not want to feel sleepy. In the case of this triad, even though there had been no explicit goal-setting, all triad members had spoken of the importance of activities that could have been classified as functional pain goals. Pain goal setting had not been explained by triad members in interviews, or observed during a joint visit, as a formal process but there seemed to have been understanding about what the patient had wanted to do from day-to-day.

In another triad, the nurse, who had prompted a patient to give a pain severity goal, had reported that sometimes there was not enough time to ask all of the pain assessment questions related to the goal-setting protocols of the hospice agency. The patient from this triad, while not having spoken of pain goals, either numeric or functional explicitly, had said that when her pain was well-controlled she had been able to do the things she had wanted, like sewing or knitting presents. However, pain had also served as an important reminder of what her physical limitations had been:

...when I do have pain, that's telling me that I probably shouldn't be doing whatever is giving me the pain. [But] if I take too much pain medication am I going to be walking around here without even thinking about the cane and then, like, just letting go? Um, I mean it's not bad enough that I am in excruciating pain.

This was an example of how complicated pain goals and goal setting could be. She had acknowledged that a degree of pain severity had reminded to use her cane, which in turn had facilitated her functional goals of walking around her home and maintaining her independence. In this triad, the caregiver's pain goal, rather than function for her mother had been total relief of her mother's physical pain. The caregiver and the patient told the author that they had not spoken with each other about pain severity or setting of formal pain goals.

Pain social processes and their goal-setting implications for the third triad were similar to those of the others—the patient had been taking medications to do things she had wanted like going shopping, or she had been resting to reduce pain when at home so she could achieve her function-related goals. Her caregiver had spoken of the daily activities valued by the patient, indicating her awareness that pain control goals had been related to function. The nurse had used the question, “Have you been able to do everything you wanted?” to ask about goals indirectly, and the caregiver had done the same. In this way, the nurse and caregiver had informally acknowledged functional goals for pain management.

The study data showed that across triads, members had not used clearly stated pain goals in the majority of reports. Despite one of the triad nurses having asked the patient for a pain severity goal at an observational visit, the patient and caregiver had not been using a numeric pain severity rating to set pain management goals. The caregiver had wanted a goal of no pain at all for the patient, but the patient’s goals had been functional and based on living with a certain amount of pain. Within this triad, the lack of understanding of the patient’s pain goals had caused emotional discord that triad members had spoken of during interviews. The caregiver had expressed frustration about what she had perceived as a lack of appreciation for her medication prompting. According to her personal pain goals for her mother, medication should have been used when any pain had been noted. However, her mother had established a tolerable level for her pain, and had self-medicated when she had felt too much pain interference. The nurse had been able to infer the patient’s functional pain goals and had made medication recommendations based upon that. The nurse had not been aware of the pain goal

disagreement occurring between patient and caregiver. The effect of not having clearly stated goals for pain which the nurse could have used for communication and education with the patient and caregiver was the emotional distress about pain management behaviors among triad members, and caregiver attempts to reduce pain which were unwanted by the patient. It is possible that if pain goals had been explicitly discussed and an understanding about them reached within the triad, the patient may have been able to remain functional and experience less pain.

### **Triad Pain Severity Goals**

Across the triads there was infrequent use of pain severity goals. To assess that patients were familiar with the recommended practice of using numeric severity ratings, the author had asked them to use the numeric rating scale to assess their pain at the first interview. The range of severity numbers for pain reported at the times of these interviews was from zero to six, with worst ratings in the past 24 hours as low as one and as high as ten (see Appendix C for a table of severity ratings, p. 133). Two of the three triad nurses had asked patients for numeric severity pain ratings during observational visits. Both nurses had followed up by asking for a numeric pain severity goal. Although all patients had demonstrated understanding and application of the numeric rating scale for assessing their pain, none of the patients had reported using a severity rating as a goal or a 'tolerable' number, which could have served as a trigger for a pain relief intervention. There was a demonstrated lack of using numeric pain severity goals for pain management by triad members regularly, despite the hospice agency having mandated use of a 'tolerable' pain number for a numeric pain severity goal.

One caregiver had reported knowing the numeric pain goal her family member had established with a nurse previously, but the patient had not reported using numeric pain severity goals. Other caregivers had been unfamiliar with using numeric pain severity assessments or numeric pain severity ratings as a way to help patients set pain severity goals. This example of nurses not having followed agency expectations or best practice guidelines for pain management was similar to results from a previous study. Herr et al. (2010) had developed and used a tool for measuring hospice agency cancer pain management best practices and reported inconsistent documentation of pain severity and functional interference goals. When nurses had been asked in a survey at the end of this study whether they thought numeric severity goals or functional goals should take precedence, there was consensus that functional goals were more meaningful for patients.

### **Functional Pain Goals**

Despite the demonstrated impacts of pain on patient function across triads in the study, no triad members had assessed what patient functional goals had been. For this study a functional goal was any stated objective that a patient had hoped to achieve which was not about physical sensation or emotions. Nurses had discussed function with patients and with the author, as an expectation of pain management behaviors. During observational visits, the author had noted nurses had asked indirect questions, like “So, were you able to do everything you have wanted to since my last visit?” No nurses had been observed asking a patient what their functional pain goals had been by having explicitly asked for goals. This has implications for understanding what patients feel and believe about pain, as confirmed in a study conducted by McDonald et al. (2009), where patients who were asked to openly discuss their pain gave the nurses more information

than those who had been asked general status questions like the question cited above. Patients had spoken of the things they had hoped to accomplish in general terms, like the activities they had participated in when pain had been well-controlled. One patient had reported that on a day of good pain control she had been alert so she could visit and play cards, or enjoy eating. Another said that driving herself to the grocery store several times a week was possible if she had taken her as-needed pain medications regularly. The third patient considered herself functional if she had been able to work on her knitting and sewing projects every day, as well as walk around her home, managing her basic needs in the house with the assistance of a rolling table, cane, or walker. They had discussed their needs to remain as independent as possible for as long as possible in this way, as being directly related to pain that was well-controlled. Family caregivers separately had reported awareness of these activities which were dependent on adequate pain control.

### **How are Pain Goals Related to Pain Management Behaviors?**

#### **Pain Perception**

Perception of pain control, or being comfortable or uncomfortable is another pain social process because it is evaluated by each triad member whether formally or informally. Pain comfort has been used as a hospice quality measure by Centers for Medicare-Medicaid Services (CMS) to determine whether or not patients receive adequate pain assessment upon admission. In a 2014 study of data collected by CMS, Kelly et al. (2014) found that for hospice patients with cancer who had been asked to rate their perception of comfort at the first visit, they were more likely than patients with other diagnoses to report increased comfort 48 hours later. Although the study did not explore causal mechanisms for this, it supports the value of assessing pain perception.

For this study, comfort and pain control were interpreted as describing the same phenomenon of pain perception. The author had asked each triad member to report their perceptions of pain control with the question, “Is your/the patient’s pain well-controlled at this time?” All patients in the triads had answered “yes” even when reporting pain severity ratings greater than zero. One patient had said, “Well compared to the worst ever, it's not beyond a three. I mean some other patients, my daughter says I always understate so some people might, I mean a man might think it was a four or a five [laughing].” There had been disagreement between most patients and caregivers about perceived comfort, a phenomenon identified in previous pain studies (Redinbaugh et al., 2002). While two triad caregivers had felt that the patients’ pain had been poorly-controlled, they had made these assessments through interpreting moods and behaviors, or asking if pain was present, rather than asking if pain was controlled, or if the patient had been uncomfortable. Each had assessed pain in a personal way. One had asked, “How are you doing today?” She had used verbal (“Not feeling so good”) and affective (“cranky”) cues to determine that pain had been present and poorly-controlled. Another caregiver had asked, “Are you in pain?” Instead of having asked a follow-up question to determine the patient’s perceived level of discomfort, these two caregivers said they offered medication at this point if any level of pain was present. When there had been a perceived disagreement it was typified by this caregiver comment:

I think I get frustrated with her because she has the ability to manage it and she chooses not to sometimes. She doesn't want to be, well sickly, but I can't say what is in her head. I don't know what she thinks, I don't know why she does it. But I imagine, I would not want to be in that kind of pain.

The third caregiver had said she accepted her family member's self-report of controlled pain. Her pain management had included asking her mother at regular intervals if she wanted a pain pill, and if her mother had said, "no", she had considered the pain to be under control. All nurses had said they accepted the patient's report of control, based upon the subjective definition of pain. However they each had said that if any pain was present, they had felt it impeded quality of life and could have been reduced.

Follow-up study questions asked participants to describe a day that the triad member had experienced good pain control. It was in these discussions that the significance of function as a pain goal had been raised. Pain had been perceived as interfering with meaningful activities in the face of limited time in which to complete them. There had been agreement across and within triads about this. One caregiver had said:

I think with good pain control you have more energy. Because your energy is not spent trying to control, not control but FEEL the pain. I think it's exhausting to be in pain. And I think when you're not in pain that energy can be spent elsewhere, so specifically with her, I think when she's not in pain she has more energy. Because right now energy is at a premium for my mom because of her situation. Pain can be very debilitating and when you're in the situation that my mom is in you don't have a whole lot of energy to waste.

The family member had told the author that she had wanted to spend as much time as possible visiting with her husband and grandchildren. A nurse in a different triad had spoken of a patient's pain control as having determined whether or not she could attend a large family gathering, at which she would have been able to visit with people for the last time in her life. Perceived control of pain had been associated by this nurse with being able to attend to important family matters.

## **Pain Management Efficacy and Coping Strategies**

Efficacy is related to meeting pain goals, because it indicates whether or not people have the knowledge and skills needed to control their pain. It has been studied in the management of medications and pain for community-dwelling cancer patients (Arraras et al., 2002; Bender et al., 2008; Byma et al., 2009; Vallerand et al., 2007). Efficacy refers to person's ability to carry out a behavior (Byma et al, 2009). In this study, efficacy for pain management was used as an umbrella term for patients and caregivers having known what to do to manage pain. To establish a baseline for efficacy, in each triad, the participants had been asked to list the prescribed pain medications, both scheduled and as-needed. Across triads, all participants had been able do this. Efficacy-related nurse social process behaviors had included educating patients and caregivers about which medications to use and when, verbal encouragement of more frequent as-needed medication dosing, or having suggested that providers be contacted to request medication changes. In all triads, patients had demonstrated pain management efficacy by having made choices to take medications or not, and when to have used other modalities like massage, heat, position changes, or rest. Caregivers had demonstrated supportive behaviors for efficacy, like having been able to suggest that an as-needed medication could have been taken, or having reminded patients to avoid certain painful activities.

How caring triad members had interacted to facilitate coping with pain included use of medications and non-pharmacological methods. One nurse had suggested massage therapy, reiki, and heat for pain coping. Another nurse had encouraged patient use of legal medical marijuana cookies. The nurses in triads whose patients had been ambulatory had encouraged use of assistive devices to reduce pain with ambulation.



Patients had all reported taking their scheduled medications as prescribed, with agreement by caregivers. One patient had had multiple as-needed opioid prescriptions and had decided which to take based upon how they affected her cognition, as opposed to nurse or family member suggestions about how they might have further reduced her pain severity. Caregivers had either suggested that family members use medications when they suspected suffering from physical pain or they had routinely asked the patient if they wished to take a pain medication dose. One triad caregiver had pulled her chair next to the patient and had held her hand as a medication adjuvant coping strategy. Multiple coping strategies were being used within and across triads.

### **Domain Two: Proximity**

*Proximity* was developed as a domain for topics which participants brought up and spoke of in relation to pain management that were related to controlling pain, but which were not derived from standards of nursing pain assessment. In addition to topics related to the domain of *Pain Control Goals*, participants had engaged in much discussion about what was or was not known to various triad members. Largely this occurred while talking about daily pain management routines, family member roles, and participants having recounted memories of family pain behaviors and beliefs. It had included things like the pain goals issues already discussed, as well as assumptions that triad members had made about one another. Key themes were identified when the author was coding this content. *Proximity* included the categories of *Physical-Emotional Distance*, *The Loop*, and *The Page*. Each had dimensions describing a range of relevant states of being or doing, and was associated with the descriptive verbs: distancing, communicating, and agreeing. These key behaviors resulted in states of being that

summarized triad pain controlling social processes. They were presented in Figure 4.2 (p. 79), and are discussed in detail below.

### **Physical-Emotional Distance**

*Physical-Emotional Distance* encompassed three dimensions of emotional or physical distance between the triad members. It had been controlled by the patient in these triads, either overtly or covertly. The three levels of proximity were: ‘arm’s length’, ‘elbow length’, and ‘inch’. An arm’s length was typified by a patient who had told a caregiver *when or not to* come to the home, or a caregiver who had not asked about pain directly even when her intention had been to assess pain severity. An example of ‘elbow length’ was a patient who had listened politely to pain medication recommendations and had then thanked the nurse without acting on that education. An ‘inch’ had been exemplified by the patient who had held hands with her caregiver during episodes of physical pain, but whose caregiver had also recounted the depth of the patient’s emotional pain during an interview, which the patient had previously shared in an interview with the author. Another triad had had categories falling into both the ‘elbow’ and ‘arm’s length’ categories. An example of the ‘elbow length’ was her statement, “Mom's never been one of those 'lovey-dovey' moms. I mean, she liked seeing me but not for more than an hour or so.” The nurse had described an example of ‘arm’s length’ for the same triad, “And her mom said, ‘No. I’m fine on my own. I don’t need anybody.’”

### **The Loop**

*The Loop* was related to the verb, communicating, and had dichotomous dimensions, ‘in-the loop’ or ‘out-of-the-loop’. It described the presence or absence of communication. ‘In-the-loop’ was associated with triad pain management efficacy. All

triad members had explained the patient's medication or non-pharmacological regimes to the author, indicating that they had communicated about these interventions. When it came to other social processes for pain management however, across triads none were 'in-the-loop' about pain goals (see Table 4.2, p. 91). In one interview, a caregiver had said of the patient, "She's probably telling hospice a lot more than she's telling me, I don't know." Being 'out-of-the-loop' was not just because of a lack of communication between the patient and caregiver. In all triads, most members had been 'out-of-the-loop' about a pain severity rating, related severity goals, and functional goals, because these had not been discussed across triad members.

### **The Page**

*The Page* category was associated with the verb, agreeing. 'On-the-same-page' referred to situations where there was congruence amongst triad members. For example in all triads, everyone had been on the same page about efficacy. They had been 'on-different-pages' about pain severity ratings and pain perception, as illustrated by a patient telling the author that her pain had been well-controlled when the caregiver's answer to the same question had been, "It could be, if she would take more of her medication." Across triads, as with *Physical-Emotional Distance*, and *The Loop*, there was variation for being 'on-the-same-page' or 'being-on-different-pages'. These variations are illustrated in Appendix I.

### **How Are Triad Proximities Associated with Controlling Cancer Pain?**

There were clear associations between *Proximity* and *Controlling Cancer Pain* in this study. As illustrated in Appendix I, Triad One had the greatest amount of physical and emotional distance at 'arm's length' and was 'out-of-the-loop' as well as 'on-

different-pages’ for all but efficacy of pain management. The case illustration for Triad Two showed that *Physical-Emotional Distance* could have been variable depending on the issue of concern and that within the triad there had been communication about some pain management issues and not others, and agreement about some issues but not others. Triad Three was almost a total contrast to Triad One, with only the pain goals categories having indicated an area where communication had not been overt. Triad Three members had otherwise exemplified closeness, agreement, and open communication. Across all triads, the only categories for which all were ‘out-of-the-loop’ were pain goals (see Table 4.2)

Table 4.2 Triad Comparison of The Loop and Pain Goals Categories

	<b>PROXIMITY</b>	<b>CONTROLLING CANCER PAIN</b>		
	THE LOOP	PAIN SEVERITY GOAL	FUNCTIONAL GOAL	PAIN PERCEPTION
<b>TRIAD ONE</b>	In-the-loop			
	Out-of-the loop	X	X	X
<b>TRIAD TWO</b>	In-the-loop	X		
	Out-of-the loop		X	X
<b>TRIAD THREE</b>	In-the-loop	X		X
	Out-of-the loop		X	

### Discussion

The gap in cancer pain social processes for the hospice caring triads in this study was a lack of explicit assessment and discussion of pain goals, either numeric comfort goals, or functional activity goals. Pain had been perceived as controlled or uncontrolled,

and within triads, individuals had reacted to their perceptions in ways that could have been in conflict with the patient's needs and desires. However, without having assessed and agreed upon pain goals, it stands to reason that discord in the triad would have been likely. The exception had been the triad in which communication about pain goals had been the sole item lacking discussion. It is possible that the overall strength of this triad's communication, agreement about other pain-related social process elements, and close *Physical-Emotional Distance*, could have served as protective factors so that assumption of pain goals had not led to differing perceptions of pain control. In the other triads, in which there had been a lack of agreement and communication about multiple social processes factors, notably the *Physical-Emotional Distance* had been greater.

Assessing for patient pain severity goals and frequent re-evaluation of pain for cancer are considered to be best practices (Herr et al., 2010). Numeric severity goals are also flexible, and can be changed by the person experiencing pain as-needed (Hjermstad, Fainsinger, & Kaasa, 2009). Fishman et al. (2013) convened an expert panel to determine core competencies for pain management education for healthcare professions which included the following recommendation, "Assess patient preferences and values to determine pain-related goals and priorities," (p. 6). They also stated that a key role is for clinicians to work with patients and families to help them meet these goals (Fishman et al., 2013). The hospice agency for which these had nurses worked, had mandated use of the numeric rating scale because of its reliability and validity, and also so that pain could be subjectively evaluated by different nurses.

In some of the triads, numeric pain severity ratings had not been consistently used. Some patients had said their pain was acceptably controlled, even if they had given

the author a numeric pain rating above three of a possible ten. Three is the cut point between mild and moderate pain (Pasero & McCaffery, 2011), and is the severity rating beyond which one study indicated a diminished functional capacity for persons with end-stage cancer (Twycross, Harcourt, & Bergl, 1996). Perhaps hospice nurses have not received education that evidence connects the association between use of numeric pain severity ratings and numeric pain goals to functional capacity. Lovell et al. (2014) suggested that effective cancer pain management practices for clinicians includes an, “Evidence base for need to conduct comprehensive assessment and management strategies,” and that clinician education should include “comprehensive assessment” (p. 6). On the agency-wide level, they indicate a need for use of clinical pathways to support these practices. One factor that may have influenced lack of agreement about pain control for the triads in this study was that each nurse had used a personalized pain assessment each time, without necessarily having repeated the same questions, even though the numeric goals were embedded in the computer documentation system. Also, they had not been observed or had not recounted narratives which had included education to patients and caregivers about how to determine and evaluate pain goals. Reasons some nurses gave for not using the numeric severity goal had included time constraints or complicated symptom clusters. One nurse had told the author that even though in this triad she had not asked for explicit pain goals, she sometimes did so, “You know, so sometimes you can't ask patients directly; you have to go at it indirectly and do what seems a casual conversation in order to see who they are and in order to obtain their goals.” She had perceived that it could have been seemed rude or inappropriate to ask patients such personal questions without already having established a relationship.

It had been the norm that triad members in this study had not been asking for functional pain goals in direct language. When functional goals were apparent, it was by way of indirect questioning or conversation about daily life, like the nurse had previously explained. Nurses are expected to have exceptional communication skills, including the ability to infer information (Burruss & Popkess, 2012). In some triads, inferring functional goals had been used regularly, and had resulted in agreement about what the patients' functional goals were when assessed after-the-fact. However, this may have been coincidental, and is not consistent with practices recommending that care be patient-centered, because not asking risks the result of incorrect assumptions about pain care preferences. Furthermore, as indicated in this study, caregivers may also be making assumptions about pain goals which result in being 'on-different-pages', and related distress about pain management behaviors.

Nurses should ask patients for functional pain management goals directly and teach caregivers how to do so. While use of assessment tools for pain interference may not accurately capture end-of-life pain interference, even dichotomous questions like pain interfering with activity provide nurses with a starting point. When they are part of the clinical pathway, they should be used to start triad conversations about actual functional pain goals. These goals should be documented in the patient care record for consistent pain management across visits. Herr et al. (2010) also suggest use of a written cancer pain management plan for use in the home. Goals could be recorded in such a plan so that when caregivers cannot be present at nursing visits, they can be updated about goals. Such written functional goals could be assessed for progress objectively by all triad

members, however such an assessment had not been apparent amongst triad members in this study.

### **Strengths and Limitations**

The study's primary strengths are a result of applying rigorous methods to obtain a data sample embodying the expertise and lived experiences of the participants involved in hospice cancer pain management at home from day-to-day. These included using multiple methods to collect data, returning to participants for additional data gathering over time, obtaining multiple perspectives about the cluster of issues studied, reflecting on the researcher's own stance and bias by writing memos and discussing interpretation of findings with the dissertation committee, drawing on clinical practice to sensitize herself to the issues involved, and providing a clear audit trail through use of written, recorded memos and software while coding, the author paid close attention to the trustworthiness, or scientific validity of the study (Creswell, 2009; Charmaz, 2010; Corbin & Strauss, 2008; Groenewald, 2008; Streubert & Carpenter, 2011).

