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UNIVERSITY OF SAN DEIGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

BARRIERS AND PERCEPTIONS TO OBTAINING PALLIATIVE CARE IN THE
EMERGENCY DEPARTMENT

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
UNIVERSITY OF SAN DIEGO

In partial fulfillment of the
Requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING

by

Jacqueline L Saucier

March 21, 2018

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Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

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TITLE OF
DISSERTATION:

Barriers and Perceptions to Obtaining Palliative Care in the
Emergency Department

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Abstract

Background:

Purpose: This study explored barriers and perceptions of providing palliative care services while patients are in the emergency department (ED) in order to increase the likelihood of caregivers to elicit palliative care methodologies for patients with chronic illness, who are not necessarily at the end of life, but rather who are identified through repeated visits to the ED.

Design and Methods: A mixed methods approach was used to explore the barriers and perceptions of providing palliative care services in the ED. By using a qualitative approach, evidenced by grounded theory, this study explored the barriers and perceptions of providing palliative care services in the ED. Structured cultural interviews were the preferred mode of data collection for this selected population. Concomitantly, the researcher conducted a survey, distributed via email further comparing relationships between the identified themes. This comparative analysis lends itself to a mixed methodological approach to explore the barriers and perceptions of providing palliative care services in the ED. Through data collection by interviews and internet survey, the researcher broadens the scope of information gathering to improve insight into this study. Eight participants working in a district hospital in southern California participated in the qualitative portion of the study. The interviews were audio-recorded during a one-on-on confidential session, transcribed verbatim, and analyzed per the extensive research conducted by Glaser and Strauss (1967). The survey questions were sent via email to the American Association of Emergency Nurses (AAENP) and respondents anonymously

selected answers. Thirty-five emergency nurse practitioners, all members of a national organization, responded to the on-line survey.

Results: Themes for the one-on-one interviews included defining palliative and hospice services, perceptions of family and patients about palliative care in the emergency department, barriers to utilizing palliative care in the emergency department, personal philosophy and palliative care services, effects of palliative care services on emergency department efficiency and hospital throughput, and vision of palliative care in the future. The conceptual model depicts the barriers and perceptions to utilizing palliative care in the emergency department, supported by Murray's (2007) transition model of care.

Conclusion: Exploration of the barriers and perceptions of caregivers illustrated initiating the conversation about palliative care services is not only a difficult discussion to broach, but also a matter of timing and sensitivity for patients and families during an acute episode of a chronic illness. Caregivers agree on the efficacy and need for palliative care in the emergency department. Further research is needed to explore concepts consistent with a successful palliative care program in the emergency departments as it relates to decreased admissions for patients with chronic illnesses, access to outpatient resources and enhanced education and knowledge for caregivers about palliative care.

Copyright

Dedication

This is dedicated to all the daughters and sons who vigilantly care for their aged parents. As we struggle with the cycle of life, we reaffirm *where* we originated, the *why* of our existence, the *who* of responsibility and accountability for decision-making, the *what* is our ultimate goal for comfort and treatment, and the *how* of ensuring our parents' time on this earth is with dignity and peace. In the transition from healthfulness to helplessness, we yearn to see the truth through the empty eyes of a person who once was and will no longer be. Our quest is to be present, be gentle, be patient, and to love like never before.

"The craving for 'the return of the day,' which the sick so constantly evince, is generally nothing but the desire for light." ~ Florence Nightingale (1992)

The Thomas theorem states: *"If men [sic] define situations as real, they are real in their consequences"* (Thomas, 1928: 584), *thereby claiming that individual definitions of reality shape perceptions and actions."*

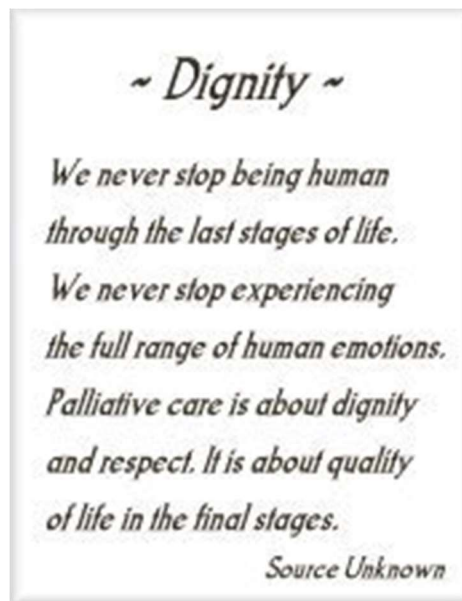


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Chapter 1

Introduction

Care systems that offer end-of-life services are underutilized (Quest, Asplin, Cairns, Hwang, & Pines, 2011); to clarify the need, a distinction between hospice services and palliative care services must be made. Hospice care, is intense palliative care provided to patients with terminal illness and a prognosis of 6 months or less (i.e., assuming the disease runs its usual course) and is utilized by less than one-half of people who die annually (Sangeeta & Quest, 2011). Although most adult patients in the United States report they would prefer to die at home, approximately 70% die in nursing homes, long-term care facilities, or acute care hospitals. Of those who die in acute care hospitals, an estimated 20% die in an intensive care unit (Quest et al., 2011). By the year 2030, an estimated 71 million persons will be over the age of 65 years and 19.5 million will be over the age of 80 years in the United States (Quest et al., 2011). The International Council of Nursing (ICN) estimates by 2020, there will be greater than 100 million people over the age of 60 and approximately three fourths of all deaths will be attributed to a non-communicable disease (Forero et al., 2012). This burgeoning senior population warrants careful evaluation of the appropriate use of emergency department (ED) visits to treat symptomatology associated with their chronic illnesses.

According to the World Health Organization (WHO, 2014), 39% of the population has some degree of cardiovascular disease, 34% have cancer, 10% suffer from chronic lung disease, 6% have HIV/AIDS, and 5% have diabetes. Concomitantly, the WHO reports 86% of people who need palliative care do not receive it, 83% of the

world's population lack access to pain relief, and 98% of children needing palliative care reside in low and middle-income countries.

Defining Palliative Care and Comfort

In 2002, the World Health Organization (WHO) defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems association with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessments and treatment of pain and other problems, physical, psychosocial, and spiritual” (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). In 2014, the WHO conducted the first ever global resolution on palliative care, World Health Assembly resolution WHA67.19, calling for improved access to palliative care through primary care and community/home-based care (WHO, 2014).

Kolcaba (1994) defines comfort as the “satisfaction of (actively, passively, or cooperatively) basic human needs for either relief, ease, or transcendence arising from stressful health care situations.” The goal of the holistic comfort theory is to provide comforting interventions for patients in their time of need. Research participants in the current study described their philosophy of providing palliative care to their patients as “putting the patient first,” “respect for the autonomy of patients and their wishes to live and get certain testing, but being able to provide them with a pain management system,” “responsible care,” and “providing a continuum of care in its’ entirety.” Palliative care was described by another participant as something “you give to people to help them feel comfortable and feel less stressed.”

The Concept of Total Suffering

At the nucleus of the concept of total suffering, patients and their needs remain the priority for goal setting and symptom management. Health care professionals must strive to listen to the story of the patient and work to build a therapeutic relationship based on trust, quality of care, and realistic solutions. It is important to respect the choices of the patient and their families, even if it may not be choices we make for ourselves.

The concept of “total pain” or “total suffering” embodies the complexities of issues that plague patients with advanced illnesses and it is crucial to recognize the impact these various issues have on the patient’s illness journey. Suffering cannot be treated in isolation, other factors such as psychological and spiritual concerns, cultural norms, intellectual needs, social difficulties, and physical symptoms must be considered. The concept of total suffering was evidenced in the definitions provided by the study participants describing palliative care as “care for symptom management of pain and anxiety,” “palliative care is provided to patients who are suffering,” “palliative care is supportive care for patients facing serious or life-threatening illness,” and “providing whatever support needed; physically, medically, spiritually with any problem, as proactive as possible.”

Total Pain and Cicely Saunders

Dame Cicely Saunders described the concept of total pain as the suffering that comprises an entire patient’s physical, psychological, social, spiritual, and practical challenges (Dobson, 2017). As the founder of the modern hospice movement, Saunders coined the phrase “total pain” to describe those instances other than the physical

sensation of pain (Saunders, Baines, & Dunlop, 1995). She believed listening to be the most important skill to reduce the patients' discomfort. The concept of total pain was in keeping with the definitions of hospice care as described by the study participants: "maintaining patient dignity, including families and patients in the decision-making process;" "focus on end of life and keeping patients comfortable." The goal of patient care is "comfort" at the end of life, "keeping patients out of the hospital and in their home," and "extra emphasis on understanding and compassion, because the person is going to die."

Triandis' Theory of Behavior and Care Seeking Behavior

Triandis's Theory of Interpersonal Behavior explains the relationship between social factors and emotions on forming intentions (Lauver, 1992). Triandis purports behavior is a result of the culmination of multiple antecedents such as norms, beliefs, physiologic arousal, past experiences, habits and outcomes (Lauver, 1992). Triandis based his theory on a mathematical model of probability showing a very strong relationship between the above-mentioned variables. Although this is a complex theoretical model, it has its merit in explaining the multiple influences inherent in certain behaviors. Consequently, it is important to understand the behavior and intent of caregivers when providing or supporting new services, for instance palliative care in the emergency department.

Care Seeking Behavior (CSB) theory is predicated on the findings of Triandis's Theory of Social Behavior (Lauver, 1992). It is important to understand why people engage or choose not to engage in certain health behaviors. Illness behaviors involve seeking care for evaluation and treatment from healthcare practitioners within a hospital

system, which is fundamentally different from prevention behaviors usually accomplished through non-acute situations. This concept is integral to understanding why emergency health care personnel may struggle with the concepts of palliative care in their action-oriented environment. Primary prevention goals are diametrically contrasted with secondary prevention goals, which consist of diagnosing disease, treating disabilities, and their associated sequelae. The distinction between primary and secondary behaviors is most notably inherent in the health care individual.