The limitations of this triadic case study are primarily associated with transferability. Qualitative research which has followed rigorous methods can be considered to speak about the real concerns for the population sampled. In this case, the population is comprised of rural older hospice patients who coincidentally happened to be female, with adult daughters as their caregivers, female nurses, and all participants of European American heritage. Therefore, while results of this study may be transferable to others with similar demographic characteristics, these experiences and phenomena could be interpreted differently for other groups of hospice patients, especially when culture-specific or religious beliefs were of strong significance to the population being studied.



Additionally, because this study did not follow any triad through to the imminently-dying phase of hospice care, it is not known if and how these social processes changed at the very end of life.

### **Conclusion**

The cancer pain social processes framework domains presented here, *Controlling Cancer Pain* and *Proximity*, described categories of behaviors, perceptions, and communication used within hospice triads while engaging in pain management activities. The triad that had agreement about *cancer pain severity* and *pain perception* also exhibited open communication and close physical-emotional distance. The triad that had the least agreement and lack of open communication, along with the greatest *Physical-Emotional Distance*, also did not agree about *pain perception* and did not consistently use pain severity ratings for goal-setting, nor did the triad members communicate about or use functional goals for pain management. The other triad had different levels of *Physical-Emotional Distance*, depending on the issue and time, with both representing distance as opposed to closeness. This third triad had also used pain severity ratings for goal-setting inconsistently, and members did not have a shared *pain perception*, or use functional goals for pain management.

### **Implications for Nursing**

Hospice caring triad cancer pain management may be improved if nurses use these social processes domains as lenses through which to examine cases of poorly-controlled pain. If nurses are caring for patients within triads, and there is disagreement about pain control, if numeric pain goals, or pain interference are not being assessed, this

study suggests that they should be. In this study, triads had varied in *pain perception* and goal-setting communication and agreement, as well as *Physical-Emotional Distance*.

Hospice nurses should facilitate triad members getting ‘in-the-loop’ and staying ‘on-the-same-page’ by educating family caregivers and patients about setting pain goals, whether these are severity or function-related, openly discussing these goals, and jointly deciding on a plan of care to facilitate meeting such pain control goals. Hospice nurses should consider asking patients to state their functional pain control goals in clear simple language, whether this is an agency expectation or not.

### **Implications for Research**

Future directions for research into hospice caring triad social processes include the need to develop and study tools for use in open-ended functional goal setting for persons with terminal cancers, which may be very different from the tools used to assess pain interference in chronic pain of non-terminal illnesses. Such tools should take into consideration the fact that the caring triad is frequently absorbed with assessment and management of other unpleasant symptoms happening simultaneously. Therefore, if possible, they should be brief and succinct. Nurses and other triad members would benefit from clear research-based guidelines about asking for and evaluating functional pain goals for persons with life-limiting cancers. Since the domains described here represent an analytical slice of the data about hospice cancer pain social processes for the caring triad, future research should seek to identify additional social processes concepts, constructs, and domains which may be affecting cancer pain outcomes.

## CHAPTER 5

### RECRUITMENT SUCCESSES AND CHALLENGES IN A GROUNDED THEORY

#### STUDY ABOUT HOSPICE CANCER PAIN

##### Manuscript 3: To be submitted to the Journal of Nursing Scholarship

###### Abstract

**Purpose:** To describe the challenges and successes of recruiting and retaining participants into a longitudinal qualitative study of the complicated, dynamic social processes involved in controlling cancer pain. Study participants were older persons receiving home hospice care, who participated along with a caregiver, and nurse, in the context of a caring triad.

**Approach:** We conducted a constructivist grounded theory study of hospice caring triads to answer the questions: (a) What are the social processes that the hospice caring triad engages in for cancer pain management? And, (b) Are social processes serving as barriers to good cancer pain control? Three hospice caring triads (patient-nurse-caregiver) and one dyad (patient-nurse) participated in multiple individual interviews, observational visits, and focus groups over the data collection period of 12 months.

**Findings:** Recruitment and retention were examined in relation to the entire hospice caring triad, as the study questions were dependent on collecting data for all members of each group within the same time frame of several weeks to several months. Recruitment required frequent contact between the researcher and nurses to enroll nurses and patients, including telephone and email reminders. Recruiting of patient participants was most effective when the researcher called potential participants within 48 hours of their expression of interest, and when participants were not within the last two weeks of their

lives. Family caregiver recruiting was effective when the patient told a family caregiver that they wanted to be in the study. Difficulty with retention was consistent with patient inability to continue participation in the study due to advancing illness, and was unpredictable. Most study participants were interviewed three times and participated in at least one other data collection activity such as a focus group, journaling, or observational visit, resulting in 49 unique data collection points.

**Conclusions:** It is possible to conduct longitudinal studies with hospice caring groups beyond the typical patient-caregiver dyad, centered on persons with pain from cancer. Care must be taken in the planning of the study to maximize data collection activities with the lowest possible burden to participants. When the researcher is part of a clinical team engaged in the research study, recruitment and retention of triads can be strong. In this case, the researcher's historical working relationship with the hospice nurses in the study strengthened recruitment and retention of hospice nurses, who then recruited the persons comprising their individual triads.

**Clinical Relevance:** Understanding the complexities related to cancer pain management for older persons with hospice care, is bolstered by research revealing underlying and previously unaddressed patient, caregiver, and nurse concerns. These concerns may lead to misunderstandings amongst the caring triad members, resulting in inadequate pain management. To increase the evidence base for hospice nursing practice, hospice agencies should encourage nurse participation in research studies, and assist nurses in preparing to do so.

**Key Words:** end-of-life cancer pain, hospice caring triad, hospice research study recruitment

## **Introduction**

Research about care at end-of-life (EOL) remains important for the patients, families and clinicians who are facing uncontrolled physical and psychosocial symptoms during a time of rapid and often unplanned-for changes, frequently occurring in the home setting. Pain is an example of a symptom experienced by many persons with end-stage cancers, which remains poorly controlled (van den Beuken-van Everdingen et al., 2007; van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). Our literature review for a constructivist grounded theory study about cancer pain management for the hospice caring triad (persons on hospice, their family caregivers, and nurses), identified a need to understand the thoughts, feelings, and behaviors engaged in when assessing and managing pain (Ehrlich & Walker, 2016). Engaging in these social processes often occurs automatically, and therefore is easy to take for granted, while social processes likely play an important role in achieving pain control outcomes. Previous studies had not investigated cancer pain social processes for all three members of the caring triad within the same study longitudinally. While some studies investigated aspects of pain management, including some social processes, they did not identify their significance within a social processes framework (Ehrlich & Walker, 2016).

Wohleber et al. (2012) have identified a gap in reporting on recruitment and retention barriers and facilitators for grounded theory studies about EOL care. In their literature review, they identified evidence-based recommendations for recruitment and retention in research studies for patients receiving palliative care, including hospice. Our grounded theory study followed best practices for end-of-life research recruitment (Hanson et al., 2014; Wohleber et al., 2012). In this article, the author presents

recruitment successes and challenges of the research study in which she obtained a triadic perspective on cancer pain at the end-of-life co-occurring in the context of a social processes framework. The intent of this article is to describe the challenges and successes of recruiting and retaining participants into a longitudinal qualitative study which examined the dynamic social processes involved in controlling cancer pain within the hospice caring triad.

Multiple agencies in the United States have recently called for increased research studies for persons receiving hospice and palliative care (Institute of Medicine, 2014; National Institute of Nursing Research, 2016). In fact, the National Institute of Nursing Research (NINR) currently is seeking research study proposals in more than eight palliative care topic areas (NINR, 2016). The Hospice and Palliative Nurses Association has been outlining research agendas since 2009 to broaden the base of evidence-based assessments and interventions (HPNA, 2015). To provide guidance to researchers about best practices for end-of-life care research, the National Hospice and Palliative Care Organization has included a section in their recently published ethics guide (NHPCO, 2016). Beginning in 2010, the Palliative Care Research Cooperative formed to develop resources and mentoring to support these demands. Another recent need identified in healthcare research is inclusion of study populations in the planning, design, conduct, and dissemination of research (PCORI, 2016). While authors have identified barriers to recruitment and retention of participants in studies about end-of-life concerns, it is clear that there is a need to identify how participants for complex studies can be recruited and retained. Such studies will advance practice by contributing to the real life interplay of patients and those involved in their daily symptom management in ways that clinical

studies of the patient or caregiver populations individually, or even the patient-caregiver dyad population, cannot adequately describe. In order to provide the multidimensional symptom care demanded of palliative and EOL care teams, more research into the caring triad should be conducted. To this author's knowledge, only one of the papers describing hospice recruitment addressed doing so in the context of the caring triad (Campbell, 2016). Campbell (2016) was similarly gathering data from all three perspectives, however her study was conducted in the inpatient hospice setting. This paper uniquely describes the challenges of recruiting participants simultaneously engaging with one another to assess, comprehend, treat, and evaluate a symptom affecting comfort and quality of life, at end-of-life in the home hospice setting.

### **Study Background**

The nature of a grounded theory research study is to obtain a body of data based on the expertise of the population being studied. In this case, we were seeking to understand the individual and collective experiences of cancer pain among members of the hospice caring triad, within the context of social processes for identifying barriers to pain control. Our population of interest was hospice cancer patients sixty years or older, and persons working with them to manage their pain. Pain can be one of the most common and distressing symptoms related to cancer (Fine, 2012; Paice, 2010). A full understanding of hospice cancer pain social processes would be incomplete without the authentic voice of each member of the caring triad—the person with pain from cancer, or patient; the person who the patient has identified as a family caregiver; and the hospice nurse, who is the hospice team member most frequently providing care. Key activities for hospice nurses include assessment of symptoms, collaborating with patients and family

members to plan interventions, and teaching those interventions (Fink & Gates, 2010; Paice, 2010). There is a solid body of theory describing the complexities of symptom management in healthcare (Brant, Beck, & Miaskowski, 2009; Dodd et al., 2001; Dodd, Miaskowski, & Paul, 2001). However, few research studies have attempted to describe such complexities by engaging all of the hospice caring triad members within a single study. By applying rigorous qualitative research methods, researchers can uncover critical underlying issues of direct relevance to clinical practice and outcomes for symptom management. We applied constructivist grounded theory methods throughout all phases of the research study upon which this article is based, in order to obtain a rich picture illustrated by the lived experiences of the hospice caring triad. It was the voices of *all* triad members, those with the genuine expertise about living with and treating a person's pain from cancer in the context of thoughts, feelings, and interactions, that were necessary to capture when recruiting the participant sample.

## **Findings**

### **Study Design and Planning**

Ethical and successful recruitment and retention of vulnerable populations begins with study design and methodology. Grounded theory was first used to research the vulnerable population of persons dying in hospitals in the late 1960's (Glaser & Strauss, 1967), and has been used by Kathy Charmaz in her life-long work about living with debilitating chronic illnesses, another population often considered vulnerable (Charmaz, 2010). One factor in our decision to use grounded theory methodology was based on precedential grounded theory research about people receiving hospice care (Barkwell, 2005; Duggleby, 2000; Zerwekh et al., 2002). The symbolic interactionism stance of



grounded theory means that associations between meanings and behaviors can be deeply examined. Therefore, we decided it was an appropriate methodology for answering the study question, “What are social processes engaged in by members of the hospice caring triad for the management of cancer pain?” Our design included observational visits at the start and end of each group’s participation, along with three semi-structured interviews for each member, journaling for those preferring to share information through private writings, and two nurse focus groups, for the data collection activities. Such varied and prolonged data collection is a hallmark of grounded theory research, which is considered one of the most methodologically rigorous for producing works reflective of the issues studied (Charmaz, 2010; Strauss & Corbin, 1990; Glaser & Strauss, 1967).

While prolonged engagement is possible for hospice study participants, current healthcare practices leading to late hospice admissions, can increase the likelihood of vulnerability for this population. The National Hospice and Palliative Care Organization reported the 2014 average length of service for all hospice diagnoses was 71.3 days, with a median length of stay of 17.4 days (NHPCO, 2014). To reduce the possible added burden of study participation in these circumstances, we carefully planned how to obtain data. Simultaneously, we needed to work with the schedules of family caregivers and nurses participating in each triad. Because of the frequent rapid physical decline known to occur with hospice cancer patients, we planned that nurses would approach potential participants early in their hospice stays, and the researcher would be available to conduct all data collection when it was most convenient for triad participants. Planning for nurse recruitment involved creating an IRB-approved slide presentation and obtaining agreement from the hospice agency to present this at a regularly scheduled nurse meeting.

We determined that nurses wanting to participate would opt in directly to the author, who collected all study data. Other elements of study planning contributing to successful recruitment included phone or email messages to recruiting nurses asking about recent activity or offering support. We planned that nurses wanting to be in the study would receive a brief written script to read to their eligible patients, and provided one-on-one recruitment training to each nurse at the same meeting during which they signed consent.

### **Ethics of Recruiting Dying Persons**

Because of public ethical dissent about whether or not persons living with serious illness should be approached for recruitment into research studies, the team carefully designed study methods that would minimize potential for harm. The primary ethical arguments relate to the potential of adding burden to the lives of people in the dying phase of illness, contributing to their suffering, or contrastingly, affording them the opportunity to voice their lived experiences (Cassarett et al., 2004; Mackin et al., 2009; Wohleber et al., 2012). The biomedical ethical principle of autonomy supports giving potential participants who are able to engage in safe decision-making for themselves the choice about whether or not they participate in research. It is the ultimate responsibility of the research team to thoughtfully plan studies so as not to ask vulnerable persons to engage in research activities that could be considered truly harmful. To ensure adequate participant protections for studying triad pain management processes, the author received expert guidance from mentors about the potential burdens of interviewing patients with advanced cancer, their caregivers, and nurses (A. H. Vallerand, personal communication, April 24, 2015; R. K. Walker, personal communication, January 15, 2015). These experts

collaborated in drafting consent documents, planning for recruitment and retention, and seeking approval from the institutional review board at UMass Amherst.

Protecting confidentiality remains a primary ethical concern for research and specific methods for doing so should be written into study protocols (Richards & Schwartz, 2002). To guard the confidentiality of participants, this study protocol used a step-wise approach. Potential participants were informed that the other members of their triad would, by necessity of the study design, know that they were taking part but that all data collected at interviews would be done so privately, and would not be shared with other triad participants. First, hospice nurses were invited to participate using an opt-in process. Then, nurses who consented to be in the study used a written script to inform patients of the study. Patients who gave the nurse permission for the researcher to contact them, were contacted privately, apart from their family caregivers via phone or email. If they gave verbal consent to participate, they were asked for permission to contact their caregiver about participating. The recruitment protocol allowed patients who wanted to discuss participation directly with a family caregiver to do so and then inform the researcher about a caregiver's choice to participate or not, prior to the researcher making contact.

McCosker, Barnard and Gerber (2001) recommend a clearly written protocol for addressing psychological distress that could occur during data collection. Richards and Schwartz (2002) point out that while health care professionals who also conduct research could be more likely to engage in inappropriate therapeutic interactions during participant interviews, they also could be more sensitive about how and when to access outside support for participants. In this case, the researcher collaborated with the hospice agency

medical social worker in anticipation of patients, caregivers or nurses needing professional support for emotional distress. It was prudent that the plan had been established, as one participant revealed that she had been feeling sad, angry, and helpless since becoming involved in caregiving. The study protocol also outlined how and when to contact the 24-hour hospice nurse triage service should pain or other physical symptom needs arise during the study. Because the researcher was herself a hospice nurse, while she had the expertise to provide triage in such cases, doing so could increase the potential for participants feeling pressured to continue in the study so as not to disappoint her (Richards & Schwartz, 2002).

### **Target Population and Sample Size**

The study's target population was the hospice caring triad group, comprised of nurses, patients, and family caregivers. Wohleber et al. (2012) include discussion about selecting the study target population, as do Charmaz (2010) and others. Eligibility criteria can limit the available participant population, however in the case of this study, the research question clearly identified the population characteristics needed for obtaining the best data about cancer pain experience in hospice. Ethical concerns of a homogenous participant population that limits generalizability for predictive research studies (Wohleber et al., 2012) was not a concern of this qualitative study. Grounded theory seeks to give voice to the experiences of participants and requires the population most able to do so (Charmaz, 2010). There was no attempt to generalize this particular triadic sample's experiences to others. With regards to sample size, grounded theory methods use data saturation in order to determine when sampling will be concluded. For this study, the need was to recruit enough triads for comparing and contrasting themes

brought up by triad members when asked to discuss their cancer pain and its management. Because data analysis followed a recursive coding and memo-writing process from the first data collection point, the concepts and themes that were identified by the early triad members were explored further with later triads, until the themes had been exhausted. Saturation was the point at which new experiences were not emerging relative to the codes and concepts identified.

### **Recruitment Practices**

Having hospice agency members on the research team, or having hospice clinicians recruit participants can be a help or hindrance. Gatekeeping is one of the most commonly cited barriers of having hospice nurses and palliative physicians as the primary recruiters (Hanson et al., 2014; Mackin et al., 2009; Stone et al., 2013; Wohleber et al., 2012). Most often gatekeeping occurs when an agency administrator, clinician, or family member controls how potential patient participants are informed of studies and their eligibility. When clinicians serve as the primary recruiters however, they may have frequent contact with potential patient participants, increasing the likelihood that potential participants would not be overlooked. Preparing the recruiters by providing unambiguous, simple criteria for identifying eligible participants could be helpful (Wohleber et al., 2012).

One of the recruitment challenges for this study was working with a single small, rural hospice agency, which limited the number of potential nurse and patient participants. To recruit nurses, the researcher held two informational meetings at the hospice agency during regular working hours. Using brief, slide-supported oral presentations she explained the study to all of the potential nurse participants. She then

held a question and answer period for the nurses. In order to avoid feelings of coercion, nurses opted into the study on a sign-up sheet after the researcher had left. As a clinician employed at the hospice, the researcher had the support of the management team, which allowed her to leave recruitment reminders for the nurses in the voice mailbox. These messages may have increased nurses' participation over the course of the study by accommodating their individual work and life commitments. Nurse recruiting was ongoing, and all eligible nurses did enroll in the study within the 12 month data collection period.

Nurses were responsible for recruiting patient participants, who in turn recruited family caregiver participants. In order to minimize nurse gatekeeping, the researcher provided one-on-one recruitment training for each nurse, based upon simple eligibility criteria that were repeated in the voicemails, and the reading of a simple script to any potential patient participant. The script to be read said:

The hospice agency providing services to you is collaborating with its nurses and patients to contribute to a study called, "Social Processes Used by the Hospice Caring Triad to Manage Cancer Pain." This study is being carried out by a University of Massachusetts PhD student of Nursing, who is also a hospice nurse. Would you like the nurse researcher to contact you about joining the study?

To overcome the potential for awkwardness, each nurse participant read it aloud several times and practiced on their own to build confidence. Nurses admitted to having different levels of comfort with recruiting. Two hospice nurses felt that they should serve as gatekeepers even when potential participants met eligibility. One of them did recruit and participate in data collection activities for a triad, while the other did not. The first nurse who volunteered for the study recruited according to eligibility using the script, and recruited three times more potential participants than other nurses, however all of them

died prior to their first data collection meeting, or did not feel well enough to participate by then.

Despite having a smaller potential nurse and patient pool from which to draw the sample, the study was able to recruit three triads, and one nurse-patient dyad as a contrast case. Of the twelve potential patient participants who gave verbal consent to be contacted, four consented and enrolled in the study. At 33%, this rate was lower than the 46% reported by older hospice patients in a survey asking if they would be hypothetically interested in participating in survey or interview research (Williams et al., 2006).

Considering the challenges of recruiting all three caring triad members within a short time window, in the context of recent hospice admission and changes due to illness, the research team felt that these numbers indicated the ability to successfully recruit for a qualitative study designed to elicit data from hospice triads. Further, every single consented participant across groups and roles gave permission for their de-identified data to be used in secondary analyses, scientific meetings, and educational activities, and all three family caregivers indicated that the researcher could contact them after scheduled data collection activities had ended if it was relevant to analyzing study data.

### **Retention**

Attrition due to worsening illness and death is to be an expected challenge for retention in research studies of hospice patients (Mackin et al., 2009). In this case, the researcher successfully conducted all data collection activities for two of three triads. In the other triad, seven of the twelve anticipated triad data collection activities were accomplished. With the single contrast case dyad, the researcher conducted seven of nine data collection activities. Attrition in both cases was because of sudden rapid disease

progression with changes to cognitive functioning leaving one patient too drowsy to engage in conversation, and the other too confused to do so. Some researchers recommend keeping data collection as brief as possible for hospice patients (Sheehan, 2010). While the research team must be acutely aware of changing needs and feelings of their hospice patient participants, research about patient preferences to continue in studies as they are able, despite disease progression, has not been conducted. To set realistic retention goals, this study began with careful planning for early recruitment. Further measures included rapid follow-up with nurses and patients interested in participating, providing a graphic timeline of study activities at the time of obtaining written consent, giving patient and family participants the choice of being interviewed on the same day, allowing participants to decide how often they wanted to participate over the course of a week, and suggesting follow-up interview dates and times at the end of each meeting. In the case of triad and dyad retention, two patient participants were unable to complete all data collection activities, and in one of those cases both the nurse participant and caregiver were unavailable to complete all data collection. In the case of one nurse who was unable to recruit a patient participant, and therefore unable to participate in a triad, only two data collection activities were conducted.

Several participants made statements over the course of their interviews that being in the study had been meaningful in different ways. One nurse said, “It’s really great to have the opportunity to participate in this research project, to be able to have this time and focus to think about, you know, what’s going on in this relationship. And I appreciate that.” A caregiver said, “I’m glad. I’m just glad that it can help.”



## **Implications**

A number of points are worth considering for future studies that will recruit caring groups in the home healthcare setting. The research team determined that in this study recruitment and retention were successful. Based on experiences in this study, and suggestions from the literature, researchers should budget for study personnel, and plan time allotted for field researchers as generously as possible, including multiple personnel available to conduct data gathering outside of usual working hours to increase the amount of data collected in a timely manner. Family caregivers and hospice nurses in this study were rarely available for interviews during the day on weekdays. Partnering with multiple hospice agencies, could have contributed to a larger triad sample, or a sample with different triad results. Also, while the data captured the voices of women, adult daughter caregivers, and a transgendered participant, male cancer patients either were not eligible, died prior to consent, or opted not to participate. The study was not able to recruit a sample reflecting the ethnic and cultural diversity of the geographic region. It is known that recruiting participants from historically marginalized populations can be challenging because of trust issues (Society for Women's Health Research-FDA Office of Women's Health, 2011). In our case, there were no hospice patients with cancer pain who identified as non-Caucasian receiving services from the agency we partnered with during the year-long recruitment period. This could be reflective of disparities in hospice use among minority groups (NHPCO, 2014), and is problematic for understanding needs that may be unique to groups not represented. Partnering with a greater number of hospice agencies would have increased the likelihood of a more diverse study population.

## **Conclusion**

It is possible to conduct longitudinal studies with hospice caring groups beyond the typical patient-caregiver dyad, centered on persons with pain from cancer. As experienced in this study, recruitment and retention were possible even when working within a limited study budget and a geographically rural area. Care must be taken in the planning of the study to maximize data collection activities with the lowest possible burden to participants. When the researcher is part of a clinical team engaged in the research study, recruitment and retention of triads can be strong. In this case, the researcher's historical working relationship with the hospice nurses participating in the study seemed to strengthen recruitment and retention of hospice nurses, who then recruited the persons comprising their individual triads. No family caregivers of the potential patient participants who requested contact from the researcher, declined to participate when the patient they were associated with wished to be part of the study. Future studies researching caring triads in hospice home care, will benefit from working with multiple hospice agencies and by employing sufficient fieldwork research staff available to meet with study participants at unusual hours. Hospice clinicians, patients, and caregivers stand to benefit from an increased number of such studies. Importantly, hospice agencies with administration teams that value research, can facilitate the participation of nurses in research studies. If nurses are encouraged to participate in studies, they in turn can successfully recruit patients, who can invite their caregivers also. This model of recruitment for qualitative research studies can broaden the body of evidence needed to improve symptom outcomes at end-of-life.

## **CHAPTER 6**

### **DISCUSSION**

#### **Introduction**

The primary goal of this dissertation study was to shed light on psychosocial factors affecting cancer pain management for older persons receiving hospice care because gaps remain in explaining high rates of poorly-controlled pain. The significant percentage of end-stage cancer patients with moderate to severe pain has not decreased over the past ten years, despite a solid body of research about how to identify different types of pain, the pharmacopeia for reducing various types of cancer pain, as well as guidelines for best practice pain management, and standardized pain assessment tools which can be accessed free of cost to individual practitioners and hospice agencies (ASCO, 2016; Fink & Gates, 2010; Foley, 1985; Herr et al., 2010; Pasero & McCaffery, 2011; Strassels et al., 2006; van den Beuken-van Everdingen et al., 2007; van den Beuken-van Everdingen et al., 2016). Recent statements by professional advocacy groups like the American Society of Clinical Oncology have joined the call previously made by nursing that pain is multidimensional and therefore must involve psychosocial assessment and treatment (ASCO, 2016; Ferrell & Coyle, 2008). This researcher used a social processes framework (NIMH, 2012) to explain how thoughts, feelings, and behaviors occurring within and among the hospice caring triad affected pain management for older persons with cancer. The social processes which served as a sensitizing lens for the systematic review of the literature included: affiliation and attachment, social communication, perception and understanding of self, and perception and understanding of other (NIMH, 2012).

In the systematic literature review, presented in Chapter Two, the authors found that few studies describing or addressing social processes for hospice cancer pain had been conducted, and only a very small number took a triadic approach (Ehrlich & Walker, 2016). Of the three studies which had examined a social process for cancer pain, two had looked at the meaning of pain (Barkwell, 1991; Ferrell et al., 1993) and one had isolated types of communication that triad members used when discussing pain management at hospice nurse visits (Ellington et al., 2012). In reviewing the literature, it became clear that separating out such social processes components of hospice cancer pain management provided possible clues to poor pain control (Ehrlich & Walker, 2016). However, understanding how cancer pain social processes contribute to overall pain management and control is difficult without a broad framework or theory within which to place them. This study identified domains for a hospice cancer pain social processes theoretical framework, as a starting point of theory development.

### **Research Question & Specific Aims**

The research question guiding this study was: “In the context of hospice, how do the social processes among the members of the hospice caring triad affect cancer pain management?” For constructing theory, in this case theory that would be clinically relevant, the research question had been designed to approach the problem of poorly-controlled cancer pain by seeking out data that would speak for the study participants. To answer this question from the perspectives of the patient, caregiver, and nurse, the researcher applied constructivist grounded theory methods. Constructivist grounded theory methods involved studying participants in natural settings, through prolonged engagement and multiple data-gathering activities including observation and

interviewing, along with recursive data analysis such as coding, memoing, theoretical sampling, and triangulation (Charmaz, 2010). The study plan included specific aims developed to guide a qualitative database that would provide sources of lived experiences and, in the case of this dissertation, were initially written in as part of a training grant proposal that required inclusion of specific aims.

### **Summary of Findings**

#### **Specific Aim 1: Describe the meaning of cancer pain and cancer pain management for each member of the hospice caring triad.**

It can be said that there is no single meaning for cancer pain, for meaning is based upon making sense of one's context, which necessarily differs based upon life circumstances. Within each triad, the various experiences the members had had over their lifetimes had shaped what these individual cancer pain experiences had meant. Variation in cancer pain meaning for persons with end-stage cancers would be expected, however variation across triad members, while consistent with pain meaning in the literature, is a sign of potential distress within the triad. Barkwell (1991) and Ferrell et al. (1993) also found that pain meaning varied for patients, caregivers, and nurses, with Ferrell et al. recommending that a key role for the nurse was helping patients and their caregivers find shared meaning in cancer pain. It is likely that nurses do engage in meaning-making with patients and caregivers to some extent, as nurses in this study seemed to corroborate the meaning of pain for their patients, and in some cases for caregivers. There are no clinical nursing tools that have been developed or tested for assessing cancer pain meaning, and for intervening to help bring all triad members to a joint understanding. Psychosocial issues like this are frequently considered the purview of hospice interdisciplinary team

members like medical social workers or spiritual counselors, however because hospice nurses make more frequent visits to triad members than the other professions, there remains a critical need for such nursing assessments and interventions. Clinical nursing assessment tools for pain meaning would contribute to the interdisciplinary team pain management plan of care.

**Specific Aim 2: Describe the social processes among the triad members during hospice cancer pain management.**

A key finding of this study was that patients, caregivers, and nurses engaged in complex, often subtle, and unspoken pain management social processes. These were typified by triads in which the nurse and patient might have used numeric severity ratings for pain assessment and re-assessment, but in which caregivers reported not asking for pain ratings, or not asking specifically about pain at all when assisting patients with pain management (see Appendix H for triadic examples of social processes). Another pain social process identified here was pain goal-setting. This social process stood out from the others because it was the only process which was related to all triads, but about which no triads had clear communication. Even within the triad that had open communication about all other pain social processes identified in the study, members of this group had not been discussing pain goals, although the caregiver had reported familiarity with numeric severity ratings.

Goal setting is a key element of the nursing process, and is also cited as one best practice for cancer pain management (Fine et al., 2010). Kathleen Foley, a renowned cancer pain advocate stated, “For patients with advanced disease, pain control should be sufficient to allow the patients to function at a level that they choose, and to die relatively

free of pain,” (1985, p. 84). For pain control interventions to be consistent and measurable, various subjective patient pain assessment scales have been developed, including one of the most widely used, the numeric rating scale (see Figure 4.1, p. 72). Pasero and McCaffery (2011) coined the term “comfort-function” goal for use of a numeric pain severity rating at which a patient is able to maintain their desired level of function (p. 51). For example, Mrs. P might say, “I would be able to shower today if my pain stayed at a four or lower.” Effectiveness of such a numeric comfort-function goal depends on a series of social processes to occur within triads. The first of these would be that the hospice nurse asks the patient to report a number for their pain severity at each visit, followed by asking for a comfort-function goal number. Then the nurse would need to evaluate the type of pain the patient was experiencing, and evaluate whether or not the prescribed medications or non-pharmacologic interventions being used were known to be effective. The nurse, whose responsibility it is to guide pain management social processes must then be able to provide education to patients and caregivers about pain management regimens so that they possess pain management *efficacy*. For comfort-function goals to be effectively used in hospice caring triads to manage pain, patients and caregivers must be taught how and when to assess pain using the numeric rating severity scale, and how the interventions available to them should be used to reduce pain, or keep pain at or below the comfort-function goal. Use of comfort-function goals had been an expectation of the study nurses by their hospice agency, however the data indicated that nurses chose when or when not to assess pain with numeric severity ratings, and also when or when not to use comfort-function goals.

Another best practice for cancer pain assessment is the use of questions that ask patients if or how much their pain interferes with daily function (Fine et al., 2010; Hjermstad et al., 2009; Paice et al., 2016; Pasero & McCaffery, 2011). The authors of the Cancer Pain Practices Index recommend that within 24 hours of admission a patient pain assessment include “impact of pain on function” (Fine et al., 2010, p. 796). While pain interference assessment scales exist for use in non-cancer pain, they do not measure impacts of pain that are likely to be sensitive to the reduced physical capacity of persons with end-stage cancers and, to this author’s knowledge, have not been tested in the hospice population (Fink & Gates, 2010). However, the documentation system used by the nurses in this study did prompt them to ask about pain interference using a check list of possible interference categories with simple “yes” or “no” options. As with comfort-function goals assessment, only one of the nurses used the interference checklist at both observational visits.

A troubling question about setting goals for hospice patients remains: “Why are functional goals not asked of patients using clear consistent language?” If the desired outcome of pain control, as Foley (1985) stated, is for hospice patients to function as they wish to, it seems plausible that an assessment tool nurses and family members could use with patients would be a question like, “What is something you would like to do when your pain is well-controlled?” The follow-up evaluation question would be, “Were you able to do \_\_\_\_\_ since our last visit?” Asking a straightforward question like this retains a patient-centered focus for pain management. It is easy to ask, easy to teach a family caregiver to ask, and equally easy to document in the health record for follow-up at the next hospice contact. Unlike interference questions, which have no follow-up instructions



after evaluating interference, a straightforward functional pain goal question would remove the tendency of triad members to assume what a person’s goals for pain control are. Table 6.1 below gives examples of the current type of pain interference assessments (modeled on observation of participating hospice nurses and the Brief Pain Inventory [Pasero & McCaffery, 2011]) and a proposed standard for assessing an open-ended functional pain goal. Cancer pain assessment guidelines call for use of both a cancer pain severity rating using the numeric rating (or another tested and validated scale) and an interference assessment, so that the clinician can compare the level of comfort to the

Table 6.1 Current and Proposed Pain Functional Goal Assessments

<b>Functional Pain Goal Assessment</b>	<b>Assessment Question</b>	<b>Assessment-derived Goal</b>
<b><i>Current standard:</i></b>  Pain interference assessment	“Does your pain affect: -sleep -relationships -appetite -activity”	Could be: -improved sleep -quality of activities spent with significant others -getting up for meals -or something not in the list
<b><i>Proposed standard:</i></b>  Open-ended functional goal assessment	“What is something you would like to do when your pain is well-controlled?”	Whatever the response to the question was

level of interference (Fine et al., 2010; Pasero & McCaffery, 2011). However, triad members, whether they are clinicians or family members, must be able to follow through a series of complicated social processes to do so. One key gap for nursing practice is clear—there are no educational resources which describe how to integrate pain severity

and functional interference findings to establish pain goals at a phase in the illness trajectory when persons have little time and may be especially vulnerable.

**Specific Aim 3: Propose a framework of and for cancer pain management social processes of the hospice caring triad.**

The purpose of constructing domains for a hospice cancer pain management social processes framework was to identify which were associated with poor pain control in order to develop assessments and interventions suited to the hospice cancer context, typified by rapid and unpredictable symptom changes and a short time frame within which to improve them. These hospice cancer pain social processes domains are:

*Controlling Cancer Pain* and *Proximity*, along with sub-categories and concepts, depicted in Figure 4.2, on page 79. Relationships amongst the domains, categories, and concepts as they are understood so far, were discussed in Chapter Four.

The intent of using the NIMH social processes framework as a sensitizing lens for the cancer pain social processes was to clarify how ‘social processes’ could be broken down into categories embodying pain management thoughts and behaviors. Identifying thoughts and behaviors was considered to be critical to determining which framework concepts could be operationalized for clinical outcomes research. Pain management processes involving thoughts and behaviors could be targeted in assessments and interventions. Assessing pain functional pain goals, as outlined in Table 6.1 above is an example.

**Extension of NIMH Social Processes to Cancer Pain Social Processes**

The NIMH framework was developed by mental health experts as one set of a large researchable variables matrix for the determinants of mental illness. While the

authors of the framework intended it only to be used for mental illness, because of the complex psychosocial factors occurring in the context of any severe illness, the framework of social processes turned out to be inclusive enough for use in describing hospice triad cancer pain social processes. This was possible because the definitions for each social process were theoretically and operationally defined (NIMH, 2012), with explanatory statements describing examples of how to use them, and how the expert panels came to consensus about each.

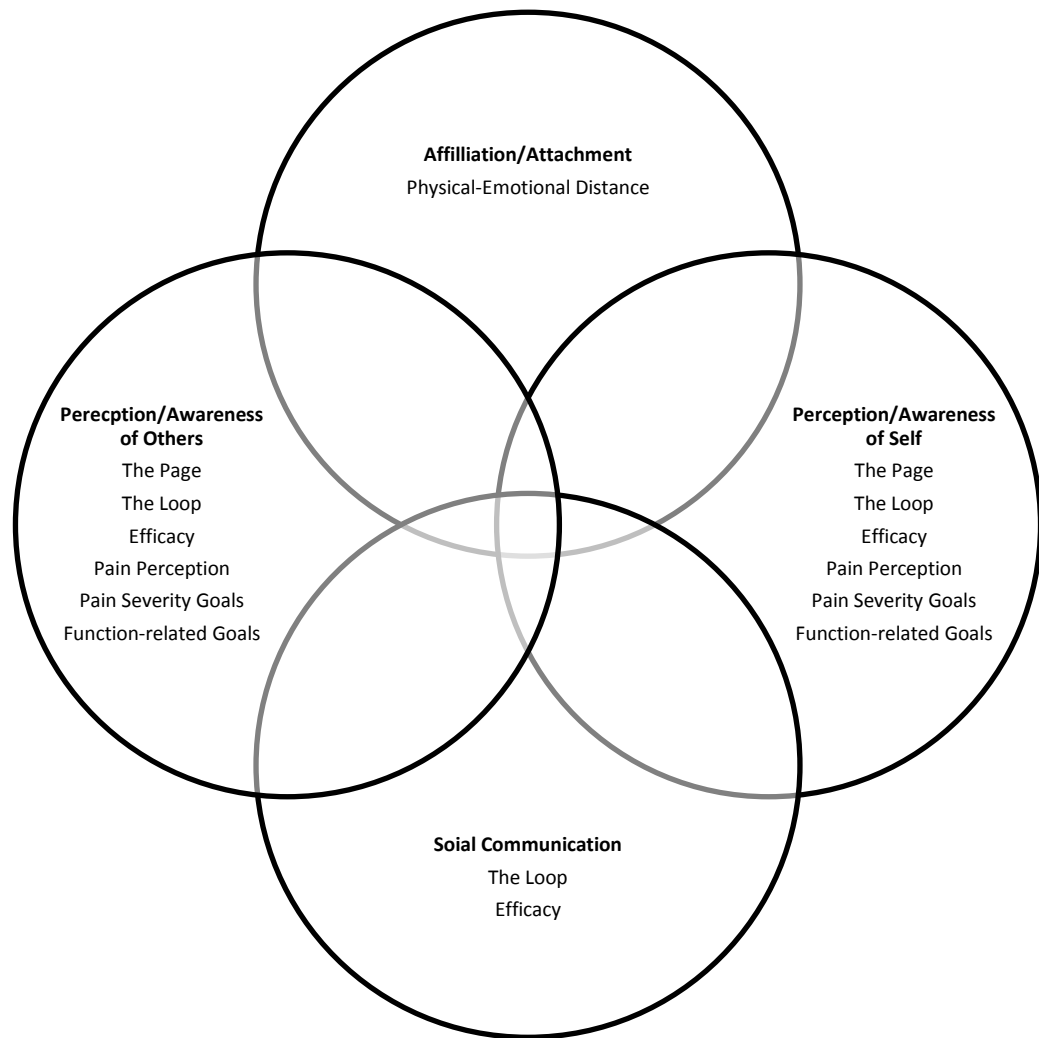
This author's framework domains, *Controlling Cancer Pain* and *Proximity*, extend the NIMH social processes framework out of the context of mental health. Although the original intention was not to test the NIMH framework for application in cancer pain management, by constantly comparing the newly constructed codes and concepts of the hospice caring triad with the NIMH processes, it became clear that many of the concepts could be clustered under the NIMH umbrella. However, the domains of this emerging hospice caring triad social processes framework include additional cancer pain specific sub-concepts like pain severity goals and pain efficacy. The NIMH framework did not specify the measurement of illness severity subjectively, or knowledge of self-management. And while the NIMH social processes framework implies the interactions between persons with mental illness and their caregivers, it also does not specify a caring group (such as a triad) within the framework variables. It is too early in the process of developing the cancer pain social processes framework to know whether this is purely coincidence or whether the NIMH processes would serve as a broad enough umbrella to eventually encompass all of them. Figure 6.1, below illustrates the integration of NIMH and cancer pain social processes domains and concepts.

### **Related Extant Theories**

Extant pain theories like that proposed in Melzack and Casey's three dimensions (the sensory-discriminative, affective-motivational, and cognitive-evaluative [Moayed & Davis, 2012]) are not broad enough to encompass the complexities for cancer pain management within a group like the hospice caring triad. Melzack and Casey's theory, typical of the received scientific view, was useful for introducing the important notion that how people in pain perceived it could influence their experiences of pain. While it may have contributed to the development of pain interference scales, it may also have contributed to accepted practice of determining pain goals by asking about interference rather than by asking patients to state a goal.

Another theory which addressed physical pain at end-of-life was Dame Cicely Saunders' theory of total pain, developed in the 1960s when she practiced nursing and medicine with persons dying in a British hospital. The total pain theory explained pain as multidimensional, and it focused on the suffering that could be related to physical pain, rather than physical pain as a symptom occurring in a social context (Saunders, 1978). Suffering was considered to be greater than pain, encompassing it, but not all persons having pain would experience suffering (Cassell, 1982). While there may be elements of suffering related to cancer pain social processes for caring triads, the proposed theory in development here calls for a framework expansive enough to encompass pain experiences both related and not related to experiences of suffering.

Figure 6.1 Social Processes Intersectionality



Nurse theorists have not developed other pain-specific theories for use in various nursing contexts such as hospice, or cancer pain. Lenz & Pugh (2008) developed the Theory of Unpleasant Symptoms, which was intended to be applicable across a variety of symptom types and contexts. It was comprised of three domains, physiologic factors, situational factors, and psychologic factors. These were seen to influence symptom quality, intensity, timing and distress. Together the domains and symptom dimensions

were said to influence functional, cognitive, or physical performance. A shortcoming of the Theory of Unpleasant Symptoms, from this author's perspective as a researcher and clinician of hospice cancer pain, is that it does not outline which social processes mediate symptom management.