Although CSB theory is similar to Triandis's theory of behavior it differs in two distinct facets: intention and physiological arousal are not part of the theoretical construct (Lauver, 1992). If researchers used CSB to explain a certain behavior, health care professionals could develop interventions consistent with the behavior to elicit change. It speaks to the "why" of the behavior. The current study identified participants using terms such as "receptive," "comfort right now," and expectations of care to describe how patients and families perceive discussions of palliative care in the emergency department.

The Theory of Planned Behavior

Ajzen (1991) developed the Theory of Reasoned Action (TRA) to describe an individual's specific intention at any given space and time. This model developed into the Theory of Planned Behavior (TPB) postulating an individual's desire to exert self-control and change behavior. The key component of this model is behavioral intent likely influenced by attitudes about the intended consequences of the outcomes related to these behaviors. There are six components of this model including attitudes, behavioral intentions, social norms, subjective norms, perceived power, and perceived behavioral control. The three critical considerations of Ajzen's (1991) constructs are behavioral

beliefs, normative beliefs, and control beliefs. Thus, TPB focuses on human behaviors that are not only affected by personal attitudes, but also by social pressures and an ability to exhibit self-control.

When using TPB, program implementers can design interventions dependent on the three types of beliefs previously discussed; behavioral, normative or control, and ultimately guide intended behaviors. Behavioral beliefs influence attitudes either positively or negatively and will result in either positive or negative outcomes.

Normative beliefs are affected by perceived social pressures and subjective norms.

Control beliefs produce a behavioral control by impacting performance of the behavior.

A persons' intention to change behavior will be stronger if they possess all three beliefs (Ajzen & Fishbein, 1980). The stronger a person's intention to have a certain behavior, the more likely it will be performed. It is important to understand the effects of external factors on performance of behaviors. To eliminate barriers to positive behavior, researchers need to study the beliefs that control the subjective norm, the intention to perform a particular behavior, and the actual behavior that is traditionally performed.

The Biopsychosocial Model

As the founder of the Biopsychosocial (BPS) Model, George L. Engel was revered for formulating a "new medical model" encompassing biological, psychological, and social factors as a way to better understand patient suffering (Engel, 1977). Using a holistic approach to patient-centered care, Engel based the model in part on Social Cognitive Theory with implications that the disease process and illness is significantly rooted in the biological, social, and psychological fundamentals within each individual (Borrell-Carrió, Suchman, & Epstein, 2004). In the psychological realm, the mechanisms

of the mind are affected by the mechanisms of the body, resulting in both indirect and direct correlations with healing and the patient's ability to accept and adhere to a treatment plan. It is the trifecta approach that enables the patients' perception of their health (or illness) combined with identified social and cultural barriers, whether they will engage in treatment behaviors.

Fundamentally, Engel struggled with the dehumanization of patient care, materialistic and reductionist "medical model of thinking", and lack of integration between the observer and the observed (Borrell-Carrió et al., 2004). It could be said that Engel single-handedly changed the clinician's gaze during the evolution of this model.

Chronic Illness Trajectory Framework

Corbin and Strauss (1991) developed the Trajectory Model also known as the Corbin-Strauss-Model based on years of interdisciplinary research related to chronic illnesses. A trajectory of chronic illness is defined as a course of action and subsequent behaviors of both the patient and caregivers to manage the different phases and stages of the chronic illness. McCorkle and Pasacreta (2001) outlined eight stages for the course of disease: (a) initial or pretrajectory phase, when symptoms are not present, (b) trajectory onset phase, when the first onset of symptoms are present, (c) crisis phase occurs when there is a life threatening situation, (d) acute phase is when the crisis phase is over and symptoms are controlled by a certain prescribed regimen, (e) stable phase occurs when the symptoms are controlled (f) unstable phase occurs when the symptoms are no longer controlled by the previously prescribed regimen (g) downward phase is

described when the patient has significant mental and physical deterioration, and (h) dying phase occurs within months, weeks, days preceding death.

Corbin and Strauss (1991) applied the above-mentioned phases to further describe the six steps in the nursing process for development of the Trajectory Model. These steps consist of identification of the trajectory phase, identification of problems and goals, actionable plans to meet the goals, potential barriers to goal attainment, interventions, and evaluation of the plan. This concept of chronic illness trajectory is consistent with the definitions provided by the research participants regarding hospice and palliative care.

Social Cognitive Theory/Self-Efficacy Theory

Social cognitive theory (SCT) was first recognized in 1931 and further investigated by Canadian psychologist, Albert Bandura. Bandura (1977) postulates a direct relationship between behavior changes and self-efficacy. He theorized behavior is influenced by the environment and is the result of learning by observing others. The three core concepts of Bandura's theory are personal, behavioral, and environmental. These determinants are interrelated and thus form the triad and basis for SCT. A person's past experiences and resultant behaviors determine whether a person will engage in specific behaviors. The six constructs of SCT are reciprocal determinism, behavioral capacity, observational learning, reinforcements, expectations, and self-efficacy (Riekert, Ockene, & Pbert, 2014).

The American Hospital Association (2016) reports the total number of hospitals in the United States is 5,627, this includes not-for-profit, for-profit, state, and local government hospitals, as well as nonfederal psychiatric and long-term care hospitals. Of these hospitals, there are only 17 states assigned an "A" grade for achieving over 80%

of hospitals (50 or more beds) with palliative care programs. For other states, 16 were assigned a “B” grade for achieving 61-80% of hospitals with palliative care programs, 9 achieved a “C” grade for achieving 41%-60%, and 7 received a “D” grade with only 21%-40% of hospitals having palliative care programs (Dumanovsky et al., 2016). Although U.S. palliative programs are increasing, it appears they are limited to large hospitals and academic medical centers.

Palliative care consults are rarely performed in hospital emergency departments (ED), especially those without an inpatient palliative care specialist program. The extent to which end-of-life issues are discussed and assessed in emergency settings is often limited to a nurse’s query about the status of a patient’s advanced directive. Nonetheless, most emergency nurses are *all too familiar* with patients who repeatedly return to the ED for worsening chronic symptom management, which is a dilemma further complicated by escalating health care costs and a rapidly aging population. A study is needed to help ascertain the optimal care resources needed for this unique patient population.

Validated instruments and screening processes that assess high-impact areas of need or help predict outcomes are emerging in the literature; however, they focus on physician interventions instead of nursing praxis (Grudzen, Stone, & Morrison, 2011). Historically, the first hospice care center appeared in London in 1967, St. Christopher’s was founded by Dame Cecily Saunders (Yang, Ewing, & Booth, 2011). The successful demonstration of projects such as St. Christopher’s Hospice and St. Joseph’s Hospice, both in London, led to the medical subspecialty known as palliative medicine (Kuebler, Heidrich, & Esper, 2007). Despite their first appearance in 1967, palliative care programs were not instituted until 1988, primarily in large academic centers caring for the

chronically ill and dying (Forero et al., 2012). This delay may partially explain the late adoption of palliative care fellowships in EDs. ED physicians are reluctant to take on the responsibility because they are not the patient's primary doctor, "they don't have time," and they lack the rapport to discuss the patient's goals of care and prognosis (George et al., 2015). The premise of providing emergency care is to intervene rapidly to save patient lives, which is contrary to the processes of implementing palliative care and symptom management.

Unlike emergency medicine, palliative medicine focuses on seven distinct skill sets: (a) effective communication, (b) patient-centered decision-making appropriate to the stage of the disease and condition of the patient, (c) management of disease complications, (d) symptom control, (e) psychosocial and spiritual care, (f) care of the dying, and (g) coordination of care and continuity (Kuebler et al., 2007). Conversely, emergency medicine generally concentrates on treating undifferentiated patients across all age, group, disease, and injury continuums, is based on time-constrained patient assessments providing resuscitation, stabilization, and an appropriate disposition or safe discharge (Forero et al., 2011). Although seemingly diametrically opposed in approach, the one constant in both practices is the shared focus on patient-centered decision-making.

Grudzen et al. (2012) conducted a qualitative study on the U.S. east coast, describing the views of hospital administrators on palliative services in their ED. The study found that barriers to the provision of services were related to palliative care staffing, medicolegal concerns, and logistics. This study did not include views from nurse practitioners, clinical nurse specialists, or emergency department case managers.

Patient Centered Care

A seminal report from the Institute of Medicine (IOM, 2001), *Crossing the Quality Chasm*, sparked a sense of urgency in making process changes to the delivery of quality health care in the United States. Subsequently, the nation embarked on aligning payment practice policies with quality care validated by measurable outcomes. Since these outcomes are publicly reported, it is imperative that individual health care organizations develop and sustain quality improvement programs. The IOM has defined patient-centered care and argues that it is one of the six approaches by which health care ought to be delivered.

Most hospital organizations have incorporated the concept of patient- and family-centered care into clinical practice. With the advent of computerized technologies, a proliferation of media and web-based health-related information, many consumers are more aware of health care and the disease process and expect the quality of care they receive to be faultless. Patients desire to be kept well informed and included in their plan of care making this practice a necessity (Hast, DiGioia, Thompson, & Wolfe, 2013).

Large knowledge gaps in the delivery of palliative care services exist in outpatient settings (Glajchen, Lawson, Homel, Desandre, & Todd, 2011; Grudzen, Richardson, Morrison, Cho, & Morrison, 2010; Quest et al., 2011). A review of the literature found numerous authors recommended further research exploring hospitals' length of stay, readmission rates, and costs associated with implementing palliative care services in their EDs. Forero et al. (2012) reported approximately one half of all medical costs are incurred in the last 6 to 12 months of a person's life.

Conducting a study to explore the barriers and perceptions to obtaining palliative care services in the ED is timely and relevant for improved quality at the end of life. The focus on patient-centered care coupled with the fiscal responsibilities of concentrating resources where they are best suited is imperative to the provision of comprehensive and effective health care. Assessing palliative care needs may also help to identify patients and families who are receiving extensive, but futile treatment in their struggle between quantity and quality of life (Hudson et al., 2012). Ultimately, this type of study may lead to a reduction in ED readmission rates, improved patient and family education, provide a venue for establishing more appropriate goals, and lead to better symptom management. End-of-life discussions need to occur in a timely and compassionate environment facilitated by knowledgeable care providers who can assess patient and family readiness to engage in these essential conversations.