### **Theoretical Framework for Hospice Cancer Pain Processes**

The emerging theoretical framework of hospice cancer pain social processes introduced by this author is comprised of two domains at this time, the result of analyzing participant data points until saturation was reached. The domains of *Controlling Cancer Pain* and *Proximity* have been defined (see Appendix H, p. 171), along with related concepts and the theoretical and descriptive definitions for them (Walker & Avant, 2011). Other elements of theory construction include making relational statements about the framework elements which can be causal, associative, or linear (Walker & Avant, 2011). The framework domains and their proposed associations are illustrated in Table 4.2, page 91, and in tables and figures in Appendix I (p. 173). The relationships between the framework domains will be tested and described in future research studies, after the concepts have been operationalized.

### **Strengths and Limitations**

One of the strengths of conducting a grounded theory study is that the researcher is well-equipped to present valid study results. In this case, the cancer pain social processes *Controlling Cancer Pain* and *Proximity* were observed by the researcher and confirmed by multiple triad members over the course of the study. These are the lived experiences of the patients, caregivers and nurses who participated in the study. To reflect differing perspectives about the same situations for pain management within and

across caring triads, observational visits and interviews with individual triad members were conducted over a time of several weeks to months. Analysis of participant themes for cancer pain social processes was started early in the study so that subsequent data gathering activities would be grounded in the data, using the method known as theoretical sampling of both participants and emerging concepts. The acknowledgement of how the author's professional clinical experiences had influenced her interpretation of the data in the researcher stance statement in Chapter One, and writing of reflexive memos over the course of the study, coupled with dissertation committee member dialoguing, and consultations with known experts in the field of cancer pain have contributed to the strength of the resulting data interpretations.

While the methods used were appropriate for answering a research question about which not much was previously known, and which had its roots in the meanings underpinning behaviors, the theoretical framework remains limited in scope to goals for controlling cancer pain. Additional social processes concepts remain to be identified and explored in future studies. While the study results can be said to represent cancer pain social processes for rural home-dwelling older female hospice patients and adult daughter caregivers, a cancer pain social processes framework would be applicable across populations if additional groups were represented in the sample.

### **Implications for Nursing Theory, Research, and Practice**

Results of this study confirm some previous findings about the varying meanings of pain for persons with cancer, their caregivers, and health professionals (Barkwell, 1991; Ferrell et al., 1993). Members of hospice triads here also spoke of their concerns voiced by previous study participants, like concern of addiction when using opioids

(Dawson et al., 2005; Fleming, 2010), not having enough time to thoroughly assess pain, or believing that the person with pain was underrating its severity (Redinbaugh, 2002). This researcher has also importantly identified and labelled new phenomena for hospice cancer pain management within proposed theoretical domains. These are the cancer pain social processes domains, *Pain Control Goals* and *Proximity*. These framework domains provide a lens through which to view perceptions and behaviors taking place in the caring triad. This new framework also moves the management of pain from the dichotomous realm of nurse-patient, to the more naturalistic realm for home hospice patients of nurse-patient-caregiver. By describing social processes that the triads engaged in, points of impact for changing outcomes have been identified at the level of action, where change is potentiated for nursing practice.

Practice implications of this study of cancer pain social processes will be valuable to clinicians who are challenged by cases involving poorly-controlled cancer pain. It is possible that nurses in practice may not be regularly using comfort-function goals or assessing pain interference. While this was already reported by Herr et al. in 2010, it is not unusual for problematic issues to be brought to awareness multiple times before changes are initiated. Attention to use of pain severity and functional goals could help direct pain control behaviors in ways that are meaningful for patients and caregivers. Recently released clinical guidelines for palliative cancer care have called for integration of elements consistent with the social processes domains identified in this study, and within the context of a caring group such as the triad (The ASCO Post, 2017). These include: “Rapport and relationship building with patients and family caregivers; Symptom and functional status; Exploration of understanding about illness and



prognosis; Clarification of treatment goals; and Coordination with other care providers.”  
(The ASCO Post, 2017, para. 5).

Besides implementing regular use of comfort-function goals and pain interference assessments, nurses can ask patients to state their functional pain control goals in clear simple language. These goals can be communicated with permission between the triad members to assure that care interventions are appropriately focused on meeting these goals stated by patients. Hospice nurses should facilitate triad members getting and staying in-the-loop by educating family caregivers and patients about setting pain goals, whether these are severity or function-related, openly discussing these goals, and jointly deciding on a plan of care to facilitate meeting such pain control goals.

This study has important research implications. As calls for patient-centered care have moved away from postal mail surveys about in-patient treatments to patient involvement in all levels of research (PCORI, 2014), it is crucial for research studies to implement inclusive methods. In this study of triads in a population considered to have triple vulnerabilities—rural home-dwelling elders, persons with unresolved pain, and persons at the end-of-life who have limited time and energy—a sample of participants was successfully recruited and retained over the course of the individual hospice service periods. The author outlined considerations for successfully conducting clinical studies with people often considered too vulnerable to participate in voicing their real life experiences, needs, and preferences.

### **Recommendations for Future Research**

To further our understanding of cancer pain management social processes in the home hospice caring triad context and to give clinicians better interventions for pain

relief, additional studies are needed. These studies should examine the social processes domains of *Pain Control Goals* and *Proximity* in samples with different demographics for further comparison and development. Additional theoretical sampling to flush out the dimensions of other preliminary social processes concepts identified in this study are needed to add to the overall framework of hospice cancer pain social processes. This emerging framework could be used to develop assessment tools for various social processes phenomena like functional pain goal-setting. Framework concepts could also be used in the development and testing of triad communication and agreement interventions specific to pain. Ongoing study of cancer pain social processes in targeted clinical group contexts, like that of the hospice caring triad, will serve to more realistically meet the needs of patients and families by giving voice to their complexity.

## APPENDICES

## APPENDIX A

### HOSPICE AGENCY MEMORANDUM OF UNDERSTANDING



168 Industrial Drive  
Northampton, MA 01060

Tel: 413-584-1060  
vnaandhospice.org

May 18, 2015

Dear University of Massachusetts Amherst Institutional Review Board,

As Director of Hospice and Palliative Care for Cooley Dickinson VNA & Hospice, it is with pleasure that I write this letter of support for the research study, *Social Processes used by the Hospice Caring Triad to Manage Cancer Pain*, to be conducted by PhD Candidate, Olga Ehrlich, RN, BSN, CHPN. Ms. Ehrlich will be recruiting hospice patients, their family caregivers, and our hospice nurses to participate in interviews, journaling, and focus groups to gather data for the study. Our participation has also been approved by Joanne Marqusee, President and CEO of Cooley Dickinson Healthcare Corporation, of which we are a part, as well as Mark Novotny, MD, Chief Medical Officer. I understand that the support our agency will provide to the study includes identifying eligible participants and the distribution of IRB-approved recruitment materials by our nurses to those individuals.

We assisted Ms. Ehrlich with recruitment of hospice cancer patients two years ago, for her University of Massachusetts Amherst, IRB-Approved study, *Pain Control: A Hybrid Concept Analysis*. Ms. Ehrlich conducted herself with the utmost professionalism during that research study, and we are confident that she will do so again. We are excited to support research which seeks to answer the call of agencies like the Institute of Medicine, National Institute for Nursing Research, and Hospice and Palliative Care Organization for improving patient-centered symptom management at end-of-life.

Sincerely,

A handwritten signature in blue ink that reads "Maureen Groden RN MS CHPN".

Maureen Groden, RN, MS, CHPN  
Director of Hospice and Palliative Care, CDHCC  
Cooley Dickinson VNA & Hospice  
168 Industrial Drive  
Northampton, MA 01060  
[Maureen\\_Groden@Cooley-Dickinson.Org](mailto:Maureen_Groden@Cooley-Dickinson.Org)  
Main: (413) 584-1060  
Fax: (413) 584-7908

## APPENDIX B IRB APPROVAL LETTER



**University of Massachusetts Amherst**  
108 Research Administration Bldg.  
70 Butterfield Terrace  
Amherst, MA 01003-9242

**Research Compliance  
Human Research Protection Office (HRPO)**  
Telephone: (413) 545-3428  
FAX: (413) 577-1728

### Certification of Human Subjects Approval

**Date:** September 30, 2015  
**To:** Olga Ehrlich, Nursing  
**Other Investigator:** Rachel Walker, Nursing  
**From:** Lynnette Leidy Sievert, Chair, UMASS IRB

Protocol Title: Hospice Caring Triad Social Processes Used to Manage Cancer Pain  
Protocol ID: 2015-2555  
Review Type: EXPEDITED - NEW  
Paragraph ID: 5.6.7  
Approval Date: 09/30/2015  
Expiration Date: 09/29/2016  
OGCA #:

This study has been reviewed and approved by the University of Massachusetts Amherst IRB, Federal Wide Assurance # 00003909. Approval is granted with the understanding that investigator(s) are responsible for:

**Modifications** - All changes to the study (e.g. protocol, recruitment materials, consent form, additional key personnel), must be submitted for approval in e-protocol before instituting the changes. New personnel must have completed CITI training.

**Consent forms** - A copy of the approved, validated, consent form (with the IRB stamp) must be used to consent each subject. Investigators must retain copies of signed consent documents for six (6) years after close of the grant, or three (3) years if unfunded.

**Adverse Event Reporting** - Adverse events occurring in the course of the protocol must be reported in e-protocol as soon as possible, but no later than five (5) working days.

**Continuing Review** - Studies that received Full Board or Expedited approval must be reviewed three weeks prior to expiration, or six weeks for Full Board. Renewal Reports are submitted through e-protocol.

**Completion Reports** - Notify the IRB when your study is complete by submitting a Final Report Form in e-protocol.

Consent form (when applicable) will be stamped and sent in a separate e-mail. Use only IRB approved copies of the consent forms, questionnaires, letters, advertisements etc. in your research.

Please contact the Human Research Protection Office if you have any further questions. Best wishes for a successful project.

## APPENDIX C

### DEMOGRAPHICS STATISTICS AND DATA COLLECTION FORMS

<b>Age range</b>	<i>Patient</i> 62-79	<i>Caregiver</i> 46-53	<i>Nurse</i> 38-62
<b>Sex</b>	<i>Patient</i> Female      4 Male        0	<i>Caregiver</i> Female      3 Male        0	<i>Nurse</i> Female      5 Male        0
<b>Prior personal hospice experience</b>	<i>Patient</i> Yes          3 Unknown    1	<i>Caregiver</i> Yes          1 No            2	<i>Nurse</i> Yes          3 No            2
<b>All participant stated spiritual or religious identity</b>	<i>Patient</i> <i>Caregiver</i> <i>Nurse</i> "Catholic"      2 "Methodist"    2 "The Great Goddess"    1 "Buddhist/Nature"    1 "None"            1 "Christian" 1 "Congregationalist"    1 "Spiritual"        2		
<b>All participant racial or ethnic identity</b>	<i>Patient</i> <i>Caregiver</i> <i>Nurse</i> "White"            4 "Caucasian"        2 "Caucasian French Canadian"    1 "WASP"            1 "Yankee Midwestern"    1 "50% Polish/25% German/25% everything else"    1 "Native American French Canadian"    1		
<b>Nurse years of hospice experience</b>	1-20	<i>Mean</i> 9.4	<i>Median</i> 10
<b>Nurses with specialty certification</b>	4	<i>Mean</i> 1.25	<i>Median</i> 4

## PARTICIPANT DEMOGRAPHICS PAIN SEVERITY RATINGS

*Participant self-report of pain severity using numeric rating scale at interview 1*

<b>Time Point</b>					
<i>Patient participant*</i>	Current	Best in 24 hours	Worst in 24 hours	Best since diagnosis	Worst since diagnosis
One	4	1	4	1	">10"
Two	6	4	10	0	10
Three	0	0	1	0	10
Four	1	1	3	0	"11"

*\*All participants were asked to rate their pain severity using the numeric rating scale, with the following question, based upon defined anchors, "Please rate your pain where zero is no pain at all and ten is the worst pain imaginable."*

## Attachment 1A

### Group P: Demographic Information Sheet\*\*

*(All data collected from interview records)*

1. **Participant:** (code name)
2. **Race/Ethnicity:**
3. **Religious/Spiritual identity:**
4. **Age:**
5. **Hospice diagnosis:**
6. **Month/year of CA diagnosis:**
7. **Relationship of FC:** (e.g. spouse)
8. **If spouse or partner, how many years together?**
9. **What is your pain number at this time?**
10. **What is the worst your pain number has been since you started having pain (0-10)?**
11. **What is the worst your pain number has been since this time yesterday (0-10)?**
12. **What is the best your pain number has been since you started having pain (0-10)?**
13. **What is the best your pain number has been this time yesterday (0-10)?**
14. **What medications are you currently using to manage pain?**
15. **What non-drug methods are you currently using to manage pain?**

**Participation:** (circle all that apply, write in “written” or “audio” for journals, write in any additional journal entry numbers and interviews below)

**Observation visit 1**

**Observation visit 2**

**Interview 1**

**Interview 2**

**Interview 3**

**Journal 1**

**Journal 2**

**Journal 3**

**\*\*Demographic information will be entered into a group spreadsheet for descriptive purposes**



## Attachment 1B

### Group FC: Demographic Information Sheet\*\* (Questions 2-9 answered by FC at first interview)

1. **Participant:** (code name)
2. **Race/Ethnicity:**
3. **Religious/Spiritual identity:**
4. **Age:**
5. **Relationship of FC:** (e.g. spouse)
6. **Cohabitates with P:** (how many days per week)
7. **If not cohabitating, how many hours per week does FC provide care?**
8. **How many hours per week do others help FC in providing care?**
9. **Has FC had prior experience caring for person receiving hospice?**
10. **Do you participate in pain assessment for your family member?**
11. **What medication is your family member using for pain control at this time?**
12. **What other methods is your family member using for pain control at this time?**
13. **In your opinion, when (the approximate date) did your family member start to have good pain control?**

**Participation:** (circle all that apply, write in “written” or “audio” for journals, write in any additional journal entry numbers and interviews below)

**Observation visit 1**

**Observation visit 2**

**Interview 1**

**Interview 2**

**Interview 3**

**Journal 1**

**Journal 2**

**Journal 3**

**Group HN: Demographic Information Sheet\*\***

*(Questions 2-8 answered by HN at time of obtaining informed consent)*

**1. Participant:** (code name)

**2. Race/Ethnicity:**

**3. Religious/Spiritual identity:**

**4. Age:**

**5. Years of hospice experience:**

**6. Hospice and Palliative Nursing certification obtained?** (yes or no)

**7. Current?** (yes or no)

**8. Experience of own family member receiving hospice care?** (yes or no)

**Participation:** (circle all that apply, write in “written” or “audio” for journals, write in any additional journal entry numbers and interviews below)

**Observation visit 1**

**Observation visit 2**

**Interview 1**

**Interview 2**

**Interview 3**

**Journal 1**

**Journal 2**

**Journal 3**

**Focus Group 1**

**Focus Group 2**

## APPENDIX D

### RECRUITMENT DOCUMENTS

#### **Invitation to Participate in Study**

Dear Hospice Nurse,

As you are aware from your participation in an informational meeting, your colleague and PhD Candidate, Olga Ehrlich, is conducting a study about management of cancer pain for older hospice patients, their family caregivers and their nurses. If you would like to participate in the study, either as a nurse who solely recruits eligible patients and caregivers, or as a member of a hospice caring triad, please contact Olga at your convenience. Your contact is private and any information discussed or provided by you will remain confidential. If you choose to participate, Olga will meet with you to explain and obtain your consent if you participate as caring triad nurse.

If you are interested in being part of the study, please call or email Olga for more information or to sign up.

Olga Ehrlich

(602) XXX-XXXX

oerhlich@nursing.umass.edu

### **Hospice Nurse Recruitment Script**

Hospice nurse recruitment statement to be read to potential participants from the person with cancer pain group and the informal family caregiver group:

“The hospice agency providing services to you is collaborating with its nurses and patients to contribute to a study called, “Social Processes used by the Hospice Caring Triad to Manage Cancer Pain.” This study is being carried out by a University of Massachusetts PhD student of Nursing, who is also a hospice nurse. Would you like the nurse researcher to contact you about joining the study?”

## **Researcher Telephone Recruitment Script**

Hello. May I please speak with...?

Hello, Mr./Mrs./Ms. ... My name is Olga Ehrlich. I am the Umass Amherst PhD student who is doing a study about cancer pain management that one of the hospice nurses told you of.

Is this a good time to talk with you about the study? It will take me just a few minutes to explain.

(When can I call back to talk with you about the study?)

I would like to tell you about the study. I'm doing this study to understand why some people receiving hospice care experience cancer pain that is not well controlled.

People who chose to participate in the study will have meetings with me, in their own homes. These meetings will be for me to observe how someone who is receiving hospice care, their family caregiver and the nurse talk about and manage pain; and also to do some interviews about experiences of cancer pain and what it is like to work with each other to improve that pain. I am also asking participants who want to, to keep a journal about those experiences.

What questions do you have for me?

People participating in this study include individuals like yourself, who have now or have had in the past, pain from the cancer. Also, family caregivers and nurses associated with patients will be part of the study.

Do you have a family caregiver who lives with you or spends several days a week helping you manage your health needs?

(Okay. At this time only patients who also have a family caregiver involved in their healthcare at least two days a week, are eligible for the study. I am sorry that you are not eligible. Thank you very much for taking the time to speak with me about the study! May I answer any other questions for you?)

*(Symptom or hospice care team questions that arise here will be addressed by, "I think that is a question your hospice team can answer. Do you have their phone number so you can call them to ask? If not, I can give you the hospice phone number.")*

Okay. If you and your family caregiver choose to participate in the study, I will interview you both. These will be private interviews with just myself and the person being interviewed. Each will last from about one to one-and-a-half hours. The information discussed during the interviews will be confidential. There will be three interviews for each person.

What questions do you have at this time?

Besides the three interviews, I will visit each patient two times along with the hospice nurse, during a regular nursing visit. During these two visits I will observe and make notes about care related to pain. The first of these two visits will be prior to any interviews. The second of these observational visits will be after your interviews have been completed. The information observed during the interviews will be confidential and will not have an effect on your care or your nurse's care for you.

What questions do you have at this time?

Thank you again for your time! One more part of the study that I want to describe is the journaling. I am asking everyone who is part of the study to write or voice record about their cancer pain experience in between the interviews. You don't have to, but it may help if you have thoughts that come up after you speak with me. Also, some people find it easier to write about things rather than talk about them. I will provide journal supplies to anyone who wants to journal. The information shared in journals will be confidential.

Lastly, I would like to tell you what kind of time frame study participants are looking at. I have planned to keep all of the meetings as close together as possible while flexing to your availability. That means all meetings could happen over as little as four to five weeks, or over a longer period of time if that works better for you

What other questions can I answer for you?

If you are thinking about participating, I would like you to discuss this with your family caregiver before letting me know if you want to join the study. Would you like me to talk with your family caregiver now to explain the study to them?

When would be a good time for me to check back in with you about your decision? If you like, you can also call or email me instead.

## APPENDIX E

### INTERVIEW AND FOCUS GROUP QUESTIONS

#### *Possible Interview Questions for Patient Participants*

---

- 1) Are you comfortable enough to meet and talk with me now?
  - 2) I'd like you to tell me about a day when your pain was in good control...
  - 3) What kinds of goals do you associate with pain control?
  - 4) What are/were you able to do when you have/had good pain control?
  - 5) What are some words or phrases you associate with pain?
  - 6) What education have you received about pain from your nurse or doctor?
  - 7) How does your nurse ask you about pain control?
  - 8) What role does your caregiver play in your pain management?
  - 9) Is there something else you would like to tell me?
  - 10) Is there anything you would like to ask me?
- (Follow up prompts: "Can you give me an example?" I'd like you to tell me more about that.")

#### *Possible Interview Questions for Family Caregiver Participants*

---

- 1) I'd like you tell me about your experience helping to manage your "relationship name's" cancer pain please.
- 2) Please describe a day or time when he/she had good pain control.
- 3) What kinds of goals do you associate with pain control?
- 4) Please describe a day or time when he/she had poor pain control.
- 5) What are some words or phrases you associate with pain?
- 6) What education have you received about pain from your nurse?
- 7) How does your nurse ask you about pain?
- 8) What role do you play in your "relationship name's" pain management?
- 9) Is there something else you would like to tell me?
- 10) Is there anything you would like to ask me?

#### *Possible Interview Questions for Nurse Participants*

---

- 1) I'd like you tell me about your experience helping to manage "patient's name" cancer pain please.
- 2) Please describe a day or time when you thought he/she had good pain control.
- 3) What kinds of goals do you associate with pain control?
- 4) Please describe a day or time when you thought he/she had poor pain control.
- 5) What are some words or phrases you associate with pain?
- 6) What education do you provide about pain?
- 7) How patients and family caregivers ask you about pain?
- 8) Do they tell you about pain if you don't ask?
- 9) What role do you play in your "relationship name's" pain management?
- 10) Is there something else you would like to tell me?
- 11) Is there anything you would like to ask me?

## Examples of Interview Questions and Follow-up Probes from Transcripts

<b>Question</b>	I'd like you to tell me please about your experience helping to manage your family member's cancer pain. Anything that comes to mind about your experience with that.
<b>Response</b>	The reason I know how severe it can be is it's just almost a year ago is when she had the severe pain in her back that she couldn't walk or stand...So when this happened it was off the charts, off the charts. So when we see her that's how, that's as bad as it ever could be.
<b>Follow-up Question</b>	I wonder if you can think back to that time that she had the pain that was so bad that you called the ambulance, and do you remember what your thoughts were at that moment?
<b>Question</b>	It's not who your mom was?
<b>Response</b>	No. Um and that has been really hard. I think that's the hardest thing.
<b>Follow-up Question</b>	Who was she?
<b>Question</b>	I'm wondering if you remember how you felt about the pain, or what you thought it might be before you went to see the doctor.
<b>Response</b>	I thought because it wasn't going away and the kind of thing it was, I thought I might have like diverticulitis or something like that. It was the kind pain that is like ripping kind of pain that you have if you get a GI bug or something. And I just couldn't make it go away no matter what I did, no matter what I tried.
<b>Follow-up Question</b>	What did you try?
<b>Question</b>	I'd like you to talk about the kinds of goals that you, as a nurse, when you're providing care for hospice patients with cancer, what kinds of goals for pain control do you typically have?
<b>Response</b>	Hm. Uh so my goal for a patient which seems obvious to me, is NO pain of course. I take that very personally if I can't always control somebody's pain. But it's not always realistic.
<b>Follow-up Question</b>	I wonder if you have a story to share with me from a real scenario that involves, you said, "It's not always realistic to reduce pain to a zero," and you gave some examples of why. Can you remember a patient and a family, especially a patient who had a family member involved where it just was not realistic to bring their pain down to a zero?



## **Suggested Journaling Prompts**

**All:** This journal is for you to share anything about your cancer pain that you would like. Please write freely and do not worry about spelling or grammar. Using a journal is a personal and judgement-free way to express yourself. Below are some ideas for you to consider in this journal, but you do not have to write/speak about any or all of them. What you choose to share is up to you.

### **Person with pain:**

- In thinking about the interview with the study nurse, please write/talk freely about any ideas, thoughts, feelings or experiences about your cancer pain that have come to you since the interview.
- Please write/talk about the difficulty cancer pain has caused.
- Please write/talk about how your cancer pain affects your relationships.
- Please write/talk about advice you would like share with another person who has pain from cancer.
- Please share a story about your cancer pain.
- Please list words that you associate with your cancer pain.
- Please tell about advice or teaching people have given you about cancer pain.

### **Family caregiver:**

- In thinking about the interview with the study nurse, please write/talk freely about any ideas, thoughts, feelings or experiences about your family member's cancer pain that have come to you since the interview.
- Please write/talk about the difficulties associated with your family member's cancer pain.
- Please write/talk about how your cancer pain has affected your relationship.
- Please write/talk about advice you would like share with another family member caring for someone who has pain from cancer.
- Please share a story about your family member's cancer pain.
- Please list words that you associate with cancer pain.
- Please tell about advice or teaching people have given you about cancer pain.

### **Hospice nurse:**

- In thinking about the interview with the study nurse, please write/talk freely about any ideas, thoughts, feelings or experiences about your patients' cancer pain that have come to you since the interview.
- Please write/talk about an important story about cancer pain care that you have experienced.
- Please write/talk about how it feels to you to give care to persons with pain from cancer.
- Please write/talk about what happens when you help people control their cancer pain.
- Please write/talk about what happens when cancer pain is not controlled.
- Please write/talk about personal beliefs and/or values that affect your cancer pain management nursing.
- Please tell about advice or teaching you have given patients and families about cancer pain.

### **Possible Nurse Focus Group Questions**

- 1) I'd like to begin by having you think back to the first time you encountered a patient with pain from cancer as a hospice nurse and tell us about that experience.
- 2) Please describe your approach to cancer pain management in the home.
- 3) Talk about how the meaning of pain affects the lives of your patients and their family caregivers.
- 4) Imagine that you can do anything needed to improve cancer pain except cure the cancer-what would you do?
- 5) Talk about how family caregivers perceive their loved one's pain.
- 6) Imagine that you were the person with pain from cancer. What would you want from your family caregiver? What would you want from your nurse?

## APPENDIX F

### INFORMED CONSENT FORMS

#### Consent Form for Participation in a Research Study

University of Massachusetts Amherst

*For Cancer Pain Participants*

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<b>Researcher(s):</b>	Olga Ehrlich, PhD Candidate, College of Nursing; Adviser and Dissertation Committee Chair, Rachel Walker, RN, PhD, College of Nursing
<b>Study Title:</b>	Hospice Caring Triad Social Processes Used to Manage Cancer Pain
<b>Funding Agency:</b>	UMass Amherst Graduate School, Sigma Theta Tau Beta Zeta Chapter, Oncology Nursing Foundation

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#### 1. WHAT IS THIS FORM?

This form is called a **Consent Form**. It will give you information about the study so you can make an informed decision about participation in this research.

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and ask questions now and at any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records.

#### 2. WHO IS ELIGIBLE TO PARTICIPATE?

Any older person receiving hospice care from Cooley Dickinson Hospice for cancer, with a history of cancer pain, meeting all of these criteria:

- Who is 60 years of age or older
- Who has a hospice diagnosis of cancer
- Who is able to have a meaningful conversation in the English language with the researcher
- Who reports a history of pain from cancer that required some form of treatment (medicine, ice, relaxation, etc.)

### **3. WHAT IS THE PURPOSE OF THIS STUDY?**

The purpose of this research study is to understand how older persons with cancer on hospice care manage their pain together with their informal family caregivers and hospice nurses. In this study, the group of people being researched is called 'the hospice caring triad'. The triad is the person with cancer, the caregiver and the hospice nurse. Some people have difficulty controlling their pain. The researcher wants to identify which interactions the triad members engage in order to describe them and how those interactions affect good pain management. The researcher will use this information to create a theory to help nurses provide effective pain management to older persons with pain from cancer.

### **4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?**

Study visits and interviews will take place in your home, unless you request to meet in a different location. The entire study may take over one year to complete, however your participation will likely be for 3-5 weeks but could take up to 3 months. You may wish to participate in all of the observational visits, interviews, and journaling opportunities, but at a pace that could extend for up to three months, if you prefer.

The study itself will consist of between two and five visits over the time period. At the first visit the researcher will observe you and your family caregiver receiving hospice care, in a regular hospice nursing visit. Then the researcher will arrange a time to interview you. These interviews will occur up to three times, for about an hour each time. All interviews will be private; you will meet individually with the researcher. You may also use a notebook (provided by the study) or voice recorder to give information to the researcher in between interviews. Notebooks will be provided and become your property after the researcher copies the pages for data analysis. You may borrow a voice recorder from the researcher if you prefer audio-recorded journaling to written. If you choose this option, you will be offered transcribed journal entries to keep. The study will conclude with another observational visit at a regular hospice nursing visit. If you wish to provide information to the researcher after your official participation has concluded you will be given contact information in order to do so.

### **5. WHAT WILL I BE ASKED TO DO?**

This study does not involve any treatment of pain or other symptoms. It involves you speaking to the researcher about your experiences.

If you agree to take part in this study, you will be asked to allow the researcher to observe two of your regularly scheduled hospice nursing visits. The researcher will also want to interview you to talk about pain from cancer and your experiences managing that pain. The study is based on three interviews per person, but if you can only be

interviewed once, you can still participate. The researcher will also ask you to spend time writing in a journal, or audio-recording thoughts and feelings you have about cancer pain between the interviews. However, if you only wish to be interviewed, you are not required to do written or audio-recorded journaling.

Interviews will be conducted privately, with only you and the researcher able to hear what is said. You will be asked to freely talk about your pain experiences. The researcher is interested in recording anything you want to say about this experience of cancer pain. You may skip any question you do not wish to reply to, or change the topic at any time. You can stop the interview at any time. You can also ask the researcher to leave at any time during a hospice visit. You may request this for any reason, and no explanation is required.

The investigator will also obtain some demographic information about you during the first interview, including your cancer type and month of diagnosis, your racial/ethnic identity, your sex, your age, your religious affiliation, your relationship to your family caregiver and how many years in this relationship. The reason for collecting the demographic information is to be able to describe some aggregate characteristics of each group when the investigator shares findings of the study. All of this information, like the other information gathered during the study will remain strictly private and confidential to anyone except yourself and the investigator.

## **6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?**

You may or may not benefit personally from participating in this study. The potential benefit to you is having the opportunity to share your story and experience with a person who cares deeply about understanding those. You may feel psychologically or emotionally better after sharing your story. However, some people will not feel any differently as a result of talking about or journaling about their experiences or stories.

The researcher hopes that your participation will benefit other older persons with cancer pain, their family caregivers, and hospice nurses in several ways. One way is that persons who read about your story and experience may feel re-assured to know that their similar experience happens for other people too, or could be expected. Another possible benefit is that hospice nurses who learn about the results of this study may be better prepared to help those older persons with cancer pain they are caring for. And lastly, this study is exploring the social processes that take place between the persons participating in the study, and will likely result in new information that hospice nurses and researchers can use to help with pain management.

## **7. WHAT ARE my RISKS OF being in THIS STUDY?**

The researcher believes there are no known risks associated with this research study; however, there could be inconvenience to you as a result of the time needed to

participate. It is also possible that talking about your cancer pain experience could cause sadness, anxiety, or other unexpected emotions. However, should any unexpected unpleasant experiences arise, the researcher will assist in getting the help needed to resolve those.

Some people can sometimes feel uncomfortable discussing personal experiences involving others, such as their family members or people providing care, like nurses. For this reason, you can decline to answer any questions that make you uncomfortable. No explanation is required.

#### **8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?**

The following procedures will be used to protect the confidentiality of your study records.

For confidentiality, your name, address, telephone number or email address will not be used in any of the recorded or written data from interviews or journals. This contact information will be kept in a single location, the study code book. This code book will be a paper notebook which will be locked in a secure cabinet in the researcher's office.

Computer files such as a spread sheet summarizing confidential data, or de-identified written records of interviews, will be securely stored on the researcher's computer. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords.

The researcher will keep all other digital recordings and transcriptions, or journal pages, in a separate locked cabinet in her office. These will only be labeled with individual codes for confidentiality. As described in the paragraph above, identifying information linking participants to their confidential code names will be kept in a code book, locked in a separate cabinet. The code book and digital recordings will be destroyed 6 years after the close of the study. The exception is that participants who sign an agreement specifying that their recordings may be used by the researcher, de-identified in public presentations, will not have those digital recordings destroyed.

At the conclusion of this study, the researcher may publish her findings. Information will be presented in summary format and you will not be identified in any publications or presentations. For example, the researcher may use phrases or words you provided in order to convey the direct meaning of participants' experiences. However, any phrases or words used *will not be used* with any other information that could allow you to be identified, such as the type of cancer a person has, or the age and sex of their caregiver.

At the end of this consent, you will be asked whether you might be willing to allow short segments of audio-recordings of your voice to be presented along with study findings. For

example, the researcher might play a few seconds of your voice to a group of hospice nurses so they can get a better sense for the meaning of the research findings than they would otherwise have from readings the findings alone. This permission is **OPTIONAL**. Voices can be recognized by others and this could affect your confidentiality. This is why, even though your name and other personal information will not be shared with the recording, we ask special permission to make small segments of the audio available.

The researcher would also like to archive recordings for possible use in future research studies. Such recordings would not be associated with your name, that of your family member, or nurse. This permission will be **OPTIONAL** for the reasons stated in the above paragraph. You will be able to choose whether or not to give this permission at the end of this document.

#### **9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THE STUDY?**

You will receive a \$30 (US dollars) gift card, of the credit-debit type, at termination of your participation in the study, regardless of how many interviews or journal entries you participate in, as an expression of gratitude and appreciation by the researcher.

#### **10. WHAT IF I HAVE QUESTIONS?**

Take as long as you like before you decide whether to participate. The researcher will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, Olga Ehrlich, RN, BSN, at (602) XXX-XXXX or oehrlich@nursing.umass.edu.

Also, you may contact the researcher's adviser at University of Massachusetts Amherst, College of Nursing at any time, without informing the researcher. The researcher's adviser is: Rachel Walker, RN, PhD, at r.walker@umass.edu, or (413) 545-0250.

If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.

#### **11. CAN I STOP BEING IN THE STUDY?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. Participation in this study will not affect the quality of care you receive from your hospice agency or any other health care providers.

#### **12. WHAT IF I AM INJURED?**

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subjects research, but the study personnel will assist you in getting treatment.



**13. SUBJECT STATEMENT OF VOLUNTARY CONSENT**

When signing this form I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.

**Audio Recording Permissions:**

\_\_\_\_\_ I agree that segments of the recordings made of my participation in this research may be used for conference presentations, as well as education and training of future researchers/practitioners.

\_\_\_\_\_ I do not agree to allow segments of recordings of my participation in this research to be used for conference presentations or education and training purposes.

\_\_\_\_\_ I agree to have my recordings archived for future research in the field of cancer pain management.

\_\_\_\_\_ I do not agree to have my recordings archived for future research in the field of cancer pain management.

**Follow-up Contact Permissions:**

\_\_\_\_\_ I agree that the research nurse may contact me for study follow-up after my participation has ended.

\_\_\_\_\_ I do not agree that the research nurse may contact me for study follow-up after my participation has ended.

By signing below I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

\_\_\_\_\_  
Participant Signature:

\_\_\_\_\_  
Print Name:

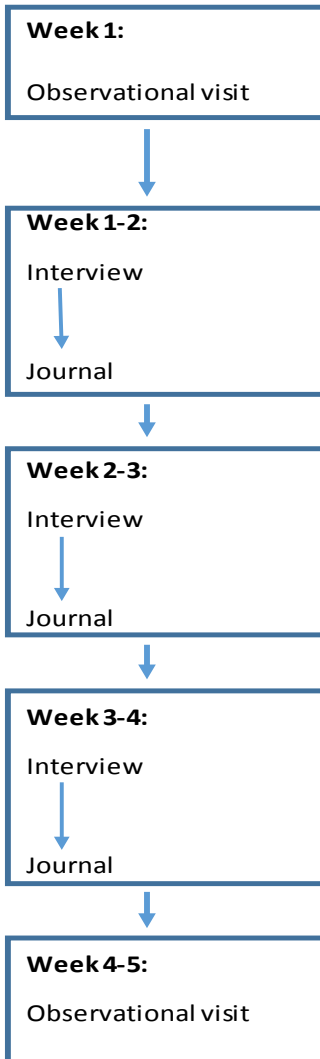
\_\_\_\_\_  
Date:

\_\_\_\_\_  
Signature of Person  
Obtaining Consent

\_\_\_\_\_  
Print Name:

\_\_\_\_\_  
Date:

### Study Participation Timeline



**Consent Form for Participation in a Research Study**  
University of Massachusetts Amherst  
*For Family Caregiver Participants*

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<b>Researcher(s):</b>	Olga Ehrlich, PhD Candidate, College of Nursing; Adviser and Dissertation Committee Chair, Rachel Walker, RN, PhD, College of Nursing
<b>Study Title:</b>	Hospice Caring Triad Social Processes Used to Manage Cancer Pain
<b>Funding Agency:</b>	UMass Amherst Graduate School, Sigma Theta Tau Beta Zeta Chapter, Oncology Nursing Foundation

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**1. WHAT IS THIS FORM?**

This form is called a **Consent Form**. It will give you information about the study so you can make an informed decision about participation in this research.

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and ask questions now and at any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records.

**2. WHO IS ELIGIBLE TO PARTICIPATE?**

If you are a family caregiver for a person with cancer receiving hospice care who has chosen to participate in the study, you may participate if you meet all of these eligibility criteria:

- You must be 18 years of age or older
- You must be identified by the hospice participant as an informal family caregiver
- You must provide care to or live with the hospice participant at least two days per week
- You must be able to have a meaningful conversation in the English language with the researcher

**3. WHAT IS THE PURPOSE OF THIS STUDY?**

The purpose of this research study is to understand how older persons with cancer on hospice care manage their pain together with their informal family caregivers and hospice nurses. In this study, the group of people being researched is called 'the hospice caring triad'. The triad is the person with cancer, the caregiver and the hospice nurse. Some people have difficulty controlling their pain. The researcher wants to identify which interactions the triad members engage in order to describe them and how those interactions affect good pain management. The researcher will use this information to create a theory to help nurses provide effective pain management to older persons with pain from cancer.

#### **4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?**

Study visits and interviews will take place in your home, unless you request to meet in a different location. The entire study may take over one year to complete, however your participation will likely be for 3-5 weeks but could take up to 3 months. You may wish to participate in all of the observational visits, interviews, and journaling opportunities, but at a pace that could extend for up to three months, if you prefer.

The study itself will consist of between two and five visits over the time period. At the first visit the researcher will observe a regular hospice nursing visit to your family member when you are present. Then the researcher will arrange a time to interview you. These interviews will occur up to three times, for about an hour each time. All interviews will be private; you will meet individually with the researcher. You may also use a notebook (provided by the study) or voice recorder to give information to the researcher in between interviews. Notebooks will be provided and become your property after the researcher copies the pages for data analysis. You may borrow a voice recorder from the researcher if you prefer audio-recorded journaling to written. If you choose this option, you will be offered transcribed journal entries to keep. The study will conclude with another observational visit at a regular hospice nursing visit. If you wish to provide information to the researcher after your official participation has concluded you will be given contact information in order to do so.

#### **5. WHAT WILL I BE ASKED TO DO?**

This study does not involve any treatment of pain or other symptoms. It involves you speaking to the researcher about your experiences caring for a family member with cancer.

If you agree to take part in this study, you will be asked to allow the researcher to observe two regular hospice nursing visits to your family member when you are present. The researcher will also want to interview you to talk about pain from cancer and your experiences helping your family member to manage that pain. The study is based on three interviews per person, but if you are only able to be interviewed once, you can still participate. The researcher will also ask you to spend time writing in a journal, or audio-recording thoughts and feelings you have about cancer pain between the

interviews. However, participants who only wish to be interviewed are not required to do journaling and audio-recording.

Interviews will be conducted privately, with only you and the researcher able to hear what is said. You will be asked to freely talk about your experience of your family member's cancer pain. The interviewer is interested in recording anything you want to say about this experience of cancer pain for your family member. You may skip any question you do not wish to reply to, or change the topic at any time. You can also stop the interview at any time. You can also ask the researcher to leave at any time during a hospice visit. You may request this for any reason, and no explanation is required.

You will also be asked to provide some demographic information such as your racial/ethnic identification, age, sex, religious affiliation, type of family caregiving relationship (e.g. adult child) amount of time spent caring for person with cancer, and whether you have had a previous hospice caregiving experience. This information will be collected in order to describe some aggregate characteristics of each group when the investigator shares findings of the study. All of this information, like the other information gathered during the study will remain strictly private and confidential to anyone except yourself and the investigator.

#### **6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?**

You may or may not benefit personally from participating in this study. The potential benefit to you is having the opportunity to share your story and experience with a person who cares deeply about understanding those. You may feel psychologically or emotionally better after sharing your story. However, some people will not feel any differently as a result of talking about or journaling about their experiences or stories.

The researcher hopes that your participation will benefit other older persons with cancer pain, their family caregivers, and hospice nurses in several ways. One way is that persons who read about your story and experience may feel re-assured to know that their similar experience happens for other people too, or could be expected. Another possible benefit is that hospice nurses who learn about the results of this study may be better prepared to help those older persons with cancer pain they are caring for. And lastly, this study is exploring the social processes that take place between the persons participating in the study, and will likely result in new information that hospice nurses and researchers can use to help with pain management.

#### **7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?**

The researcher believes there are no known risks associated with this research study; however, there could be inconvenience to you as a result of the time needed to participate. It is also possible that talking about your family member's cancer pain experience could cause sadness, anxiety, or other unexpected emotions. However,

should any unexpected unpleasant experiences arise, the researcher will assist in getting the help needed to resolve those.

Some people can sometimes feel uncomfortable discussing personal experiences involving others, such as their family members or people providing care, like nurses. For this reason, you can decline to answer any questions that make you uncomfortable. No explanation is required.

#### **8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?**

The following procedures will be used to protect the confidentiality of your study records.