Research Questions

1. How do emergency health care providers and administrators define palliative care and hospice?
2. How have perceptions and barriers of palliative care services in the ED changed for health care providers and administrators. What is the evidence of a “unified theoretical explanation” (Creswell, 2013, p.83) for the beliefs and attitudes for this study?
3. What is a description of the collaboration and functionality between the ED and palliative care service?

Purpose

The purpose of this study was to understand and enhance knowledge about the barriers and perceptions of providing palliative care in the ED.

Specific Aims

Aim 1. Gain a broader understanding of health care providers' definitions of palliative care and hospice.

Aim 2. Describe how perceptions of and barriers to palliative care services in the ED changed for health care providers and administrators?

Aim 3. To explore the feasibility and acceptability of obtaining palliative care services in the ED as a standard of practice.

Palliative care equates to quality, especially for patients and their families who are attempting to cope with myriad needs associated with chronic and life-threatening illnesses. The ability to communicate with a team of experts skilled at navigating the daily tribulations of hospital bureaucracy and uncertainty may help alleviate stress during a time of great need. Information gleaned from this study may assist in evaluating palliative care and the clinical pathway for optimal patient care in the ED setting (Hast et al., 2013).

Chapter 2

Review of Literature

This review provides an analysis of the concept of palliative care and explores implications for future research. Included in this analysis is a distinction among hospice care, end-of-life care, and terminal care, terms used to describe a time when treatment modalities define chronic disease and nursing outcomes. Concept analysis as described by Walker and Avant (2011) will be used to explore the model of palliative care. As a theoretical framework, it incorporates both holism and patient-centered goals that most aptly align with the concept of palliative care (Peterson & Bredow, 2011).

Identification of Uses of the Concept

The researcher performed an extensive literature search to identify the various uses of the term, *palliative care*, as the first step in performing a comprehensive concept analysis. Subsequently, the researcher will concentrate the discussion of palliative care on its relevance in the emergency care setting and the need of early assessment for patients and families.

Merriam-Webster (n.d.) defined palliate as to reduce the violence of a disease or to ease symptoms without curing the underlying disease. Originating from the 15th century, the word palliate derived from middle English, late Latin, *pallitus*, a past participle of palliare (to cloak), conceal, and from Latin *pallium*, cloak.

The World Health Organization (2013) defined adult palliative care (A)s an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of

suffering by means of early identification, impeccable assessment, and treatment of pain and other problems, physical, psychosocial, and spiritual. (p. 1)

The Center to Advance Palliative Care (2013) defined palliative care as:

(S)pecialized medical care for people with serious illnesses focusing on providing relief from symptoms, pain, and stress – whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. The palliative care team of doctors, nurses, and other specialists work together with the patient's other doctors to provide an extra layer of support. It is appropriate at any age, at any stage in a serious illness, and along with any curative treatment. (p. 1)

The American Academy of Hospice and Palliative Medicine (2013) stated the goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

The National Council for Palliative Care (NCPC, 2013) actually defined supportive caregiving out of a segment of its aims and goals to describe palliative care as the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social, and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for

patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

The National Institute for Clinical Excellence (NICE) stated patients want to be treated as individuals, with dignity and respect, and to have their voices heard in decisions about treatment and care. Should they need it, they expect to be offered optimal symptom control and psychological, social, and spiritual support. They want to be assured their families and carers will receive support during their illness. (Cheshire Hospices Education, 2013, p. 1)

The National Hospice and Palliative Care Organization (NHPCO) (2015) founded in 1978, added Palliative Care to its name in 2000. This organization purported hospice and palliative care share the same values and *raison d'être* to address issues of physical pain, spiritual, emotional, social well-being, and improving quality of life for patients and their families.

Essentially, palliative care offers the most basic concept of interventions – that of providing for the needs of the patient irrespective of the care setting, at home or in the hospital. The European Association of Palliative Care (2013) argues palliative care is the active, total care of the patients whose disease is unresponsive to curative treatment. Control of pain, other symptoms, social, psychological, and spiritual problems is integral to palliative care. Notably, its interdisciplinary approach encompassed the patient, the family, and the community in its scope.

Defining Attributes of the Concept

The five most prevalent characteristics of palliative care emerging from a comprehensive literature review and consideration of the definitions included (a) patient-

centered decision-making, (b) communication, (c) specialty team, (d) pain and symptom management, and (e) preservation of a quality of life until death. Throughout the search for palliative care attributes, the researcher's focal point remained on the distinguishing factors relevant to the needs of patients experiencing chronic illnesses seeking specialized care, specifically holistic and therapeutic approaches to address their pain, suffering, and imminent death.

First Model Nursing Case

A model case exemplar defining the characteristics of palliative care was that of Amy Berman. Her story depicted how to “bridge the gap to patient centered care” (National Institutes of Health, 2012, p.1). Berman, a nurse and senior program officer at John A. Hartford Foundation, discovered an odd appearing red lump on her breast and, by the time she consulted her physician, was diagnosed with Stage IV inflammatory breast cancer. She chose palliative care over aggressive chemotherapy based on research about the disease process, advice from her oncologist, and extensive conversations with family. Over a brief period, the cancer metastasized to her spine. Nurse Amy declared, “I want a good quality of life for, as long as I can and a bad quality of life for as short as possible” (p. 1). She opted for daily medication and a monthly infusion. She shared her experiences at the *National Institute of Health: Mind the Gap* presentation on women's health and discussed her experiences with what she coined the “Niagara Falls Trajectory” (p. 1). A state of being can change so significantly, from elation, to despair, to right off the cliff. Her story exemplified the attributes of patient-centered care, she choose the course of treatment, communicated with health care providers and her family, and consulted a team of palliative care specialist to help extend her quality of life.

Second Model Nursing Case

Patient A was a retired New England professor experiencing chronic peripheral neuropathy that continued to worsen over time (Wilmot, 2013). He lived in a small rural community with limited specialty care access. After falling at home and fracturing his hip and fibula, he developed severe Stage 4 ulcers on his lower extremities requiring antibiotics and subsequent surgeries to repair the deep tissue injuries. The local team decided to use the palliative care model to discuss treatment options and determined his care needed to be transferred to a tertiary facility. The professor was sent to a facility near his daughter's place of residence where he remained for 1 year. During the year his leg was amputated; he rehabilitated with a prosthetic replacement, and resumed ambulation. He remained in communication with the multi-disciplinary team. Patient A typified the five attributes of palliative care in a real life situation.

An Associated Model Case

This situation relates to the previous case illustrating the surgeon's experience (Patient B) to the New England professor in the same small rural community (Wilmot, 2013). Patient A's surgeon became suddenly ill and was diagnosed with acute myeloid leukemia. Remembering the success of Patient A's palliative experiences, when transferred to a nearby Cancer Center, she quickly opted for their services. Her family, particularly her husband, was unable to cope with her diagnosis and devastating disease progression. Patient B experienced horrific symptomology associated with the medications, including nausea, anxiety, pain, and fever. If not for the alternative therapies offered by the palliative care team, she admittedly would have succumbed to the treatment. She learned how to incorporate poetry, massage, art, and music while

receiving unpleasant diagnostic tests and visiting family members. Upon discharge, she integrated these new skills into her routine to help her deal with her negative emotions. This model case also exemplified the attributes of palliative care.

Identification of Additional Cases

Kaufman (2006) embarked on a 2-year journey, fully immersed in the lives of hundreds of critically ill and dying patients receiving care in three California community hospitals. Her research was grounded in two medical anthropological theories: (a) medical practices and responses were social enterprises influenced by cultural activities, and (b) the practice of medicine was one of the most powerful frameworks for understanding hospital culture. Having embraced the environment, she described poignant details shared by families and caregivers that brought an undeniable perspective to the issue of death in hospitals. As a medical anthropologist, Kaufman's research offered a dramatic depiction of the strengths of ethnographic fieldwork: living with the *natives*, capturing the ordinary and everyday experiences, and recounting the relationships of the individuals within the environment under review. Kaufman met with physicians, nurses, and medical personnel prior to engaging in observational studies with patients to establish relationships and to explain her purpose. Although not specifically labeled palliative care, the stories Kaufman described related to patients and families who would benefit from palliative care interventions and highlighted the importance of early assessment and the need for a focus on quality of care.

Kaufman (2006) explicitly described the frequently tumultuous decisions families faced at the end of life. This monograph explored the lived experiences of those experiencing dying and ultimately death in the hospital. The purpose of her study was to

enhance the understanding of the phenomena of dying within the social and cultural constructs of the complicated American health care system. Kaufman attended to the specific time known as the threshold between life and death, listening to conversations about control and *better dying*. Through the lens of nurses, physicians, patients, families, social workers, and chaplains, she garnered a greater understanding of death and how hospital cultures subsequently influenced the final days of one's life, both for the dying patient and his/her survivors. Kaufman described a *gray zone* period between life and death whereby medical technology infringed on one's psyche leading to the misperception that one's loved one might live when death was imminent. Raw emotions coupled with righteous indignations allowed for a sanctioned prolonging of death in spite of advanced directives, failing body systems, or simply waiting for *the right time*. With problematic deaths in the hospital, the aims of her study were to (a) describe how hospitals excluded the lay person in discussions about dying, (b) define rhetoric used at the bedside to control the dying transition, (c) provide full disclosure of information sharing between hospital personnel, patients, and their families during the gray zone, and (d) explain control at the end of life in the hospital.