For confidentiality, your name, address, telephone number or email address will not be used in any of the recorded or written data from interviews or journals. This contact information will be kept in a single location, the study code book. This code book will be a paper notebook which will be locked in a secure cabinet in the researcher's office.

Computer files such as a spread sheet summarizing confidential data, or de-identified written records of interviews, will be securely stored on the researcher's computer. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords.

The researcher will keep all other digital recordings and transcriptions, or journal pages, in a separate locked cabinet in her office. These will only be labeled with individual codes for confidentiality. As described in the paragraph above, identifying information linking participants to their confidential code names will be kept in a code book, locked in a separate cabinet. The code book and digital recordings will be destroyed 6 years after the close of the study. The exception is that participants who sign an agreement specifying that their recordings may be used by the researcher, de-identified in public presentations, will not have those digital recordings destroyed.

At the conclusion of this study, the researcher may publish her findings. Information will be presented in summary format and you will not be identified in any publications or presentations. For example, the researcher may use phrases or words you provided in order to convey the direct meaning of participants' experiences. However, any phrases or words used *will not be used* with any other information that could allow you to be identified, such as the type of cancer a person has, or the age and sex of their caregiver.

At the end of this consent, you will be asked whether you might be willing to allow short segments of audio-recordings of your voice to be presented along with study findings. For example, the researcher might play a few seconds of your voice to a group of hospice nurses so they can get a better sense for the meaning of the research findings than they

would otherwise have from readings the findings alone. This permission is OPTIONAL. Voices can be recognized by others and this could affect your confidentiality. This is why, even though your name and other personal information will not be shared with the recording, we ask special permission to make small segments of the audio available.

The researcher would also like to archive recordings for possible use in future research studies. Such recordings would not be associated with your name, that of your family member or nurse, your type of cancer, or your exact age, or other identifying information. This permission will be OPTIONAL for the reasons stated in the above paragraph. You will be able to choose whether or not to give this permission at the end of this document.

#### **9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THE STUDY?**

You will receive a \$30 (US dollars) gift card, of the credit-debit type, at termination of their participation in the study, regardless of how many interviews or journal entries you participate in, as an expression of gratitude and appreciation by the researcher.

#### **10. WHAT IF I HAVE QUESTIONS?**

Take as long as you like before you decide whether to participate. The researcher will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, Olga Ehrlich, RN, BSN, at (602) XXX-XXXX or oehrlich@nursing.umass.edu.

Also, you may contact the researcher's adviser at University of Massachusetts Amherst, College of Nursing at any time, without informing the researcher. The researcher's adviser is: Rachel Walker, RN, PhD, at r.walker@umass.edu, or (413) 545-0250.

If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.

#### **11. CAN I STOP BEING IN THE STUDY?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. Participation in this study should not affect the quality of care you receive from your hospice agency or any other health care providers.

#### **12. WHAT IF I AM INJURED?**

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subjects research, but the study personnel will assist you in getting treatment.



**13. SUBJECT STATEMENT OF VOLUNTARY CONSENT**

When signing this form I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.

**Audio Recording Permissions:**

\_\_\_\_\_ I agree that segments of the recordings made of my participation in this research may be used for conference presentations, as well as education and training of future researchers/practitioners.

\_\_\_\_\_ I do not agree to allow segments of recordings of my participation in this research to be used for conference presentations or education and training purposes.

\_\_\_\_\_ I agree to have my recordings archived for future research in the field of cancer pain management.

\_\_\_\_\_ I do not agree to have my recordings archived for future research in the field of cancer pain management.

**Follow-up Contact Permissions:**

\_\_\_\_\_ I agree that the research nurse may contact me for study follow-up after my participation has ended.

\_\_\_\_\_ I do not agree that the research nurse may contact me for study follow-up after my participation has ended.

\_\_\_\_\_  
Participant Signature:

\_\_\_\_\_  
Print Name:

\_\_\_\_\_  
Date:

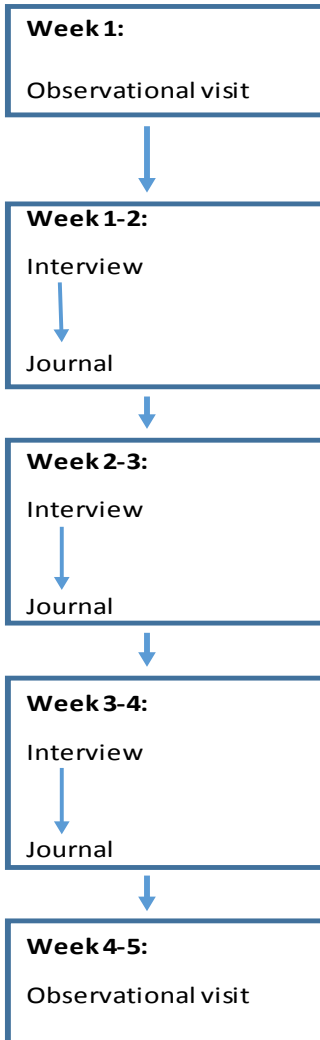
By signing below I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

\_\_\_\_\_  
Signature of Person  
Obtaining Consent

\_\_\_\_\_  
Print Name:

\_\_\_\_\_  
Date:

### Study Participation Timeline



**Consent Form for Participation in a Research Study**  
University of Massachusetts Amherst  
*For Hospice Nurse Caring Triad Participants*

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<b>Researcher(s):</b>	Olga Ehrlich, PhD Candidate, College of Nursing; Adviser and Dissertation Committee Chair, Rachel Walker, RN, PhD, College of Nursing
<b>Study Title:</b>	Hospice Caring Triad Social Processes Used to Manage Cancer Pain
<b>Funding Agency:</b>	UMass Amherst Graduate School, Sigma Theta Tau Beta Zeta Chapter, Oncology Nursing Foundation

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**1. WHAT IS THIS FORM?**

This form is called a **Consent Form**. It will give you information about the study so you can make an informed decision about participation in this research.

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and ask questions now and at any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records.

**2. WHO IS ELIGIBLE TO PARTICIPATE?**

Hospice nurses who wish to participate in the study as a member of the caring triad, to both recruit participants and provide data about their experiences may do so if they meet all of these eligibility criteria:

- They provide hospice nursing visits for Cooley Dickinson Hospice to patients who have cancer
- They have attended a study informational meeting for nurses
- They have read, understood, and signed this consent form
- They have worked as a hospice nurse at least two eight hour shifts per week for no less than the previous twelve months
- They are able to have a meaningful conversation in the English language with the researcher

### **3. WHAT IS THE PURPOSE OF THIS STUDY?**

The purpose of this research study is to understand how older persons with cancer on hospice care manage their pain together with their informal family caregivers and hospice nurses. In this study, the group of people being researched is called 'the hospice caring triad'. The triad is the person with cancer, the caregiver and the hospice nurse. Some people have difficulty controlling their pain. The researcher wants to identify which interactions the triad members engage in order to describe them and how those interactions affect good pain management. The researcher will use this information to create a theory to help nurses provide effective pain management to older persons with pain from cancer.

### **4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?**

If you are a hospice nurse participating as caring triad member, you will be observed by the researcher in the home of your participating patient two times, for approximately one hour each time. You will also be interviewed by the researcher in a private location of your choice, which could be your own home, the hospice offices, or another location you request. There will be three private interviews, lasting from 60 to 90 minutes each. Also, you will be offered the opportunity to complete written or audio-recorded journals between interviews. Lastly, you will be invited to provide information to the researcher at two nurse focus groups, early on and later in the study. These focus groups would last one to two hours each.

The entire study make take over one year to complete, however your participation will likely be for three-to-five weeks. You may wish to participate in all of the observational visits, interviews, and journaling opportunities, but at a pace that could extend for up to three months, if you prefer. Also, as a nurse caring triad participant, you can choose to participate in more than one caring triad. As such, your study participation would be prolonged by the amounts of time described above for each additional triad participation. There is no expectation that a nurse will participate in more than one triad.

### **5. WHAT WILL I BE ASKED TO DO?**

This study does not involve any treatment of pain or other symptoms. It involves you speaking to the researcher about your experiences.

If you agree to take part in this study, you will be asked to bring a packet with you when you visit a patient who has cancer. The packet will contain a written recruitment statement from the researcher which you will read aloud to the potential participant. It will also include a paper asking you to record whether or not the person would like to be

contacted by the researcher, the date, and for those who would like to be contacted, a section in which you will write their preferred contact information. You will return this packet to the hospice office contact person.

Once one of your patients has agreed to participate, you will be asked to allow the researcher to observe two of your regularly scheduled hospice nursing visits. The researcher will also want to interview you to talk about your patient's pain from cancer and your experiences managing that pain. The study is based on three interviews per person, but if you are only able to be interviewed once, you can still participate. The researcher will also ask you to spend time writing in a journal, or audio-recording thoughts and feelings you have about cancer pain and its management in the hospice context between the interviews. However, if you only wish to be interviewed, you are not required to do journaling, whether written or audio-recorded.

You will be asked to freely talk about your experience helping cancer patients and their family caregivers manage pain. The interviewer is interested in recording anything you want to say about these experiences of cancer pain. You may skip any question you do not wish to reply to, or change the topic at any time. You can also stop the interview at any time. You can also ask the researcher to leave at any time during a hospice visit. You may request this for any reason, and no explanation is required.

Besides the participation activities described above, you will be invited to participate in one or two focus groups with other nurses in the study to talk about your experiences of cancer pain management for members of the hospice caring triad. These will last for up to two hours, will be facilitated by the researcher or her dissertation study adviser (an experienced nurse researcher), and will be audio and/or video recorded with permission from all participants. While every effort will be made to maintain confidentiality, because of the recordings it is possible that you could be recognized by your voice or physical characteristics (even though names will not be used during the focus groups, and you will be asked to keep anything stated during them completely confidential) if you and others agreed be recorded.

You will also be asked to provide some demographic information such as your racial/ethnic identification, sex, age, religious affiliation, years of hospice nursing experience, if you have Hospice and Palliative Care Nurse Certification, and hospice experience with one of your own family members. This information may be used for describing some aggregate characteristics of each group when the investigator shares findings of the study. All of this information, like the other information gathered during the study will remain strictly private and confidential to anyone except yourself and the investigator.

## **6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?**

You may or may not benefit personally from participating in this study. The potential benefit to you is having the opportunity to share your story and experience with a person who cares deeply about understanding those. You may feel psychologically or emotionally better after sharing your story. However, some people will not feel any differently as a result talking about or journaling about their experiences or stories.

The investigator hopes that your participation will benefit other older persons with cancer pain, their family caregivers, and hospice nurses in several ways. One way is that nurses who read about these stories and experience may feel re-assured to know that their similar experiences happen for other nurses too, while providing care for older patients dying from cancer. Another possible benefit is that other nurses who learn about the results of this study may be better prepared to help those older persons with cancer pain they are caring for. And lastly, this study is exploring the social processes that take place between the persons participating in the study, and will likely result in new information that can be used in future pain management research and treatment guidelines development.

#### **7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?**

The researcher believes there are no known risks associated with this research study; however, there could be inconvenience to you as a result of the time needed to participate. It is also possible that talking about your experiences helping patients and family members manage cancer pain could cause sadness, anxiety, or other unexpected emotions. However, should any unexpected unpleasant experiences arise, the researcher will assist in getting the help needed to resolve those.

You can decline to answer any questions during interviews or focus group discussions that make you uncomfortable. No explanation is required.

#### **8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?**

The following procedures will be used to protect the confidentiality of your study records.

For confidentiality, your name, address, telephone number or email address will not be used in any of the recorded or written data from interviews, journals or focus groups. This contact information will be kept in a single location, the study code book. This code book will be a paper notebook which will be locked in a secure cabinet in the researcher's office.

Computer files such as a spread sheet summarizing confidential data, or de-identified written records of interviews, will be securely stored on the researcher's computer. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords.

The researcher will keep all other digital recordings and transcriptions, or journal pages, in a separate locked cabinet in her office. These will only be labeled with individual codes for confidentiality. As described in the paragraph above, identifying information linking participants to their confidential code names will be kept in a code book, locked in a separate cabinet. The code book and digital recordings will be destroyed 6 years after the close of the study. The exception is that participants who sign an agreement specifying that their recordings may be used by the researcher, de-identified in public presentations, will not have those digital recordings destroyed.

At the conclusion of this study, the researcher may publish her findings. Information will be presented in summary format and you will not be identified in any publications or presentations. For example, the researcher may use phrases or words you provided in order to convey the direct meaning of participants' experiences. However, any phrases or words used *will not be used* with any other information that could allow you to be identified, such as your age, type of education, nursing certifications, race or ethnic identity.

At the end of this consent, you will be asked whether you might be willing to allow short segments of audio-recordings of your voice or video recordings from the focus groups to be presented along with study findings. For example, the researcher might play a few seconds of your voice to a group of hospice nurses so they can get a better sense for the meaning of the research findings than they would otherwise have from readings the findings alone. This permission is **OPTIONAL**. Voices and physical characteristics can be recognized by others and this is why, even though your name and other personal information will not be shared with the recording, we ask special permission to make small segments of the audio available.

At the end of this form you will be asked to specify your choices about the archiving and use of either audio or video recordings in presentation of study findings.

#### **9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THE STUDY?**

All study participants will receive a \$30 (US dollars) gift card, of the credit-debit type, at termination of their participation in the study, regardless of how many interviews, journal entries, or focus groups you participate in, as an expression of gratitude and appreciation by the researcher.

#### **10. WHAT IF I HAVE QUESTIONS?**

Take as long as you like before you decide whether to participate. The researcher will be happy to answer any question you have about this study. If you have further questions

about this project or if you have a research-related problem, you may contact the researcher, Olga Ehrlich, RN, BSN, at (602) XXX-XXXX or oehrlich@nursing.umass.edu.

Also, you may contact the researcher's adviser at University of Massachusetts Amherst, College of Nursing at any time, without informing the researcher. The researcher's adviser is: Rachel Walker, RN, PhD, at r.walker@umass.edu, or (413) 545-0250.

If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.

### **11. CAN I STOP BEING IN THE STUDY?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. Participation in this study will not affect your job or case load.

### **12. WHAT IF I AM INJURED?**

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subjects research, but the study personnel will assist you in getting treatment.

### **13. SUBJECT STATEMENT OF VOLUNTARY CONSENT**

When signing this form I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.

#### **Audio Recording Permissions:**

\_\_\_\_\_ I agree that segments of the audio recordings made of my participation in this research may be used for conference presentations, as well as education and training of future researchers/practitioners.

\_\_\_\_\_ I do not agree to allow segments of audio recordings of my participation in this research to be used for conference presentations or education and training purposes.

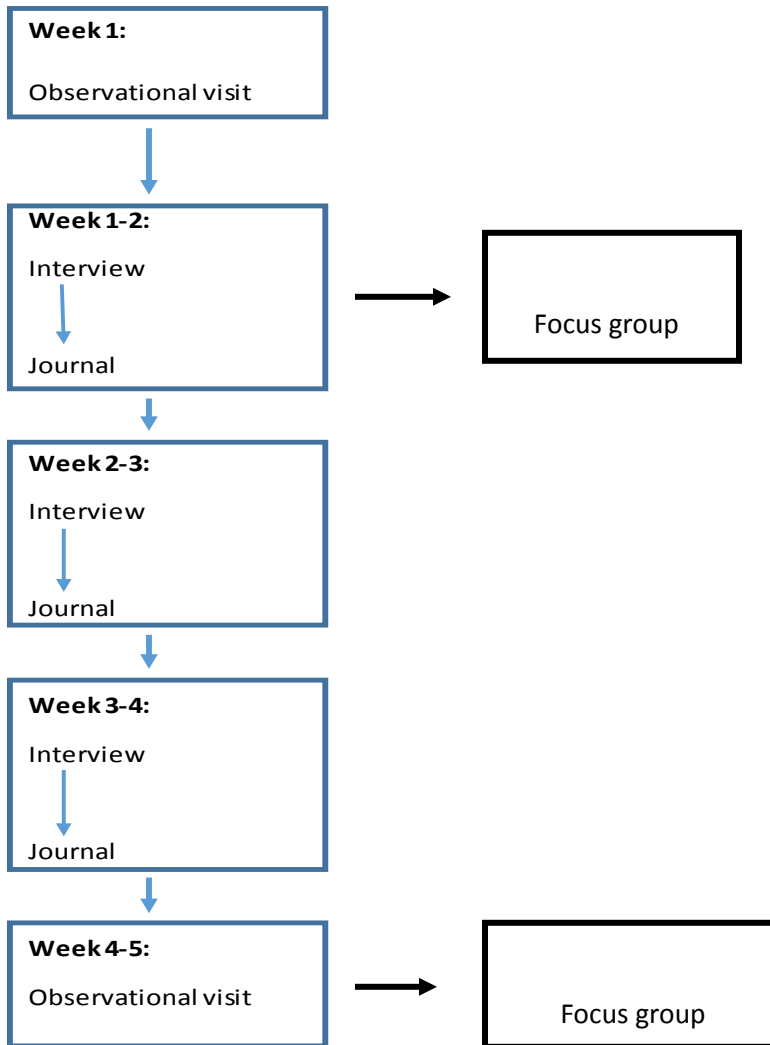
\_\_\_\_\_ I agree to have my audio recordings archived for future research in the field of cancer pain management.

\_\_\_\_\_ I do not agree to have my audio recordings archived for future research in the field of cancer pain management.





### Study Participation Timeline



## APPENDIX G

### STUDY LOGISTICS PLAN

#### Simple Weekly Logistics for Study

1. Each time a potential participant contact is made, log it into Potential Participants spreadsheet (in Dissertation Study subfolder of Dissertation folder)
2. For each informational visit with potential participant:
  - a) Bring three copies of IC form
  - b) Bring business cards and give to potential participant whether consented or not
  - c) Leave copy of unsigned IC form with each consented participant
  - d) For PP and FCs, remind them of upcoming observational visit and if possible, set date for interview number one for each PP and FC
3. Each time a new participant is consented:
  - a) Create and log the code name
  - b) Note the consent date on the Potential Participants spreadsheet
  - c) File the signed consent in the locked box
  - d) Enter the set observational visit and interview dates into the Study Demographic Spreadsheet  
(in Dissertation Study subfolder of Dissertation folder)
4. At the observational visits:
  - a) Confirm consent to observe and remind that note taking will occur
  - b) Confirm next appointment dates for interviews to follow prior to leaving home
5. After observational visits:
  - a) Enter notes into related coded PP file (either MSWord or NVivo)
  - b) Code observational visits initially with line-by-line gerund codes
  - c) Confirm observational visit and interview dates in the Study Demographic Spreadsheet
6. At the interview visit:
  - a) Confirm consent to interview and remind participant that they may end at any time without giving an explanation
  - b) Interview 1: begin with demographic questions
7. Once per week email or text participating RNs thanking them and asking what questions or concerns they have about how things are going.

## APPENDIX H

### SOCIAL PROCESSES FRAMEWORK ELEMENTS

#### Framework Definitions

<b>Domain:</b> Proximity	<i>Is a state of being between people, which includes degrees of physical and emotional distance, degree of communication, and presence or absence of agreement, as defined in the concept of Physical-Emotional Distance, The Loop, and The Page</i>
<b>Domain:</b> Controlling Cancer Pain	<i>Includes thoughts, feelings, and actions taken by people to manage cancer pain, as defined by the concepts Pain Goals (Severity-related and Functional-related), Pain Perception, and Efficacy</i>
<b>Concept:</b> Pain Perception	<i>A subjective determination of whether or not pain is discomforting</i>
<b>Concept:</b> Pain Goals	<i>Objectives used in deciding how and when to treat pain</i>
<b>Concept:</b> Efficacy	<i>Knowing what to do to reduce and control pain</i>
<b>Concept:</b> Physical-Emotional Distance	<i>An interpersonal state between people based upon how distant or close they are to one another, with three dimensions: -Inch: intimate closeness which is indicated by regular affectionate physical contact or speaking accurately of another's thoughts or feelings -Elbow Length: intermittent positive physical touch, or intermittent correct understanding of another's thoughts, communication is usually in person -Arm's Length: lack of physical or emotional closeness is demonstrated even if it is desired on the part of one or more people, frequent misunderstanding of the other person's feelings or thoughts, communication is over the phone or is infrequent and involves assumptions about others</i>
<b>Concept:</b> The Loop	<i>Refers to the degree of communication between persons and is described with dichotomous dimensions: -In-the-Loop: indicates that all triad members are talking about or actively engaged in other forms of communication -Out-of-the-Loop: indicates that active communication is not occurring across triad members</i>
<b>Concept:</b> The Page	<i>Refers to agreement between persons and has dichotomous dimensions: -On-the-Same-Page: Triad members agree -On-Different-Pages: There is disagreement within the triad</i>

**Proximity and Controlling Cancer Pain Triadic Comparison**

TRIAD ONE		TRIAD TWO		TRIAD THREE	
'Arm's Length'		'Elbow Length'	'Arm's Length'	'Inch'	
'In-the-loop' -Efficacy	'Out-of-the-loop' -Pain severity rating  -Functional goals  -Pain perception	'In-the-loop' -Efficacy  -Pain severity rating	'Out-of-the-loop'  -Functional goals  -Pain perception	'In-the-loop' -Efficacy  -Pain severity rating  -Pain perception	'Out-of-the-loop'  -Functional goals
'On-the-same page'	'On-different-pages' -Pain severity rating  --Functional goals  -Pain perception	'On-the-same page'  -Functional goals	'On-different-pages' -Pain severity rating  -Pain perception	'On-the-same page'  -Functional goals  -Pain perception	'On-different-pages'

## APPENDIX I

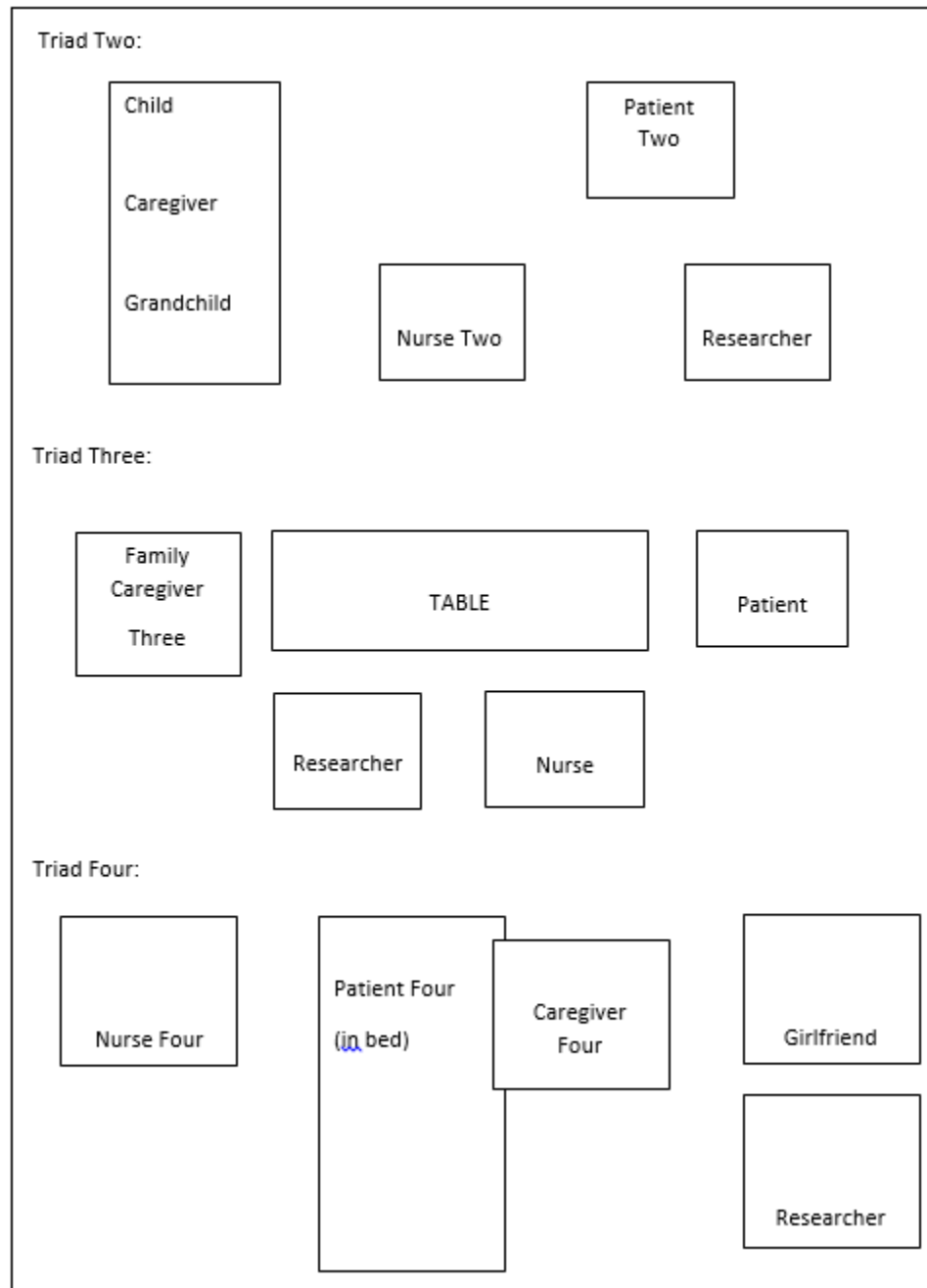
### METHODOLOGICAL DOCUMENTS

#### Examples of Codes

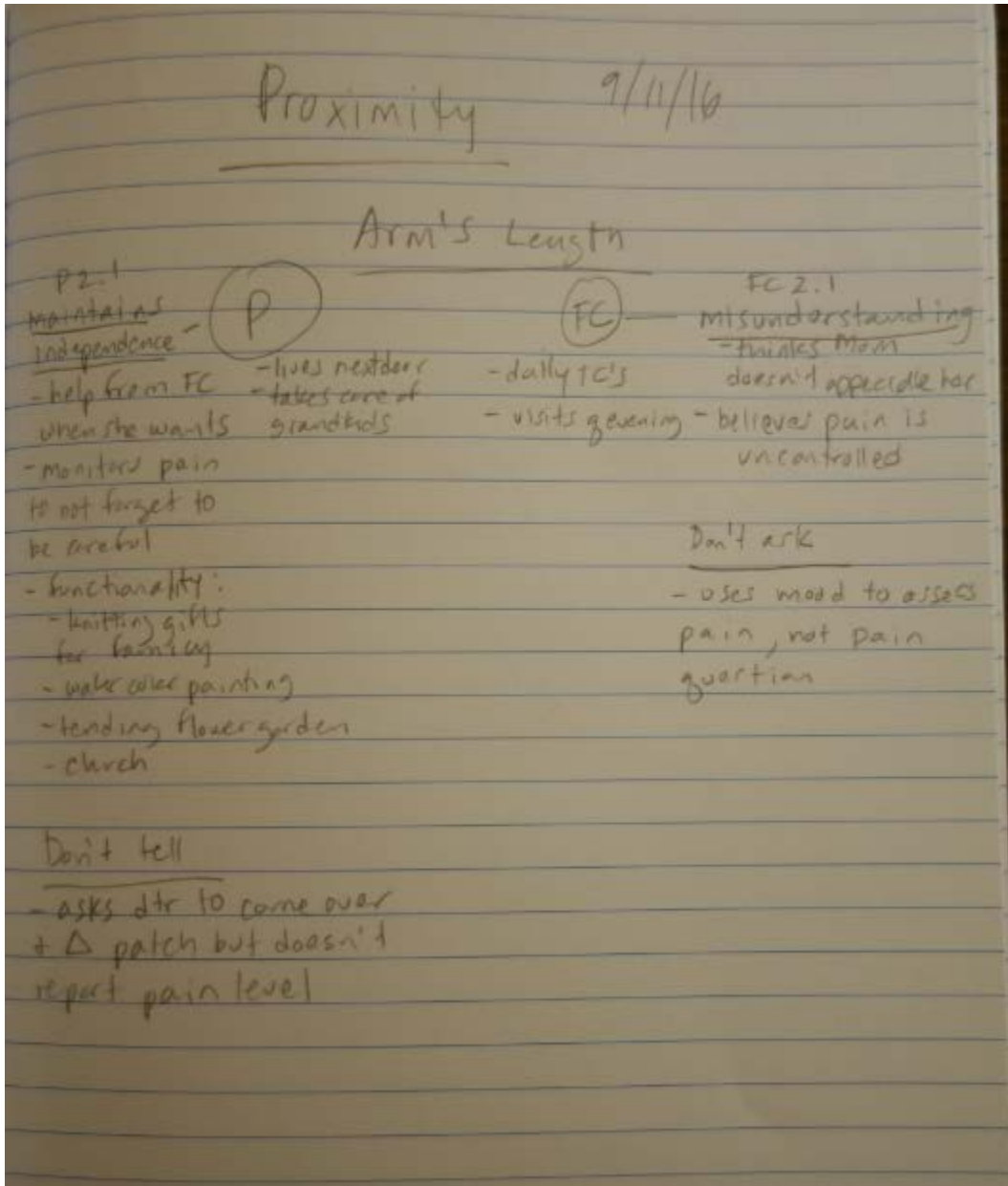
Triad	T 2, T 3, T 4
Triad Member	-RN 2, RN 3, RN 4  -P 2, P 3, P 4  -FC 2, FC 3, FC 4
Visit Type	OV, INT, FG
NIMH Lens (perception of self or other)	-PPOS, PPOO -FCPOS, FCPOO RNPOS, RNPOO
Line-by-line Gerund Codes	-Being there for mother since the beginning -Disagreeing with mother's pain management choices -Feeling out of control because of cancer -Assigning pain hierarchies -Giving away responsibility -Being doped up -Losing strength
Concepts	-Pain severity goal -Functional pain goal -"My dilemma" -Efficacy -Pain perception

## Drawing of Physical Proximity at Visits from Field Notes

*Triad members physical proximity at observational visit one*

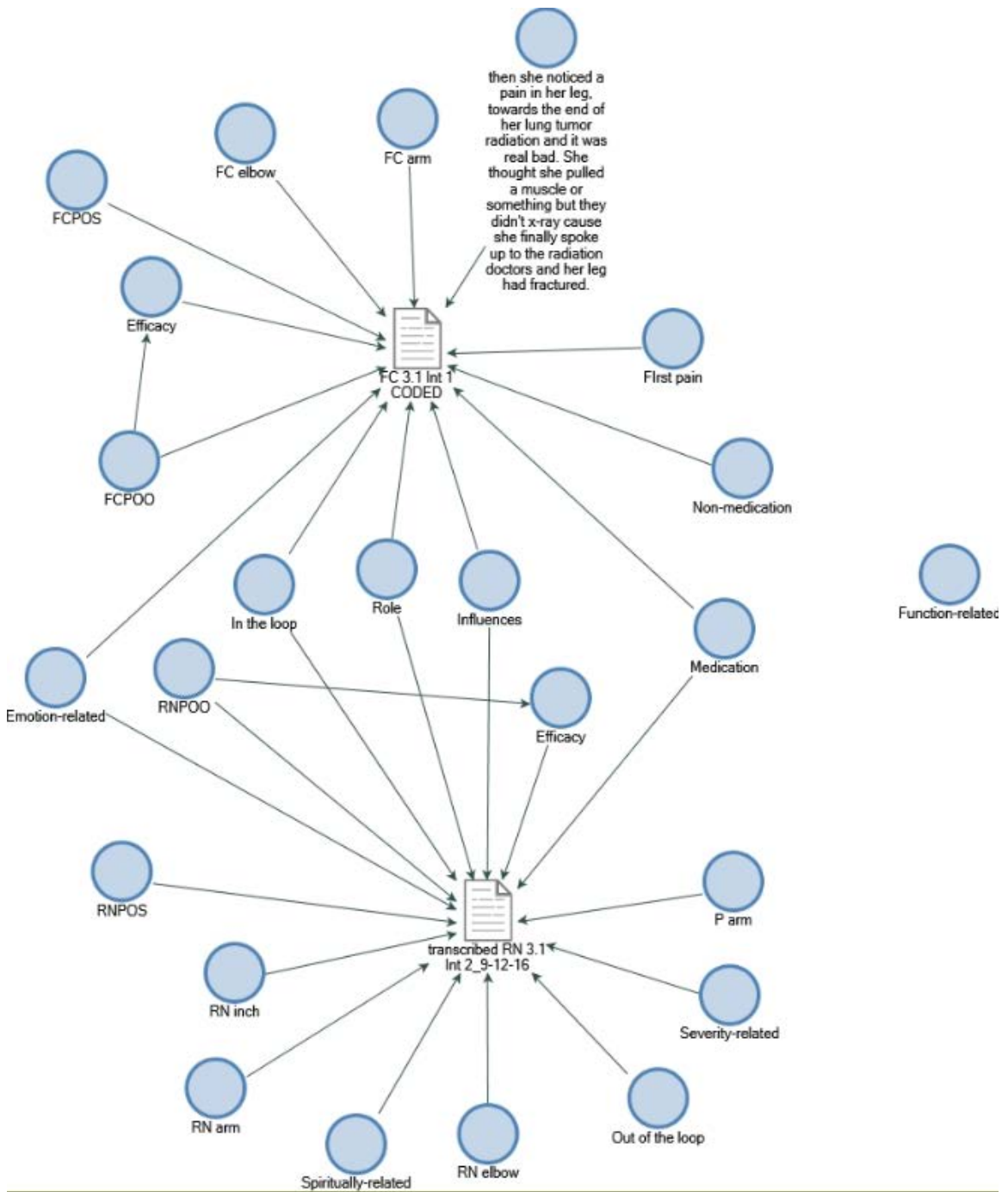


Early Proximity Memo

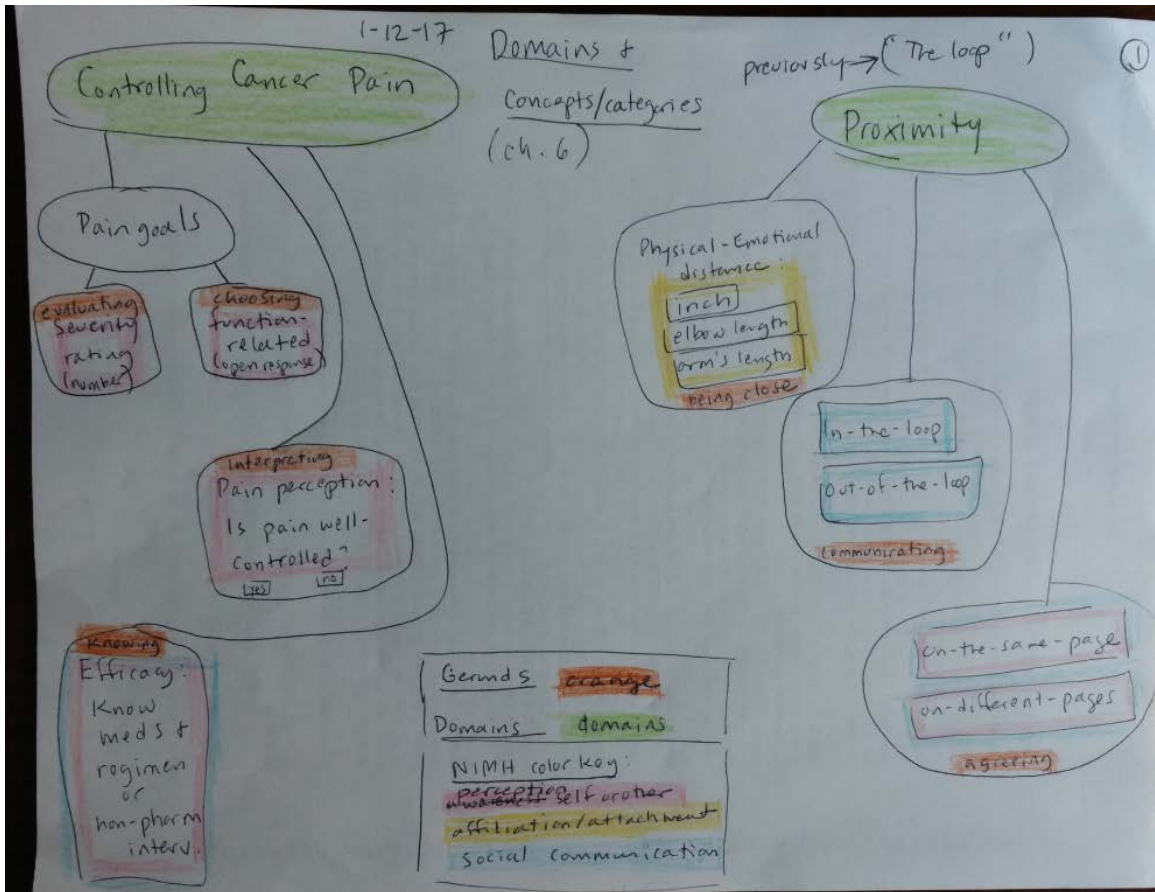




**Sample of Early Coding Chart from NVIVO**



## Concept Map for Framework Domains



## BIBLIOGRAPHY

- Ahmedzai, S. (1997). Pain control in patients with cancer. *European Journal of Cancer*, 33(4), 65-72.
- American Pain Society. (2011). Press room. Retrieved from:  
[http://www.ampainsoc.org/press/2011/pain\\_committee.htm](http://www.ampainsoc.org/press/2011/pain_committee.htm)
- American Society for Pain Management Nursing. (n.d.). Retrieved from:  
[http://www.aspmn.org/organization/documents/UPDATED\\_NonverbalRevisionFinalWEB.pdf](http://www.aspmn.org/organization/documents/UPDATED_NonverbalRevisionFinalWEB.pdf)
- American Society of Clinical Oncology (2016). Management of chronic pain in survivors of adult cancers. Retrieved from:  
<https://pilotguidelines.atlassian.net/wiki/display/ChronicPain/Chronic+Pain+Home#space-menu-link-content>
- Arraras, J., Wright, S., Jusue, G., Tejedor, M., & Calvo, J. (2002). Coping style, locus of control, psychological distress and pain-related behaviors in cancer and other diseases. *Psychology, Health and Medicine*, 7(2), 181-187.
- ASCO Post. (2017). ASCO clinical practice guideline update: Integration of palliative care into standard oncology care. Retrieved from:  
[http://www.ascopost.com/News/45258?utm\\_medium=Email&utm\\_source=ExactTarget&utm\\_campaign=&utm\\_term=6233858](http://www.ascopost.com/News/45258?utm_medium=Email&utm_source=ExactTarget&utm_campaign=&utm_term=6233858)
- Barkwell, D. P. (1991). Ascribed meaning: A critical factor in coping and pain attenuation in patients with cancer-related pain. *Journal of Palliative Care*, 3, 5-14.
- Barkwell, D. (2005). Cancer pain: Voices of the Ojibway people. *Journal of Pain and Symptom Management*, 30(5), 454-464.
- Beck, S. L., Towsley, G. L., Berry, P. H., Lindau, K., Field, R. B., & Jensen, S. (2010). Core aspects of satisfaction with pain management: Cancer patients' perspectives. *Journal of Pain and Symptom Management*, 39(1), 100-115.
- Bender, J., Hohenadel, J., Wong, J., et al. (2008). What patients with cancer want to know about pain: A qualitative study. *Journal of Pain and Symptom Management*, 35(2), 177-187.
- Berry, P. E., & Ward, S. E. (1995). Barriers to pain management in hospice: A study of family caregivers. *Hospice Journal*, 10(4), 19-33.

- Bostrom, B., Sandh, M., Lundberg, D., & Fridlund, B. (2004). Cancer patients' experiences of care related to pain management before and after palliative care referral. *European Journal of Cancer Care*, 13, 238-245.
- Brant, J. M., Beck, S., & Miaskowski, C. (2009). Building dynamic models and theories to advance the science of symptom management research. *Journal of Advanced Nursing*, 66(1), 228-240.
- Byma, B. A., Given, B. A., Given, G. W., & You, M. (2009). The effects of mastery on pain and fatigue resolution. *Oncology Nursing Forum*, 35(5), 544-551.
- Burruss, N., & Popkess, A. (2012). The diverse learning needs of students. In D. M. Billings & J. A. Halstead, (Eds.), *Teaching in nursing: A guide for faculty*. St. Louis, MO: Elsevier Saunders.
- Campbell, E. L. (2016). A team approach to recruitment in hospice research: Engaging patients, close people and health professionals. *International Journal of Hospice Nursing*, 22(7), 324-332.
- Caraceni, A., Davies, A., Polain, P., Cortes-Funes, H., Panchal, S. J., & Fanelli, G. (2013). Guidelines for the management of breakthrough pain in patients with cancer. *Journal of the National Comprehensive Cancer Network*, 11, S29-S36.
- Cassarett, D., Kassner, C. T., & Kutner, J. S. (2004). Recruiting for research in hospice: Feasibility of a research screening protocol. *Journal of Palliative Medicine*, 7(6), 854-860.
- Cassell, E. J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, 306(11), 639-645.
- Cepeda, M., Chapman, C., Miranda, N., et al. (1999). Emotional disclosure through patient narrative may improve pain and well-being: Results of a randomized controlled trial in patients with cancer pain. *Journal of Pain and Symptom Management*, 35(6), 623-631.
- Chen, M. (1999). Validation of the structure of the perceived meanings of cancer pain inventory. *Journal of Advanced Nursing*, 30(2), 344-351.
- Charmaz, K. (2010). *Constructing grounded theory: A practical guide through qualitative analysis*. London: SAGE Publications.
- Charmaz, K. (July 22-23, 2013). *Introduction to constructivist grounded theory*. Lecture Notes. Research Talk. University of Chapel Hill, NC.