Identification of Antecedents and Consequences

According to Walker and Avant (2011), antecedents and consequences are critical steps in the process of concept analysis. They help to clarify and define the attributes of palliative care from the social or contextual perspective. Compassion, effective nurse-patient or nurse-family relationships, knowledge, and sensitivity are antecedents of palliative care (Kehl, 2006). Conversely, the consequences of palliative care include a more comprehensive understanding of patient/family belief system, patient's increased in

feeling valued, decreased patient/family fear, patient/family increased feeling of control, and decreased burden for family and patients (Guo, Jacelon, & Marquard, 2012).

Definition of Empirical Referents

Walker and Avant (2011) described the final step of concept analysis as defining the empirical referents of the concept. The researcher must be able to measure the existence of the concept by using an instrument and thus test its occurrence. Steel et al. (2003) tested the Resident Assessment Instrument for Palliative Care (RAI-PC) in five disparate settings to assess the palliative care needs of patients and research outcomes affecting quality of life. This instrument has not typically been utilized in the acute care or ED settings of the hospital. A plethora of palliative care and end-of-life instruments assess patient and family needs. However, palliative care instruments and assessments in the emergency setting are absent in the literature.

Implications for Future Research

The researcher purports a need to explore the usefulness of palliative care assessments in the emergency setting. The defining attributes of palliative care are patient centered decision-making, communication, specialized team members, pain and symptom management, and quality of life need to be explored and addressed before admission to the hospital and the ensuing illness trajectory.

Summary

In summary, palliative care equates to quality, especially for patients and their families who are attempting to cope with myriad needs associated with chronic and life-threatening illnesses. The ability to communicate with a team of experts skilled at

navigating the daily tribulations of hospital bureaucracy and uncertainty may help alleviate stress during a time of great need.

Chapter 3

Methodology

The purpose of this study was to understand and enhance knowledge about the barriers and perceptions of providing palliative care in the ED. Research questions raised included: 1) How do emergency health care providers and administrators define palliative care and hospice? 2) How have perceptions and barriers of palliative care services in the ED changed for health care providers and administrators in the past 3-4 years? 3) What is the evidence of a “unified theoretical explanation” (Creswell, 2013, p. 83) for the beliefs and attitudes for this study? and 4) What is a description of the collaboration and functionality between the ED and palliative care service? In this chapter the research methodology including study aims, research design, sample and sampling, instruments, data collection procedures, data analysis, and protection of human subjects is presented.

Specific Aims

Aim 1. Gain a broader understanding of health care providers’ definitions of palliative care and hospice.

Aim 2. Describe how perceptions of and barriers to palliative care services in the ED changed for health care providers and administrators?

Aim 3. To explore the feasibility and acceptability of obtaining palliative care services in the ED as a standard of practice.

Design: A mixed methods approach was used to explore the barriers and perceptions of providing palliative care services in the ED. By using a qualitative approach, evidenced by grounded theory, this study explored the barriers and perceptions of providing palliative care services in the ED. Structured cultural interviews were the

preferred mode of data collection for this selected population. Concomitantly, the researcher conducted a survey, distributed via email, further comparing relationships between the identified themes. This comparative analysis lends itself to a mixed methodological approach to explore the barriers and perceptions of providing palliative care services in the ED. Through data collection by interviews and internet survey, the researcher broadens the scope of information gathering to improve insight into this study.

Grounded Theory

The classic work of researchers Glaser and Strauss (1967) serves as the basis for grounded methodological theory (GT). It is currently considered the *global phenomenon* and many researchers embrace the strategies of inductive, deductive, and verification reasoning to generate a descriptive explanation of occurring processes in the social setting (Fawcett, 1999; Holloway & Wheeler, 2010). Because of the scarcity of knowledge regarding the barriers and perceptions of palliative care in the ED, GT is the preferred approach to study this phenomenon. Through a systematic generation of theories, GT researchers constantly compare their data and search for themes and relationships between the concepts to move beyond simple description, but ultimately, toward explanation (Creswell, 2013).

Originating from a naturalistic paradigm, GT encompasses four philosophical assumptions; ontological (i.e., the nature of multiple realities), epistemological (i.e., knowledge enhanced by proximity to the participants), axiological (i.e., the researchers personal value to the study), and methodological (i.e., flexibility by the researcher to embark on another plan). Conversely, the positivists' paradigm purports the assumption of an objective reality known by the researcher and therefore critical to preventing bias.

It is considered a more logical approach, reductionist, cause-and-effect oriented, and reads like a scientific report (Creswell, 2013). The positivists believe in a *universal truth* and objective reality, whereas the naturalists' reality can be subjective (Ruben & Ruben, 2012). The active participation of both the researcher and the participants foster an environment based on their reality and behaviors; a more valid, reliable, and generalizable study (Cohen & Crabtree, 2006).

Responsive Interviewing

Described by Rubin & Rubin (2012), responsive interviewing is the preferred method of collecting information when the subject matter is personally sensitive or morally ambiguous, as is the case when considering palliative care services in the ED. The benefits of conducting qualitative interviews include reconstructing events, challenging long-standing assumptions, and portraying social processes; subsequently, the researcher anticipates responses that are intricate, exploratory, and counterintuitive (Holloway & Wheeler, 2010).

Study Population

Emergency physicians, hospital administrators, nurse practitioners, clinical nurse specialists, and case managers are integral to the understanding of providing palliative care services in the ED. Their perceptions and willingness to openly discuss the issues of palliative care, barriers, and availability of services to patients is integral to the generation and development of future plans. Other than the 2012 study conducted by Grudzen et al., there are no qualitative studies addressing the barriers and perceptions to providing palliative care in the ED.

The interviews were conducted at their workplace located in a southern California hospital. Privacy was maintained by using a closed office space. The hospital is located in a small suburban community and is part of a larger district organization. The interviewees signed a Research Participant Consent Form (Appendix C) and agreed to have their interview audio recorded and transcribed verbatim. The interview questions, included in Appendix D, were also followed by other inquisitive questions appropriately discussed during the interview session. Participants were encouraged to add any supplemental commentary that would help the researcher derive further analysis.

Setting

The interviews were conducted either over the telephone or in person. The geographic area for the interviews was confined to southern California, specifically Los Angeles and San Diego counties. The survey participants were physician members of the Emergency Medicine Oversight Committee (EMOC) for San Diego County and emergency nurse practitioners who are members of the American Academy of Emergency Nurse Practitioners' group (AAENP). There are no previous studies found using these study groups.

Sample Selection and Size

Inclusion:

- a. Emergency Physician
- b. Emergency Nurse Practitioner
- c. Emergency Clinical Nurse Specialist
- d. Hospital administrator
- e. Emergency Nurse Director/Emergency Nurse Manager

- f. Emergency Department Case Manager
- g. For on-on-one structured interviews, reside in southern California
- h. Able to converse in English
- i. Agreement to have audio recording for the interview

Exclusion:

- a. Non-emergency trained or non-currently practicing emergency physicians or nurses.
- b. Non-English-speaking practitioners

An email (Appendix B) was sent to personal contacts and colleagues who met the above inclusion criteria. The researcher's goal was to conduct enough 1:1 semi-structured interviews to reach theoretical sampling (Holloway & Wheeler, 2010).

Protection of Human Rights

Prior to any data collection, IRB approval was obtained from the University of San Diego. There is no risk to the participants of this study. The participants were asked to describe their perceptions and barriers to providing palliative care in the ED. The researcher de-identified interviewees so anonymity was achieved. All audio recordings were transcribed verbatim and discarded after retrieval of the interview. The participants did not receive any monetary compensation and were permitted to withdraw from the study at any time. Permission for access to the email recipients' list from AAENP was obtained prior to dissemination of the survey.

Data Collection

The purpose of this study was to identify specific barriers and perceptions to obtaining palliative care consults in the emergency department. The assumption of the

study is that barriers do exist and perhaps there are common themes and perceptions amongst the participants needing further exploration and research. Validity refers to the truthfulness of the data, as well as the results, analysis, and interpretations (Waltz, Strickland, & Lenz, 2010). During the face-to-face interviews, the researcher tape recorded all conversations on two separate devices and transcribed the documents verbatim. These documents were carefully reviewed and examined for common themes and used as part of the final data analysis process. The researcher determined if the questions asked of the participants accurately depict clear answers.

Initially, all interview participants received either an email or personal phone call eliciting their support for this study. If consent was obtained, participants received a verbal explanation about the purpose of the study, length of time for the interview (30-45 minutes), confidentiality measures, and dissemination of research outcomes. To ensure accuracy of data collection, all interviews were recorded, transcribed, and will be destroyed once the study is completed. Additionally, the researcher used field notes as indicated by this approach. The participants were asked the following questions:

(Appendix A)

1. How do you define palliative care?
2. How do you define hospice care?
3. Describe how patients and families perceive discussions regarding palliative care in the ED?
4. What barriers do you experience with utilizing palliative care services while patients are still in the ED?
5. How does palliative care fit with your philosophy of providing patient care?

6. How would palliative care services contribute to improved ED efficiency and hospital throughput?
7. How do you envision palliative care services in the future?

After obtaining permission from the president of AAENP, a survey was sent to the members of the listserv for the AAENP, included in Appendix E. The purpose of eliciting data from this study group was to examine if nurse practitioners experience the same or similar barriers and perceptions to obtaining palliative care consults in the ED as the participants in the semi-structured interview group previously discussed. The researcher utilized Survey Gizmo to develop the PowerPoint and record data. The participants were provided with an informational page describing the study, included in Appendix F. The online survey questions are included in Appendix C. The survey consisted of 10 questions including number of years in practice, practice status, age, gender, whether the participant has an advanced directive, religious or spiritual affiliation, personal experience with a family member or close friend enrolled in palliative care services, utilization of the palliative care service in their organization, how do they perceive their palliative care referral pattern and does their lack of knowledge of palliative care services and eligibility requirements limit their use of palliative care.

Data Analysis

This study used both a qualitative and quantitative approach to understand the barriers and perceptions of providing palliative care services in the ED. Grounded theory suggests a narrative presentation of the theoretical scheme drawing a relationship between the existing knowledge about barriers and perceptions to providing palliative care in the ED and the generation of a new theory (Creswell, 2013). The data analysis

included coding of similar concepts, categorization of those codes into a more abstract phenomenon, and subsequent formulation of constructs to ultimately amass the theoretical model (Holloway & Wheeler, 2010). The researcher identified that this study represents a causal, consequence, or conditional model of grounded theory and possesses “explanatory power” (Holloway & Wheeler, 2010).

Chapter 4

Results

The findings of both the structured interviews with an identified subgroup of hospital study participants and the national advanced emergency nurses practitioner organization survey results are presented in this chapter. As a result of the data analysis, a theoretical model is conceptualized based on grounded theory (Glaser and Strauss, 1967) and a description of a matrix consistent with a plausible explanation and theory development for understanding barriers and perceptions to providing palliative care in the emergency department is discussed.

Data Collection

A total of 8 participants were recruited and enrolled to participate in a semi-structured confidential interview with the researcher. The researcher found all interviewees to be extremely receptive, participative, and willing to discuss the topic of palliative care in the ED and expressed interest in the findings of the research.

Findings

It became resoundingly apparent during each interview that the topic of palliative care is one of great interest and need as evidenced by the responses of executive leaders, clinical nurse specialists, physicians, and case management. In keeping with the methodologies of Glaser and Strauss (1967), all interviews were scrutinized for similar verbiage, phrases, and refrains to further group and code for correlation of themes. The process is considered complete once theoretical saturation is noted. Once there is no new development of data or themes theoretical saturation is reached and the process is complete. The researcher is now able to create a grounded theory based on identifying

perceptions and barriers to obtaining palliative care services in the emergency department.

Participant characteristics. All study participants met the inclusion criteria. The participants consisted of 2 physicians (1 Emergency Director-Medical Director and 1 hospitalist), 3 executive leaders, 1 case manager/social worker, and 2 clinical nurse specialists. These participants were volunteers for the study and met the intended participant guidelines. Each interview concluded with a final question and opportunity for the participant to offer any further input or insight into the researchers' study.

Thematic analysis. There were six major themes derived from the semi-structured interview data analysis. The themes included the definition of palliative care, the definition of hospice, family and patient perceptions about discussing palliative care in the ED, barriers to using palliative care services in the ED, personal philosophy and palliative care in the ED, and the effects of providing palliative care in the ED related to hospital throughput and efficiency. Each of the major themes and subthemes will be further discussed below:

Definition of palliative care. The participants were asked to describe their understanding of palliative care and most of the participants associated palliative care with any individual requiring long-term care for chronic illnesses or conditions. Five subthemes emerged when defining palliative care including a holistic approach to delivery of care, symptom management, care given to relieve suffering, supportive care, and part of the continuum of care to provide comfort for the patient and family.

Holistic approach. Participant C defined palliative care as a holistic approach to delivering and meeting all the patient care needs. It is for patients with long-term chronic illnesses requiring long-term care.

Symptom management. Participants D, F, and G defined palliative care as a methodology for providing symptom management, whether it is pain, anxiety, nausea, or stress. The goal is to make patients feel better and have a little bit more control of their illness.

Care given to relieve suffering. Participant A specifically identified palliative care as a means to relieve suffering during illness or at the end of life. Palliative care is “care” to relieve suffering. In a recent literature review by Sacks (2013), there is a noticeable disparity of interventions to aid sufferers and caregivers of sufferers. Suffering is considered one of the most debilitating conditions faced at the end of life and caregivers rarely ask patients “if they are suffering” (Black & Rubenstein, 2004).

Supportive care. Five participants (A, B, C, G, H) defined palliative care as supportive care for patients who are facing a serious or life-threatening illness. Ideally, care is provided by a palliative care team who surround the patient with what the patient needs to support them physically, medically, and spiritually to help patients deal with any problems as proactive as possible. Another participant defined palliative care as to assist with activities of daily living, hydration, eating, and toileting.

Part of the continuum of care and to provide comfort. One participant defined palliative care as care for two types of patients; patients who are chronically ill and need a level above and beyond what can be managed in a doctor’s office and care provided to patients who are not dying, but are chronically ill and need resources for pain

management, access to care and continuum of care. One participant defined palliative care has a continuum of care to give the patient comfort, and said it “makes me sad when someone reaches the decision to need palliative care.” Another participant defined palliative care as something you give to somebody to help them feel comfortable and less stressed. It is care that we would give to somebody who was unable to do for themselves.

Definition of hospice. Participants (A, B, C, D, E, F, G) defined hospice as care provided to terminally ill patients at the end of life; some of them targeting specific time frames such as eminent death within 6 months while incorporating some degree of comfort either through pain management or symptom control. Primarily, hospice focuses on end of life, keeping patients comfortable, and including families and patients in decision-making processes. There were four subthemes identified through the interviews including location of hospice care, dying with dignity, relationship to palliative care, and compassion.

Location of hospice care. One participant (F) defined hospice care as keeping the patient out of the hospital. We’ve come to a point where we decide hospital-based interventions aren’t going to offer this person anything of value any longer. How do we keep the patient home? What is needed to manage the patient at home? What kind of resources and support might they need to manage their care at home? Another participant described hospice has an entirely different level of care because it is for someone who is at the end stage of life. We should allow them to stay home as much as possible, if acute care admissions are needed for example pneumonia for a patient with lung cancer, the goal should be to return home as soon as possible.

Dying with dignity. One participant (E) described hospice care as a type of care that is given usually with a terminal illness at the end of life to provide pain relief and suffering relief so that a person can pass in a dignified way. Another participant added hospice provides wonderful services to people who are the last stages of life, allowing them to be pain-free, but to be with their loved ones and die with dignity.

Relationship to palliative care and compassion. One participant (G) described hospice care as palliative care that can go into acute care at different stages of the patient condition. It's palliative care with an "extra emphasis on understanding and compassion because the person is going to die." The patient has a terminal disease and is going to die. Hospice is a comforting kind of care, "a little extra."

Another participant (H) described hospice care as encompassing palliative care but there is a stricter definition to hospice care. Usually there are certain diagnoses that meet criteria for hospice care.

Family and patient perceptions about discussing palliative care in the emergency department. Six of the eight participants (80%) agreed that discussions about palliative care in the ED were necessary and at minimum, planting the thought about alternative care options is considered progress. Several subthemes arose during the analysis including how the subject was approached, stigma, external influences on decision-making, and confusion about the differences between palliative care and hospice care.

How to approach the subject. Several participants found the issue to be sort of awkward, a "weird thing," but very positive responses from family members who appear to appreciate that we were bringing this up to start. We were not forcing them, but rather,

informing them that “this is available to you.” Doctors are more comfortable now with that discussion as opposed to 5 to 10 years ago. But now, we are getting to an area where it is more of an accepted practice to begin that conversation. Participants found that how they were approached and whether it was truly a palliative care discussion or a hospice discussion was important to discern. We tend to wait to address end-of-life options with patients until it is too late for hospice, let alone too late for palliative care. The ED is a good place to begin the discussion, but the primary care physician’s office would be a better place to continue the discussion.

Stigma. One participant (D) believes palliative care has a stigma associated with it, but if presented appropriately, families and patients are open to the concepts of palliative care. Again, if it is presented in the right way and thoroughly explained, patients are receptive. One participant described perceptions of patients as families as “poor,” but it at least puts the idea in their heads and gives them some time to consider their options. The idea is starting to take hold after the ED treatment has progressed.

External influences. One participant (H) described perceptions as being influenced by television and media. People think certain things should happen in an ED. They chose to visit the ED to get their needs met, but fear that will not happen. Families want everybody to do “full-guns” on them, just as they have seen on television. Staff often find it difficult to reassure patients and families that what they need is not medical intervention, but rather, comfort care.

Confusion about the difference between palliative care and hospice care. One participant (F) described how patients who have not been previously exposed to palliative

care in the ED may not be receptive, but once on the medical/surgical unit, they have a change of heart.

Another participant (G) described the ED as a place to get your immediate medical needs addressed and may be receptive to initial conversations about palliative care after the emergency is dissipated. There is still confusion over the definitions of hospice and palliative care. If we provide some clarity and explain the differences between the two concepts, patients and families would likely be more receptive to learning more about palliative care.

Barriers of using palliative care services in the emergency department. A majority of the participants (A, B, C, E, D, G) described barriers to using palliative care services in the ED based solely on “being in an emergency department” and the competing priorities to provide immediate treatment and disposition. Some of the subthemes that emerged were access to palliative care services, staff shortages, and lack of education.

Access to palliative care services. Several participants (A, D, E) described access to the consult-quick access, is not always available. Is there a palliative care team that can actually go to the ED to complete the consult and perhaps, discharge the patient home? This is not commonplace in most EDs. The availability of the service in the ED and putting a process in place for patients to be appropriately identified for a palliative care consult are challenging. If that structure were in place, nursing and medicine would likely be more open to facilitating the conversation between the palliative care team and patients and families,

Staff shortages. Several of the participants (C, G, H) were familiar with the national shortage of qualified personnel, especially those who can provide information pertinent to palliative care. In fact, one participant (H) believed their staff does not even think of palliative care when in the ED.

Lack of education. Most of the participants (A, B, C, D, E, G) believed there is a knowledge deficit about palliative care for both physician and social workers. This lack of knowledge complicates the critical need to have a well-defined program and process to offering palliative care services. A huge barrier is understanding the program itself. There seems to be a generalized lack of understanding of what palliative care is, and often patients in the ED are more prepared for the conversation than their families. Palliative care discussions go by the wayside because staff are in a hurry to accomplish tasks and move on to the next patient.

How does your personal philosophy fit with palliative care in the emergency department? Two subthemes emerged from the data when asking about the participants' personal philosophy of palliative care in the emergency department. All participants agreed the concept of "patient first" is of paramount importance when developing a plan of care for their patient. The plan should provide responsible care while respecting the autonomy of patients and their wishes to live with a pain management system that provides a certain quality of life.