- Clark, D. (1999). 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Social Science & Medicine*, 49, 727-736.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research, 3e: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage Publications.
- Coyle, N. (2004). In their own words: Seven advanced cancer patients describe their experience with pain and the use of opioid drugs. *Journal of Pain and Symptom Management*, 27(4), 300-309.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: SAGE Publications.
- Dawson, R., Sellers, D. E., & Spross, J. A. (2005). Do patients' beliefs act as barriers to effective management behaviors and outcomes in patients with cancer-related or non-cancer-related pain? *Oncology Nursing Forum*, 32(2), 363-374.
- DiCenso, A., Ciliska, D., & Guyatt, G. (2005). Introduction to evidence-based nursing. In DiCenso, A., Guyatt, G., & Ciliska, D. (Eds.) *Evidence-based nursing: A guide to clinical practice*, (pp. 3-19). St. Louis, MO: Mosby, Inc.
- Dodd, M. J., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., Lee, K., ... Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing* 33(5), 668-676.
- Dodd, M. J., Miaskowski, C., & Paul, S. M. (2001). Symptom clusters and their effect on The functional status of patients with cancer. *Oncology Nursing Forum*, 28, 465-470.
- Duggleby, W. (2002). The language of pain at the end of life. *Pain Management Nursing*, 3(4), 154-169.
- Ehrlich, O. (April, 2014). A hybrid concept analysis of pain control. Podium paper, Sigma Theta Tau Beta Zeta at-Large Chapter Scholarship Day, Holyoke, Massachusetts.
- Ehrlich, O., & Walker, R. K. (2016). Pain and social processes for hospice cancer patients. *European Journal of Oncology Nursing*, 83-89.  
DOI: 10.1016/j.ejon.2016.10.001.
- Ellington, L., Reblin, M., Clayton, M., Berry, P., & Mooney, K. (2012). Hospice nurse communication with patients with cancer and their family caregivers. *Journal of Palliative Medicine*, 15(3), 262-268.

- European Oncology Nursing Society. (2013). Breakthrough cancer pain guidelines. Retrieved from: <http://www.cancernurse.eu/documents/EONSBreakthroughCancerPainGuidelines.pdf>
- Fawcett, J. (2007). The metaparadigm of nursing: Present status and future refinements. *Journal of Nursing Scholarship, 16*(3), 84-87.
- Ferrell, B. (2000). The cost of comfort: Economics of pain management in oncology. *ONE, 1*(9), 56-61.
- Ferrell, B. (2004). Palliative care: An essential aspect of quality cancer care. *Surgical Oncology Clinics of North America, 13*, 401-411.
- Ferrell, B. R., & Coyle, N. (2008). The nature of suffering and goals of nursing. *Oncology Nursing Forum, 35*, 241-247.
- Ferrell, B., Ferrell, B., Ahn, C., & Tran, E. (1994). Pain management for elderly patients with cancer at home. *CANCER Supplement, 74*(7), 2139-2146.
- Ferrell, B., Grant, M., Chan, J., Ahn, C., & Ferrell, B. (1995). The impact of cancer pain education on family caregivers of elderly patients. *Oncology Nursing Forum, 8*, 1211-1218.
- Ferrell, B. R., Taylor, E. J., Sattler, G. R., Fowler, M., & Cheyney, B. L. (1993). Searching for the meaning of pain: Cancer patients', caregivers' and nurses' perspectives. *Cancer Practice, 1*(3), 185-194.
- Fine, P. G. (2012). *The hospice companion: Best practices for interdisciplinary assessment and care of common problems during the last phase of life*. New York, NY: Oxford University Press.
- Fine, P., Herr, K., Titler, M., Sanders, S., Cavanaugh, J., Swegle, J., Forcucci, C., ... Reyes, J. (2010). The Cancer Pain Practice Index: A measure of evidence-based practice adherence for cancer pain management for adults in hospice care. *Journal of Pain and Symptom Management, 39*(5), 791-802.
- Fink, R. M., & Gates, R. A. (2010). Pain assessment. In B. R. Ferrell & N. Coyle (Eds.), *Oxford textbook of palliative nursing*. New York, NY: Oxford University Press, Inc.
- Fishman, S. M., Young, H. M., Arwood, E. L., Chou, R., Herr, K., Murinson, B. B., Watt-Watson, J., ... Strassels, S. A. (2013). Core competencies for pain management: Results of an interprofessional consensus summit. *Pain Medicine, 1*-11.

- Flemming, K. (2010). The use of morphine to treat cancer-related pain: A synthesis of quantitative and qualitative research. *Journal of Pain and Symptom Management*, 39(1), 139-154.
- Foley, K. M. (1985). The treatment of cancer pain. *New England Journal of Medicine*, 313(2), 84-95.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Groenewald, T. (2008). Memos and Memoing. In Given, L. M. (Ed) 2008. *The SAGE encyclopedia of qualitative research methods* (pp. 505-506). Los Angeles, Thousand Oaks, CA: SAGE Publications.
- Gunnarsdottir, S., Donovan, H. S., & Ward, S. (2003). Interventions to overcome clinician- and patient-related barriers to pain management. *Nursing Clinics of North America*, 38(3), 419-434.
- Hanks, G. W., de Conno, F., Cherny, M., Hanna, N., Kalso, E., McQuay, H. J., ... Ventafridda, V. (2001). Morphine and alternative opioids in cancer pain: The EAPV recommendations. *British Journal of Cancer*, 84(5), 587-593.
- Hanson, L. C., Bull, J., Wessell, K., Massie, L., Aziz, N. M., & Abernethy, A. (2014). Strategies to support recruitment of patients with life-limiting illness for research: The palliative care research cooperative group. *Journal of Pain and Symptom Management*, 48(6), 1021-1029.
- Hauser, J. M., & Kramer, B. J. (2004). Family caregivers in palliative care. *Clinical Geriatric Medicine*, 20, 671-688.
- Herr, K., Titler, M., Fine, P., Sanders, S., Cavanaugh, J., Swegle, J. ... Xiongwen, T. (2010). Assessing and treating pain in hospices: Current state of evidence-based practices. *Journal of Pain and Symptom Management*, 39(5), 803-819.
- Hjermstad, M. J., Fainsinger, R., & Kaasa, S. (2009). Assessment and classification of cancer pain. *Current Opinion in Supportive and Palliative Care*, 3(1), 24-30.
- Hospice and Palliative Nurses Association. (2015). 2015-2018 Research agenda.
- Institute of Medicine. (2011). *Relieving pain in America: A blueprint for transforming prevention, care, education, and research*. Washington, DC: The National Academies Press.

- Institute of Medicine. (2014). Dying in America: Improving quality and honoring individual preferences near the end of life: Key findings and recommendations. Retrieved from: <http://iom.nationalacademies.org/~media/Files/Report%20Files/2014/EOL/Key%20Findings%20and%20Recommendations.pdf>
- Interagency Pain Research Coordinating Committee (IPRCC). (2016). National pain strategy: A comprehensive population health-level strategy for pain. Retrieved from: [https://iprcc.nih.gov/National\\_Pain\\_Strategy/NPS\\_Main.htm](https://iprcc.nih.gov/National_Pain_Strategy/NPS_Main.htm)
- International Association for the Study of Pain. (2014). IASP taxonomy. Retrieved from: <http://www.iasp-pain.org/Taxonomy?navItemNumber=576>
- Jensen, M. P., & Karoly, P. (1992). Self-report scales and procedures for assessing pain in adults. In D. C. Turk, & R. Melzack (Eds.), *Handbook of pain assessment*. New York, NY: Guilford Press.
- Jerant, A., Franks, P., & Kravitz, R. L. (2011). Associations between pain control self-efficacy, self-efficacy for communicating with physicians, and subsequent pain severity among cancer patients. *Patient Education and Counseling*, 85, 275-280.
- Jho, H. J., Myung, S. K., Chang, Y. J., Kim, D. H., Ko, D. H. (2013). Efficacy of pain education in cancer patients: A meta-analysis of randomized controlled trials. *Supportive Care Cancer*, 21(7), 1963-1971.
- Kaasa, S., Apolone, G., Klepstad, P., Loge, J. H., Hjermstad, M. J., Corli, O., . . . Caraceni, A. (2011). Expert conference on cancer pain assessment and classification—the need for international consensus: working proposals on international standards. *BMJ Supportive & Palliative Care*, 1, 281-287.
- Kelley, M., Demiris, G., Nguyen, H., Oliver D. P., & Wittenberg-Lyles, E. (2013). Informal hospice caregiver pain management concerns: A qualitative study. *Palliative Medicine*, 27(7), 673-682.
- Kelly, L., Bender, L., Harris, P., & Casarett, D. The “comfortable dying” measure: How patient characteristics affect hospice pain management quality scores. *Journal of Palliative Medicine*, 17(6), 721-724.
- Larsson, A., & Wijke, H. (2007). Patient experiences of pain and pain management at the end of life: A pilot study. *Pain Management Nursing*, 8(1), 12-16.
- Lau, D. T., Berman, R., Halpern, L., Pickard, A. S., Schrauf, R., & Witt, W. (2010). Exploring factors that influence informal caregiving on medication management for home hospice patients. *Journal of Palliative Medicine*, 13(9), 1085-1090.



- Lau, D. T., Joyce, B., Clayman, M. L., Dy, S., Ehrlich-Jones, L., Emanuel, L. ... Shega, J. W. (2012). Hospice providers' key approaches to support informal caregivers in managing medications for patients in private residences. *Journal of Pain and Symptom Management*, 46(3), 1060-1071.
- Lenz, E. R., & Pugh, L. C. (2008). Theory of unpleasant symptoms. In Smith, M. J. & Liehr, P. R. (Eds.), *Middle Range Theory for Nursing* (pp. 159-182). New York: Springer Publishing Company.
- Lewis, F. M. (1982). Experienced personal control and quality of life in late-stage cancer patients. *Nursing Research*, 31(2), 113-119.
- Ling, C., Lui, Y., & So, K. (2012). Do educational interventions improve cancer patients' quality of life and reduce pain intensity? Quantitative systematic review. *Journal of Advanced Nursing*, 68(3), 511-520.
- Lobchuk, M., & Vorauer, J. (2003). Family caregiver perspective-taking and accuracy in estimating cancer patient symptom experiences. *Social Science and Medicine*, 57, 2379-2384.
- Lovell, L. R., Lockett, T., Boyle, F. M., Phillips, J., Agar, M., & Davidson, P. M. (2014). Patient education, coaching, and self-management for cancer pain. *Journal of Clinical Oncology*, 32(16), 1712-1721.
- Mackey, M. C. (2012). Evaluation of qualitative research. In Munhall, P. L. (Ed.), *Nursing research: A qualitative perspective*, 5<sup>th</sup> ed. (pp. 517-531). Sudbury, MA: Bartlett & Jones Learning.
- Mackin, L. M., Herr, K., Bergen-Jackson, K., Fine, P., Forcucci, C., & Sanders, S. (2009). Research participation by older adults at the end of life: Barriers and solutions. *Research in Gerontological Nursing*, 2(3), 162-171.
- McCaffery, M. (1968). *Nursing practice theories related to cognition, bodily pain, and man-environment interactions*. Los Angeles: UCLA Students Store.
- McCaffery, M., Herr, K., & Pasero, C. (2011). Section II: Assessment. In C. Pasero & M. McCaffery (Eds.), *Pain assessment and pharmacologic management*. St. Louis: Mosby, Inc.
- McCosker, H., Barnard, A., & Gerber, R. (2001). Undertaking sensitive research: Issues strategies for meeting the safety needs of all participants. *Forum: Qualitative Research*, 2(1), Art 22. Retrieved from: <http://www.qualitative-research.net/index.php/fqs/article/viewArticle/983/2142>

- McDonald, D. D., Shea, M., & Rose, L. (2009). The effect of pain question phrasing on older adult pain information. *Journal of Pain and Symptom Management*, 37(6), 1050-1060.
- medpac. (2016). A data book: Healthcare spending and the Medicare program. Retrieved from: <http://www.medpac.gov/docs/default-source/data-book/june-2016-data-book-health-care-spending-and-the-medicare-program.pdf?sfvrsn=0>
- Middleton-Green, L. (2008). Managing total pain at the end of life: A case study analysis. *Nursing Standard*, 23(6), 41-46.
- Miles, M. B., Huberman, M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook*. Thousand Oaks, CA: SAGE Publications, Inc.
- Minson, F. P., Assis, F. D., Vanetti, T. K., Sarda Jr, J., Mateas, W. P., & Del Giglio, A. (2012). Interventional procedures for cancer pain management. *Einstein*, 10(3), 292-295.
- Moayedi, M., & Davis, K. D. (2012). Theories of pain: From specificity to gate control. *Journal of Neurophysiology*, 109, 5-12.
- Monin J., & Bohulz, R. (2009). Interpersonal effects of suffering in older adult caregiving relationships. *Psychology and Aging*, 24(3), 681-695.
- Munhall, P. L. (2012). *Nursing research: A qualitative perspective*, 5<sup>th</sup> ed. Sudbury, MA: Jones & Bartlett Learning.
- National Hospice and Palliative Care Organization. (2014). NHPCO's Facts and figures: Hospice care in America. Retrieved from: [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2014\\_Facts\\_Figures.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf)
- National Hospice and Palliative Care Organization. (2016). Hospice. Retrieved from: <http://www.nhpco.org/about/hospice-care>
- National Hospice and Palliative Care Organization. (2016). *Ethical principles: Guidelines for hospice and palliative care clinical and organizational conduct*.
- National Cancer Institute. (2014). Pain (PDQ®). Retrieved from: <http://www.cancer.gov/cancertopics/pdq/supportivecare/pain/HealthProfessional/page1#Reference1.2>

- National Institute of Mental Health. (2012). Social processes: Workshop proceedings. Retrieved from: <http://www.nimh.nih.gov/research-priorities/rdoc/social-processes-workshop-proceedings.shtml>
- National Institute of Nursing Research. Spotlight on end-of-life and palliative care research. (October 26, 2016). Retrieved from: <https://www.ninr.nih.gov/researchandfunding/spotlight-on-end-of-life-research#.WBPY6iOrKwU>
- Nay, R., & Fetherstonhaugh, D. (2012). What is pain? A phenomenological approach to understanding. *International Journal of Older People Nursing*, 7, 233-239.
- Paice, J. A. (2010). Pain at the end of life. In B. R. Ferrell & N. Coyle (Eds.), *Oxford textbook of palliative nursing*. New York, NY: Oxford University Press, Inc.
- Pasero, C. & McCaffery, M. (2011). *Pain assessment and pharmacologic management*. St. Louis, MO: Mosby, Inc.
- PCORI. (2014). About us. Retrieved from: <http://www.pcori.org/about-us>
- Redinbaugh, E., Baum, A., DeMoss, C., Fello, M., & Arnold, R. (2002). Factors associated with the accuracy of family caregiver estimates of patient pain. *Journal of Pain and Symptom Management*, 23(1), 31-38.
- Registered Nurses Association of Ontario. (2007). Assessment & management of pain. Retrieved from: <http://www.guideline.gov/content.aspx?id=11507&search=assessment+and+management+of+pain>
- Registered Nurses Association of Ontario. (2013). Assessment and management of pain, 3<sup>rd</sup> ed. Retrieved from: <http://rnao.ca/bpg/guidelines/assessment-and-management-pain>.
- Richards, M. R., & Schwartz, L. J. (2002). Ethics of qualitative research: Are there special issues for health services research? *Family Practice*, 19, 135-139.
- Roy, C. L. (1994). Developing nursing knowledge: Practice issues raised from four philosophical perspectives. *Nursing Science Quarterly*, 8(2), 79-85
- Rustoen, T., Torbjorn, M., Padilla, G., Paul, S., & Miaskowski, C. (2005). Predictors of quality of life in oncology outpatients with pain from bone metastasis. *Journal of Pain and Symptom Management*, 30, 234- 242.

- Sandelowski, M., & Leeman, J. (2012). Writing usable qualitative health research findings. *Qualitative Health Research, 22*(10), 1404-1413.
- Sanders, S., Herr, K., Fine, P. G., Fiala, C., Tang, X., & Forcucci, C. (2013). An examination of adherence to pain medication plans in older cancer patients in hospice care. *Journal of Pain and Symptom Management, 45*(1), 43-55.
- Saunders, C. M. (1978). *The management of terminal malignant disease*. London: Edward Arnold.
- Sheehan, D. K. (2010). Recruiting for end of life research: Lessons learned in family research. *Nursing Clinics of North America, 45*, 441-448.
- Society for Women's Health Research-FDA Office of Women's Health. (2011). Dialogues on diversifying clinical trials: Successful strategies for engaging women and minorities in clinical trials. Retrieved from: <http://www.fda.gov/downloads/ScienceResearch/SpecialTopics/WomensHealthResearch/UCM334959.pdf>.
- Stone, P. C., Gwilliam, B., Keeley, V., Todd, C., Kelly, L. C., & Barclay, S. (2013). Factors affecting recruitment to an observational multicentre palliative care study. *BMJ Supportive and Palliative Care, 3*, 318-323. doi:10.1136/bmjspcare-2012-000396
- Strassels, S. A., Blough, D. K., Hazlet, T. K., Veenstra, D. L., & Sullivan, S. D. (2006). Pain, demographics, and clinical characteristics in persons who received hospice care in the United States. *Journal of Pain and Symptom Management, 32*(6), 519-531.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia, PA: Wolters Kluwer Health.
- Twycross, R. G., Harcourt, J., & Bergl, S. (1996). A survey of pain in patients with advanced cancer. *Journal of Pain and Symptom Management, 12*, 273-282.
- Vallerand, A. H. & Ferrell, B. R. (1995). Issues of control in patients with cancer pain. *Western Journal of Nursing, 17*(5), 467-483.
- Vallerand, A., Saunders, M., & Anthony, M. (2007). Perceptions of control over pain by patients with cancer and their caregivers. *Pain Management Nursing, 8*(2), 55-63.

- van den Beuken-van Everdingen, M. H., de Rijke, J. M., Kessels, A. G., Schouten, H. C., van Kleef, M., & Ptijn, J. (2007). Prevalence of pain in patients with cancer: A systematic review of the past 40 years. *Annals of Oncology*, *18*(9), 1437-1449.
- van den Beuken-van Everdingen, M. H., Hochstenbach, L. M., Joosten, E. A., Tjan-Heijnen, V. C., & Janssen, D. J. (2006). Update on prevalence of pain in patients with cancer: Systematic review and meta-analysis. *Journal of Pain and Symptom Management*, *51*(6), 1070-1090.e9.
- Ware, L., Epps, D. F., Herr, K., et al. (2006). Evaluation of the revised faces pain scale, verbal descriptor scale, numeric rating scale, and Iowa pain thermometer in older minority adults. *Pain Management Nursing*, *7*(3), 117-125.
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546-553.
- WHO. (2015). Definition of an older or elderly person. Retrieved from: <http://www.who.int/healthinfo/survey/ageingdefnolder/en/>.
- WHO. (2017). WHO's cancer pain ladder for adults. Retrieved from: <http://www.who.int/cancer/palliative/painladder/en/>.
- Wiffen, P. J., Wee, B., & Moore, R. A. (2016). Oral morphine for cancer pain. *Cochrane Database Systematic Review*. Retrieved from: <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD003868.pub4/full>
- Wilkes, E. (1988). The control of cancer pain in the community: Science or pragmatism? *Cancer Surveys*, *7*(1), 209-222.
- Williams, C. J., Shuster, J. L., Clay, O. J., & Burgio, K. L. (2006). Interest in research participation among hospice patients, caregivers, and ambulatory senior citizens: Practical barriers or ethical restraints? *Journal of Palliative Medicine*, *9*(4), 968-974.
- Wohleber, A. M., McKittrick, D. S., & Davis, S. E. (2012). Designing research with hospice and palliative care populations. *American Journal of Hospice & Palliative Medicine*, *29*(5), 335-345.
- Wuest, J. (2012). Grounded theory: The method. In Munhall, P. (Ed.) *Nursing research: A qualitative perspective* (pp. 225-256). Sudbury, MA: Jones & Bartlett Learning.
- Yang, P., Sun, L., Qian, I., Pang, D., & Ding, Y. (2012). Quality of life in cancer patients with pain in Beijing. *Chinese Journal of Cancer Research*, *24*(1), 60-66.

Zerwekh, J., Riddell, S., & Richard, J. (2002). Fearing to comfort: A grounded theory of constraints to opioid use in hospice care. *Journal of Hospice and Palliative Nursing*, 4(2), 83-90.

Zylla, D., Larson, A., Chuy, G., Illig, L., Peck, A., Van Peurse, S., Fulbright, J. W. ... Mettner, J. (2016). Establishment of personalized pain goals in oncology patients to improve care and decrease costs. *Journal of Oncology Practice* (online edition), 1-7. DOI: 10.1200/JOP.2016.017616