Patient first. The patient first experience focuses on the continuum of care and incorporates the patients' complete medical and nursing care needs. While we manage the acute needs, we also are able to spend time focusing on the long-term care needs. A structured method and modality of delivers the best care for patients with long-term and

chronic needs. *Patient first* promotes decision-making and allows staff to still treat the patient and help control symptoms associated with chronic illnesses. It is important to set realistic goals of care and to expect reasonable outcomes. One of the emergency medicine physicians commented, “I think palliative care is an absolutely critical piece of what we do in the emergency department, but I didn’t think so twenty years ago.” One of the benefits of palliative care not only helps the patient, but actually helps family members because they see their loved ones suffering less.

Responsible care. Providing responsible care, palliative care specifically is hardwired in other countries such as Canada. Countries that have national health care programs allow their doctors to make decisions based on science and care. The continuum of care in its entirety should be utilized and the patient should be in the right setting. When patients are dying, they need to be in the right place. Another participant stated, “I believe in my mind anybody who has a serious illness would be wise to get a palliative care team on board and manage their care with the help of that team as opposed to just managing it with one care provider.”

How would palliative care services contribute to improve ED efficiency and hospital throughput? Five subthemes emerged from the question of how palliative care can improve ED efficiency and hospital throughput. These subthemes included early identification, realistic expectations of care, appropriate care, decreased utilization of the emergency department, and ongoing communication between the primary care physicians/nurse practitioners and the patient/family.

Early identification. Patients who may benefit from palliative care are utilizing EDs every day. If a structured program is established, patients can be identified earlier during the emergency visit.

Realistic expectations. If the patient and family have realistic expectations of care and understand what to expect from the treatment plan, it helps not to aggressively treat someone who might be more appropriate for palliative or hospice care. “Patients have unrealistic expectations of care fueled by social media, television, and news”. “A different level of care is needed for patients”.

Appropriate care. Participants stated, “We might be able to start to provide more appropriate care by coordinating care plans tailored toward the patient’s prognosis.” “Provide better care for patients and they would suffer less if they get adequate pain control or relief from chronic respiratory symptoms. We can avoid an admission to the hospital if we really offer them appropriate services.” “Appropriate level of care is needed to avoid an environment with too much activity and sensory overload.”

Decreased utilization of the emergency department. Alternative treatment modalities need to be explored such as home health, palliative care, and hospice. One participant stated alternative treatment modalities would mean “more transitions out of the emergency department to a lower level of care and placing patients in the right clinical setting.”

Communication with primary care physicians/nurse practitioners and the patient/family. Participants stated, “Ideally, if the palliative care conversation is happening by the primary care provider, reaching out to the team for symptom control, and maybe not even necessitating an emergency room visit. It’s better to have that

decision before they are in the emergency department or intensive care unit on a ventilator with three vasopressors, if that's not what the patient ever wanted." "People come to the emergency department as much because they are scared as because they are sick and dying."

How do you envision palliative care services in the future? The respondents unanimously agreed palliative care services are part of the continuum of care supporting the chronic and seriously ill patients in the future. There were four subthemes identified during the data analysis: palliative care is a growth industry, standard of care in the emergency department, less stigma, and technological opportunities to improve patient care.

Growth industry. One participant commented, "Palliative care is a growth industry, so it's important for caregivers to understand early and start those discussions about patient wishes." "The idea of palliative care medicine needs to get out to the masses and it is different than hospice." "Grow it and educate people that it is an option to addressing issues associated with chronic illnesses." Another respondent stated, "Palliative care services will be broadened and expansive as we focus on early identification and recognition of patients who can benefit from palliative care type modalities."

Standard of care. One respondent stated, "Palliative care services should be the staple of what we do in the emergency department. I envision using palliative care services much more in the future. I think it's an absolute must for the population health initiatives to succeed in all the different health systems."

Less stigma. One participant said “I envision palliative care services to be more open, hopefully less stigma, more education provided to providers so that it is offered very quickly to those that are suffering.” Another respondent commented, “Palliative care is much more resourced for efficient care of the patient. It is doing the right thing and build programs that are going to be resource efficient and support best practice outcomes. It is an opportunity for advanced nursing practice.”

Technological advances to improve patient care. One respondent stated, “Palliative care improves outpatient care, and possibly even delivered by things like telemedicine. The patient calls to tell you about specific symptoms, shortness of breath for congestive heart failure. The patient weighed himself and is four pounds heavier than yesterday. The care provider is utilizing telemedicine to visualize the patient and provide treatment, additional dose of Lasix.” This is fast and efficient service, allowing service to meet the patients where they live.

Survey Data Collection

Participant characteristics. The participants in the survey included 35 emergency nurse practitioners who are current members of the American Academy of Emergency Nurse Practitioners (AAENP). They were recruited via a posting on the website endorsed by the president of the organization. All participants met the inclusion criteria. The participants ranged in years of practice from 1 to >10 years, 39.4% of the participants practiced >10 years and 30.3% practiced between 1 and 5 years. (See Table 1).

Table 1.
Participant Demographics

Characteristics	<i>n</i>	<i>Total</i>	<i>%</i>
<i>Age</i>			
20-30 years of age	10		30.3
31-40 years of age	8		24.2
41-50 years of age	8		24.2
51-60 years of age	5		15.2
61+ years of age	2		6.1
<i>Gender</i>			
Male	8		23.5
Female	16		47.1
Other	3		8.8
Prefer not to answer	7		20.6
<i>Religious or spiritual affiliation</i>			
Catholic	3		9.1
Protestant	10		30.3
Jewish	4		12.1
Buddhist	2		6.1
Hindu	2		6.1
Unitarian	2		6.1
Agnostic	1		3.0
Muslim	3		9.1
No religious affiliation	2		6.1
Prefer not to answer	0		0.0
Other	4		12.1
<i>Advanced Directive</i>			
Male	12		37.5
Female	15		46.9
Other	5		15.6
<i>Number of Years in Practice</i>			
< 1 year in practice	4		12.1
1-5 years in practice	10		30.3
6-10 years in practice	4		12.1
> 10 years in practice	13		39.4
Other	2		6.1
<i>Practice Status</i>			
Clinic-based (urgent care) practice status	8		25.0
Hospital-based practice status	20		62.5
Other	4		12.5

Characteristics	<i>n</i>	<i>Total</i>	<i>%</i>
<i>Personal Experience in Palliative Care Service</i>			
Yes	15		45.5
No	17		51.5
Other	1		3.0
<i>Palliative Care is Underutilized Service</i>			
Yes	21		67.7
No	6		19.4
Other	4		12.9
<i>Perception of Palliative Care Referral Pattern</i>			
Under referred	17		51.5
Refer when appropriate	9		27.3
Over refer	1		3.0
Other	6		18.2
<i>Lack of knowledge eligibility requirements limit use of Palliative Care</i>			
Yes	13		38.2
No	12		35.3
Other	9		26.5
<i>Source countries</i>			
United States	35		100.0
<i>Source Cities</i>			
Atlanta	1		3.0
Durham	1		3.0
East Meadow	1		3.0
Indianapolis	1		3.0
Macedonia	1		3.0
Naperville	1		3.0
New Hyde Park	1		3.0
Phoenix	1		3.0
San Marcos	20		60.6
Tahlequah	1		3.0
Texarkana	1		3.0
Tok	1		3.0
Voorhees	1		3.0
Weymouth	1		3.0

The largest percentage of participants is hospital-based at 62.5%, while 25% are clinic-based. Only a small percentage, 6.1% are 61 years of age or older, 30.3% are between 20 and 30 years of age; and 24.2% were those who are 31 to 40 years of age and 41 to 50

years of age. Slightly less than half (48%) were female, 23.5% male, and approximately 21% chose not to answer the question.

Notably, when participants were asked the question “if they had their own advanced directives,” 46.7% responded negatively and 37.5% responded affirmatively. Religious affiliations included 32.3% of the participants were Protestant, 12.9% were Jewish and 9.7% were Catholic.

Slightly more than half (51%) have no experience with a family member or close friend who have enrolled in palliative care services; 67.7% agree palliative care services are underutilized in their organization compared to 19.4% who have access to palliative care services. These findings are consistent with the 51.5% of the participants who under-refer to palliative care consultants, while 27.3% report an appropriate referral base. Lastly, 38% of the participants agree that lack of knowledge about palliative care services and eligibility requirements limit their use of palliative care compared to 35.3% who disagree.

Theoretical construct. Glaser and Strauss (1967) purport the development of a theoretical construct as the final phase of incorporating data analysis and grounded theory methodology. As a result of the data analysis, a theoretical comfort care construct was embedded within the four tenets of patient centered palliative care strategies (Figure 1). The central focus of the proposed model is the construct of enhanced comfort and patient-centered care. In keeping with the tenets of the palliative care model; physical, spiritual, social, and emotional principles are further juxtaposed with the nine components of Kolcaba’s comfort theory. Strategies that incorporate the patient-centered approach to providing care were clearly identified by the participants in this study. The need for

caregivers to promote patient autonomy and independence are aligned with the proposed construct and will be further compared to other models in Chapter 5.

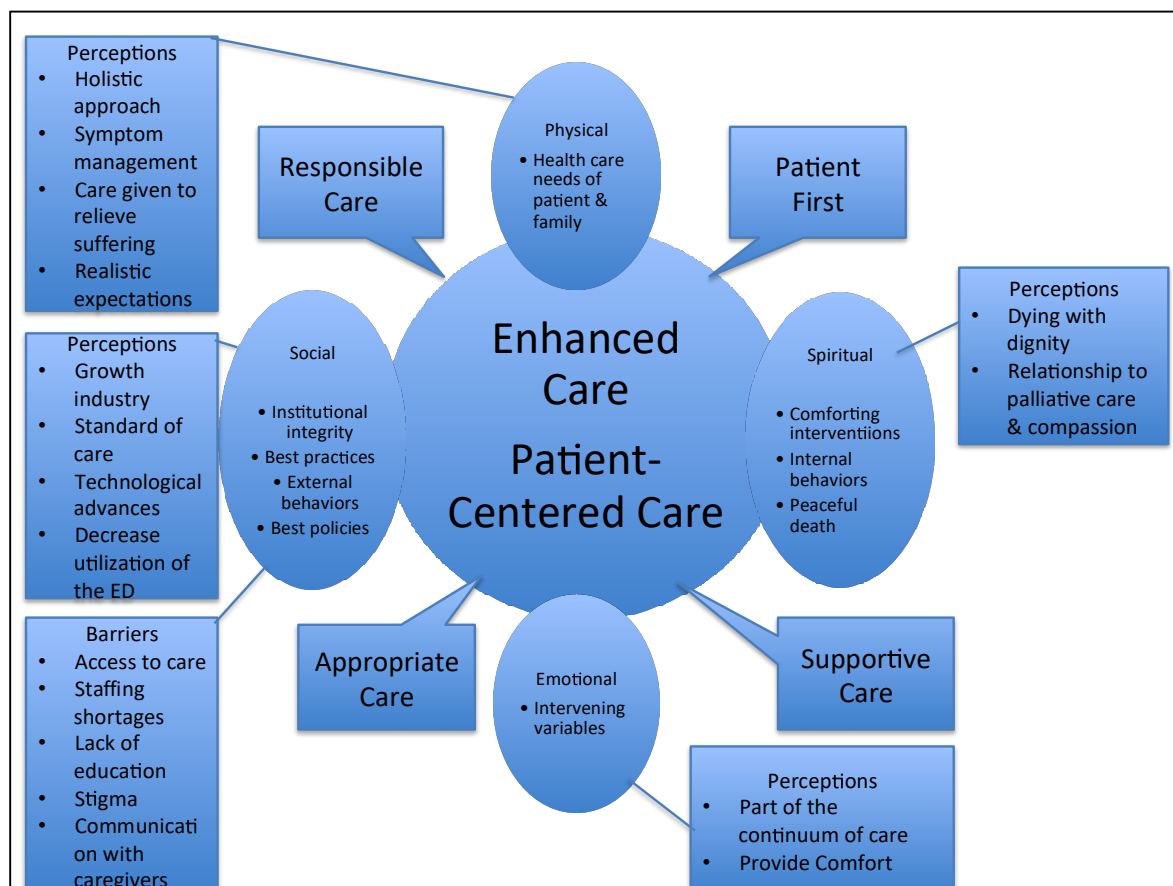


Figure 1. Theoretical Comfort Construct

Chapter 5

Discussion

The findings of this study are consistent with the complex nature of caring for patients suffering with chronic and debilitating illnesses. The barriers and perceptions associated with palliative care and the emergency department are consistent with the findings of Rodriguez, Barnatao, & Arnold (2007), Grudzen et al. (2012), Lamba, Nagurka, Zielinski, & Scott (2013), and Aldridge et al. (2016). The fundamental principles inherent in the palliative care model (physical, emotional, spiritual, and social) are the foundation of providing patient centered care and promoting comfort as described by Kolcaba (2011). In this chapter, the researcher will provide a brief description of the development of palliative care and the definition of comfort theory as it pertains to the model previously described in Chapter 4. Comparison models will be presented along with credibility of the findings and implications for future research and practice.

The current study identified barriers the participants experience with utilizing palliative care services while patients are still in the ED such as the need for more comprehensive training of all staff who touch the patient, the need for a well-defined and accepted palliative care approach, and immediate access to the consultative partners who are the experts. Because the initial focus in the ED is managing the patients' acute problem, there needs to be a process for identifying palliative care patients.

Not surprisingly, the physician participants in the current study are very receptive and enthusiastic about broadening palliative care services in the ED. They envision palliative care as a growth industry, a staple of the standard of practice, and they are

hopeful that with more education to providers, less stigma will be associated with asking patients the difficult questions of palliative care.

The influence of SCT on the current study is whether caregivers will be receptive to the concepts of discussing and implementing palliative care in the ED. If their beliefs are predicated on saving lives and moving patients through the continuum, will there be resistance to change based on personal and professional dictum? This notion was not realized during the current study.

Comparisons with Prior Research

The nursing research involving barriers and perceptions to obtaining palliative care consultations in the ED is limited. Grudzen et al. (2012) conducted a focus group involving 20 emergency physicians to explore the beliefs and attitudes surrounding palliative care. This study also used grounded theory to uncover significant themes and subthemes consistent with analysis process. The study concluded the many benefits of palliative care in the ED, but also recognized there is no instrument that clearly characterizes a palliative care patient. This study was limited to ED providers. Even in 2018, the current study had similar findings with respect to the benefits of improving quality of life for patients with chronic illnesses and simply identifying the need for palliative services early in the disease trajectory.

Smith et al. (2009) conducted three focus groups of 26 participants which included physicians (predominantly residents and low participation from attending physicians), nurses, social workers, and technicians at two academic hospitals in Boston, Massachusetts. Participants discussed their attitudes, beliefs, and experiences with palliative care in the ED and concluded communication and documentation from

outpatient providers held the greatest need for improvement. Secondly, the barriers to utilizing palliative care in the ED centered around attitudes such as, “I’m here to save lives,” and structure such as availability of the palliative care team. The current study also identified the lack of availability of the palliative care team in the ED.

Stone et al. (2011) conducted a study in Los Angeles, California, using semi-structured interviews to probe emergency physicians regarding perspectives and benefits of palliative care in the ED. The results showed a need for more extensive education and training around palliative care and end of life, as well as ensuring palliative care teams can meet the demands of the emergency setting. Shearer, Rogers, Monterosso, Ross-Adjie, & Rogers (2014) had similar results in their study conducted in Australia with emergency nurses and physicians. This theme was also identified in the current study.

Lamba et al. (2013) investigated responses from 30/45 emergency department physicians about the barriers associated with palliative care provisions in the ED. The study consisted of a 23-question survey using a Likert scale (highly agree to highly disagree) to determine barriers to palliative care. Similar to the current study, the concerns identified were lack of availability of the palliative care team and access to the patient’s outpatient medical care and plan of care.

In a recent observational study conducted by Green et al. (2017), concepts were explored regarding why patients with palliative care needs present to Eds. The acute crisis of shortness of breath and increasing pain for palliative care patients suggest emergency visits may be appropriate. Results conclude symptomatology is the primary driver for repeated visits to the ED and thus, the need to further explore patients’ perception of palliative care in the ED.

In another study conducted by Grudzen et al. (2013), hospital administrators were interviewed at three different health care settings; tertiary care center, community hospital, and public hospital. Researchers explored the perceptions of hospital administrators about providing palliative care services in their respective organizations. Just as in the current study, several factors remain outstanding and require further exploration such as the lack of palliative care staffing and logistic issues. Resoundingly, the hospital administrators supported palliative care services in the ED to decrease unnecessary admissions to higher level of care (ICU) and to improve quality of patient care and patient satisfaction. The current study identified the same objectives.

Credibility of the Findings

The researcher will discuss the topics of validity, reliability, and generalizability as it relates to this nursing study (Waltz et al., 2010). These components of evaluating the effectiveness and trustworthiness from the data obtained during both the interview and survey process supports the researcher in advancing nursing science and strengthen new methodologies.

Reliability refers to the consistency of results over time and between researchers during the same or similar circumstances (Waltz et al., 2010). As part of internal reliability, the researcher reasonably presumes similar constructs can be identified by other researchers using the same study questions. Transcriptions contain all conversations recorded during the interview process and can be used to authenticate dependability and auditability of the presented data. External reliability describes the extent to which this study can be replicated through explicit details and processes outlined by the researcher.

The content of the interview questions was devised to prompt further dialogue and introspection by the participants.

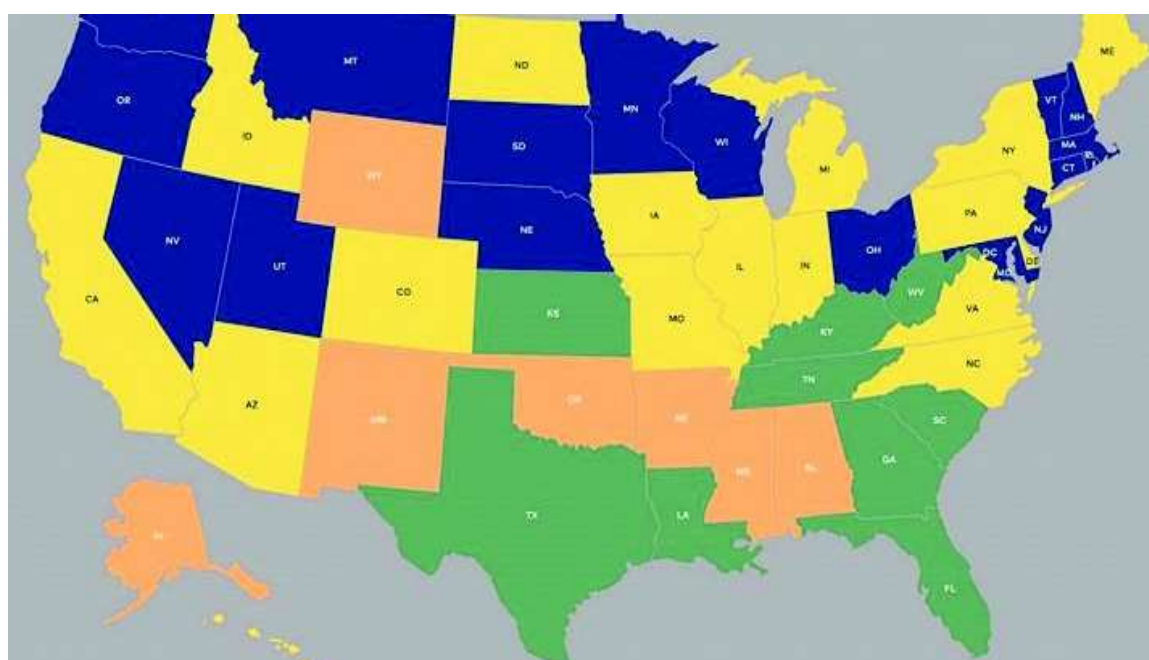
Generalizability is defined as the ability to transfer the same or similar information to other groups or settings not particularly used in the present study (Waltz, et al., 2010). The researcher believes the theoretical construct identified can be utilized by other interdisciplinary care teams to identify barriers and perceptions to obtaining palliative care consults in the ED or outpatient setting.

The researcher confirms the existence of the following threats to validity, reliability, and generalizability within this study: (a) the face-to-face interview participants work with the researcher on a daily basis, (b) the researcher is the interviewer, and (c) the use of structured interview questions as a technique to guide the collection of data. The researcher made every attempt to maintain neutrality during the interviews, allowing for open dialogue and fact-finding regarding the subject matter.

Study Limitations

It is vital to the integrity of the study to analyze limitations. The researcher identified several limitations in this study. In order to include a broader study group, the researcher obtained data from emergency nurse practitioners via internet access. After receiving IRB approval to study this specific population, emergency nurse practitioners associated with the American Association of Emergency Nurse Practitioners (AAENP) were solicited to answer questions pertaining to their practice, particularly their experience with palliative care services. The sample size was small (35), considering the organization has over 240 members. This may not be a sufficient representative sample size.

The face-to-face interviews were conducted in California and did not include participants from other geographic locations in the United States. The availability of palliative care services in the study region (California) is identified by the Center to Advance Palliative Care (CAPC) (2015) as receiving an average “B” rating for overall comprehensive palliative care programs. If interviews were conducted with care providers in “A” rated states, for example, New Hampshire, Vermont, Massachusetts, or Oregon, the results may differ. These states have less workforce, research, and cost constraints when implementing palliative care programs. (See Figure 2),



A grades = over 80% of hospitals had palliative care programs
 B grades = 61%–80% of hospitals with palliative care programs
 C grades = 41%–60% of hospitals with palliative care programs
 D grades = 21%–40% of hospitals with palliative care programs.



Figure 2. Prevalence and Distribution of Palliative Care Programs in the U.S. (+50 beds) CAPC (2013)

Because the study group supports the concept of palliative care in the ED opposing dialogue was not explored. These care providers expressed interest, receptivity, and genuine responsiveness to the questions and ideas about obtaining palliative care consults in the ED. When they identified barriers, it was related to the availability of palliative care practitioners and not an unwillingness to speak with patients and families about the subject matter.

Implications for Practice and Research

According to the Center for Disease Control and Prevention (2013), by the year 2050, the total number of Americans aged 65 and older will be greater than 89 million; the leading cause of death is proposed to be infectious diseases and acute illnesses. Currently, the leading cause of death is chronic disease and degenerative illnesses. This epidemiological transition is a challenge for our health care systems and economic viability in the future. In the United States, approximately 80% of all persons aged 65 or older have at least one chronic illness and 50% have two chronic illnesses. Chronic conditions can lead to debilitating disabilities such as arthritis, Alzheimer's Disease, renal failure, cancer, and heart disease; arthritis affects 59% of all persons 65 years or older and is the leading cause of disability. People living with chronic illnesses often suffer from a decline in quality of life and experience challenges with normal activities of daily living.

The major contributor to rising health care costs in the United States is treating individuals with chronic illnesses (Centers for Disease Control and Prevention, 2013). This population accounts for two thirds of all health care costs in the United States. By 2020, Medicare spending costs are projected to rise as high as \$903 billion dollars.

According to the CAPC (2014), if interdisciplinary palliative care programs were fully implemented within hospitals, savings could reach \$6 billion dollars per year. Rising costs of health care coupled with limited resources are the motivators to limiting unnecessary hospital admissions for patients who can be better treated with appropriate symptom management for chronic illnesses.

The implications for research are vast, particularly focused on nursing interventions and early identification of patients who can benefit from a team approach to palliative care. Easy-to-use assessment instruments in the ED and other outpatient settings need to be developed to trigger consults for palliative care and open the lines of communication between patients, families, and caregivers. The CAPC supports concentrating on three distinct federal policy recommendations to improving access to palliative care; workforce, research and payment models consistent with quality initiatives (2014).

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Appendix A

Interview Questions

1. How do you define palliative care?
2. How do you define hospice care?
3. Describe how patients and families perceive discussions regarding palliative care in the emergency department?
4. What barriers do you experience with utilizing palliative care services while patients are still in the emergency department?
5. How does palliative care fit with your philosophy of providing patient care?
6. How would palliative care services contribute to improved ED efficiency and hospital throughput?
7. How do you envision palliative care services in the future?

Appendix B

Letter to the participants

Dear [Name],

I am doctoral nursing student working on my dissertation at the University of San Diego. The topic of the study is to explore the barriers and perceptions of palliative care services in the emergency department. I am interviewing emergency department stakeholders (e.g., physicians, nurse administrators, hospital administrators, clinical nurse specialists, nurse practitioners). Your input is valuable to the ongoing pursuit of excellence in patient-centered care, particularly to those patients who frequent the emergency department with chronic and debilitating illnesses.

At your convenience, I would welcome the opportunity to conduct a 30-minute telephone interview. Prior to the meeting, you will receive an email confirming the specified date and time.

Please do not hesitate to call me with any questions, or to notify me if any colleagues who would also be willing to participate in this study.

Respectfully,

Jacqueline L. Saucier, MSN, MBA, RN

Appendix C

Survey Questions

Clinical Attributes

1. Number of years in practice:
 - <1
 - 1–5
 - 6–10
 - >10
2. Practice status:
 - Clinic-based
 - Hospital-based
 - Other
3. Role:
 - Physician, MD/DO
 - Nurse Practitioner
 - Other
4. Age, yrs.:
 - 20–30
 - 31–40
 - 41–50
 - <51
5. Gender:
 - Male
 - Female
6. Do you have an advance directive?
 - Yes
 - No
 - Religious or spiritual affiliation:
 - Catholic or Protestant
 - Jewish
 - Buddhist
 - Hindu
 - Unitarian
 - Agnostic
 - Muslim
 - Jewish/Buddhist
 - Yes, unspecified
 - None
7. Personal experience with a family member or close friend enrolled in palliative care service?
 - Yes
 - No

8. Is palliative care an underutilized service?
Yes
No
9. How do you perceive your palliative care referral pattern?
Under refer
Refer when appropriate
Over refer
10. Does a lack of knowledge of palliative care services and eligibility requirements limit your use of palliative care?
Yes
No

Appendix D

Statement of Support for Access to Emails from AAENP**Fwd: Student request**

Jacqueline Saucier [jsaucier76@gmail.com]

Sent: Tuesday, March 08, 2016 6:49 PM**To:** Jane Georges; Cynthia Connelly; Ruth Bush

FYI. Here is the statement!

Sent from my iPhone

Begin forwarded message:

From: Margaret Carman <margaret.carman@duke.edu>**Date:** March 8, 2016 at 3:32:55 PM PST**To:** Jacqueline Saucier <jsaucier76@gmail.com>**Subject: RE: Student request**

Dear Jackie,

Thank you for discussing your dissertation project with me. I will be happy to facilitate making your survey accessible to our AAENP membership for the purposes of recruitment to your study.

Sincerely,

Dr. Margaret Carman DNP, RN, ACNP-BC, ENP-BC, FAEN

Board of Directors, AAENP

Co-Chair, Practice committee

Research and Translational Partnership

Appendix E

Email Solicitation and Informational Page

Hello,

My name is Jacqueline Saucier. I am a PhD student in the School of Nursing at the University of San Diego, San Diego, CA. I am conducting a research study about palliative care services in the emergency department and I would like to invite you to participate.

The purpose of this study is to identify barriers and perceptions to obtaining palliative care services in the emergency department. This study involves emergency physicians, emergency department directors/managers, nurse practitioners, health care administrators, clinical nurse specialists, and case managers.

If you decide to participate, you will be asked to complete an online survey that takes about 15 minutes to complete. You will be asked about things like if you have personal experience with a family member or close friend who is receiving palliative care services, and do you think palliative care services are underutilized. Also, you will be asked to describe your palliative care referral patterns and does having a lack of knowledge of palliative care services and eligibility requirements limit your use of palliative care.

You will also be asked a few questions about yourself, such as your age, role (MD, NP, etc.), years of practice, ethnicity, religious preference and whether you have an advanced directive.

If you feel tired during the survey, you can take time out to rest and finish it at another time. Your responses will be kept confidential and all your information will be coded with a number. Your email or IP address will automatically be deleted, and nobody will know your identity. I will keep the study data for a minimum of 5 years.

Taking part in this study is entirely optional. ***Choosing not to participate will have no effect on your employment status or any other benefits to which you are entitled.*** You may also quit being in the study at any time or decide not to answer any specific questions. Should you decide to participate, ***please print out a copy of this page for future reference.***

I will be happy to answer any questions you have about the study. You may contact me at (760) 519-9623 or (jsaucier76@gmail.com). You can also contact my advisor, Dr. Cynthia Connelly at (619) 260-7938 or (connellyc@sandiego.edu.)

If you would like to participate, please click on this link to begin the study: (<http://www.surveymoz.com/s3/2608245/Palliative-Care-in-the-Emergency-Department>).

Thank you for your consideration.
Jacqueline Saucier RN

Appendix F

IRB Approval Form



Institutional Review Board Project Action Summary

ENTERED
4/15/16

Action Date: April 15, 2016

Note: Approval expires one year after this date.

Type: ☐ New Full Review ☒ New Expedited Review ☐ Continuation Review ☐ Exempt Review
☐ Modification

Action: ☒ Approved ☐ Approved Pending Modification ☐ Not Approved

Project Number: 2016-04-199

Researcher(s): Jacqueline Saucier Doc SON
Dr. Cynthia Connelly Fac SON

Project Title: Barriers and Perceptions to providing palliative care services in the Emergency Department

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

Modifications Required or Reasons for Non-Approval

None

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited review at any time.

Dr. Thomas R. Herrinton
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